NHS
South East
Clinical Delivery and Networks

Wessex dementia research

Closing the gap between research and the implementation of evidence based healthcare practice.

Closing the gap

A paper published in 2014[1] concluded

> *….the most frequently reported barriers to evidence uptake were poor access to good quality relevant research, and lack of timely research output. The most frequently reported facilitators were collaborations between researchers and policy makers and improved relationships and skills……*

In light of this, the Clinical Network dedicated the December Strategy group meeting to the topic of research.

Research in Wessex

Wessex is a research active area with well-respected universities and partners in health and care working alongside patients and public.

Wessex ARC

In 2019 the Wessex ARC (Applied Research Collaboration) was given funding by the National Institute for Health Research to work with local partners to conduct applied health research (previously NIHR CLAHRC Wessex)

The ARC has four key programmes including

- Ageing and Dementia
- Healthy Communities
- Long term conditions
- Workforce and Health systems

Interdisciplinary Dementia and Ageing Centre (iDeAC)

iDeAC was created in the summer of 2019 as a collaboration between the Institute for Life Sciences Southampton University and the University Hospital Trust of Southampton. iDeAC is a dedicated interdisciplinary dementia and ageing research centre bringing together local expertise including scientists, clinicians, health and care delivery researchers, epidemiologists, imagers, mathematicians and computing and data scientists.

The key themes are

- Basis and translational science
- Diagnosis and prognosis
- Clinical trials and therapeutics
- Dementia care and prevention

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[1] Oliver et al, A systematic review of barriers to and facilitators of the use of evidence by policymakers, BMC, Health Sciences research, 14(1),2

Improving dementia diagnosis using brain imaging

Dr Angus Prosser

SPECT imaging maps blood flow indicating neural activity and can improve the accuracy of dementia diagnosis over clinical assessment alone. Angus used a series of questionnaires to understand clinical confidence in diagnosis pre and post SPECT imaging.

In a sample of 79 patients referred by 41 clinicians, the SPECT scan resulted in a change of diagnosis in 44% of cases.

Following a SPECT scan

- 41% of pre-scan diagnoses of Alzheimer's disease were altered (14% to MCI, 10% to psychological issues, 7% to VaD, 4% to FTD, 3% to other dementia and 3% to other causes)
- 60% of pre-scan diagnoses of Frontotemporal dementia were altered (40% to AD, 13% to VaD, 7% to other misc.)

Improving diagnostic confidence

The study concluded that

- SPECT provides additional value beyond the standard diagnostic workup
- There was a significant increase in diagnostic confidence for those with low confidence pre-scan
- The SPECT scan confirmed diagnosis or prompts reassessment for high confidence clinicians (where SPECT and clinician disagree)
- SPECT cans were valued by clinicians as a contributor to the diagnostic process and to improve understanding of patient disease

__Implication for policy:__ Improved accuracy of diagnosis enables the provision of appropriate post diagnostic care. In our aim to diagnose early in disease progression SPECT becomes a useful tool in diagnostic confidence.

Maximising recruitment in Dementia (MINDS) study

Sandra Bartolomeu Pires, Clinical nurse researcher, UHS

Clinical research requires patient participants often with strict criteria for inclusion.

Sample sizes and funding for research trials is reliant on recruitment of the right people for the right trial. This can be challenging especially in progressive conditions like dementia.

Improving recruitment to dementia trials

National recruitment often does not provide the detail on which selection can be made or support geographical preferences. Failure to be recruited to a trial can result in patient disappointment.

The MINDS study is a local online recruitment platform which aims to improve the success in matching patients to clinical trials and improve the prediction of eligibility from clinical features through

- MATCHING participants to appropriate trial using pre-screening protocols
- MONITORING disease progression via online assessments
- TRAINING of memory assessment raters
- PPI activities are supported

The study is due to start in early 2020 and will be promoted through local clinical teams and clinical pathways.

Implication for policy: *Promoting a local research database with increased specificity will enable more patients to take part in research.*

Material Citizenship

Dr Kellyn Lee, Research fellow in Ageing and Dementia

Dr Lee asks the question "How do you feel when you wake up and the clothes you like to wear have disappeared? The clothes in the wardrobe are not yours and you have no access to everyday items around which you have built a lifetime of behavioural habit, a kettle or your shaver?"

Improving person centred care – enabling choice and control

Our material possessions support and maintain our identity, connect us to our functional abilities, influence how other see us, support lifetime rituals and provide choice, comfort and control.

Kellyn's research demonstrated that people with dementia are often not included in decision making about their own possessions. Care staff view possessions with a risk or hazard perspective and mange or limit possessions on the grounds of maintaining safety. These factors result in a lack of control and choice for the person.

From her research Kellyn has developed a Material Citizenship Framework defined as...

'The right to be included in decision making relating to personal possessions and the right to have opportunities to use everyday functional object to perform everyday tasks.'

The framework balances personal empowerment with risk management and protection.

As a practice the framework will:

- Evidence person-centred care – enabling choice and control
- Uphold a person's human rights
- Create practices which evidence healthy ageing and independence
- Provide care staff permission to deliver person-centred care
- Provide more efficient working practice (provide the right care to the right people)
- Improve the lives of those who live, work and visit care homes

Kellyn's work has been awarded further funding from the Economic and Social Research Council (ESRC), the Alzheimer's Society and Brendon Care to progress this work and develop a training programme.

Implication for policy: *Consideration of mechanisms to support care home organisations to adopt the Framework.*

How does living with early onset dementia affect continued internet use?

Alex Young, Researcher

Alex used questionnaires to survey people with younger onset dementia (YOD) on their use of technology and the internet post diagnosis.

Questions related to types of technology (touch screen and conventional keyboards), voice assistants, software, passwords and account management.

In summary the study identified that

- Traditional technology was more used than touch screen technology as it gives direct physical feedback to the user
- Internet use does not necessarily change although accessibility becomes an issue including password management and coping with software upgrades.

Improving our understanding of technology use in people with YOD

- Social media sites like Facebook had variable use while Twitter use was consistently valued for its online community of support and information

Implication for policy: *How can we design and implement online support across geographically dispersed populations for people with YOD*

Quality of Life (QoL) and health economics in Younger Onset Dementia

Dr John Spreadbury, Senior Research Fellow

Quality of life or how 'good' someone perceives their life to be can be measured in different ways. QoL can be measured in terms of life areas (psychological wellbeing, health, relationships, environment, finances) or in relation to a specific clinical condition.

Health economics relates to the costs of healthcare. These can be measured in terms of informal or formal care costs, and may be cost to the individual or the system. Productivity or delivery can also be costed.

A literature review showed that there was little information on QoL of economics in YOD and so a study was stablished to look at the factors and methods of measurement.

Improving care giver quality of life as an economic asset

Findings showed that

- The cost of informal care (patient supervision, self-care, help with activities of daily living) was statistically greater than the costs of formal care (health care usage, social care usage).
- Care givers often sacrificed their own QoL to support the person with dementia (care giver burden)

Implication for policy: *If care givers provide an economically valuable role, how can care organisations them to ensure that care giver burden is minimised and personal QoL is not sacrificed.*

Global Research

Dr Chris Kipps, Consultant Neurologist and research lead, University Hospital Southampton and University of Southampton.

Research programmes looking to address this require significant investment over long time periods, a research active community with world leading knowledge and expertise and require significant numbers of participants to ensure results are generalizable and statistically evidenced.

These research programmes require global communities including many organisations and partners. The Aducanumab Phase 3 studies EMERGE and ENGAGE are examples of the work of one such global research community including

- 3285 patients
- 348 sites across 20 countries
- 2x 18 month, randomised, double blind, placebo-controlled clinical trials
- High and low dose regimes
- A range of primary and secondary end points

Finding a cure for dementia is a global challenge

Aducanumab appears to act in Alzheimer's disease removing amyloid from the brain.

Positive results of the drug trial were presented at the CTAD (Clinical Trials on Alzheimer's Disease) congress in December 2019 bringing us one step closer to a clinical solution.

Implication for policy: *As new treatments become ever closer what impact will they have on all parts of the system?*

Discussion and Next Steps

The Dementia Strategy Group comprises experts working along all parts of the Wessex dementia care pathway. They understand the

commissioning and care needs of people with dementia (and carers) and look to identify creative solutions to meet both opportunities and challenges. Their individual roles enable them to affect change in their own areas and to work as a group to support system change.

With research and clinical advance comes further challenge.

Questions arise which commissioners and health care providers will need to work together to consider including:

- Which patient groups will benefit most from new treatments and care models?
- What are the cost benefits and cost pressures?
- How do we administer medication and care? Do existing pathways and processes need to change or adapt?
- How will we monitor and provide governance?
- What is the impact on QoL and social care?
- Are there unintended consequences or impacts in other parts of the system?

The Wessex Dementia Strategy group is well placed to consider dementia care in Wessex and consider these challenging questions.

The Wessex Dementia Strategy Group is hosted by the Wessex Clinical Network. Members include local experts in the commissioning and delivery of dementia services with the aim of ensuring that

Care, for those with dementia in Wessex, **is Excellent**

If you would like any further information on the group, please contact Rachel.chappell2@nhs.net