Lancashire Care NHS
NHS Foundation Trust

Greater Manchester, Lancashire and South Cumbria
Strategic Clinical Networks

Living Well with Dementia: Changing Services to Empower Communities

Dr Amanda Thornton

Dementia Clinical Lead. GM, Lancashire and South Cumbria Specialist Clinical Network

Clinical Director, Adult Community Services, Lancashire Care NHS Trust

Personal Introduction

Consultant Psychologist for Older People:

- Salford (1999-2005)
- Lancashire (2005-2015)

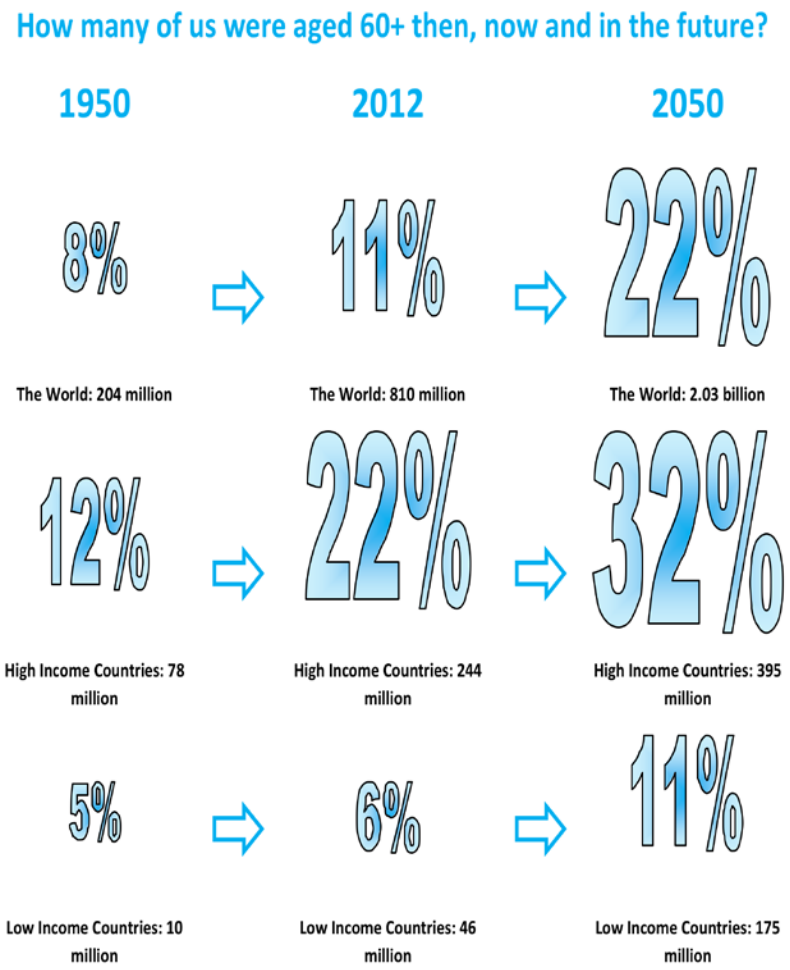
Research and Development

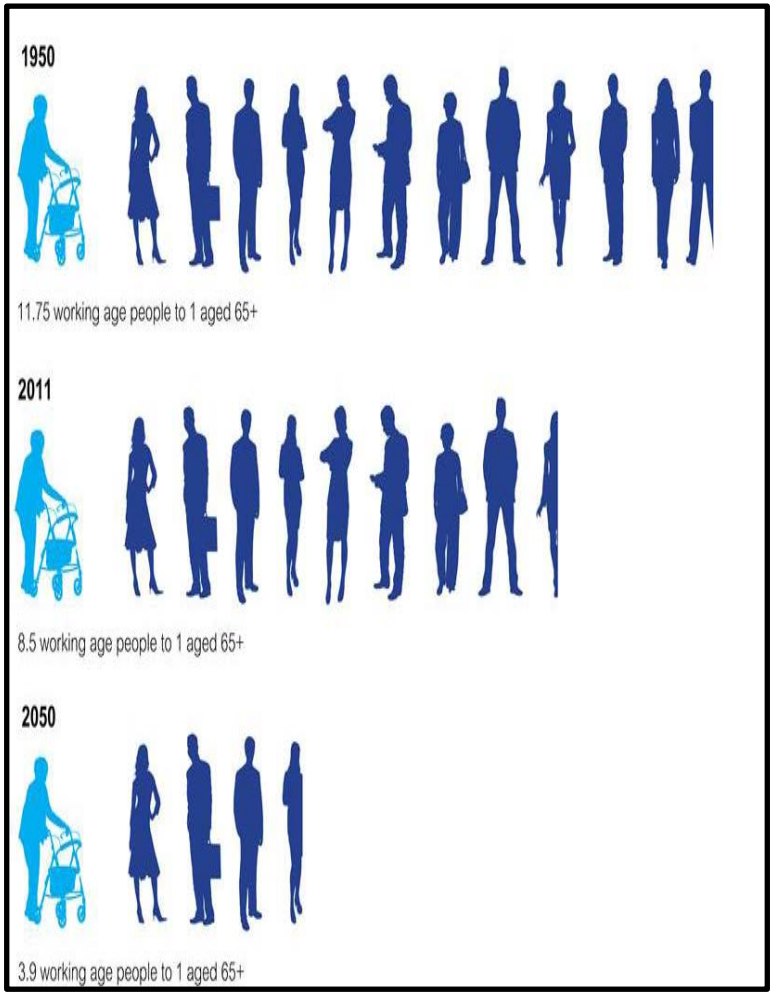
- Crime Prevention and Older People
- Older People as vulnerable and intimidated witnesses
- Impact of Crime
- Dementia Care

Leadership

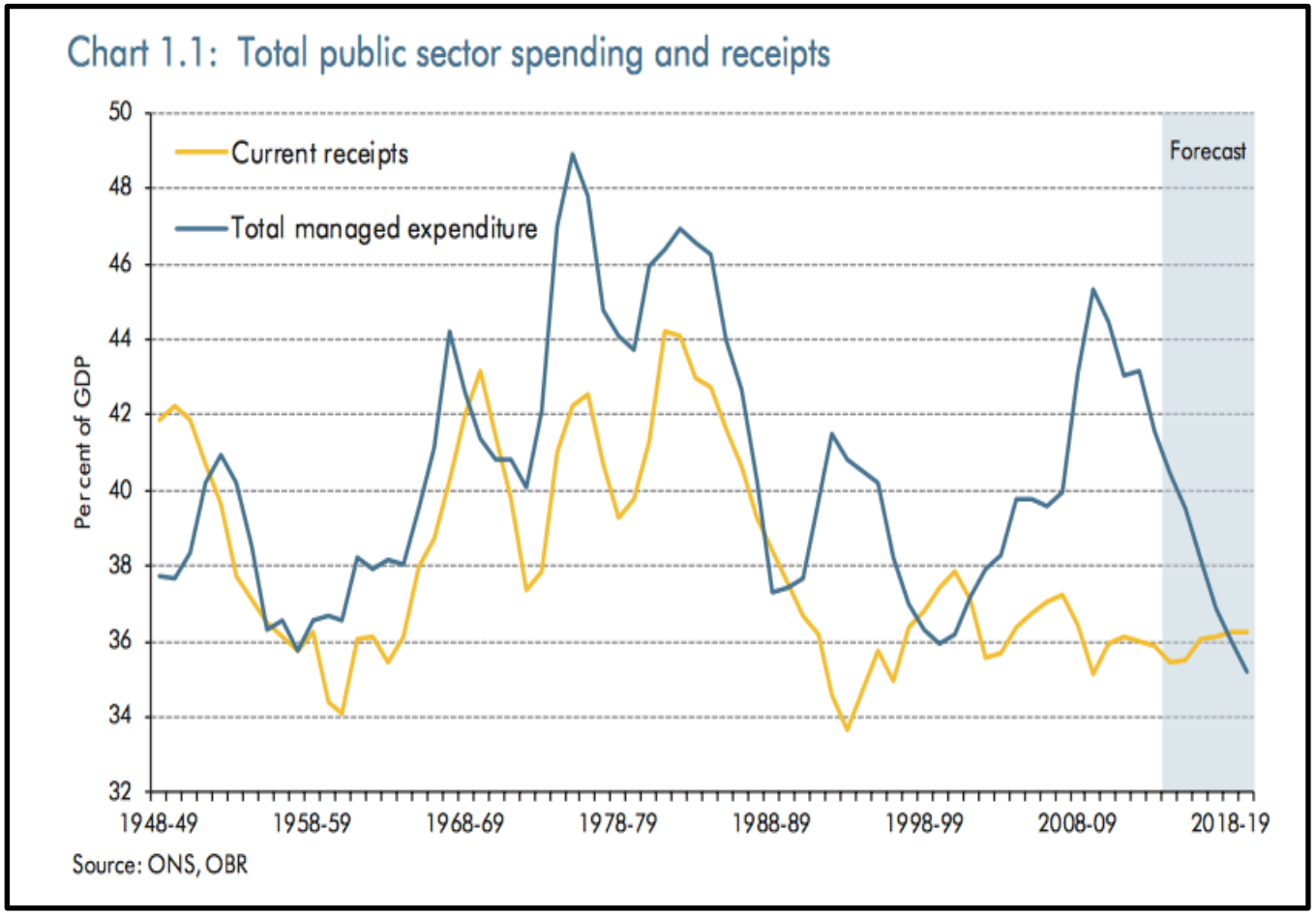
- Clinical Lead, Dementia Services Redesign (2010-2015)
- Clinical Director, OAMH and Community Services (2012-2015)
- Dementia Clinical Lead, NHS England SCN (2015)

The Context


How many of us were aged 60+ then, now and in the future?
1950
2012
2050
8%
11%
22%
The World: 204 million
The World: 810 million
The World: 2.03 billion
12%
22%
32%
High Income Countries: 78 million
High Income Countries: 244 million
High Income Countries: 395 million
5%
6%
11%
Low Income Countries: 10 million
Low Income Countries: 46 million
Low Income Countries: 175 million


1950
11.75 working age people to 1 aged 65+
2011
8.5 working age people to 1 aged 65+
2050
3.9 working age people to 1 aged 65+

Public spending to fall dramatically



Total public spending projected to fall to 35.2 per cent of GDP in 2019-20, taking it below the previous post-war lows reached in 1957-58 and 1999-00 to what would probably be its lowest level in 80 years.

Public spending and deficit reduction

The Headline Message
The prospect is one of immediate and substantial reductions in public spending for the next two years and beyond. NHS/Schools/Aid protected. Social care not protected.

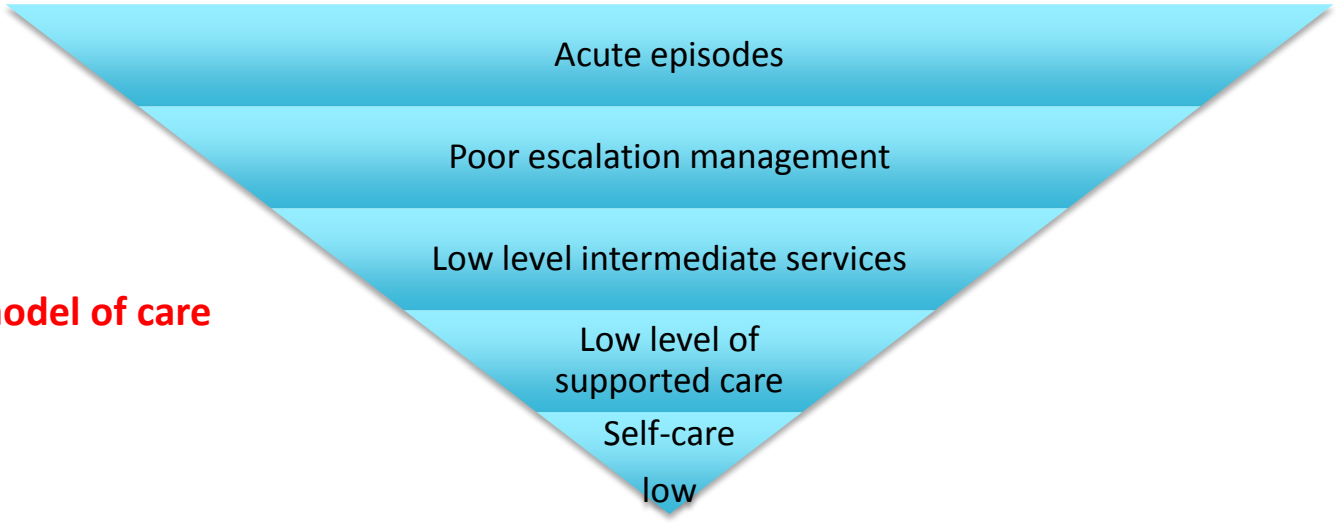
Social Care Funding Gap
300,000 fewer older people receiving social care per year in 2013/14 compared to 2010/11

NHS Funding Gap
- Financial pressure from growing and ageing population
- £30bn gap by 2021
- Close gap through 3% efficiencies
- But previous average 0.8%
- £8bn extra for NHS but no extra for social care

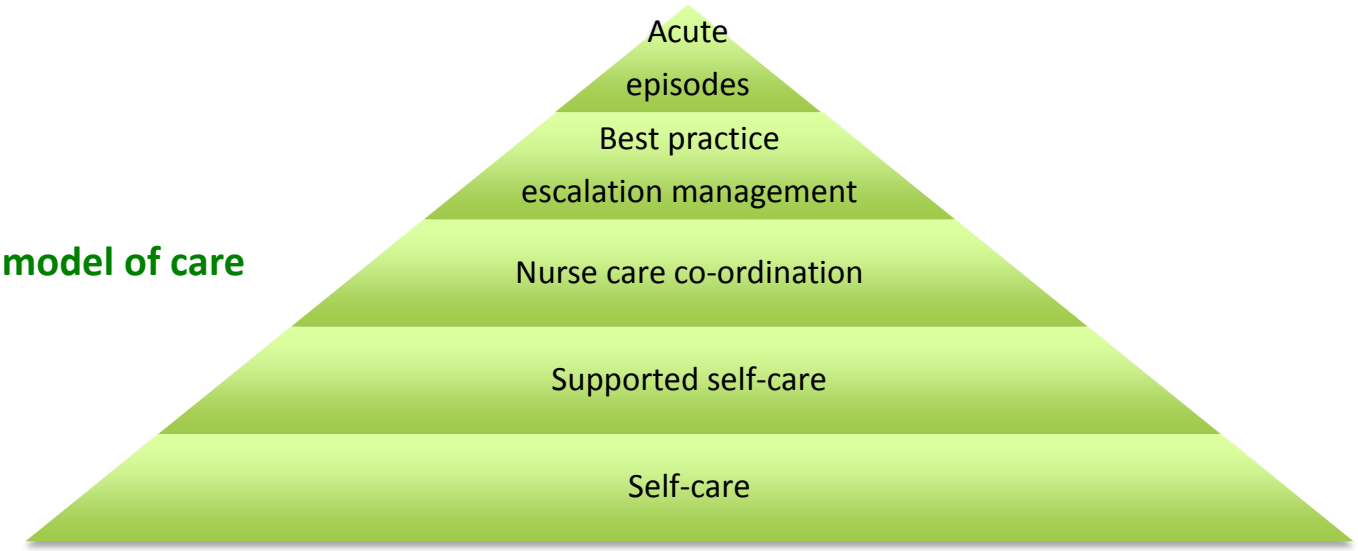
Older people
- 65% of public spending on benefits is focused on older people = £100bn pa
- Cost of health services for 85+ is three times greater than for 65-74
- Added spend of £10 billion per year for every additional one million people over working age

Consensus: invert care pyramid: better outcomes at lower cost

Existing model of care



Future model of care



New NHS Priorities (1)

New approaches to improving care

1. Radical upgrade in prevention and public health – obesity, smoking, alcohol and major health risks
2. Patients to have more control over their own care including:
   - Shared health and social care personal budgets
   - New support for carers
   - NHS working with voluntary organisations
3. Break down barriers between providers:
   - Family doctors/hospitals
   - Physical/mental health
   - Health/social care
   - More care delivered locally/some services in specialist centres

New NHS Priorities (2)

New approaches to reducing costs to deliver 3% annual efficiencies

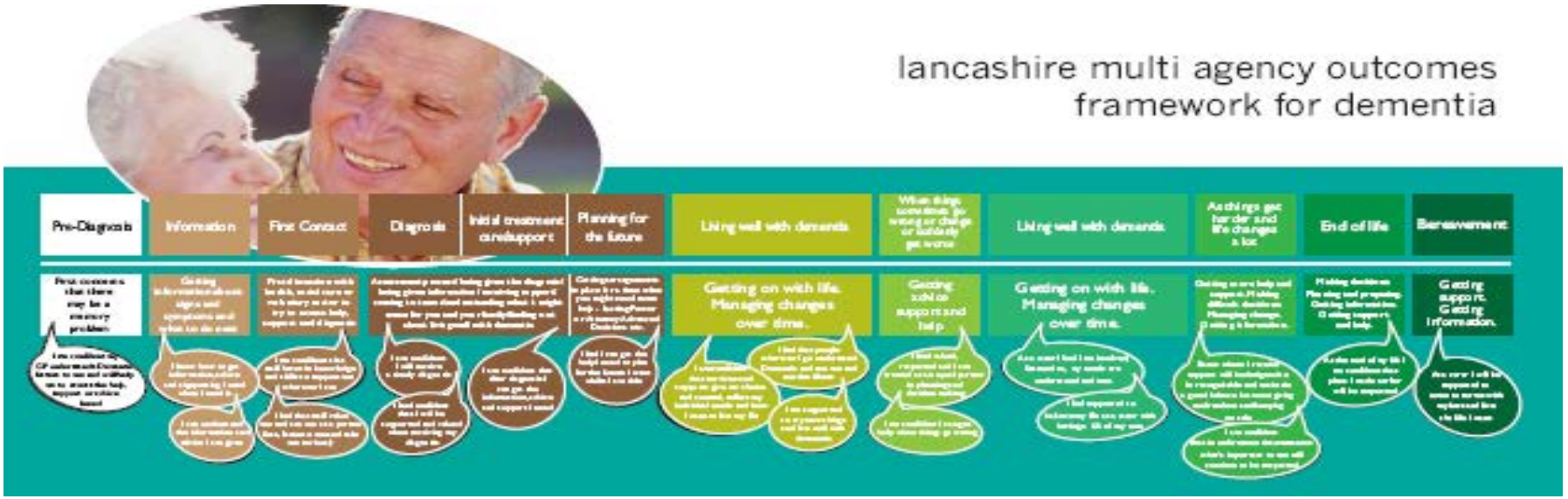
- Prevention to reduce demand for NHS services
- New care models to reduce costs and shift care closer to home
- Sustaining social care services to keep people independent and well in their own homes
- Wider system improvements that lower average cost of care per patient

New care models

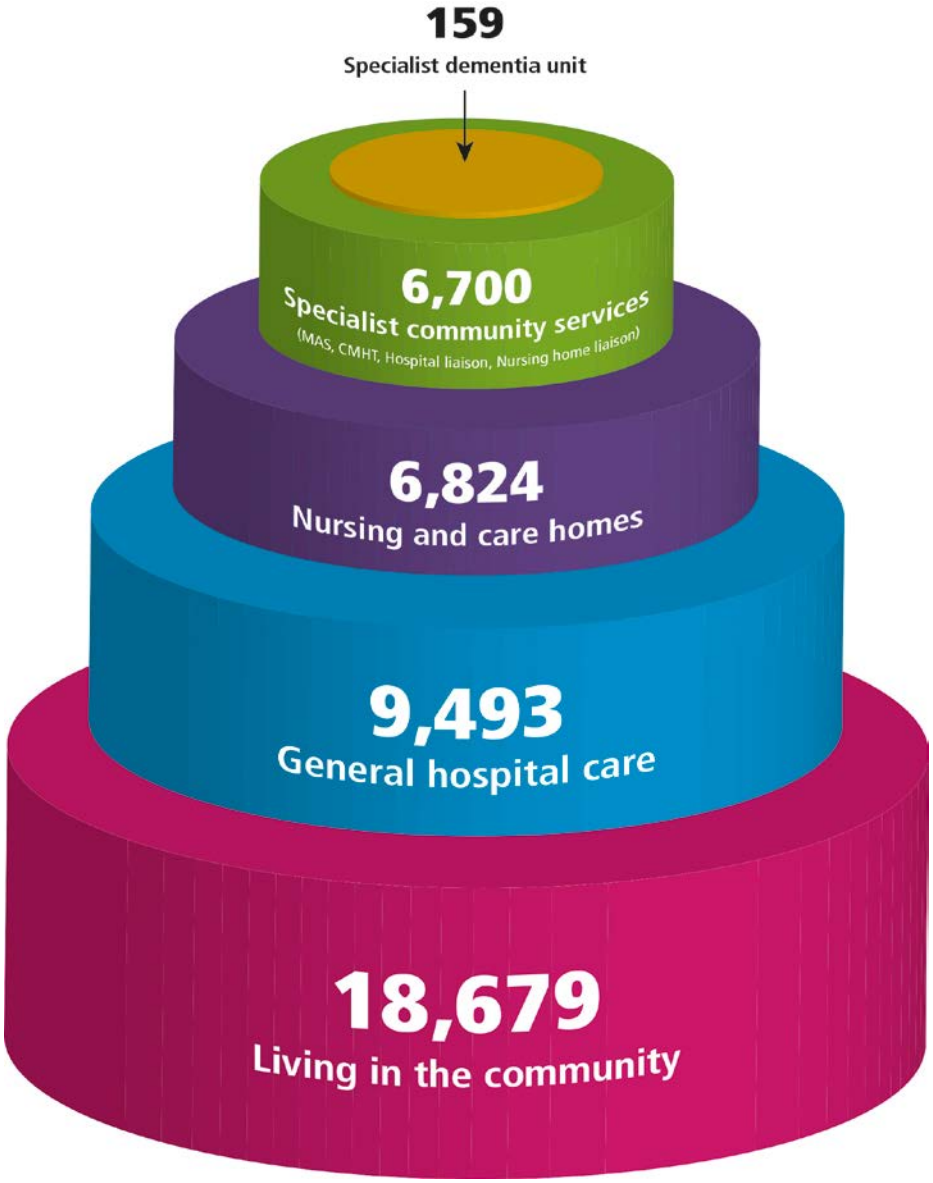
- New Multispeciality Community Provider organisations (MCPs)
- Integrated Primary and Acute Care Systems (PACS)
- Viable smaller hospitals
- Primary care – new deal for GPs – as foundation of NHS
- Enhanced health in care homes
- Integrated personalised commissioning + year of care

The meaning to People with dementia

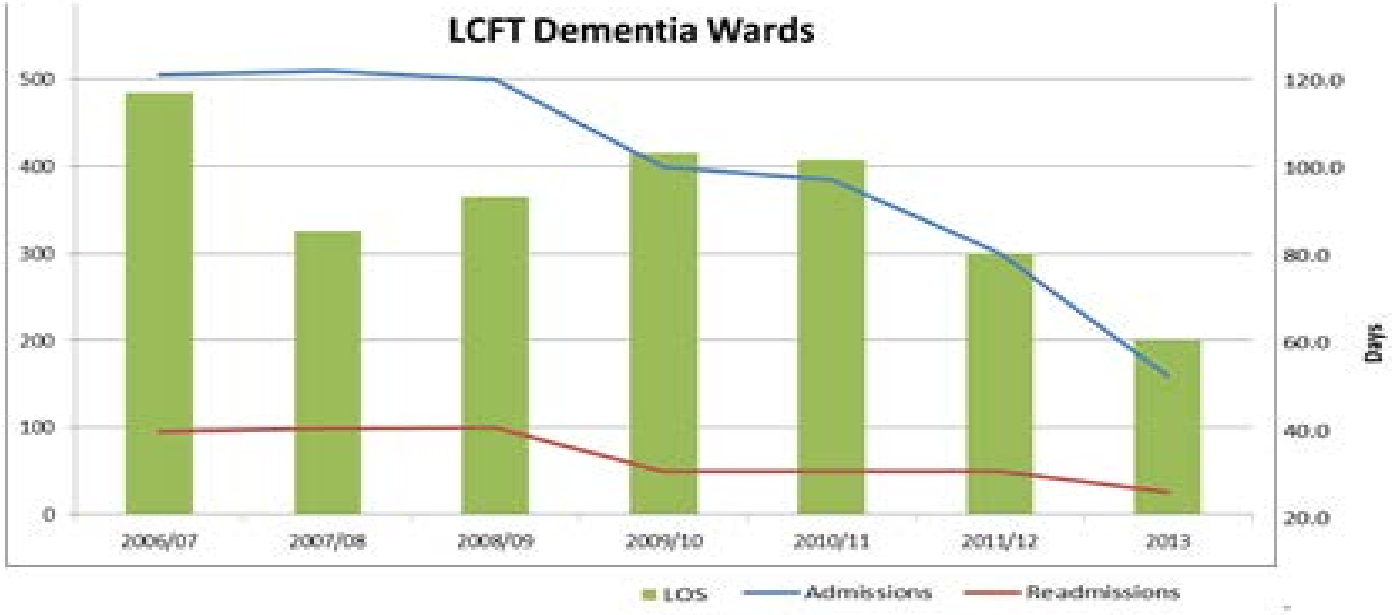
- **Understanding views of users and carers**
- **20 outcomes from pre-diagnosis to bereavement - some examples:**
  - **I am confident I will receive a timely diagnosis**
  - **I feel valued and supported and I am treated as an equal partner in planning and decision making.**
  - **I am confident I can get help when things go wrong.**
  - **As a carer I feel I am involved, listened to, my needs are understood and met.**
  - **I am supported to try new things and live well with dementia.**



Dementia in Lancashire



*Fewer **people** are spending time on dementia wards*



Consultation – Agreed single site option

Community health services:

- Closing the diagnosis gap
- Foundation of specialist community care
- Rapid Intervention and treatment Teams
- Specialist Assessment & advice for acute hospitals

Specialist hospital services:

- 30 dementia beds at ‘The Harbour’ in Blackpool

Key themes - Lancs Case for Change

- Promote the importance of diagnosis, challenge the stigma and myths and share the opportunities to 'live well with dementia'
- Develop the skills and knowledge of staff in all care settings to drive up quality
- Improve and increase ongoing support and respite options for carers to aid resilience
- Develop community infrastructure to delay the need for longer term formal support or admission to hospital services
- Improve the co-ordination of support services and consider the integration of teams and opportunities for co-location

Key themes – Lancs Case for Change

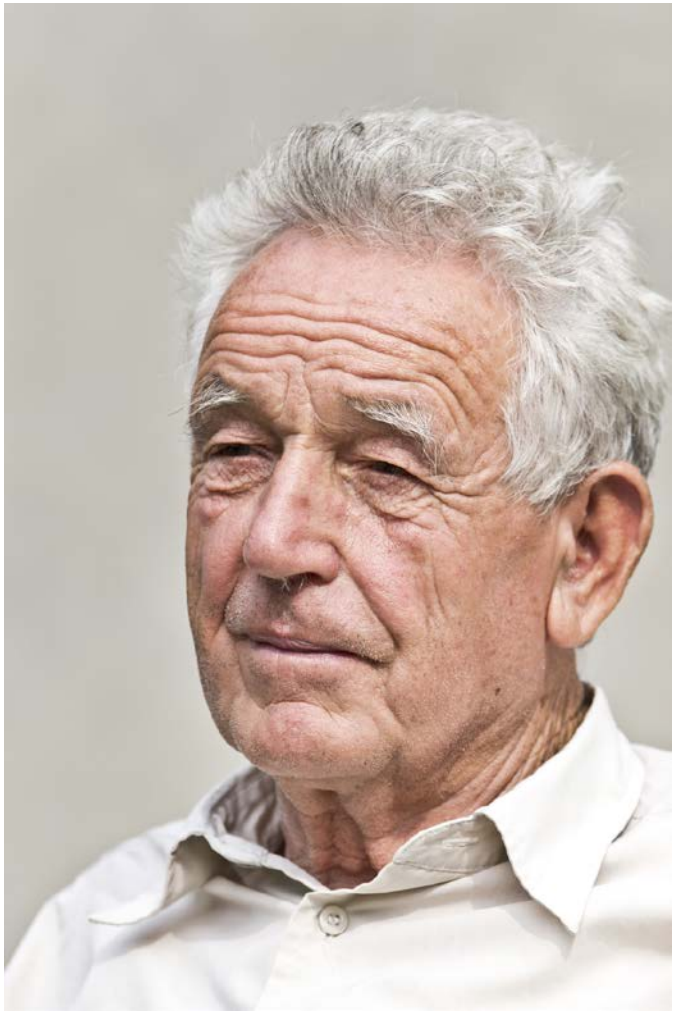
- Commit to the review of antipsychotics and the use of non-pharmacological as the first-line treatment
- Drive up quality of care following admission to general acute care
- Increase the use of assistive technology
- Improve environments across all service settings
- Collect data systematically and understand the intelligence

- Link to the Google View page for the Harbour:

https://www.google.co.uk/maps/place/The+Harbour/@53.799146,-2.989021,3a,75y,69.61h,90t/data=!3m4!1e1!3m2!1s5pSkEW8lZUMAAAQpjCtdWw!2e0!4m2!3m1!1s0x0:0xb881816b5ef3cb1a!6m1!1e1

Harold's Story

- Harold, 72
- Diabetes, Heart disease
- Stroke 3 months ago
- Personality change after stroke and paranoia
- Refuses help from family and assessment from professionals
- Physical aggression
- Combination of physical risk, psychotic symptoms, lack of insight and unwillingness to engage in assessment results in admission under MHA



Winnie's Story

- Winnie, 80
- Alzheimer's dementia for 4yrs in rest home
- Now agitated, wandering, losing weight
- GP assessment and referral to mental health services
- Treatable aspects identified
- Psychological understanding of behaviour
- Environmental and Care plan changes supported
- Best achieved in current environment with those responsible for her long term care

Anne’s Story

- Anne, 90
- Arthritis
- Mixed Dementia
- Diagnosed 6 years ago
- Supportive family
- Refuses most home help but determined to stay at home
- Fall 3 years ago and acute hospital recommended a care home to family (not taken up)
- Anne has had several ‘incidents’ – times of paranoia, the fall, wandering
- A combination of Specialist mental health community support, DNs, GP, friends and relatives have supported her in her own home
- Anne still lives in her own home

Lancaster University

SAMS

Software Architecture for
Mental Health Self-Management

Pete Sawyer
Professor of Software Systems Engineering
School of Computing and Communications
Lancaster University

Partners:

The University of Manchester

King's College London

Alzheimer's Society — Leading the fight against dementia

DeNDRoN — Dementias & Neurodegenerative Diseases Research Network

EPSRC *working together* project EP/K015796/1

Dementia in the UK

- c. 900,000 people affected in the UK
  - Projected to reach over 1 million by 2021
  - Annual cost currently c. £23 billion
- Only 44% of people receive a diagnosis
  - Diagnosis is often late

- Being able to monitor the progression of dementia from the early 'preclinical' or 'prodromal' (e.g. MCI) stage is of potential benefit for prognosis of how the condition is likely to develop
- It also opens up the possibility of intervening with disease-modifying therapies, which may slow the progression

What SAMS does

- SAMS monitors people as they use their home computer
- SAMS looks for signs of cognitive decline over time
- If decline is consistent with decline from healthy to MCI or early dementia SAMS will prompt the user to take a follow-up test and/or see their GP

Why monitor computer use? (1)

- When we use a computer, we use a range of cognitive domains
  - Motor control; executive function; memory recognition & recall; language; visio-spacial reasoning
- The development of dementia will lead to deficits in at least some of these same cognitive domains
  - Typically these are what are tested at a memory clinic by (e.g.) Mini Mental State Examination (MMSE)
- So, if we are finding it harder and harder to use our computer, it *might* be because our cognitive health is declining

Why monitor computer use? (2)

- Opportunism: it's increasingly normal for older people to use a computer for keeping in touch with family, shopping, banking, etc.
- It gives us ecological validity if we simply monitor peoples' routine, daily use of their computer.
- We hope it will help persuade people to refer themselves to their GP who might otherwise not have done so.

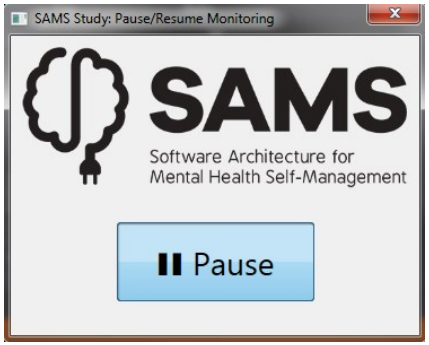
The challenge

- Instrumenting the computer to collect user data
- Interpreting the collected data in terms of cognitive health
- Validating SAMS' interpretation
- Overcoming the barriers to adoption

Instrumenting the computer (1)

- This means writing software that collects data as the user interacts with their computer

  - It needs to be completely unobtrusive
  - But the user needs to be aware that they are being monitored, so they can turn it off if desired

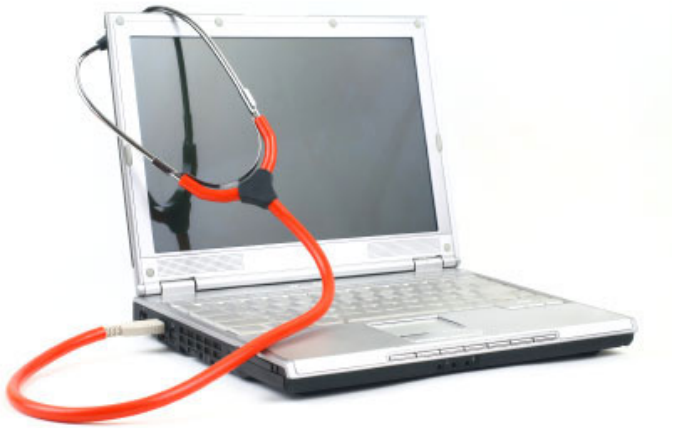


Instrumenting the computer (2)

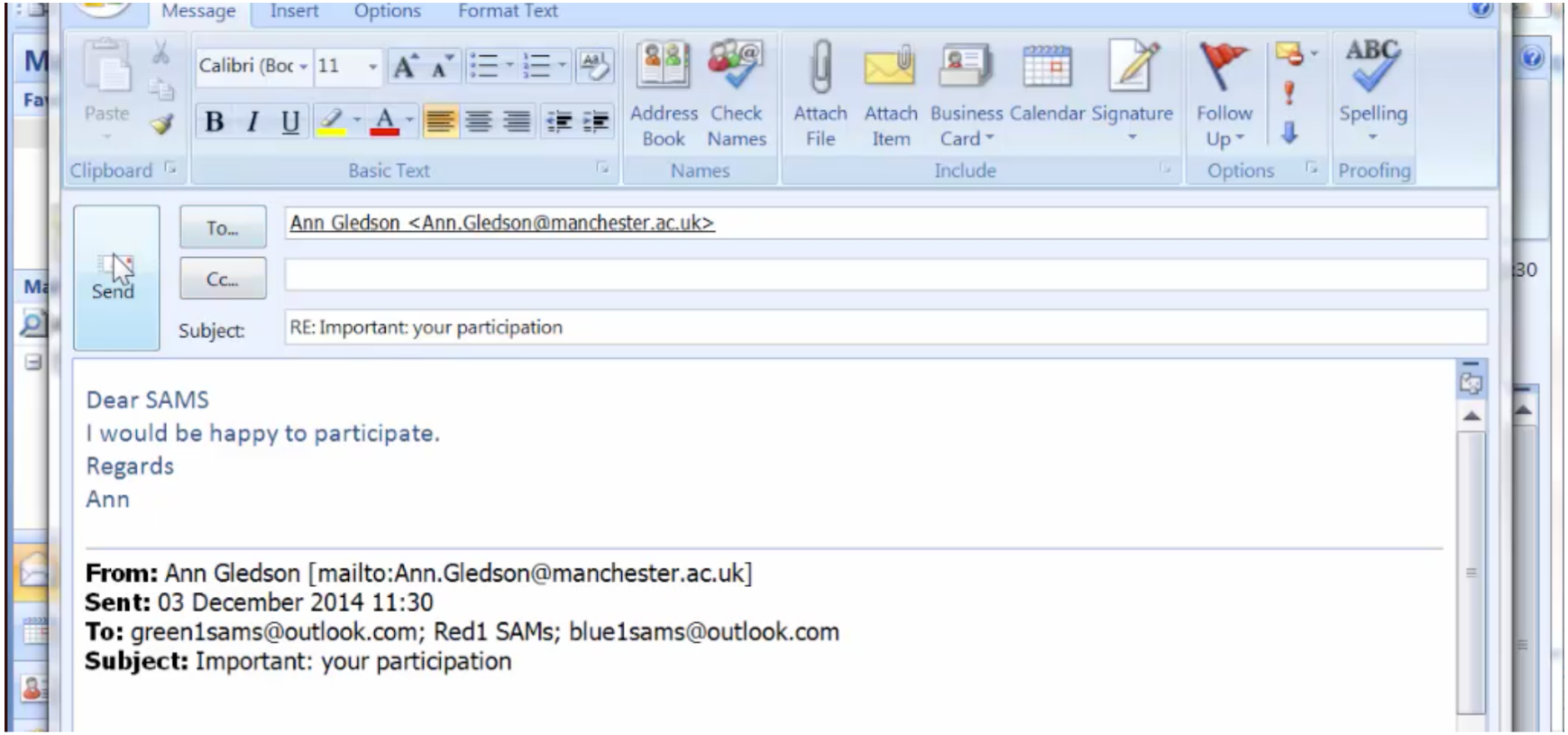
- What do we instrument?
  - The operating system for general housekeeping activity (MS Windows 7, 8, 10)
  - Microsoft Office applications (Word, Outlook, Excel, ..)
  - Browsers and webmail (IE & Gmail)

Instrumenting the computer (3)

- What do we collect?
  - A range of stuff, e.g.:
    - Mouse moves, tracking the cursor as the user moves it from one part of the screen to another
    - Selection, drag, resize actions
    - Authored text



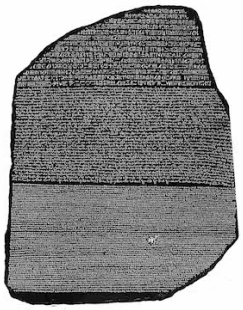
Instrumenting the computer (4)



Interpreting the data (1)

- We need to collect data that tells us something about the health of the user's different cognitive domains.
  - e.g. we can collect mouse-movement data, but what does that tell us about motor control, executive function, etc.?
  - Can we get enough data? Can we get sufficiently frequent data?
  - Can we infer user intent?

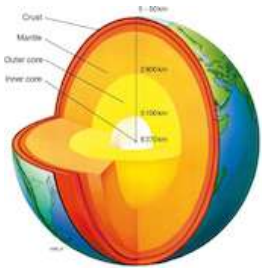
Interpreting the data (2)



- For example:
  - Easy(ish)
    - Reduction in vocabulary, idea density - **language**
    - Hunting for commonly-used menu items - **memory**
  - Not so easy
    - Failing to complete common sequence of tasks, e.g. email - **Memory** or **executive function** or **both**?
      - [reply, compose, but no send] OR [reply, no compose, send]
- Needs
  - Expert reference group to help us identify the most fruitful user actions to data-mine
  - Uncertainty inference
  - Post-hoc mining of data looking for patterns

Validation

- Small-scale pilot study (c. 10 ppl)
- Cross-sectional study (30 MCI/early AD, 30 healthy controls. All 65+)
  - In lab, identical computer set-up, paper-based test battery then set of computer tasks
- Longitudinal study (12 months, c. 60 ppl All 65+)
  - SAMS software installed on participants' home computers; data (anonymized & encrypted) uploaded periodically to LU



Barriers to adoption

- Why would anyone want to run SAMS?
- How can they be sure we won't (e.g.) read their passwords?
- If SAMS thinks there's something wrong, how can we get the user to take action?

Thanks for listening

Drugs developed to treat diabetes show effects in Alzheimer's and Parkinson's disease

Prof. Christian Hölscher, PhD
Biomed and Life Sciences
Faculty of Health and Medicine
Lancaster University, UK

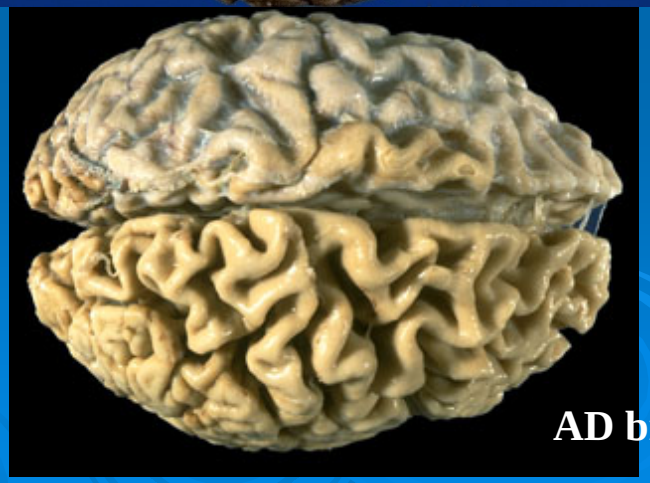
Alzheimer's & Parkinson's Trust - NorthWest

Lancaster University

Alzheimer's & Parkinson's Trust - NorthWest

Alzheimer's disease

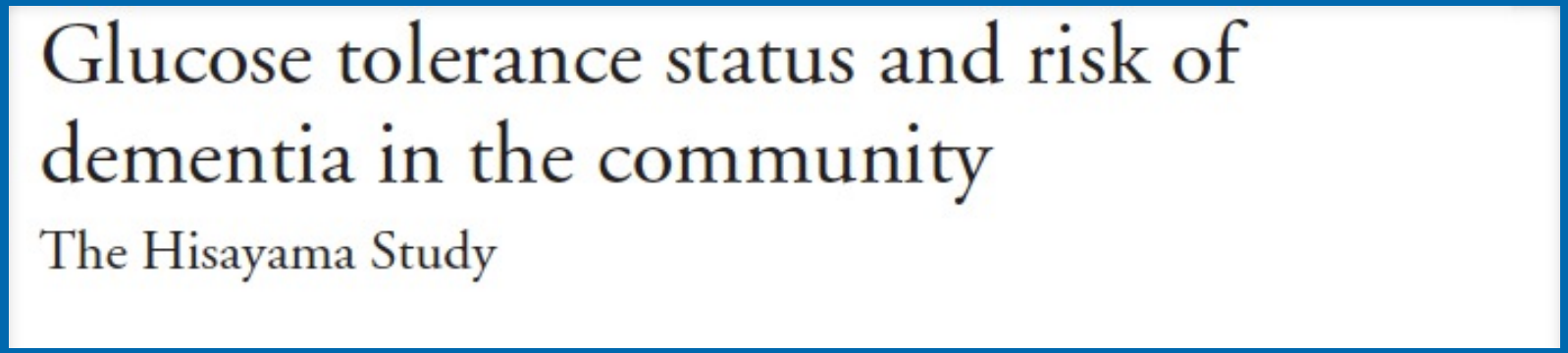
- Pre-morbid dementia, 50-60 years of age
- Memory loss, desorientation
- Brain shrinkage, large loss of neurons
- Histology: 'plaques & tangles'



What causes Alzheimer's?

- few genetic links
- 'sporadic' onset
- Risk factors are known:
  - high blood pressure
  - head trauma
  - high cholesterol
  - diabetes

Diabetes – Alzheimer's disease



Neurology, 2011, 77:1126-1134

Type 2 Diabetes sufferers have a 80-100% increased risk of developing AD

Diabetes- a risk factor in Alzheimer's disease

- Insulin not only acts as a hormone to regulate blood glucose
- Insulin acts as a growth factor in all tissues
- Protects neurons from stress
- Enhances neuronal cell repair

- Insulin loses its effects in the brains of Alzheimer patients

Diabetes- a risk factor in Parkinson's disease

- Insulin de-sensitisation the brains of people with Parkinson's disease
- Reduce dopamine release in the brain
- Higher numbers of diabetic people in PD patients compared to age-matched controls

Novel strategies for treatments

- Novel drugs that prevent the de-sensitisation of insulin signaling in diabetes could be used to treat AD and PD
- Making use of the findings from diabetes research
- Prevention of neurodegeneration at an early stage

Promising diabetes drugs

- Currently on the market to treat type 2 diabetes:
- Twice daily: exendin-4 (*Byetta*®)
- Once daily: Liraglutide (*Victoza*®), Lixisenatide (Lyxumia®)

Liraglutide is neuroprotective

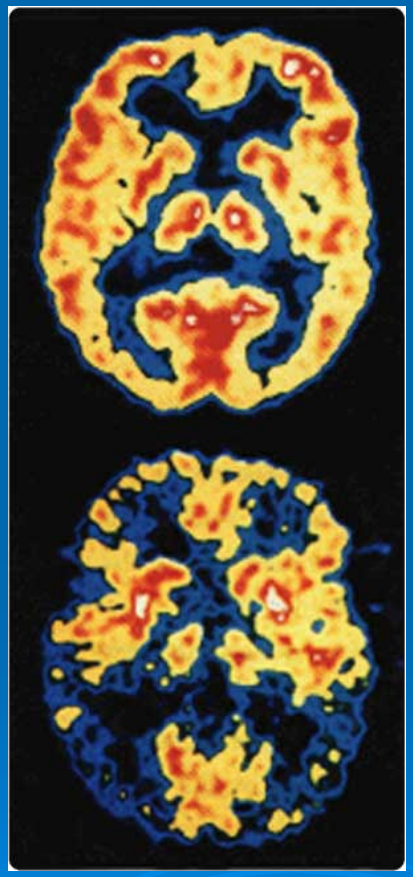
- The drug can cross into the brain (blood-brain barrier)
- Protects neurons in cell culture from oxidative stress
- Protectes learning and memory in animal tests

Liraglutide reverses insulin desensitisation in people with Alzheimer's disease

- Analysing the brains of people with AD showed that liraglutide reverses the loss of insulin signaling
- Brain activity and metabolism can be normalised

Talbot et al., 2012

Brain imaging: Neuronal metabolism is compromised in AD



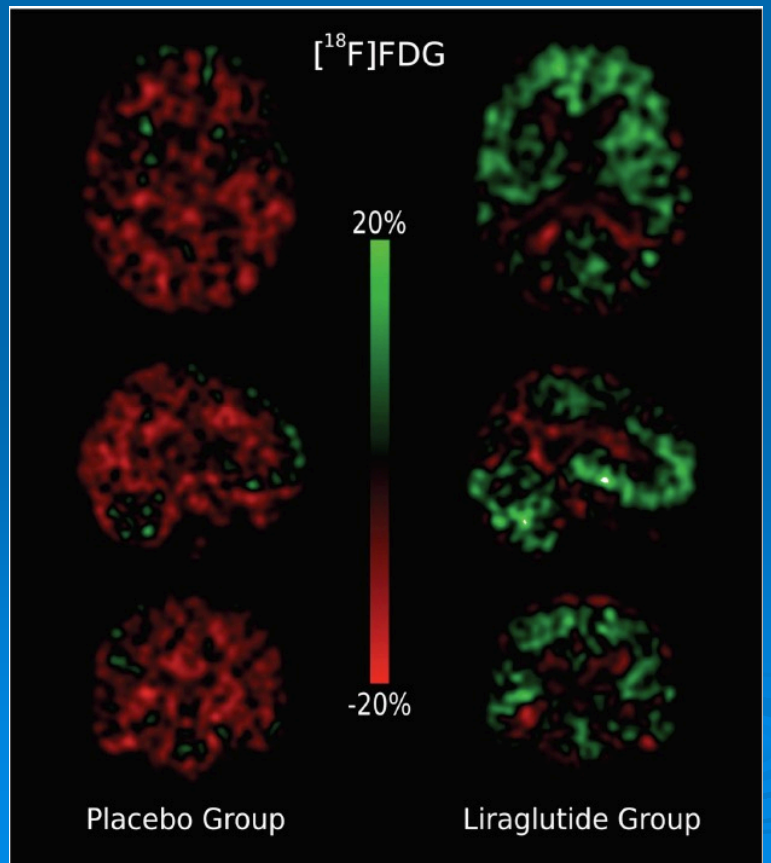
control subject

AD patient

In ^{18}FDG-**PET** imaging in AD patients, neuronal metabolism in the brain is visibly impaired.

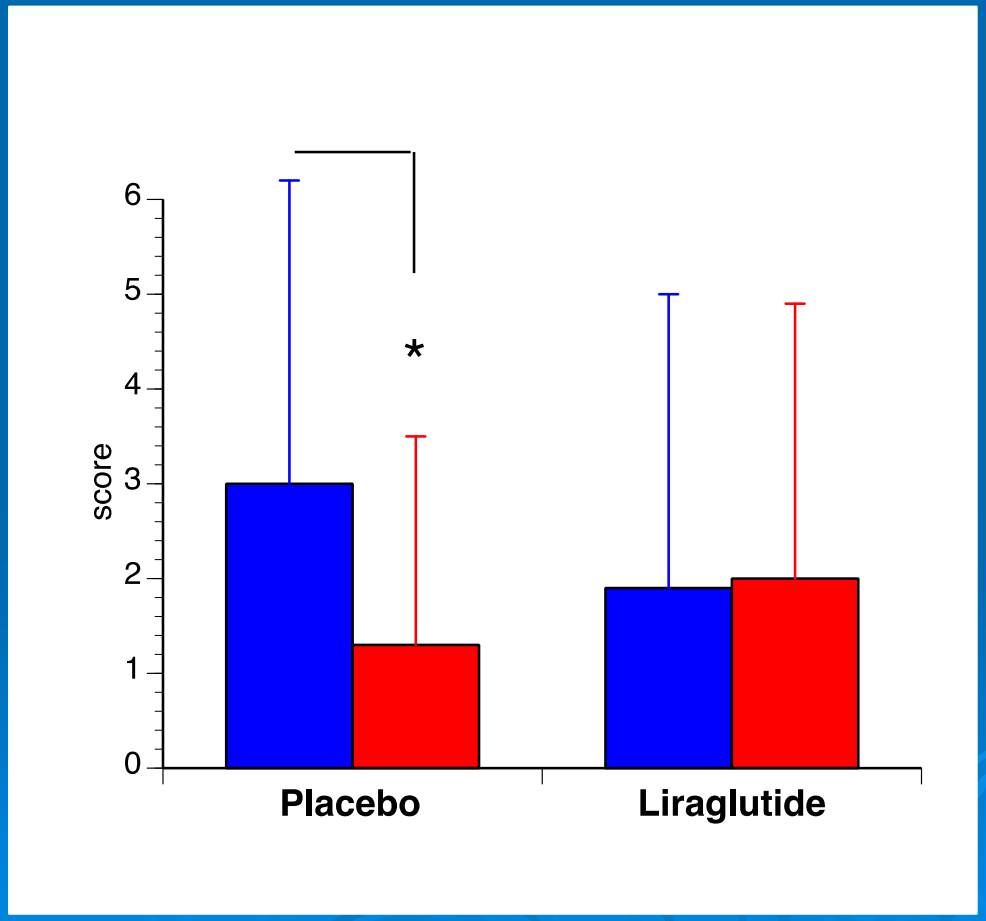
Liraglutide reverses this!

In a pilot clinical trial, liraglutide prevented the decrease of brain activity and energy metabolism!



M. Geijl et al., 2015

Cognition is stabilised



Gejl et al., 2015

Our clinical trial, testing liraglutide in AD

- Testing liraglutide in Alzheimer's patients

  Takes place at the Hammersmith hospital, London

  206 patients, placebo controlled study, 12 months duration

  Funded by the Alzheimer's Society and the ADDF

Motor Neurone Disease

- Motor Neurone Disease is a progressive degenerative disorder of motor neurones
- About 6,000 people in the UK have it
- The only available drug is riluzole, which only extends life expectancy by 3-5 months
- Little improvement in day-to-day activity and muscle strength
- A great need for new treatments that stop disease progression

A clinical trial in MND

- Testing liraglutide in patients with MND
- At Preston Royal Hospital
- Donations currently at £100,000
- £450,000 will be raised in total
- Projected starting date early 2016
- Will run for 18 months

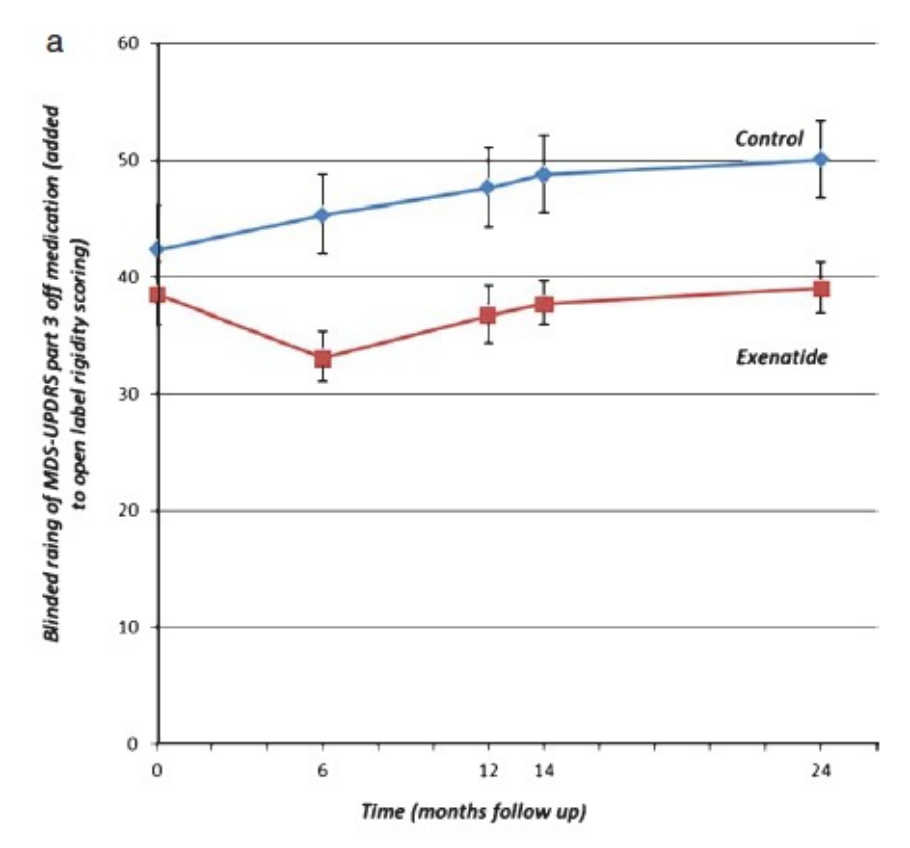
Clinical trials in Parkinson's disease

A clinical trial of Byetta in Parkinson's disease

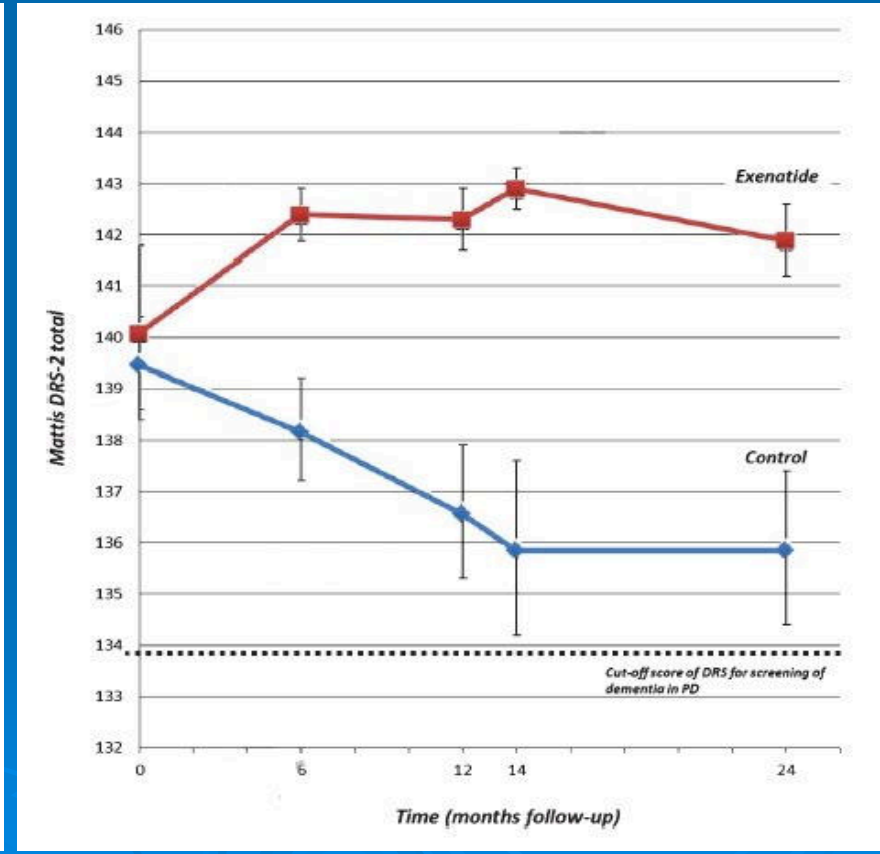
- 45 patients, open label pilot study
- Conducted at University College London
- Showed improvements in motor activity and in cognition

Major improvements found

Motor skills



Cognitive performance



Aviles-Olmos et al., 2013

A clinical trial of Liraglutide in Parkinson's disease

- 100 patients, placebo controlled
- Conducted at Cedars-Sinai hospital, L.A.
- Starting January 2016
- Funded by the Cure Parkinson's Trust, UK and the Michael J Fox foundation

Alzheimer's & Parkinson's Trust - NorthWest

We are a group of scientists working at Lancaster University who are developing promising new drug treatments

Please support our research and donate generously to make both Alzheimer's and Parkinson's disease history

Trustees:
Prof. Christian Holscher
Prof. David Allsop
Dr. Ed Parkin
Dr. Neil Dawson

Alzheimer's &
Parkinson's
Trust - NorthWest

Contact us on Facebook or on www.APT-NorthWest.org

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Lancaster University

Eye Gaze: A New Tool in the diagnosis of Alzheimer's disease

Alzheimer's Disease: The Diagnostic Problem

- Psychological Diagnosis, rests on gradual decline of short term memory.
- By the time this appears, brain damage is too severe to be reversed or halted.
- Currently no medication is able to reverse or slow down damage, probably **too late**.
- **Urgent** need for **early** diagnostic markers

Dementia: A Global Problem

- Many western psychological tests are NOT suitable for developing countries.
- Urgent need for valid diagnostic tests across cultures.

Somewhere in the world, someone develops Alzheimer's every 7 seconds

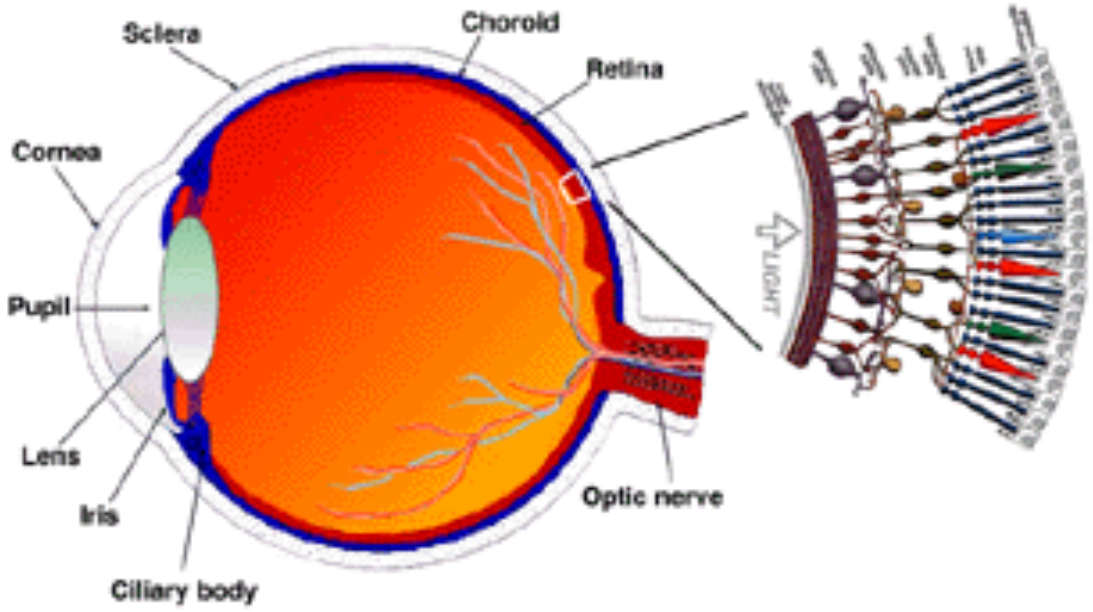
Lancet. Dec. 2005

Eye gaze:
A new approach:

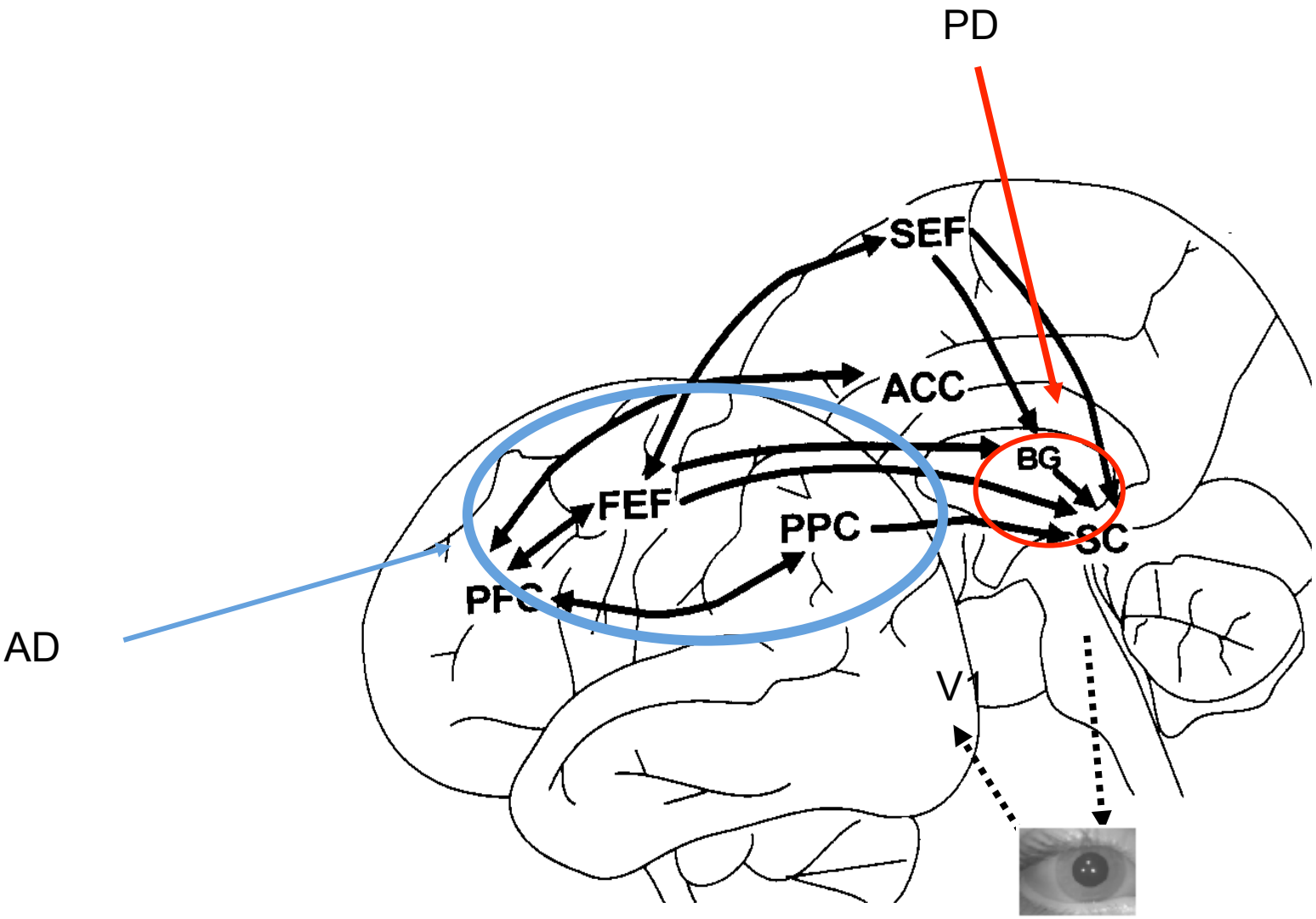
Why do we move our eyes? Photoreceptors are not equally distributed on the retina

EXAMPLE Can you discriminate these letters?

COD COD



Saccadic eye movements are control by subcorticical and cortical networks



The mind in the ‘Eyes’:

- Where you ‘look’ reflects where you attend, and is the gateway to information flow to the brain.

- Most of human behaviour is controlled by what we see.

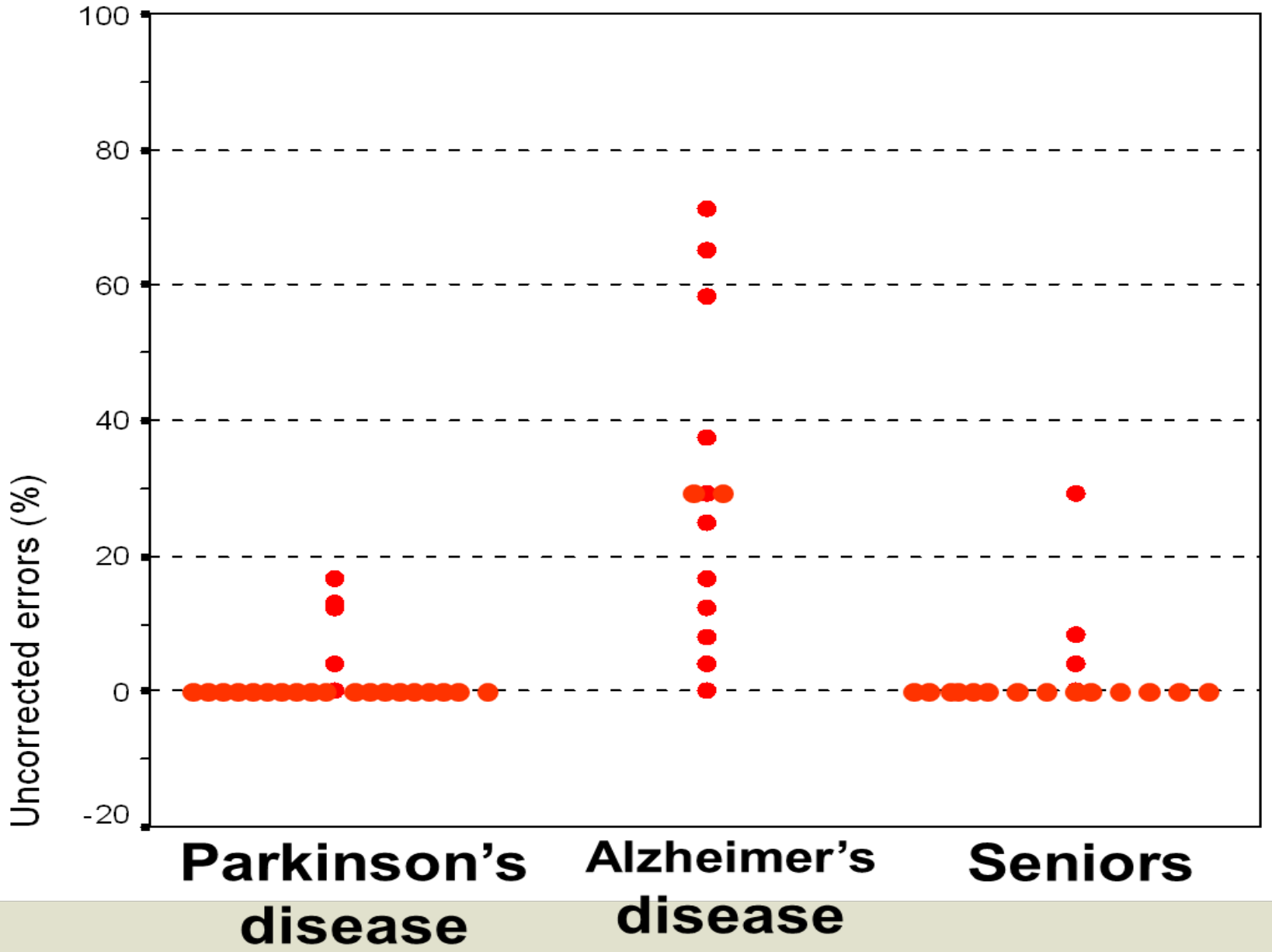
Research Questions

1. **Can tests of saccadic eye movements detect dementia in the early stages of Alzheimer's disease?**

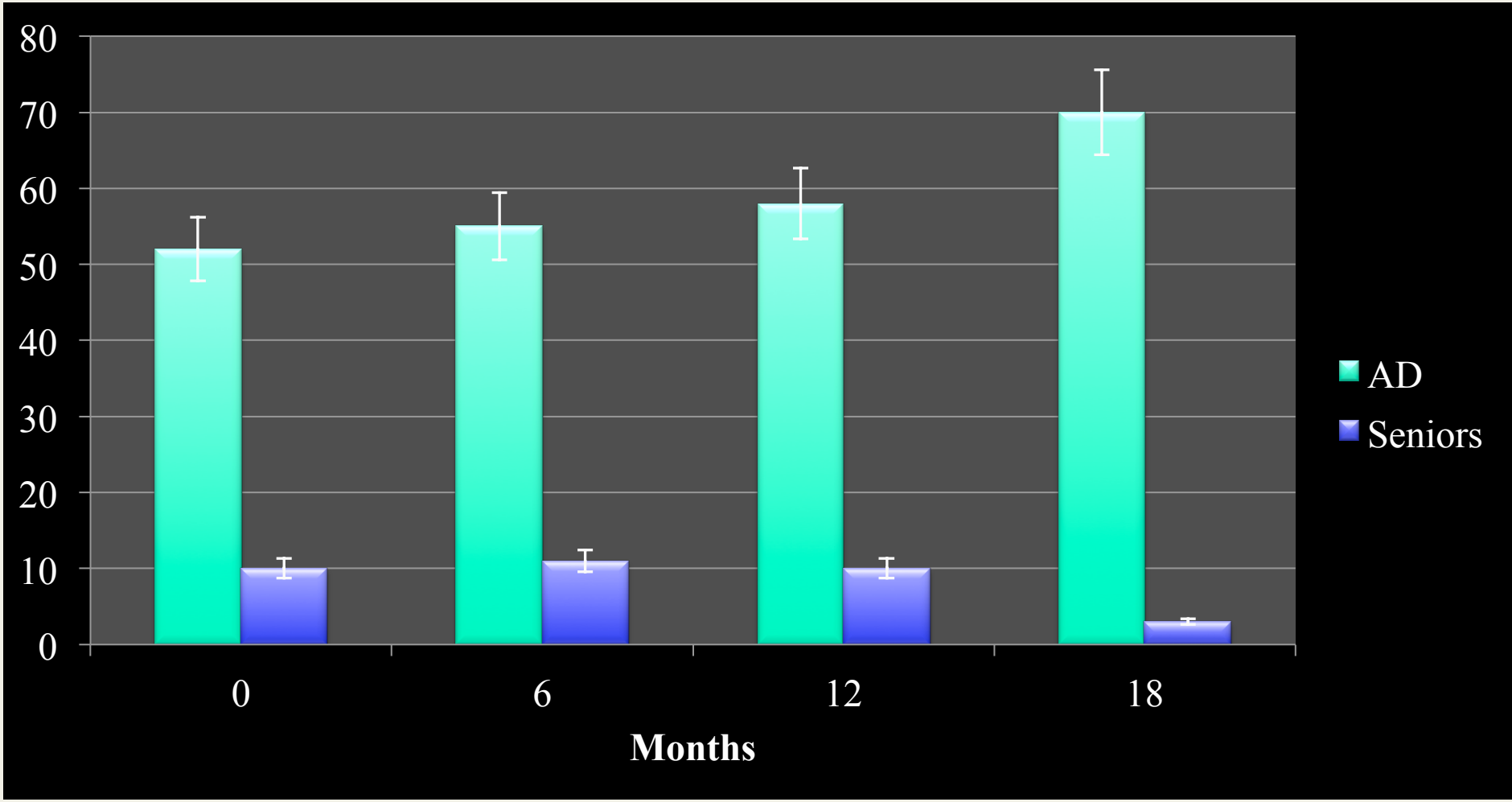
2. **Can these tests provide a measure of the severity of dementia as the disease progresses?**

3. **Are the disease effects distinct from normal aging?**

Uncorrected errors (%)



Inhibitory Errors: Group Data The Longitudinal Study:



MODEM project
Eye gaze: in the home

Is it possible to diagnose & monitor dementia by monitoring eye gaze while you are watching a TV?

EPSRC MODEM Lancaster University & Manchester University colleagues
Sawyer, Gellersen, Kwang, Leroi, Wilcockson, Shukla, Devereaux, Kelly.

Acknowledgements

- **Colleagues: Drs Ira Leroi, Steve Higham, Ted Renvoice, Mark Dale, Julie Patel, Jenny Mayes, Ivonne Solis-Trapala, Pete Sawyer, Hans Gellersen, Alex Deveraux, Claire Kelly, Thom Wilcockson**

- **Funders: Lancaster University, Sir John Fisher Foundation, Lytham League of Friends, Lancashire Teaching Hospital, Novartis, EPSRC**

Defying Dementia:
From Compound to Clinic

Dr Penny Foulds

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MAC

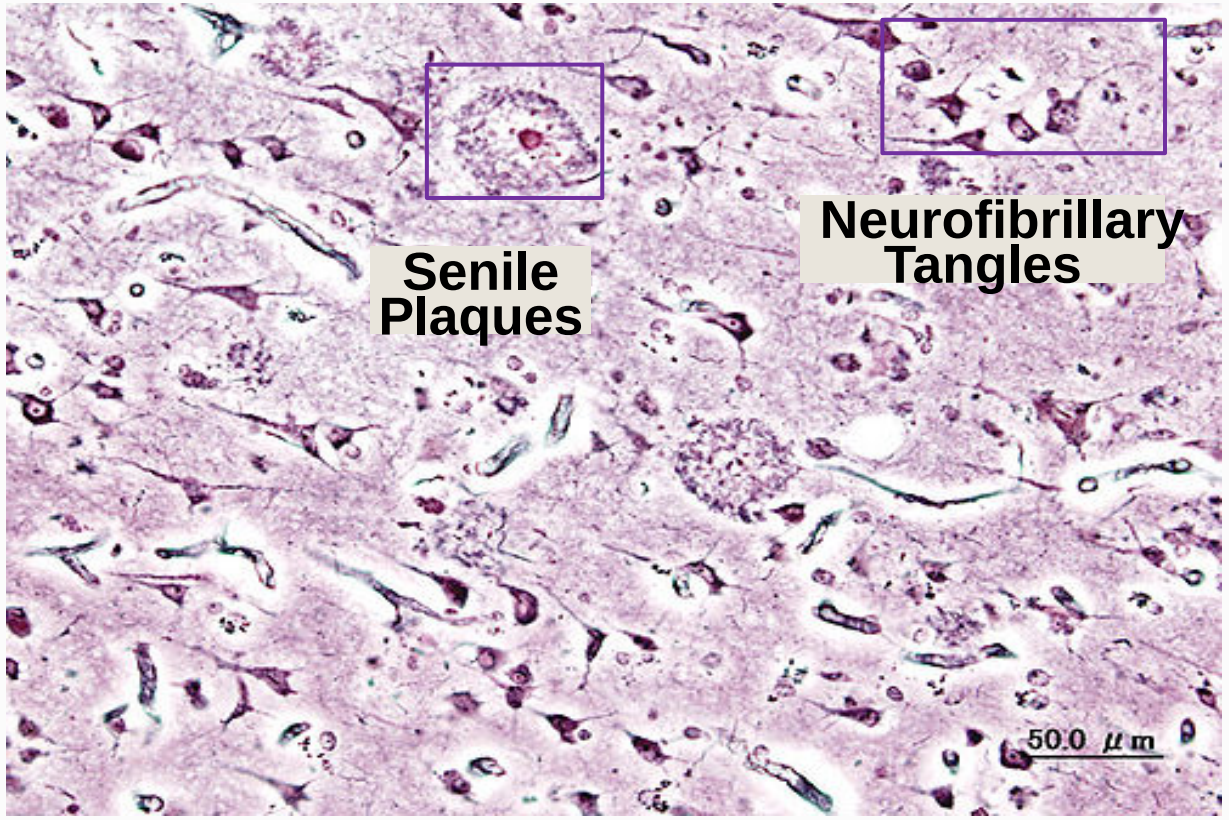
Lancaster University

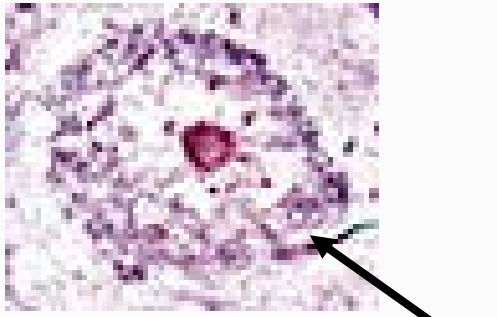
#defyingdementia

Defying Dementia

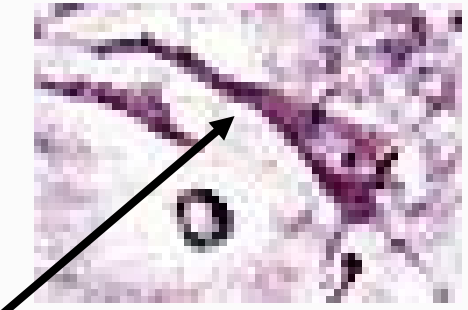
Pathology of Alzheimer's

Electron microscope image of an amyloid fibre



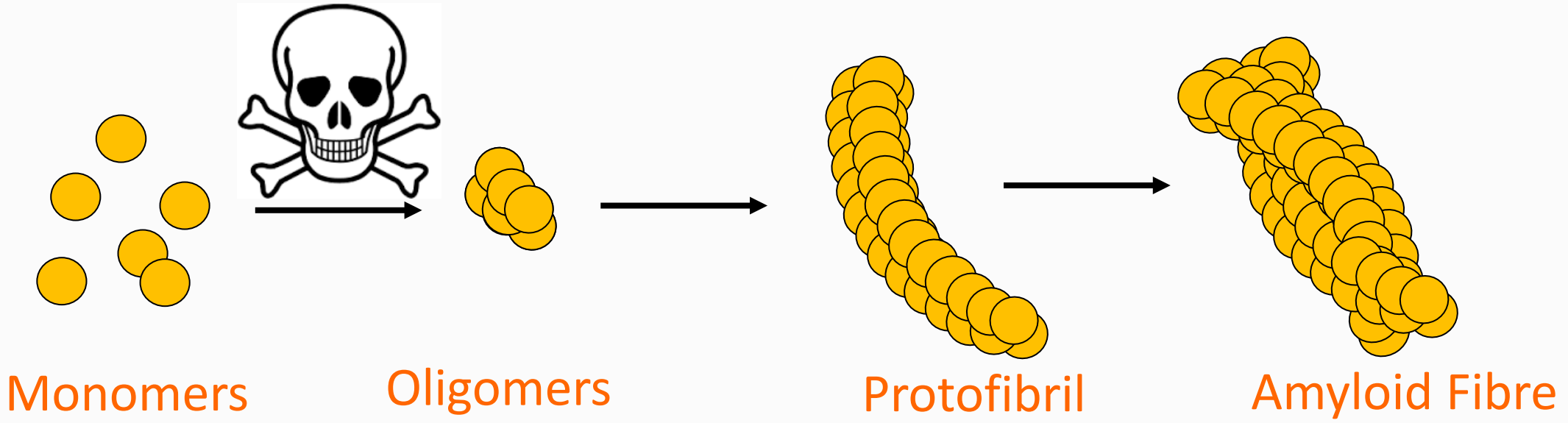


Fibres outside nerve cells made of **beta amyloid**

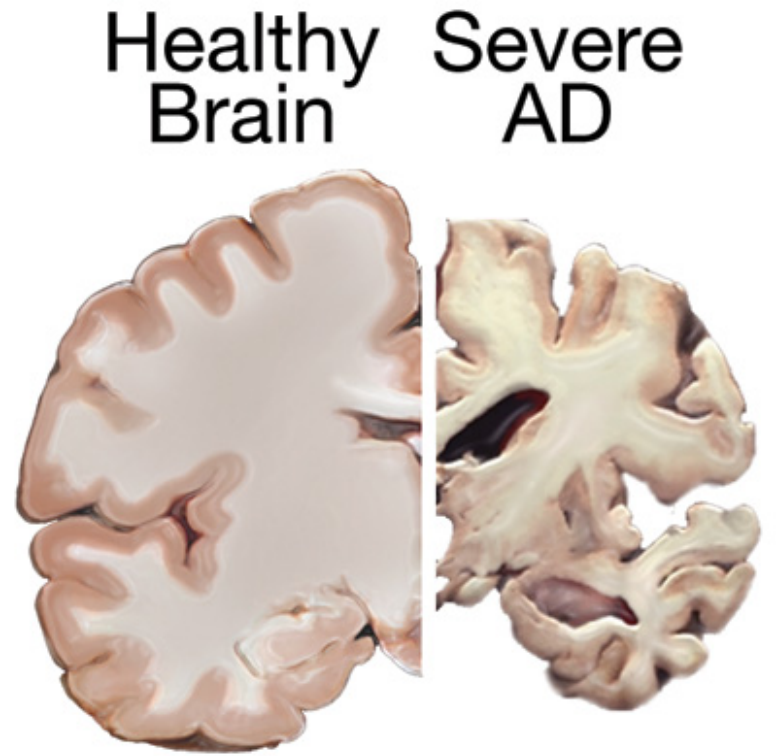


Filaments inside nerve cells made of **tau**

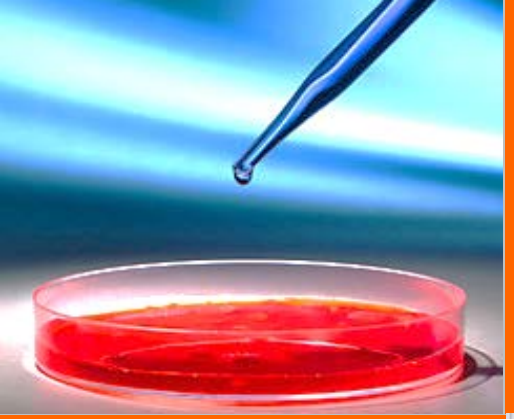
Beta-amyloid molecules form harmful fibres:



Pathology of Alzheimer's



Disease progression → Substance build up → 'Senile plaques' & 'tangles' → Loss of nerve cell connections → Nerve cell death → Loss of brain tissue





Our Work at Lancaster University

1. Determining the mechanism of toxicity caused by the beta-amyloid proteins

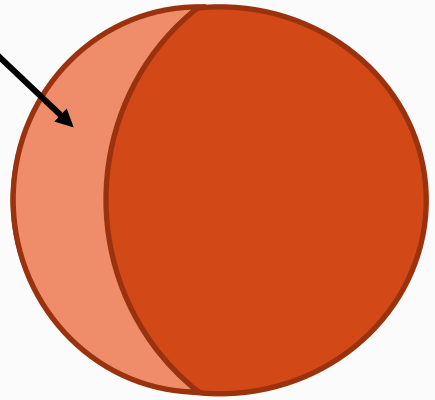
2. Investigating the use of amyloid proteins as ‘biomarkers’ for Alzheimer’s disease

3. Developing a drug to stop the formation of the senile plaques

Meet the ‘Defying Dementia’ team!

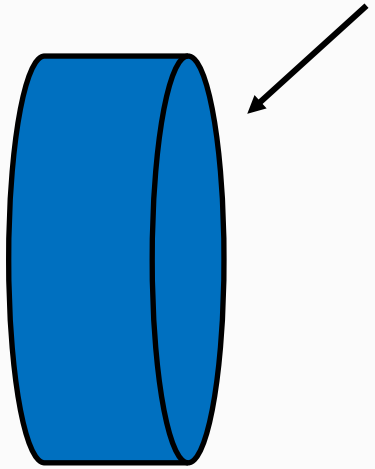
Our Drug: An Explanation

The part of the molecule that binds to other amyloid molecules



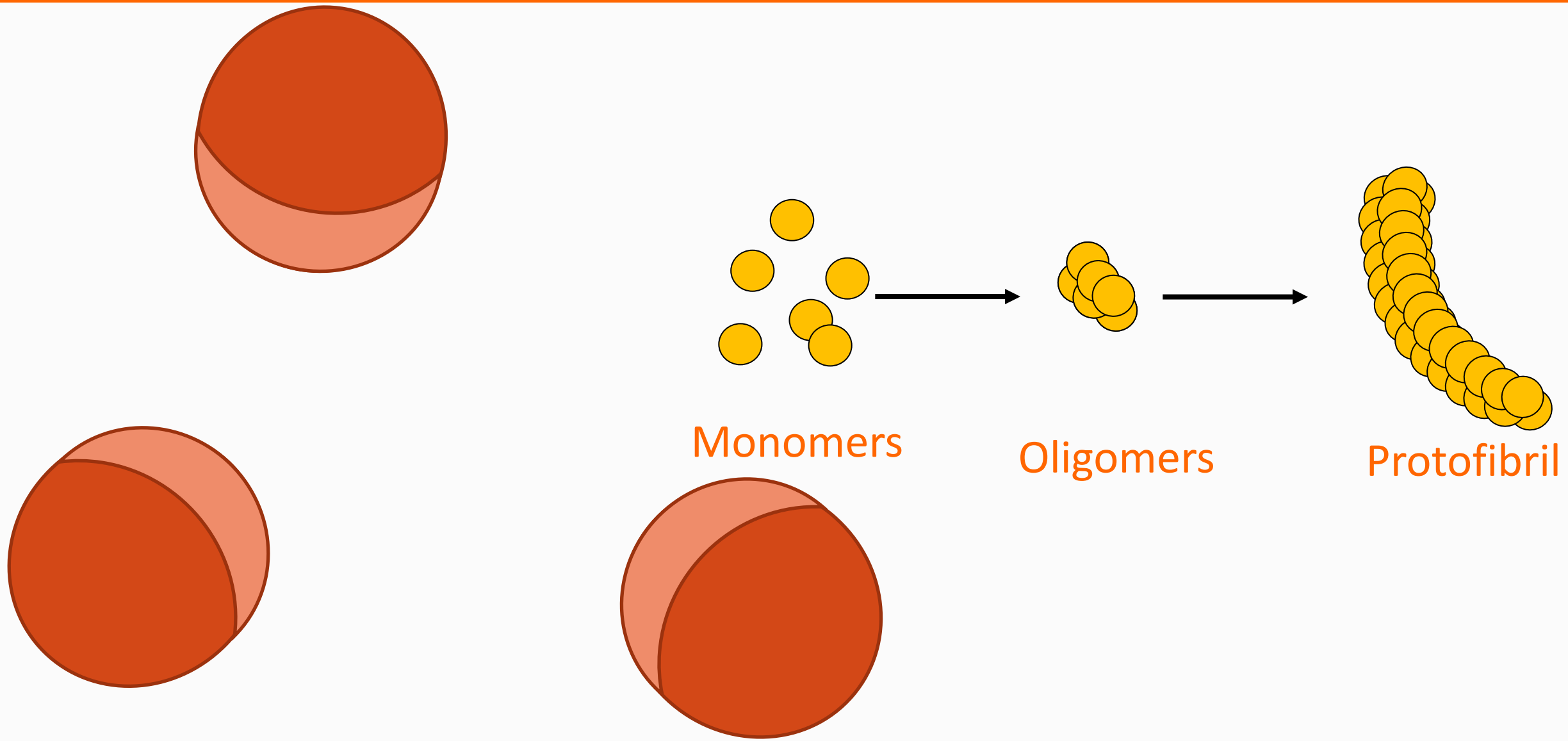
A Single Amyloid Molecule

Our drug is attracted to the ‘sticky’ part of the amyloid

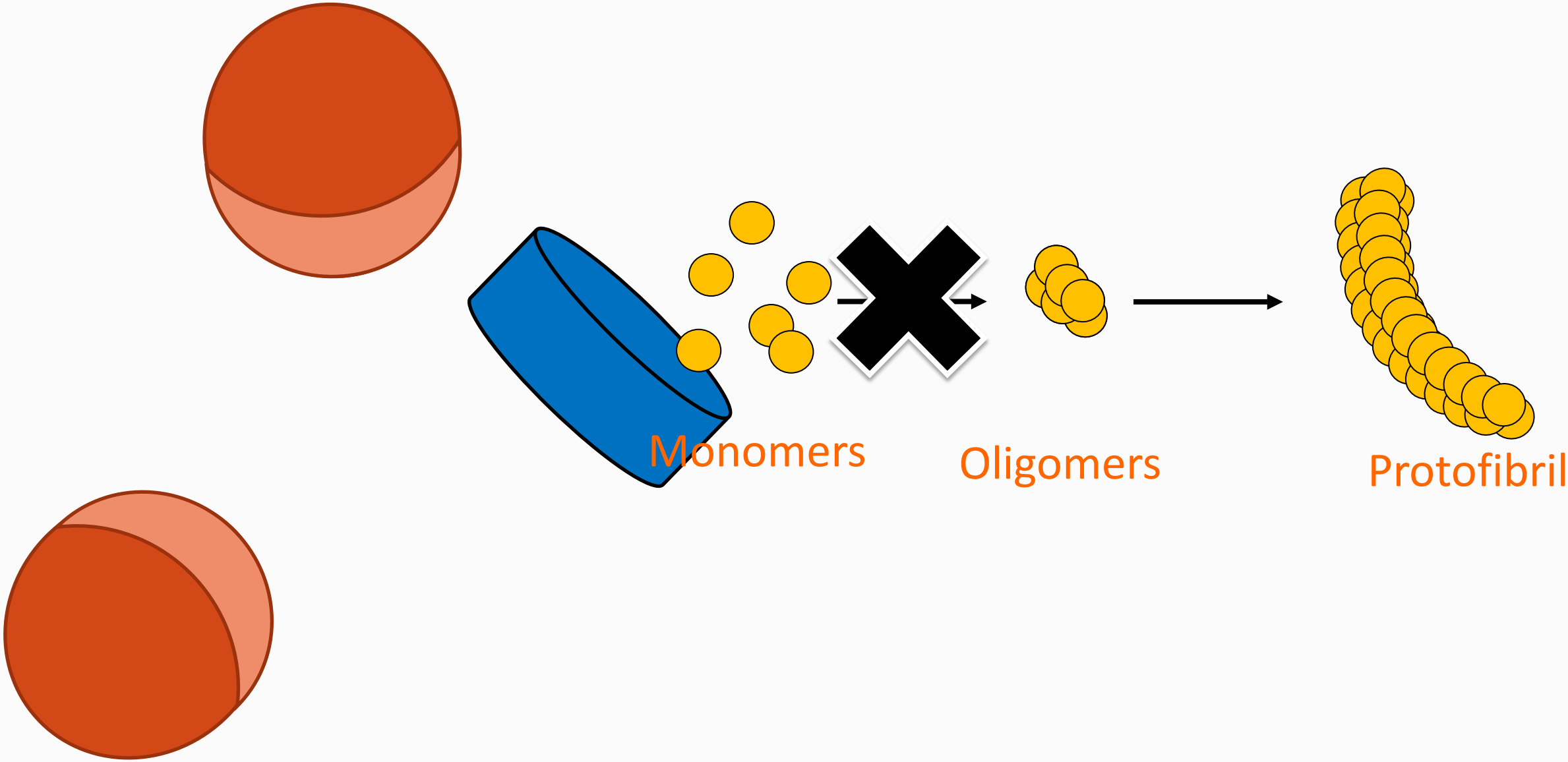


Our Drug

In Alzheimer's



With Our Drug



What Do We Know About Our Drug?

Stops molecules forming the toxic fibres

Blocks the toxic effects on nerve cells

Gets into the brain

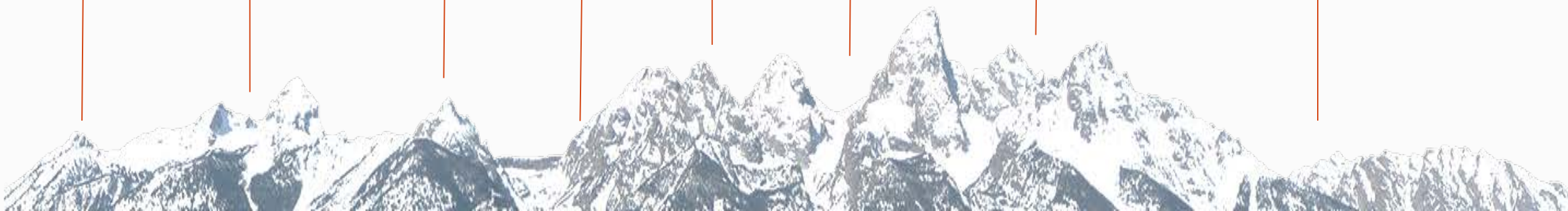
Reduces plaque formation

Reduces brain damage

Encourages nerve cell growth

Protects against memory loss in AD models

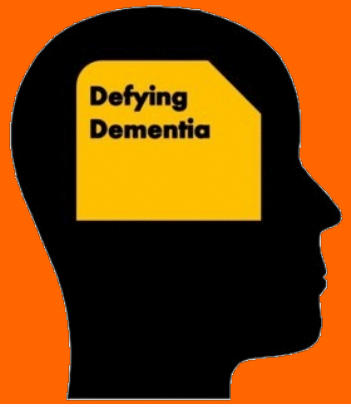
It is a non-toxic drug



What Now?

What still needs to be done before the drug can be given to humans?

- Toxicity testing on nerve/heart/liver cells
- Route of administration tests
- Drug distribution and brain penetration tests
- Behavioural tests
- Genetic mutation testing
- Determine optimal dose



DefyingDementia

► A campaign to raise awareness and funds that will help speed up the pre-clinical tests and get the drug ready to trial in humans as soon as possible

► The first university in the UK to fundraise for medical research in this way

MAC Clinical Research is the UK's largest company committed totally to the recruitment and conduct of clinical trials through its own dedicated research sites and staff.

MAC Locations

- Manchester
- Blackpool
- Cannock, Staffordshire
- Leeds
- **Next – Lancaster!**

About MAC

	CNS Disorders	Analgesics	Endocrinological Disorders
Specialise in:			
For example:	• Alzheimer's • Schizophrenia	• Acute pain • Chronic pain	• Diabetes • Dyslipidemia

- 200+ Clinical Studies Successfully Completed
- Europe's first Memory Assessment and Research Centre (established 1987)

Current Memory Research at MAC

TRx 15/20

This drug is targeted at removing tangles (tau protein) from the brain. Potential next licensed treatment.

Amaranth (AZ)

Aims to reduce the formation of senile plaques (beta-amyloid protein).

TOMM 40

Investigating a new genetic test for Alzheimer's.

Otsuka

A potential treatment for agitation in Alzheimer's.

Our Aim

Develop an Alzheimer's drug that can stop the disease process early in its tracks

A Walk to Defy Dementia

Follow the two mile scenic woodland trail around the edge of Lancaster University's campus, with lots of fun activities on the way!

11.00 am
18th October

Tickets: **awalktodefydementia.eventbrite.com**

For more information visit out Facebook page:
www.facebook.com/DefyingDementia

Is dementia becoming a human rights issue?

Toby Williamson
Head of Development & Later Life

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UK's dementia care betrayal: Nine in ten care homes and hospitals fail patients, says damning report

- **CQC review finds widespread neglect, lack of care and poor training**
- **Report's conclusion: 'This unacceptable situation cannot continue'**
- **Most of the 400,000 elderly in Britain's care homes have dementia**
- **Inspectors visited 129 care homes and 20 hospitals across England**
- **They found that 90% had some aspect of poor or inconsistent care**

By BEN SPENCER, SCIENCE REPORTER FOR THE DAILY MAIL

PUBLISHED: 00:01, 13 October 2014 | **UPDATED:** 09:18, 13 October 2014

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Dementia Friendly Crawley

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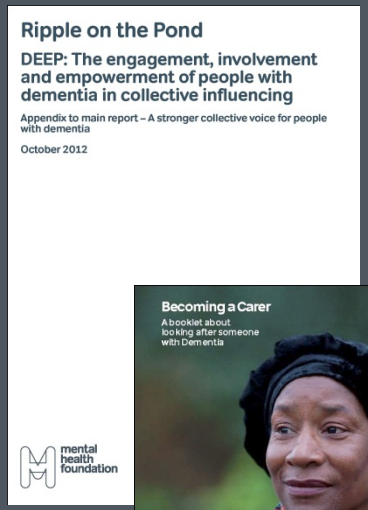

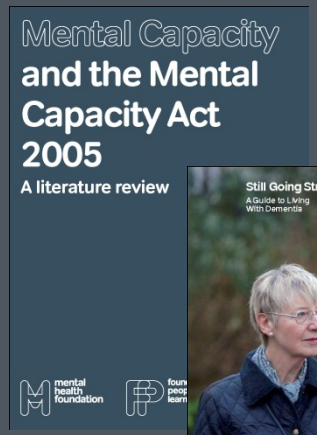

- UK charity
- Social research, service development, influencing, information and guidance
- Mental health problems, learning disabilities, dementia, public mental health – all ages

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Dementia, rights and the social model of disability

- 9 month project funded by the Joseph Rowntree Foundation
- Policy report, briefing and easier read version to be published in September 2015
- Co-produced

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- ‘Dementia friendly’ communities are good…
- …but access, inclusion, and participation in society goes beyond being friendly
- People with dementia and their supporters are talking more about ‘rights’…

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Rights…and rights

- …not only rights to services because of a dementia diagnosis (these <u>are</u> important) e.g.
  - rights to health care (diagnosis and treatment),
  - rights to social care (care and support in the community or in residential care)
  - rights to welfare benefits, social housing, etc.
- …but legal rights as citizens – including human rights

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- United Nations Declaration of Human Rights 1948
- Human Rights Act 1998 (and European Convention on Human Rights)
- United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD)
- Equality Act 2010
- (Mental Capacity Act 2005 and Care Act 2014)

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Disability - definitions

Equality Act:

“a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on a person’s ability to do normal daily activities”

CRPD:

”those who have long-term physical, mental, intellectual or sensory impairments in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”

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United Nations Declaration of Human Rights 1948

Article 1

- All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood

Article 25

- (1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

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- Human Rights Act 1998 (and European Convention on Human Rights)

- Articles include:
  - right to life
  - freedom from torture and inhuman or degrading treatment
  - right to liberty and security
  - respect for private and family life
  - freedom from discrimination

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- United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD)

- Articles include:
  - accessibility
  - equal recognition before the law
  - living independently and being included in the community
  - health
  - participation

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- Equality Act 2010
  - Disability as a ‘protected characteristic’
  - Prohibits discrimination in the provision of good and services
  - ‘reasonable adjustment’

- Mental Capacity Act 2005
  - rights and safeguards about decision making

- Care Act 2014
  - ‘well being’ principle

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The Social Model of Disability

- Legislation underpinned by the social model of disability
- Developed by disability activists in the 1970s
- Focused on the negative attitudes, behaviours and obstacles in society preventing people with disabilities from participating – not on the individual and their disability
- Society, not individuals with disabilities, need to change
- Variations on the model

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The medical model encourages attitudes which say:	The social model says
YOU are the problem. It is about what you CAN'T do. The most important thing is a cure for dementia.	A cure would be great of course, but meanwhile there are lots of barriers to people with dementia. These include the attitudes of others and the physical environment. Let's look at what people with dementia CAN do.
People with dementia can't make decisions.	People with dementia should be at the centre of the process of making decisions wherever possible, and should be supported to do so.
People with dementia are "victims" "sufferers" and need our sympathy.	People with dementia have rights, deserve respect, and are much more than their dementia.
People with dementia are passive dependents.	People with dementia can be active citizens.
Dementia policy and services do things "to" or "for" people with dementia.	Policy and services do things "with" people.

Human-rights based approach (HRBA)

- To promote change and embed the social model of disability in policy making, research, service and community development through the 'PANEL' principles:

- P – participation (in decisions)
- A – accountability (monitoring and ensuring adherence to human rights)
- N – non-discrimination and equality (prohibiting discrimination)
- E – empowerment (information and support to enable participation)
- L – legality (rights are represented and complied with in law)

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PANEL principles

- P – participation
  - are people with dementia actively involved in the process of developing dementia friendly communities (DFCs)?
  - Are any barriers to participation being addressed?

- Examples
  - Dementia Engagement & Empowerment Project network (DEEP): www.dementiavoices.org.uk

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PANEL principles

- A – accountability
  - is it clear who has what responsibilities for developing DFCs? Is there a way of checking on them?

- Examples
  - Local Dementia Action Alliances
  - Scottish national dementia policy

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PANEL principles

- N – non-discrimination and equality
  - – is there a risk that DFC activities could discriminate or exclude particular groups of people with dementia?

- Examples
  - – working with ‘seldom heard’ groups – (e.g. Alzheimer Society’s Connecting Communities programme, University of Worcester)
  - –Dementia Words Matter – National Dementia Action Alliance: http://www.dementiaaction.org.uk/dementiawords
  - – physical environments (e.g. signage)

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PANEL principles

- E – empowerment
  - are people with dementia and carers given the right information to enable them influence decisions about the development of DFCs?

- Examples
  - Scottish Charter of Rights for People with Dementia and Carers
  - National Dementia Declaration – the 'I' statements
  - co-producing with people with dementia – Innovations in Dementia/Local Government Association dementia friendly community resources

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PANEL principles

- L – legality
  - are DFC activities compliant with human rights and other relevant legislation?

- Examples
  - Ensuring correct use of the law e.g. MCA, Care Act
  - Case work on employment protection, welfare benefits
  - British Standards Institute guidance on dementia friendly communities
  - ‘Getting it right’ - Mersey Care NHS Trust

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Some objections…

"*I'm not disabled, I have Alzheimer's disease and I want an effective treatment or cure*"

"*The social model of disability doesn't make sense for me because I experience symptoms that I really can't cope with, like confusion and forgetfulness*"

"*Rights come with responsibilities and using human rights law in dementia is too heavy handed*"

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Conclusion

- A rights-based approach and the social model of disability is relevant and potentially very useful to people with dementia, carers, and services and policies affecting their lives – and resonates with people with dementia

- This includes dementia friendly communities – at policy and practice levels

- Moving towards ‘dementia friendly’ and ‘dementia inclusive/accessible’

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Thank you

twlilliamson@mentalhealth.org.uk

www.mentalhealth.org.uk

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Creativity and connectivity: Exploring the impact of painting remembered landscapes on older people's subjective wellbeing

Creativity and Connectivity

This study provides more precise insights into how a participatory painting activity, with a communal theme of remembered landscapes, impacts older people's subjective wellbeing

It is conducted within a framework of relational aesthetics

Creativity and connectivity

Three core impacts are investigated:

- Improving social connectivity and inclusion
- Improvements to self-value, self-identity and continuation of self into older age
- The value of new challenges and gaining new skills

Creativity and connectivity

- Painting workshop situated in the North West of England
- 23 individuals of old and older old people between 65-85 years
- Recruited from two community groups from different geographic locations and economic capacity

Why do this research?

- Research supports older people's engagement in leisure activities for maintaining positive wellbeing
- The contribution of creative and participatory arts has only recently been explored
- Current research limited in rarely distinguishing between arts, therefore does not attach beneficial impacts to specific activities

Context: Successful ageing

- Social isolation and loneliness in older people: detrimental to health, wellbeing and quality of life
- Mental and physical repercussions range from debilitating to life threatening
- Increased risk of depression, projected to be the leading disease burden in middle and higher income countries by the year 2030
- Estimated 750,000 people with dementia in UK, projected to rise by 1 million by 2021 and 1.7 million by 2051 (Alzheimer's Society)

Creativity and Connectivity: The Study

Painting workshop:

- Remembered landscapes emphasis on participants' life experiences, memories and repertoires
- Encouraged participants to locate past memories within a nexus of social connections, historical events, and life experiences
- The subject-matter had to be remembered and visually imagined to be represented

Painting workshop

Painting workshop

Painting workshop

Findings

Participating in the painting workshop substantially improved social connections

Prompted connectedness with family members through the exchange of memories

Improved self-identity and continuation of self into older age

Paintings helped bridge their older and younger-age self

Improved zest for life and new skills

Creativity and Connectivity

One hour radio broadcast -BBC Radio Lancs with Sally Naden

Dementia Futures

The next step…

How does painting remembered landscapes in a participatory activity impact the subjective wellbeing of people experiencing dementia?

Improving Dementia Care Research

- Neighbourhoods and Dementia Programme
- Two Lancaster University dementia care studies
- Involvement of people with dementia in the N & D programme
- The research team:
  - Siobhan Reilly
  - Hazel Morbey
  - YingYing Wang
  - Marie Crane

DEMTRAIN: dementia training in NHS hospitals

Health Research | Lancaster University

How does staff training lead to improvements for people with dementia and their carers?

1/4
hospital beds

£250,000,000
PER YEAR

430,000
STAFF TRAINED

97%
NURSES WORK WITH PEOPLE WITH DEMENTIA

3hrs
dementia care training

56%
variable /poor care

Dementia Care: ‘What is important to you?’ study

Health Research | Lancaster University

Over 850,000 people with dementia in the UK

2/3 of people with dementia live in the community

We want to create a ‘set of outcomes’ to be used in future studies that evaluate dementia care and services, so we can then have like with like comparisons between studies.

We will explore many different areas of life, to find out:

What is MOST important to people with dementia ?

Health Research | Lancaster University

Dementia Futures

Lancaster Town Hall

19th September 2015

Dr Hazel Morbey h.morbey@lancaster.ac.uk
Dr YingYing Wang y.wang45@lancaster.ac.uk

Neighbourhoods & Dementia Programme www.neighbourhoodsanddementia.org

Rethinking dementia at Age UK: inclusion rather than specialism

Susan Davidson

Research Adviser
Age UK

Age UK Services

- For the whole person
- Examples: exercise classes, help with shopping, many activity groups and clubs, handyperson, clipping nails, I&A, advocacy, befriending

What about services for dementia?

- Increasing numbers
- Specific needs, some services already on offer
- What else do people want? Don’t want to replicate…

Issues that older people with dementia, and their carers, and told us:

- Don’t necessarily want to go to specialist dementia places because of stigma – want to go to mainstream services
- Have more needs and wants than just around dementia, but all those often get ignored

From the focus groups:

“I would like to do more things that I am interested in like perhaps a discussion group or an art group - nothing to do with dementia necessarily.”

“There are some services in this are like Singing for the Brain and a dementia cafe - and they are good for some people, but are not for me - many of the people with dementia in those groups are much older or much more advanced in their dementia than me”

"One thing that would have made a huge difference after diagnosis would have been information - both about dementia but also about local services and things that were going on - and not just dementia or care things - you know - about ordinary things."

1. ‘Dementia-friendly’

- services are accessible to everyone
- staff are knowledgeable and can act and help appropriately
- shops etc. are easy to navigate, understand and get around

2. Pilots to fill the gaps

Commonalities:

- addressing the whole person and their carers – while the services are targeted at people with dementia, they aren't solely about that, and they try to get people engaged in the wider community
- primary desired outcomes are to improve wellbeing (both in the person with dementia and their informal carers).

Specifics:

- providing information and advice
- help finding services and assistance that the person wants and needs (including help with getting benefits and managing money, home adaptions, transport, domestic tasks, etc.)
- support in re-engaging with hobbies and interests
- home-from-hospital support
- teaching carers how to cope and work with their cared-for person to reduce crises and residential care admissions.

What's next?

Interim report in December

Hope to apply learnings to all services, and especially for people with multiple, complex needs

Thank you!

Susan Davidson

Feel free to contact me:

susan.davidson@ageuk.org.uk