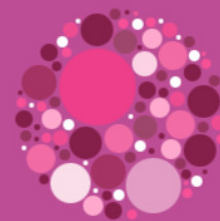


Dementia Action Alliance



Board Meeting – 4th November 2013

This is a report prepared for the Dementia Action Alliance Board meeting on the 4th November 2013. It provides an update on progress made against the DAA Strategy since August 2013 and outlines some of the decisions to be made by the Board.

It includes monies committed to the Alliance for 2013/14 from the members.

Creating a Board to guide the work of the Alliance

What was said in the Strategy

A Board will be formed to guide the work of the Alliance. It will include two permanent members, six elected members and four invited individuals to provide clinical expertise and experience of living with dementia and caring for someone with dementia.

November 2013 update

The DAA Board will meet for the third time on 4th November 2013

Additions to the Board since the August meeting will be, National Clinical Director Alistair Burns (who replaces Gill Ayling who has stepped down from the Board), PwC accountant Dan Snipe who will act as Treasurer and Karen Harrison Denning who will act as clinical representative. The Board now has a full coverage of roles as specified within the Governance Framework and Strategy.

Dan Snipe will be conducting an audit of Alliance finance after the Board meeting.

Issues to resolve

The previous DAA Co-chairs who were elected in spring 2012 are now coming to the end of their terms. The Board will need to confirm the process for re-election of the private, not-for-profit and statutory sector representative (though the latter can be technically filled by Prof Alistair Burns).

It is proposed that the election process is announced to the national membership at the Annual Event with nominations taking place between Annual Event and Christmas and an online election in the New Year. The new representatives will be announced at the Spring Quarterly event. At the Annual Event the national membership will be asked to ratify the extension of the existing co-chairs positions until the new members are in post.

Building the network

What was said in the Strategy

The Alliance will continue to grow. Membership is expected to reach 680 members by 2015: comprising approximately 180 national members and 500 local members.

November 2013 update

There are approximately 700 members of the Dementia Action Alliance. Of these, 137 are national members and 580 are local members.

Enhancing member work

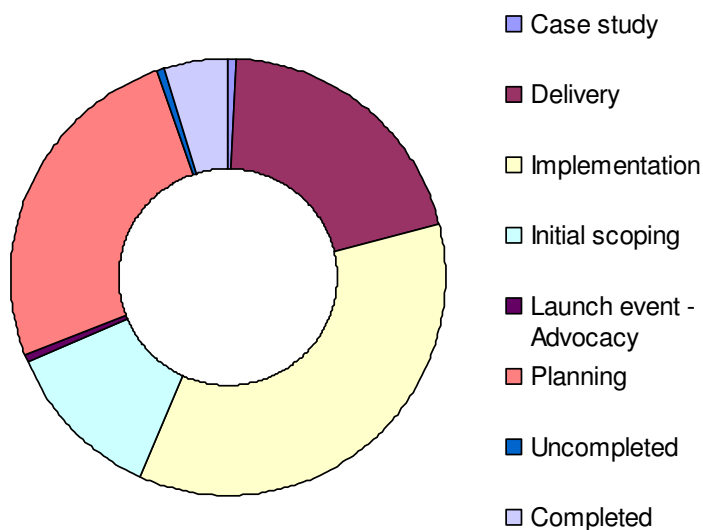
What was said in the Strategy

Alliance staff will continue to enhance the impact of member actions through encouraging information sharing, providing an active 'dating service', promoting collaboration, and suggesting actions.

November 2013 update

Over the last three months Alliance staff supported national members in using the website by creating a short guidance and providing one to one tuition over the phone when requested. The Secretariat has also commissioned web developer Tictoc to create a 'one stop shop' sign up page with advice on actions to take and signposting to local Alliances. This is due for completion before the end of the year.

The DAA website tells us that 3366 actions have been committed by members. 2056 have tagged the stages of their actions of which 95 are classed as Completed. The full break down is as follows.



Delivering joint work

What was said in the Strategy

Between 2012 and 2015 the Alliance will conduct ongoing programmes of joint work that will be funded externally. This will include the Right Care, Early diagnosis and post diagnosis care pathway Action Group and the Carers Call to Action.

November 2013 update

Right Care

The DAA Secretariat, with the aid of contractor Catherine Holmes, has run three Right Care webinars with three more planned for autumn and winter. The webinars have so far covered the D-Kit, the role of pharmacy and the healing environment. Future webinars will cover the workforce, education and carers.

The Secretariat is currently in conversations with the potential donor to fund Phase 2 of the Programme. Project plan and

Diagnosis

The Early Diagnosis and Post Diagnostic Pathways Action Group received £8,500 from 2011/12 DAA surplus income to part fund, with the Department of Health, Alliance research into the benefits of early diagnosis and pilot information prescriptions to improve post diagnostic pathways.

The research is complete and signed off by Prof Alistair Burns. The Secretariat will attempt to launch the report ahead of the DAA Annual Event on the 20th November to drum up interest on the day.

Carers Call to Action

The Carers Call to Action will be launched at the Annual Event on 20th November. The 'ask' is for Health and Wellbeing Boards (HWB) to sign up to a shared vision of the call by the end of March 2014. A tool kit will be produced after the launch to support HWBs in fulfilling their commitments.

The £10k from Nutricia for 2013/14 and previous Carer's Call to Action underspend has been used to employ two contractors: Rachel Niblock (recently of Guideposts Trust) to project manage the call and Steve Crabb (formerly Head of Communications at Alzheimer's Society and British Lung Foundation) to draft external communications for the launch.

Dementia Care and Support Compact

The DAA continues to host the Dementia Care and Support Compact on its website. A combined Compact and DAA Guidance note has been created to facilitate joint sign up.

Culturally competent services

Following the success of the presentations on culturally competent at the last quarterly event, the Secretariat has been working with the presenters to set up a series of webinars for the membership in the New Year.

Local Dementia Action Alliance Programme

The Alliance has supported Alzheimer's Society in developing Local Dementia Action Alliances across England. This includes producing toolkits, guidance notes and creating a central hub for Local Alliances and their members on the DAA website. There are now 51 Local Dementia Action Alliances each with its own dedicated website page on the DAA website.

Since August 2013 the focus of Secretariat support has been on:

- Working with our web-developers to create a one stop 'Join the Alliance' page. This will have a fully automated sign up form with action recommendations broken down by organisation type.
- Working with DAA coordinators to develop a local alliance presence at the Annual Event. This will bring local and national members together for the first time, with break-out sessions run for Local Alliances and Right Care members.
- Working with Alzheimer's Society Dementia-Friendly Communities Programme Manager to integrate local Alliances with the dementia-friendly communities recognition process
- Contract managing consultants ICF GHK to conduct an independent evaluation of the Local Dementia Action Alliance Programme. The draft scoping report has been published, which the DAA Local Board Representative has reviewed. An Executive Summary will hopefully be presented to the Board on the 4th November. Outcome indicators can be found in Annex 3.
- Working with the Alzheimer's Society legal team to develop a draft Charitable Incorporated Organisations (CIO) template for Local Dementia Action Alliances wishing to do local fundraising. The ambition is to provide a fast track route for Charity Commission approval and to pin local alliance objectives to coordination and engagement rather than the direct delivery of services that might duplicate existing member activity.
- Working with the Alzheimer's Society legal team to trademark the term Dementia Action Alliance. The trademark will be held by the Alzheimer's Society on behalf of the DAA Board. Trademarking the term will give the Board control over the title, including local alliances, and prevent another organisation trademarking it first. It will also support the development of the Dementia Action Alliance approach as a franchise, with action at the core of all who use it and provide options for dealing with 'rogue' Dementia Action Alliances that might undermine concept.

Public Affairs around local and general elections

The public affairs role of the Dementia Action Alliance was announced at the last quarterly meeting including the Board's proposal that the Alliance should focus on post diagnostic support and post code lottery.

Members were supportive of the role and the focus but would welcome further consultation on the detail.

Issues to resolve

DAA Board provides a national perspective on local Dementia Action Alliances going for charitable status including approval of the two different CIO versions.

Confirmation of process for agreement between national and local Alliances

Involvement of the wider DAA membership in general election advocacy work

Outcome indicators

What was said in the Strategy

The Alliance will work closely with the Alzheimer's Society to continue to develop their Dementia Report, which collects statistics against the outcomes of the Declaration, and use it to monitor the progress of the Alliance.

November 2013 update

The ICF GHK have produced a draft copy of their Interim Evaluation report that has recommended a number of output indicators for the Dementia Action Alliance. An Executive summary will be presented to the Board on the 4th November and will form the basis of outputs collected by the Secretariat to monitor its impact. Please see Annex 3.

Issues to resolve

The Board to review the indicators from ICF GHK to confirm their applicability. Suggest replacements / additions where gaps exist.

Alliance Events

What was said in the Strategy

Quarterly meetings will remain primarily for national members and the Annual Event will be formalised as the place where local and national members meet.

November 2013 update

Since September the Secretariat has been busy organising the Annual Event of the Dementia Action Alliance. The centre piece of the day being delegates given a 'personal budget' of £30,000 to spend on services, research and support.

Director General Jon Rouse and National Clinical Director of Dementia Prof Alistair Burns have been confirmed as keynote speakers and the event has been raised as a possible launch venue for the Dementia Atlas. There will be a musical session, break-out workshops for local and Right Care members, the launch of DAA research into diagnosis and the Carers Call to Action.

Central Hall, Westminster has been booked for the annual event, along with additional breakout space to accommodate local members. Bupa have agreed to continue sponsoring the event.

Staffing

What was said in the Strategy

In line with the DAA Strategy, the Alliance core staff team was to be increased by one full time equivalent in 2012/13 and by an additional part time equivalent in 2013/14. The principal reason for these changes was to boost the Alliance team's capacity and bring in external communications and social media expertise.

November 2013 update

Staff numbers

The Secretariat is pleased to announce the employment of Renee Arceo as the part time Dementia Action Alliance Assistant and Sarah Tilsed formally starting her full time role as the Dementia Action Alliance Engagement Officer.

The Stakeholder Relations Manager has also negotiated a change in job title to 'Dementia Action Alliance Executive Lead'.

The Alliance is also employing several contractors to fulfil bespoke projects for the Alliance. These include:

- Rachel Niblock - Carers Call to Action Project Manager
- Steve Crabb – Carers Call to Action and DAA Communications (covering the role vacated by Sarah Gillam)
- Renee Arceo – part time to develop the Right Care online community (fulfilling the contract with NHS Institute)

Income and expenditure (see Annex 3)

What was said in the Strategy

Alliance income is expected to rise from **£124,625** in 2011/12 to **£174,550** in 2014/15 through modest growth of national membership (DAA Financial Years run from July to June).

Alliance expenditure is expected to rise from **£126,686.72** in **2011/12** to **£171,704.09** in **2014/15** to fund an increased core staff team, larger annual event and dedicated website budget.

November 2013 update

The Dementia Action Alliance has raised commitments for the 2013/14 financial year of **£166,225** of which **£10,000** has been allocated to the Carers Call to Action (see Annex 4). This leaves the Alliance **£10,000** short of hitting the projected costs of **£166,703.00** set out within the strategy (see Annex 5). The shortfall will be made up from the monies registered under last DAA financial year from the NHS Institute contract to develop an online community.

The DAA has also raised an additional **£66,900** of in-kind support of which **£35,000** will be registered as a direct financial within the Annual Report following a request from the member.

Member support to Action Groups and in kind contributions include:

- £35,000 from the Age-Related Diseases and Health Trust to run the Action Group on Diagnosis and Post Diagnosis Care Action Group;
- £25,00 hosting support for Secretariat by Alzheimer's Society;
- £3,400 from Royal College of Nursing for hosting Quarterly Event
- £2,000 Dementia Web supported by Guideposts; and
- £500 venue and event management for Second Quarterly meeting of 2013 by the Royal Pharmaceutical Society.

Annex 1: Dementia Action Alliance Strategy Summary

Goal - 2015 and beyond

The Dementia Action Alliance becomes the hub of the health and social care element of the dementia sector. When the current phase of the Prime Minister's Challenge on Dementia ends in March 2015, members will co-produce priorities for this element of the sector and initiate joint programmes of work to fulfil them.

Route to achieving this:

Creating a Board to guide the work of the Alliance

It will include two resident members, six elected members and four invited individuals to provide clinical expertise and experience of living with dementia and caring for someone with dementia.

Building the network

The Alliance will continue to grow. Membership is expected to reach 680 members by 2015: comprising approximately 180 national members and 500 local members.

Enhancing member work

Alliance staff will continue to enhance the impact of member actions through encouraging information sharing, providing an active 'dating service', promoting collaboration, and suggesting actions.

Delivering joint work

Between 2012 and 2015 the Alliance will conduct an ongoing programme of joint work that will be funded externally. This will include the Right Care, Early diagnosis and post diagnosis care pathway Action Group and the Carers Call to Action.

Outcome indicators

The Alliance will work closely with the Alzheimer's Society to continue to develop their Dementia Report, which collects statistics against the outcomes of the Declaration and use it to monitor the progress of the Alliance.

Alliance Events

Quarterly meetings will remain primarily for national members and the Annual Event will be formalised as the place where local and national members meet.

Staffing

The Alliance core staff team is to be increased by one full time equivalent post, bringing in external communication expertise to promote member work and freeing up capacity to initiate further areas of joint work (business case included below).

The Alzheimer's Society has agreed to continue hosting the Alliance core staff team for the next four years.

Income and expenditure

Alliance expenditure is expected to rise from **£126,686.72** in **2011/12** to **£171,704.09** in **2014/15** to fund an increased core staff team, larger annual event and dedicated website budget. Alliance income is expected to rise from **£124,625** in **2011/12** to **£174,550** in **2014/15**.

Annex 2: Dementia Action Alliance Charity Summary

Introduction

A few LDAAS have indicated that they wish to establish themselves formally as organisations so that they can engage in local initiatives, comment on local issues and raise funds.

To date they have been encouraged to seek governing documents and role profiles from their local CVS. We have been sent a sample of such a document, which is attached to this note. This document is not entirely suitable and I would recommend that the Society provides a standard governing document for LDAAs to use. Specifically, I would suggest LDAAs be established as Charitable Incorporated Organisations ('CIO'). This would have a number of advantages, which have been set out in this paper.

Charitable Status

If an organisation is set up to further charitable objectives for the public benefit it is, as a matter of law, a charity and is required to comply with charity law. If its annual income exceeds £5,000 it is required to register with the Charity Commission. Without such registration such organisations are still charities, albeit unregistered charities. The committee members of any organisation that is legally a charity are charity trustees, whether or not they use that term and whether or not they realise that they have that role. This brings about certain legal obligations so it is important that people who take this role understand it.

While most LDAAs will initially have incomes that are lower than the £5,000 threshold, some of them may grow, especially if they receive a grant or take over the employment of a coordinator or administrator after Alzheimer's Society stops employing them. Once an LDAA has exceeded this threshold it will be required to register as a charity at the Charity Commission. Registering an LDAA as a charity when it is established removes the risk that an LDAA will be established and will operate for a few years then discover on trying to register that its objects are not entirely charitable or its governing document is not suitable.

Being a registered charity and having a registered charity number also gives an organisation credibility and can assist in fundraising as potential funders can see that the organisation is legitimate and its affairs are subject to scrutiny.

Charitable Incorporated Organisations

A CIO is a new legal form of charity which became available in 2012. It is the first legal structure to be established specifically for charities. CIOs, like companies, have their own legal identity, but they are only regulated by the Charity Commission and charity law unlike companies which are also regulated by Companies House and company law. This reduces the amount of reporting that the charity must do, while ensuring that the charity is regulated and reports to a regulator as all CIOs, whatever their size, must be registered with the Charity Commission.

Consistency, Suitability and Compliance with Charity Law

Providing a standard governing document with standard objects would ensure that each LDAA is established and has a governing document in accordance with charity law (which requires charities to operate in particular ways and have particular terms in their governing documents). In particular, charity legislation sets out strict requirements regarding terms that all CIOs must have in their governing document. The Charity Commission will also register CIOs more quickly if their governing document is as close as possible to the Charity Commission model.

Using a standard model will also ensure that the governing document contains all the terms necessary to set out how the organisation will be governed e.g. how trustees are appointed, who can be a member, how meetings should be run and how decisions should be taken, all of which can give rise to disputes if they are not agreed when the organisation is established.

Accountability

Charity legislation places a number of requirements on registered charities including submitting annual returns and accounts (in the case of small CIOs these are only required to be receipt and payments accounts rather than more complex accruals accounts) to the Charity Commission.

Registering LDAAs as charities would ensure that they are subject to an appropriate level of scrutiny and accountability that Alzheimer's Society might not have the resources to provide itself, particularly as the number of LDAAs grows. This is particularly important as the name 'Dementia Action Alliance' is a trademark of the Society (and will in due course be a trademark of the DAA) so any negligent or fraudulent failing on the part of an LDAA would have an effect on the reputation of the Society and the DAA.

Legal Identity and Personality and Limitation of Liability

A further advantage of registration as a CIO is that the LDAA would have its own legal identity. This would mean that it could take actions itself, enter into contracts (including employment contracts and leases) itself.

The draft governing document that was provided by the CVS was for an unincorporated association – such organisations do not have their own identity and it is the committee or the members who enter into any contracts and bear any liability that may arise in relation to them. Such liability is not limited. By contrast, if an incorporated organisation, such as a CIO, enters into such a contract it bears all the liability and responsibility so the trustees will not have unless they do something fraudulent or exceptionally negligent.

An incorporated organisation can also own its own property e.g. it can have a bank account in its own name. This would make it easier to trace the assets of the LDAA. The governing document of CIOs sets out clearly that if the organisation is wound up its assets must be given to another charity. This reduces the risk of an LDAA being set up, operating for a few years and accumulating funds then being wound up or becoming dormant and its assets disappearing or an argument arising regarding how the assets should be distributed.

Setting up an LDAA as an organisation also gives it more permanence and stability as individuals involved change.

Next Steps

The objectives set out in the LDAA model documents and the model documents themselves must be considered by the DAA board and (once revised in accordance with their comments) agreed. Once the governing documents have been agreed it will be necessary to prepare a briefing note for the LDAAs on using the governing document and on applying for registration as a charity.

In addition to the governing document, it would be advisable to have a written agreement between the LDAAs and the DAA covering issues such as the respective roles of the LDAA and DAA; representation of LDAAs on the DAA Board; use of the DAA trademarks; requirements to provide content for the Annual Report and update action plans on website; and not taking any action that could bring the Society, the DAA, LDAAs or their members into disrepute.

It would also be advisable to prepare a role description for the members of the committees of the LDAAs.

Rachel Wellman
Alzheimer's Society Legal Team
21 October 2013

Annex 3: Outcome indicators for the Alliance

Mapping the outcome indicators to the National Dementia Declaration produced by GHK

Outcome indicator	Source	National Dementia Declaration statement(s)
% of people who use services and their carers who reported that they had as much social contact as they would like	Adult Social Care Outcomes Framework	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
% of people who use services and their carers who find it easy to find information about support	Adult Social Care Outcomes Framework	I have the knowledge and know-how to get what I need
% of carers who report they have been included or consulted in discussions about the person cared for	Adult Social Care Outcomes Framework	I have support that helps me live my life
People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to their circumstances	Adult Social Care Outcomes Framework	I live in an enabling and supportive environment where I feel valued and understood I know that services are designed around me and my needs
% of people who use services who have control over their daily life	Adult Social Care Outcomes Framework	I have personal choice and control or influence over decisions about me
% of people using social care who receive self-directed support	Adult Social Care Outcomes Framework	I have personal choice and control or influence over decisions about me
Dementia diagnosis rate	NHS Outcomes Framework	Overall indicator
Percentage of people with dementia on GP registers who had a review of their care	Quality and Outcomes Framework	I know that services are designed around me and my needs
Number of people over the age of 75 admitted to hospital being asked about their memory; quality of the dementia care delivered	CQUN	I know that services are designed around me and my needs I live in an enabling and supportive environment where I feel valued and understood
Dementia as a cause of death	Death certificates	Overall indicator
Number of inappropriate prescriptions of antipsychotic medication for people with dementia	Health & Social Care Information Centre	I know that services are designed around me and my needs
Number of people with personal budgets	Health & Social Care Information Centre	I have personal choice and control or influence over decisions about me

Outcome indicator	Source	National Dementia Declaration statement(s)
		I have support that helps me live my life
% of older people who were still at home 91 days following discharge from hospital into rehabilitation services	Health & Social Care Information Centre	I have support that helps me live my life I live in an enabling and supportive environment where I feel valued and understood
Percentage of people with dementia who stay in hospital longer than people without do for similar conditions	Hospital Episode Statistics	I know that services are designed around me and my needs
% of patients of all ages/over 75 discharged back to usual place of residence within 28 days of emergency readmission	Hospital Episode Statistics / NCHOD	I know that services are designed around me and my needs
% of people with long-term conditions feeling supported to manage condition	Labour Force Survey	I have support that helps me live my life
% of people with long-term conditions where day to day activity affected	Labour Force Survey	I live in an enabling and supportive environment where I feel valued and understood I have support that helps me live my life
Sign up to the Dementia Care and Support Compact	Alzheimer's Society data	I know that services are designed around me and my needs
Number of dementia-friendly communities	Alzheimer's Society data	I have a sense of belonging and of being a valued part of family, community and civic life
DAA/LDAA action plans submitted/completed	Alzheimer's Society data	I have a sense of belonging and of being a valued part of family, community and civic life
Number of Dementia Friends trained	Alzheimer's Society data	I have a sense of belonging and of being a valued part of family, community and civic life
Number of Dementia-friendly Communities	Alzheimer's Society data	I have a sense of belonging and of being a valued part of family, community and civic life

Annex 4: Income for 2013/14

Organisation	Contribution	Event Sponsorship / Stalls	Financial Action Group support	Total Finance	In kind Action Group support	General In kind support	Total in kind support
Age Trust				£0	£35,000		£35,000
Age UK	£5,000			£5,000			£0
Alzheimer's Research UK	£2,000	£300		£2,300			£0
Alzheimer's Society	£30,000			£30,000		£25,000	£25,000
Anchor	£5,000			£5,000			£0
Association for Dementia Studies, University of Worcester	£500			£500			£0
Barchester Healthcare	£1,500	£300		£1,800			£0

British Association for Counselling and Psychotherapy	£500			£500			£0
British Psychological Society	£3,000			£3,000			£0
Bupa	£5,000	£15,600		£20,600			£0
Carers Trust	£1,500			£1,500			£0
Citrus Training Solutions	£500			£500			£0
College of Occupational Therapists				£0	£1,000		£1,000
Dementia Adventure CIC	£250			£250			£0
Dementia Advocacy Network	£125			£125			£0
Dementia Web hosted by Guidepost				£0	£2,000		£2,000

Trust							
Department of Health	£50,000			£50,000			£0
Excelcare	£5,000			£5,000			£0
Faculty of Old age psychiatry, Royal College of Psychiatrists	£250			£250			£0
Guinness Care and Support	£1,000			£1,000			£0
Hallmark Care Homes	£4,500			£4,500			£0
Hft	£250			£250			£0
Jewish Care	£1,500			£1,500			£0
Joseph Rowntree Foundation	£5,000	£300		£5,300			£0
Ladder to the Moon	£250			£250			£0

Lilley	£5,000			£5,000			£0
Lost Chord	£250			£250			£0
MHA	£250			£250			£0
My Life Software	£1,000			£1,000			£0
MyAmego Healthcare Ltd	£250			£250			£0
National Care Forum	£250			£250			£0
Norfolk & Suffolk Dementia Alliance	£500			£500			£0
Nutricia			£10,000	£10,000			£0
Prestige Nursing + Care	£3,000			£3,000			£0
Royal College Nursing				£0		£3,400	£3,400
Royal Pharmaceutical Society				£0		£500	£500

Social Care Institute for Excellence	£2,500			£2,500			£0
Southern Healthcare	£250			£250			£0
The Alzheimer's Show organised by Draw Events.	£250			£250			£0
The Direct Marketing Association	£500			£500			£0
The Life Story Network CIC	£250			£250			£0
Thomas Pocklington Trust	£2,000	£300		£2,300			£0
Track Your Ltd		£300		£300			£0
trueCall	£250			£250			£0
Totals	£139,125	£17,100	£10,000	£166,225	£37,000	£29,900	£66,900

Annex 5: Expenditure

Dementia Action Alliance: Table 1 Expenditure

Table 2: Dementia Action Alliance expenditure		
Item	Actual Spend 2012/ 13	Predicted Spend 2013/ 14
Secretariat staffing	£83,017	£121,010
Venue hire and subsistence for Alliance meetings	£57	£2,060.00
Accommodation and travel costs for people with dementia and carers	£3,690	£5,150.00
An Annual Report	£2,812	£3,182.70
An Annual Event	£16,285	£25,000.00
Website development	£16,090	£10,300
Unrecoverable VAT	£7,613	
Total Budget	£129,563	£166,703.00