

### Join Dementia Research & Identifying Research Priorities in BME Communities

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Delivering clinical research to make patients, and the NHS, better

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# • Research?

# Clinical Research?

#### What is Research/Clinical Research?



- Collection of data, information and facts for the advancement of knowledge
- Clinical Research- determines the safety and effectiveness of medications, devices, diagnostic products and treatment regimens intended for human use.
- These may be used for **prevention**, **treatment**, **diagnosis** or for **relieving symptoms** of a disease.
- Clinical Research is **different** from clinical practice.
  - Clinical practice -established treatments
  - Clinical research-evidence is collected to establish a treatment



# • NIHR Clinical Research Network?

• Join Dementia Research?

### NHS Constitution



- "Research is a core part of the NHS. Research enables the NHS to improve the current and future health of the people it serves. The NHS will do all it can to ensure that patients, from every part of England, are made aware of research that is of particular relevance to them. The NHS is therefore putting in place procedures to ensure that patients are notified of opportunities to join in relevant ethically approved research and will be free to choose whether they wish to do so."
- NIHR Clinical Research Network provides infrastructure to support high quality world-class clinical research within the NHS
- Join Dementia Research- A place to register your interest in participating in dementia research

### Why do we do dementia research?



Clinical Research Network Greater Manchester

# In 10 year's time, ONE million people in the UK will have Dementia

# The only way to beat the condition is through research

### There are no Disease Modifying Therapies

### Why do we do dementia research?



Clinical Research Network Greater Manchester

Memory Medications-first drugs developed for Alzheimer's disease (AD) were the acetylcholinesterase inhibitors (AChEI)
Licensed for the treatment of mild-to-moderate AD.
a further therapeutic option available for moderate-to-severe AD is memantine.
These treatments are symptomatic ONLY
Drugs under development are intended to modify the pathological steps leading to AD, thus acting on the evolution of the disease and therefore termed 'disease-modifying' drugs.

#### **Current Funding Picture**



Clinical Research Network Greater Manchester

- April 2015-Dementia research gets **13 times less funding than cancer** even though the cost to society is far greater (*Oxford University*)
- Treating and caring for cancer patients currently costs Britain around £5 billion a year, but the health & social care bill for **dementia is £11 billion**.
- Yet despite the huge burden of dementia just 8p is spent on researching new treatments for each £10 spent looking after people with the condition. In contrast, cancer research receives £1.08, more than 13 times more.

"We will work towards recruiting 10% of patients into clinical trials" (for 2015) Prime Ministers Challenge on Dementia - March 2012

#### Living with Dementia in Greater Manchester



- A population approaching 3 million with over 11% from an ethnic minority group.
- High levels of social deprivation and social isolation
- Record levels of poor health outcomes leading to some of the lowest life expectancy nationwide.
- Currently there are 18000 people living with a diagnosis of dementia across Greater Manchester and a similar number who do not have a diagnosis and therefore are not accessing any support.
- It was reported by the All-Party Parliamentary Group on Dementia in July 2013 that in England and Wales 'there are nearly 25,000 people with dementia from Black, Asian and Minority Ethnic communities and this number is set to increase seven-fold to over 170,000 by 2051 ... awareness of the condition in minority ethnic groups is low and current provision of appropriate support is lacking'
- The report also highlighted that diagnosis rates amongst these groups are low, social isolation, stigma and a lack of awareness of available support are evident

# Clinical Research for people living with Dementia in Greater Manchester



Clinical Research Network Greater Manchester

In 2014/15 Greater Manchester supported 35 Dementia NIHR Portfolio Studies at 10 sites

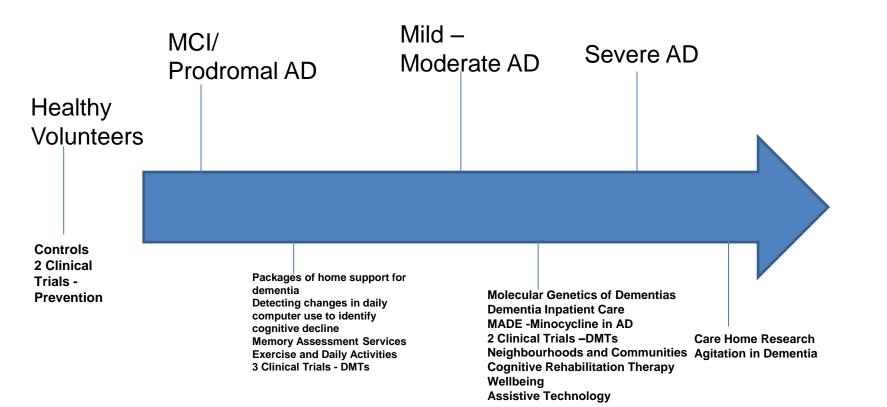
- Over 2300 participants recruited
- Exceeded PM's Challenge 12%

In 2015/16

- 33 studies open and recruiting at 9 sites
- 1165 participants recruited

#### **Current Involvement in Clinical Research for People living with Dementia in Greater Manchester**





### What happens if I am in a Study?



- Some studies may involve a certain degree of inconvenience or burden.
  - Having to stay in hospital for a while
  - Having to fill out lengthy forms and questionnaires
  - Having to be available for several visits perhaps at inconvenient times
  - Having to travel to where the research is being carried out
  - Being observed or monitored/Invasion of privacy e.g. having interviewers in one's home
  - Being asked about or reminded of very personal issues
  - Sticking to strict guidelines e.g. with regard to behaviour, exercise or diet
  - Being subjected to various tests e.g. blood tests, scans, tests involving reaction times or memory

### Are there any risks taking part in research?



- Unrealistic expectations about the drugs' efficacy
- No access to drug after the trial even if there was a positive effect
- Interference with personal treatment plan
- Unforeseen side effects: unpleasant, serious or even lifethreatening
- Having foregone other recognised treatment possibilities
- Being in the placebo group
- The frustration of not knowing which group one is in

# Are there any advantages taking part in research?

- To do something different and challenging
- To contribute towards the possibility of finding a cure
- To have a closer alliance with a treatment team
- To promote self-management of one's condition
- To help manage feelings of helplessness

# Are there any advantages taking part in research?

- To exercise one's autonomy and take an active role in society
- To have the possibility of being prescribed a novel therapy particularly since no disease modifying drugs are yet available
- To access treatments which are not yet widely available
- To have the chance to improve one's own condition, wellbeing or quality of life



## How can you be involved? Introducing Join Dementia Research



NHS National Institute for Health Research



#### Welcome to 'Join dementia research', a place to register your interest in participating in dementia research.

Anyone, with or without dementia, can register as a volunteer. Signing up is the first step in becoming involved, supporting vital research studies across the country.

The service is currently being tested, and only includes research studies from the North London area, Essex, Hertfordshire and Luton. However, we will soon invite everyone to register as studies from across the country will be added over the next six months, and some studies will consider volunteers from further afield.

Your stories

What's new



📏 Sign up

Sign up for someone else

If you already have an account please login.

#### Key things you should know about the service

- Sign up today
- Answer as many of the questions as you can
- · View the studies you match to
- Share this page and encourage your friends and family to sign up
- Visit the website regularly to see your study

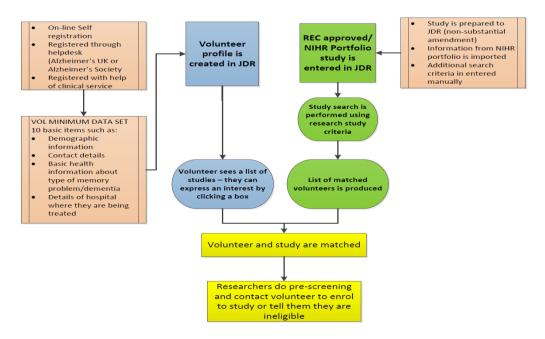






Volunteer registration

**Study registration** 



'Join dementia research' is funded by the Department of Health and delivered in partnership with the National Institute of Health Research, Alzheimer's Research UK and the Alzheimer's Society..



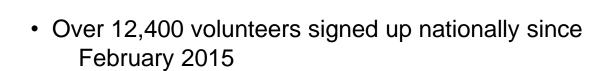
Alzheimer's Society

Leading the fight against dementia





Yes!



- 469 people signed up in Greater Manchester
- 15% enrolled on to a study in Greater Manchester
  - surpasses Prime Minister's Challenge!

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Leading the

dementia

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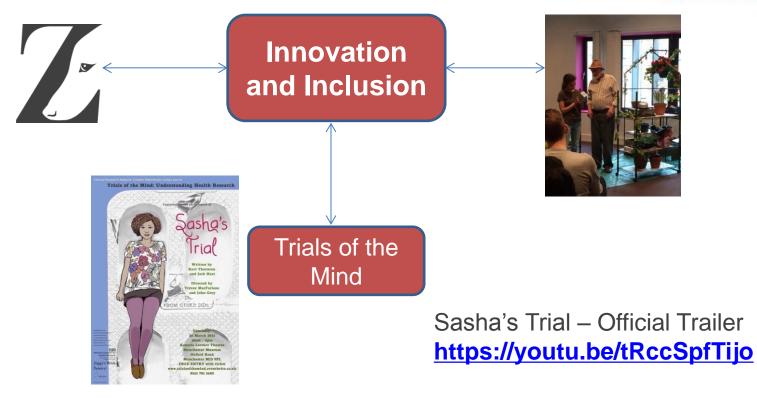
fight against



## What are your priorities?









### Dementia Research is a Partnership









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Leading the fight against dementia