NIHR | Oxford Health Biomedical Research Centre

Engaging people with MCI in ageing and dementia research

The challenge

There is now compelling evidence that Alzheimer’s disease takes hold some years before dementia symptoms appear. As a result, today’s research increasingly focuses on this pre-symptomatic phase, with the aim of finding ways to delay or prevent the disease. This means patients with a diagnosis of mild cognitive impairment (MCI) are becoming increasingly important to dementia research.

Yet they are hard to reach; there is currently no formal pathway within the NHS beyond diagnosis and an annual check-up. Social groups and events specifically for MCI patients are scarce. Discussions with Dementia Oxfordshire (a partnership between Age UK Oxfordshire, Guideposts and YoungDementia UK) and Alzheimer’s Society led to the observation that people with MCI tend to avoid resources with a dementia label.

A novel solution was needed for engaging people with an MCI diagnosis in research, so a collaboration between Oxford Health NHS Foundation Trust, the Department of Psychiatry and Oxford Health Biomedical Research Centre was formed to tackle the challenge.

Department of Psychiatry
Medical Sciences Division

Brain Health Centre

NHS
Oxford Health
NHS Foundation Trust

Involving patients in designing the solution

Face-to-face

We contacted a group of MCI patients from the memory clinic in Abingdon Community Hospital. They were invited to a PPI event at The Guildhall in Abingdon in autumn 2019 to talk about their experience of getting an MCI diagnosis and life afterwards. Participants were encouraged to talk about **how they believed their practical and emotional needs could be better supported**.

Postal survey

The reach of the PPI activity was extended with a survey to people who were unable to attend the event. Direction was taken from the Department of Health's "Dementia 2020 Citizens' Engagement Programme Survey on Dementia Care, Support and Awareness" from 2016.

Around 30 people with an MCI diagnosis provided input as well as family members, local healthcare professionals and providers of relevant services (e.g. Age UK Oxfordshire, Alzheimer's Society).

Findings

People told us about **life after diagnosis**; how they often disengage from work and hobbies. Over time this creates a void in daily life and a break with established routines. These changes come when people are already low on resilience and can result in social isolation. They prioritised **unmet needs** as

- information about the condition and prognosis
- evidence-based direction about how to protect our brains as we age
- connection with others who share similar experiences
- new fulfilling ways to spend their day
    - things of real interest rather than just passing time
    - appropriate work or volunteering opportunities
- stress management strategies
- access to 'experts' to get their questions answered

Considerations that arose included:

- easy access via public transport or good parking
- the possibility of including a companion
- demonstrating the credibility of any solution
- fear of engaging with people who have dementia
- fear of the language of dementia

The solution: The Abingdon Afternoon Tea Club

The result is the Abingdon Afternoon Tea Club (AATC) held monthly at the Guildhall in the centre of town. It aims to **connect people with MCI with the information they seek and an informal network of people with experience of the condition**. Sessions consist of 3 short talks around the following topics:

- the science of MCI and memory problems
- local social and leisure events (e.g. community gardening, therapeutic dance, choir)
- modifiable lifestyle factors and brain health with practical take-outs
- local ageing and dementia research opportunities

Then there is a break for afternoon tea and general chat. Attendees take this time to talk to the University researchers and Abingdon Clinic staff about anything that is on their mind.

We **collect feedback** on forms left on each table. There is also a **'wishing line'** where we capture participants' suggestions for future content.

NHS Oxford Health
NHS Foundation Trust

Free

Afternoon tea club

for

People with mild memory problems

Monthly at the Guildhall, Abingdon
Abbey Close, Abingdon, OX14 3JD

from 2.30 – 4.00pm on

- 22nd January 2020
- 26th February 2020
- 25th March 2020
- 22nd April 2020
- 20th May 2020
- 24th June 2020

Get useful Information about living well with memory problems and meet people with relevant tips and experiences to share.

If you need transport, please call 01865 283806 to leave your details and we'll call you back to arrange.
Or email us at brainhealthresearch@oxfordhealth.nhs.uk

EPAD European Prevention of Alzheimer's Dementia Consortium
Brain Health Centre
NIHR | Oxford Health Biomedical Research Centre

Promotion

Patients of Abingdon Memory Clinic are told about AATC at appointments and by post. Where the AATC has permission to recontact attendees (collected at the events) an email or letter is sent directly from AATC. Flyers are distributed in doctor's surgeries in central Abingdon as well as in the library, cinema and coffee shops. AATC is also posted on the events pages of 'Healthy Abingdon' and Abingdon Town Council websites.

Link Workers for the Abingdon Central Primary Care Network are now aware of AATC and will be visiting the group to assess suitability as a social prescribing intervention.

Results

Each month 12 - 20 people with MCI come along, some with a family member.

AATC has a permissioned database of 30 people who are happy to be contacted about any of the content of the sessions, including research. Research assistants have begun calls to follow up on research opportunities.

The most popular content appears to be about very local activities and modifiable lifestyle factors. However it is clear the social occasion in itself is an attraction.

> *"Really high quality speakers…very helpful"*
>
> *"It's lovely to know someone cares"*

Contact: Shona Forster, Public Engagement & Communications, Department of Psychiatry, University of Oxford, shona.forster@psych.ox.ac.uk

AATC is funded by Oxford Health NHS Foundation Trust

What we have learned

- **Don't mix services for people with dementia and those with MCI**
- **Keep content hyper-local**
- **Ensure transport links are good**
- **Build in plenty of informal chat time and have people in attendance who can answer questions**
- **Stay relevant - get attendees to tell you what they want to hear next time**
- **Be prepared to print information as people may not engage online**