NIHR Three Schools: Dementia Programme

Improving the lives of people living with dementia and carers

2021-2024

Programme of Work, 2021-2029

ANNEX A: Three Schools Dementia Research Themes

Dementia presents many challenges for individuals, families, communities, health and care systems and more broadly. Nationally, there are rapidly growing numbers of people with dementia who, on average, are living longer post-diagnosis and with multiple other long-term health problems and associated needs. [1,2] Meanwhile, the availability of family and other unpaid support appears to be dwindling (certainly relative to demand) as a result of changes in demography, migration and employment patterns.[3]

Research responses to these trends fall into three broad categories: upstream prevention, early detection/diagnosis of proposed specific elements of the syndrome itself and mitigation through appropriate care and support for people living with dementia and their families and other carers.

Dementia is already costly.[4] Given the projected increase in prevalence in England if the reduction in age-specific risk is not maintained, health and care costs will increase rapidly if we continue with today's diagnostic approaches, medication, care and support arrangements.[5] Current arrangements are recognised to be far from ideal, with poor and highly variable practice in terms of risk-reduction, diagnosis, post-diagnostic support, treatment and carer support. There is also the vexed question of funding of social care for people living with dementia, which is currently means-tested.

The most recent national policy statement, *The Prime Minister's Challenge on Dementia 2020*, [6] included four research-related priorities:

- "Delivering increases in research funding;
- Increasing dementia research capacity;
- Delivering better treatments, faster;
- Improving the lives of people with dementia." (Paragraph 5.132)

The *PM's Challenge* included a range of research recommendations, from basic science and drug discovery to treatment and care. It emphasised that research should particularly look at ways to improve the lives of people with dementia:

"Research into dementia care is essential to find new and innovative ways for our health and social care systems to support the increasing numbers of people living with dementia and help them live well in all community and care settings." (Paragraph 5.156)

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[1] Kingston A, Robinson L, Booth H, Knapp M, Jagger C (2018) Projections of multi-morbidity in the older population in England to 2035: estimates from the population ageing and care simulation (PACSim) model. *Age & Ageing* 47(374-80).

[2] Kingston A, Comas-Herrera A, Jagger C (2018) Forecasting the care needs of the older population in England over the next 20 years: estimates from the Population Ageing and Care Simulation (PACSim) modelling study. *The Lancet Public Health* 3(9):447-455.

[3] Brimblecombe N, Fernandez JL, Knapp M, Rehill A, Wittenberg R (2018) *Unpaid care in England: future patterns and potential support strategies*. London: CPEC (formerly PSSRU).

[4] Wittenberg R, Knapp M, Hu B, Comas-Herrera A, King D, Rehill A, Shi C, Banerjee S, Patel A, Jagger C, Kingston A (2019) The costs of dementia in England. *International Journal of Geriatric Psychiatry* 34:1095-1103.

[5] Wittenberg R, Hu B, Jagger C, Kingston A, Knapp M, Comas-Herrera A, King D, Rehill A, Banerjee S (2019) Projections of care for older people with dementia in England: 2015 to 2040. *Age and Ageing* 49(2):264-269.

[6] Department of Health (2016) *The Prime Minister's Challenge on Dementia 2020: Implementation Plan*. London: DH.

> "NIHR themed calls for research on dementia, as well as related topics such as comorbidity in older adults, and research commissioned through the NIHR School for Social Care Research, have pump primed the field. In addition, the ESRC and NIHR have funded £20 million of research into care and support through the Living Well Dementia programme." (Paragraph 5.158)

New research studies were commissioned. Shortly afterwards, the Alzheimer's Society convened a group, including people living with dementia and carers, to produce a 'Roadmap' for research.[7] The group made 30 recommendations for research, grouped around five 'prioritised goals':

1. Prevent future cases of dementia through increasing knowledge of risk and protective factors.
2. Maximise the benefits to people living with dementia and their families when seeking and receiving a diagnosis of dementia.
3. Improve quality of life for people affected by dementia, by promoting functional capabilities and independence, while preventing and treating negative consequences of dementia.
4. Enable the dementia workforce to improve practice and skills by increasing evidence to inform changes in practice and culture.
5. Optimise the quality and inclusivity of health and social care systems that support people affected by dementia (Pickett et al. 2018, p.902).

These are helpful recommendations because they have strong roots in the everyday realities and experiences of people living with dementia and family or other carers as well as looking forward to future generations.

These priorities are also broadly consistent with recommendations for research that have emerged from other sources, including the Lancet Commission on Dementia[8 9] and an earlier Lancet Neurology Commission.[10] The priorities resonate with gaps in the evidence base identified by NICE when it most recently produced dementia guidelines,[11] and also with a very recent collective exercise to describe the impact of COVID-19 on dementia wellbeing and identify directions for future research.[12]

Research across the three NIHR Schools

The territories spanned by the three NIHR Schools are clearly very relevant when thinking about health and care responses to dementia and the people it affects:

- Many people experiencing what they might perceive to be the early signs of dementia will initially consult their GP or other member of the primary care team. Moreover, people living with dementia in the UK have, on average, three other long-term conditions that may well be managed through **primary care**.
- On the **public health** side, evidence is accumulating rapidly in relation to early, mid- and

[7] Pickett J, Bird C, Ballard C et al. (2018) A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *International Journal of Geriatric Psychiatry* 33(7):900-906.

[8] Livingston G Sommerlad A Orgeta V et al. (2017) Dementia prevention, intervention, and care. *The Lancet*. 2017; 390: 2673-2734.

[9] Livingston G, Huntley J, Sommerlad A et al. (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet* 396 (10248), 413-446.

[10] Winblad B, Amouyel P, Andrieu S et al. (2016) Defeating Alzheimer's disease and other dementias: a priority for European science and society. *The Lancet Neurology* 15(5):455-532.

[11] National Institute for Health and Care Excellence (2018) *Dementia – Assessment, management and support for people living with dementia and their carers*. London: NICE

[12] Liu K, Howard R, Banerjee S et al. (2021) Dementia wellbeing and COVID-19: systematic review and expert consensus on current research and knowledge gaps. *International Journal of Geriatric Psychiatry*, doi.org/10.1002/gps.5567.

later-life risk factors for various dementias.[13,14] These are highly clustered for communities that experience disadvantage, creating conditions in which whole communities are at increased risk of dementia.[15] The fact that many of those risk factors for dementia are also associated with other long-term conditions (such as coronary heart disease and cancer) makes the prevention challenge more compelling but also perhaps more complicated. In addition, various long-term conditions are very common among people with dementia (as noted, on average, they will have at least three other such conditions[16]).

- **Social care** is the main sector of support for people living with dementia, whether measured in terms of people or expenditure, and across all levels of severity. The great majority of older people living in care homes have dementia. Social care is also key in supporting family and other carers.

Research areas

Drawing on the Alzheimer's Society Roadmap (as a careful and robust prioritisation exercise with interdisciplinary and public involvement), and reflecting the priorities identified in *The Prime Minister's Challenge*, there are many suggestions that we can already outline as examples of projects – many of them collaborative across two or three Schools – that could be developed further and commissioned.

These examples are just for illustration at this stage and require further consultation across the membership of all three Schools.

- Primary care services are often first points of contact for people experiencing memory problems or other symptoms that might suggest dementia. Primary care services are very often the gateway to secondary care. Primary care staff are also often asked to advise on social care support. How can primary and social care best connect to support people and their families in the early stages of their dementia?
- Family carers of people living with dementia often experience significant health issues, particularly mental health problems. The strain on, and poor health of carers is often the precipitating factor for admission of someone with dementia into a care home or hospital. Primary care will be the main point of contact for carers with mental health or other health issues. How can the health needs of carers best be identified and managed?
- There are huge inequalities in risk of dementia and in the consequences. For example, diabetes and hypertension in mid-life are not evenly distributed across the population; involvement in education (in childhood and continuing into adulthood) is similarly unevenly spread. Inequalities are already wide, and probably widening, in relation to socioeconomic status, ethnicity, gender, and disability. Clustering of risk within communities means that many disadvantaged areas of the country are likely to experience higher risk of dementia at younger ages. Building on the existing expertise within SPHR that relates to upstream risk-reduction, as well as optimising health in the context of existing morbidity, research could be developed to look at locality approaches to healthier brain ageing.
- As research gives us more evidence on early-, mid- and late-life risk factors for dementia, attention needs to focus on how to create healthier environments across the lifecourse that promote healthier brain ageing, building on our UK evidence that dementia risk can be changed in populations across generations. The clinical, economic and moral case for better access to evidence-based healthcare (in relation to those health-related risk factors) is greater if the links to dementia (and other long-term conditions) are recognised. What can and should be done earlier in life in society and within appropriate health and social care systems to reduce the risk of dementia in older age? What public health measures will

[13] Livingston et al. (2017, 2020) op. cit.

[14] WHO (2019) *Risk reduction of cognitive decline and dementia: WHO Guidelines*. Geneva: WHO.

[15] Basta NE, Matthews FE, Chatfield MD, Brayne C, MRC-CFAS (2008) Community-level socio-economic status and cognitive and functional impairment in the older population. *European Journal of Public Health* 18(1):48-54.

[16] Kingston et al. (2018) *Ageing & Ageing* op.cit.

achieve better health behaviours?

- Approximately 80% of people with dementia in England in 2015 were living in the community.[17] The needs of these people, as well as the needs of those who support them (both unpaid and paid carers) must be met. Many of these individuals with dementia live alone, with varying levels of community network support. Primary and social care play major roles in this regard, but evidence is scarce on the best ways to support people.
- Most residents living in care homes now have dementia, even if it is not always diagnosed prior to admission, as well as other major care needs. Dementia considerably complicates care and support in those settings, making it harder to provide personalised responses to needs and preferences. How can healthcare best be delivered to care home residents? Should primary care continuities be maintained as older people make the transition from their own homes to these congregate settings? What are the advantages of different models of primary care support across care homes? With Primary Care Networks developing, is there potential for innovative models to develop, and what are their impacts?
- There is growing interest in psychosocial and community interventions to support people living with dementia and carers, alongside clinical interventions such as symptomatic medications. For example, social prescribing is being explored as a potential approach to capitalising on societal assets for those in populations who might benefit, whatever their needs. The evidence base is growing, but the role of social prescribing for the complexity of need that accompanies changes in health and wellbeing in older age, including cognitive decline, is relatively under-explored. What, then, would be the benefits of coordinated approaches to social prescribing and other approaches?

NIHR priority areas

Research topics and questions will also be informed, but not limited, by the potential areas of interest identified in the NIHR Highlight Notice – Dementia:

- Meeting the needs of people affected by dementia in under-served groups
- Research gaps identified in the Dementia wellbeing and COVID-19: review and expert consensus on current research and knowledge gaps
- Prevention
- Research needs identified in the Dementia research roadmap for prevention, diagnosis, intervention and care by 2025
- Research recommendations identified by NICE Dementia: assessment, management and support for people living with dementia and their carers (June 2018).

[17] Wittenberg et al (2019) *International Journal of Geriatric Psychiatry* op.cit.