

Involving people with dementia



Innovations in Dementia:

working on positive projects *with* people with dementia

- Projects that enable people to **live better**
- Projects that **amplify the voices** of people with dementia
- Projects that **challenge** the way we view dementia





The Dementia Engagement
and Empowerment Project

Dementia Voices: "together we are strong"

"There is power in numbers"

"We are the grassroots - the ground
workers"

"DEEP works because it is the real
voices of people with dementia"

JRF JOSEPH
ROUNTREE
FOUNDATION

INSPIRING
SOCIAL
CHANGE

A STRONGER COLLECTIVE VOICE FOR PEOPLE WITH DEMENTIA

What's the Issue?

A growing number of people with dementia in the UK have become actively involved in groups to try to influence services and policies affecting the lives of people with dementia. The Dementia Engagement & Empowerment Project (DEEP) aimed to investigate, support, promote and celebrate these groups.

Ways Forward

- Groups led by or actively involving people with dementia need to identify how they want to develop their influencing activities, and how they want a network to engage with them, including people with dementia from ' seldom heard ' groups, and the support they need to do this.
- Governments and the Department of Health need to ensure that all dementia policy initiatives have clear plans for involving people with dementia, offer support and resources and promote positive stories to the national media. Specialist health and social care media need to incorporate regular features and comments written by people with dementia, and promote positive stories of involvement to the wider media.
- National and local organisations providing services or working with people with dementia need to develop and implement involvement plans, allocating resources to develop new groups, link groups together and help them share resources.
- Event organisers need to incorporate sessions at dementia-related events for groups of people with dementia to talk about their involvement work, and provide support and resources to enable people with dementia to attend these events. Trainers and educators need to build in regular sessions led by people with dementia in the training of students and staff.
- Researchers and research networks need to involve groups of people with dementia in helping to identify research topics, advise on research findings and undertake research on topics identified as important by people with dementia.

Authors

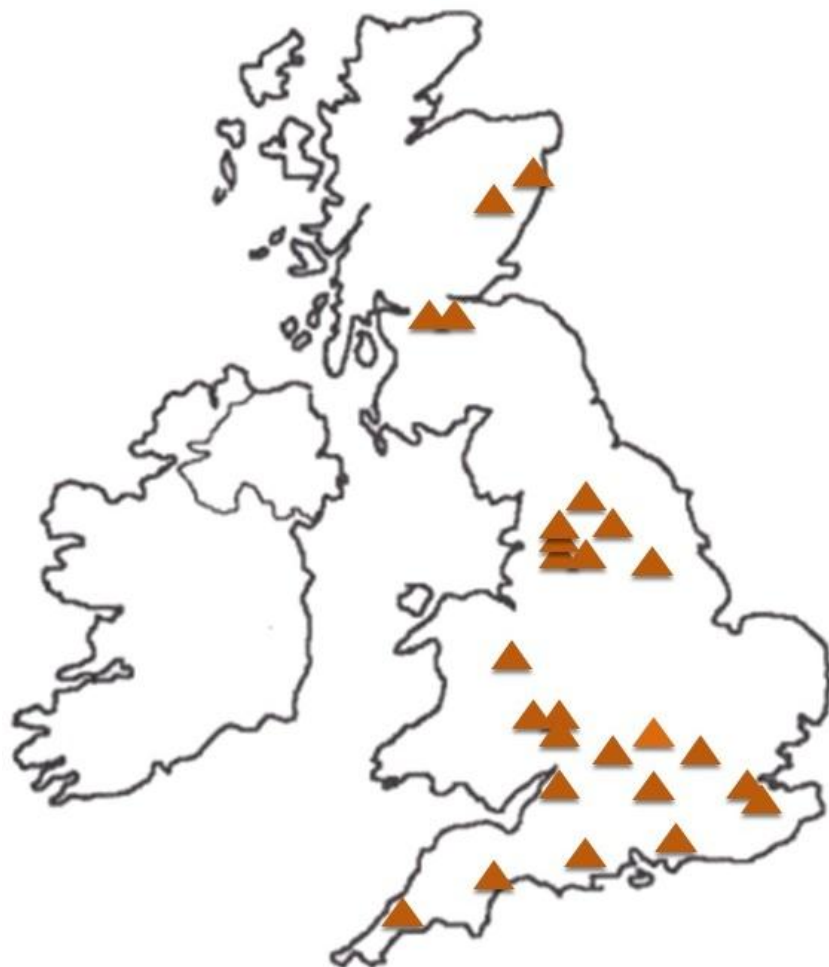
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- 37 groups = more than 400 dementia voices
 - Groups are all shapes and sizes
 - Local and national influence
- People with dementia as contributors, participants and citizens
- Developing a national dementia movement



Work of the groups

- Education, training, presentations - about living with dementia
- Campaigning and influencing the dementia agenda and other issues of importance
- Making decisions about services
- Challenging stigma and discrimination
- Recruiting new members of staff
- Employing someone with dementia in paid role
- Influencing the design and layout of facilities - dementia friendly communities
- Lobbying politicians
- Fundraising

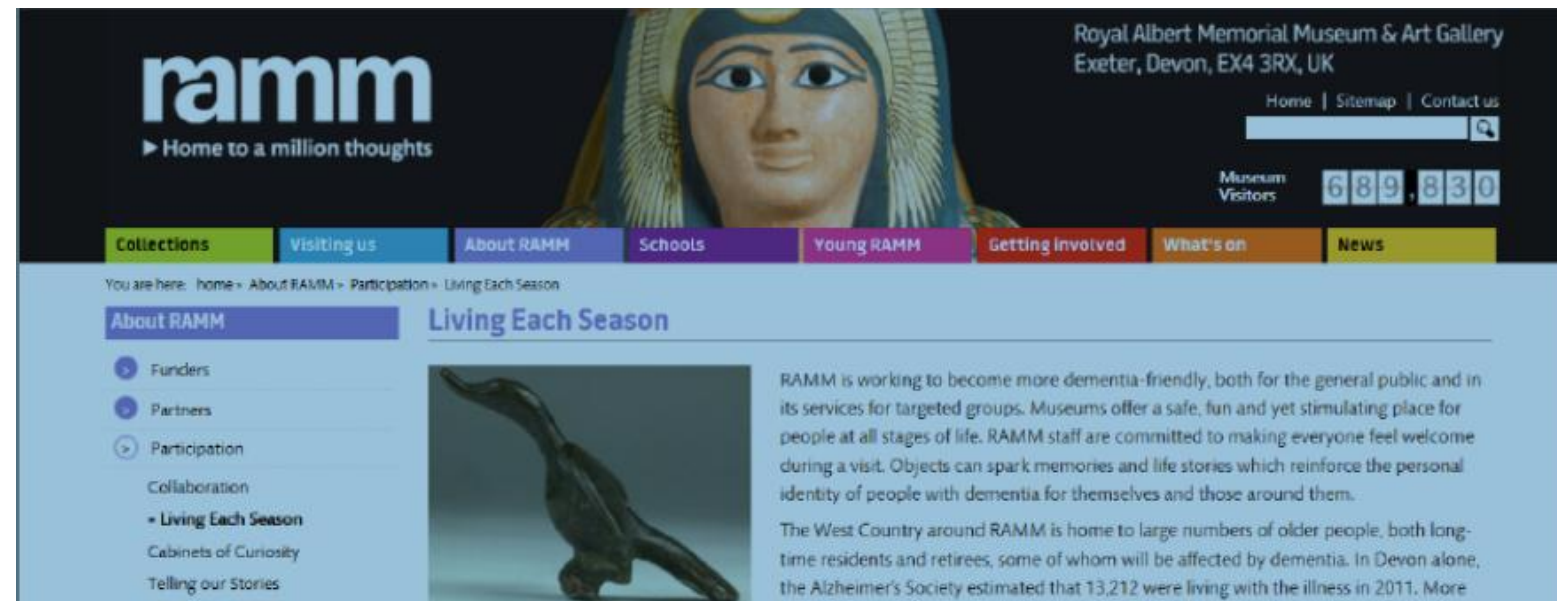
DEEP offers groups...

- Development support
- Small involvement grants
- National opportunities for people to have their voices heard; a stage through which to have high level influence
- Opportunities for consultancy for groups
- Ideas and mentoring
- Training e.g. public speaking, using technology
- A chance to meet other groups
- Regular updates
- Ideas, inspiration, guidance
- The chance to be part of a growing network

What is a dementia friendly community?



A unique perspective



DEEP Guide

Involving people with dementia in recruitment and selection

Key messages

- Many organisations recruit staff or external organisations to work with people with dementia.
- As customers of these services, people with dementia are in a unique position to assess whether an applicant has the right attributes to work with people with dementia.
- There are many ways of involving people with dementia in recruitment processes.
- People with dementia have the right to a say in decisions that affect their lives.

Why involve people with dementia in recruitment and selection

Many different individuals and organisations are recruited to work with people with dementia. They range from permanent support staff to organisations recruited through competitive tender processes for specific pieces of work.

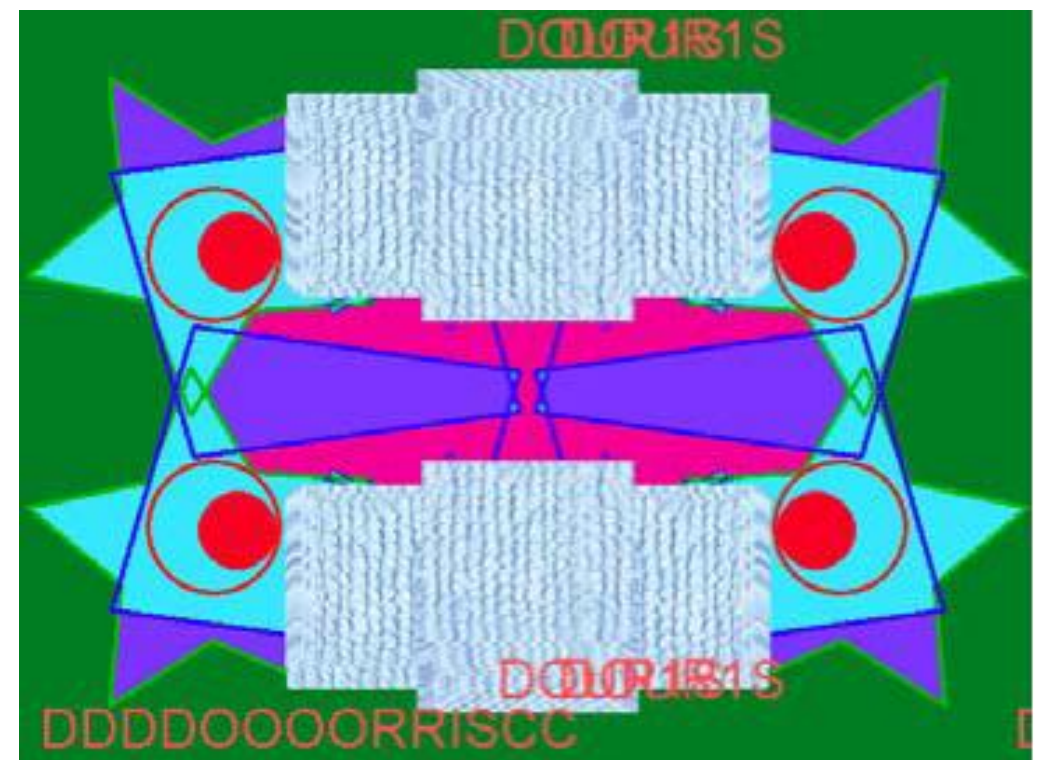
People with dementia have a unique perspective on the skills and attributes that will work well for them. The recruiting organisation may also learn more about the services they provide for people with dementia through the process of involving people with dementia. For example, people might reflect on the aspects of a job description that are particularly important to them, which might provide valuable information about how a role is delivered and the relative importance of key tasks.



Walking the patch



Using technology



Everyday involvement



General principles when involving people with dementia

- Enhance understanding of the context
- Consider choice of language and where to 'pitch' the discussion
- Provide reminders of important points discussed
- Check and double check people's viewpoint
- Visual cues are really helpful
- Give time and listen well
- Be aware of emotions but don't avoid emotions
- Accessibility issues – but don't patronise!
- Layers and levels of involvement
- Where is the power held...?

Power and Control and Dementia

These words evoked strong feelings.

You said:

“Blimey!”

“This is the first time I have thought about that.”



We talked about **power** and **control** and living with **dementia**

- don't want to lose control
- you can be smothered by people who care
- carers can be protective
- need to give some strength to ourselves so we can come out of it
- you try and exercise power in day-to-day life
- domestic politics can get in the way
- you need power in order to achieve your goals



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Power and Control and DEEP



We talked about where the **power** and **control** should lie in groups and DEEP

You said:

- It's important that power and control is with people with dementia - that they are the leaders
- Paid staff and volunteers are there for support and facilitation
- Paid staff and volunteers are the assistants of group members
- People with dementia should be the ones who lay down the mandate
- Respect is important
- We should write guidelines about people with dementia as leaders within groups



VISION

* NEED LOCAL GROUPS ACROSS UK THAT ARE SUPPORTED TO MEET NATIONALLY *

What if these isn't a group locally / or if it closes down / or if how to get around this? / or if you go next?

MOVE TO SWINDON!

Scottish Dementia Group - working to aspire to as strong - funded by but independent of Alz. Soc. Scotland.

£ a room + tea + coffee + expenses

Needs the right individual - a paid co-ordinator / someone to make it happen. ~~can't it go on?~~

online 'chat' rooms for carers etc. But more out there for carers living with dementia.

people develop their own links / contacts by chance or word of mouth or invites. also through internet eg. Facebook but not local - value of meeting locally.

Value of face to face meeting - even if once a year.

NETWORK

contacts

learning from Admiral Nurses - rather than 'helpers'

learning from the past - Peter Fehley - conference in Newcastle - organised by Alz. Soc on part of the Living with Dementia working group - but this then stopped with contacts.

London: fragmentation of boroughs - blocks people going / linking if not from the borough.

web-based resources / information page be overwhelming but also useful.

- Role of Alzheimer's Society + local branches? Impact of changes on local groups.

- Lack of people with dementia + carers involved in lobbying at a national level in England.

Age can be another barrier for people under 65y.

Barnsley independent Alzheimer's grp. Sunderland group.

"it's not a job for us"