

NIHR Three Schools: Dementia Programme
Improving the lives of people living with dementia and carers
2021-2024

Programme of Work, 13 September 2021

1. BACKGROUND

The NIHR Schools for Primary Care Research (SPCR), Public Health Research (SPHR) and Social Care Research (SSCR) (“three Schools”) have joined together in a unique collaboration between leading academic centres in England¹ to collaborate on two programmes of work funded through the National Institute for Health Research (NIHR): one on mental health led by SPCR and the second on dementia led by SSCR.

This document sets out the Three Schools’ Programme of Work for *dementia* funded by NIHR. It will be reviewed regularly over the period to 30 April 2024.

2. MISSION AND ACTIVITIES

2.1 Mission

Dementia presents many challenges for individuals, families, communities, health and care systems and more broadly. Commitments under the Government’s Challenge on Dementia and the G8 Dementia Summit have highlighted the need to boost dementia research, and NIHR has funded an extensive portfolio of dementia research.

Our ambitions align with those of DHSC and NIHR: the Three Schools will carry out research to address key gaps in the evidence base, working collaboratively across primary care, public health and social care. Collectively, we are well placed to carry out research that is cross-cutting and community-orientated, and able to develop relevant research for whole populations as well as (importantly) specific groups of individuals within them, most importantly within context. We will draw on our experience and established networks to ensure patient, carer, service user, public and community engagement. We will work across traditional disciplinary and sector boundaries.

2.2 Activities

We will pursue this mission through the following activities:

- conducting high-quality peer-reviewed research to produce new knowledge including, where appropriate, reviewing and synthesising existing knowledge, to inform the further development of dementia-related practice;
- investing in ongoing efforts to build and strengthen research capacity and build research awareness and utilisation;
- involving people living with dementia, carers and practitioners throughout the programme;
- supporting the generation of impact from the research, and supporting wider knowledge exchange and implementation activities.

¹ See Annex A.

3. MANAGEMENT AND GOVERNANCE

3.1 Governance

The governance of this Programme will follow the processes developed by the School for Social Care Research (SSCR) which will be lead contractor for the Programme.² The London School of Economics and Political Science (LSE) will take responsibility for financial monitoring and reporting, and will lead contracting with partners.

3.2 Management

The Director of each School will be responsible for the operationalisation of this Programme within their School, and collectively across the Three Schools. The SSCR Director - Professor Martin Knapp (LSE) - will have overall responsibility for leading, managing and directing the Programme.

Three School's Dementia Research Group

We will establish the *Three School's Dementia Research Group*. In addition to the Directors of each School and relevant administrative leads, this Group will include appointed members from all three Schools, including people with considerable experience of dementia research, as well as people living with dementia and carers. There will also be representation from DHSC and NIHR.

The Group will provide academic leadership for the Programme and be responsible for supporting the Directors of the three Schools in management and reporting. The Group will make decisions on commissioning processes, appointment of reviewers for proposals, commissioning decisions, monitoring of ongoing studies, assessment of final reports, and decisions regarding knowledge exchange and impact. The Group will also take responsibility for monitoring the spread of topics and funding allocations across the Three Schools.

The Group will meet regularly, as required to commission projects and other activities, and to review progress. The SSCR Director will chair meetings. Quorum will be 70% of the membership. Decisions will be made by simple majority voting.

Advisory Board

The three Schools will consult with their respective Advisory Boards for advice on the programme of research; development of research capacity and research literacy; opportunities for maximising impact from the research.

Research Advisors Group

A key aim for this Programme is to involve people living with dementia, carers, health and social care professionals, policy makers and relevant others in all the stages of research and across all Programme activities.

We will establish a Research Advisors Group to provide strategic inputs into the Programme. The Group will consist of people living with dementia, carers and practitioners. They will advise the Three School's Dementia Research Group on all research and related activities, including identification of research questions, reviewing proposals, participating in other ways in the commissioning of research, reviewing reports and other outputs, and communicating findings so as to support impact. A key role will be to advise on innovative ways for the Three Schools to continue to develop our engagement with people living with dementia, carers and practitioners, including groups who are not often involved in research and people with advanced dementia.

The Group will support engagement with relevant external organisations and groups, such as Alzheimer's Society's research advisory panel, Join Dementia Research, relevant user-led and carer organisations.

² These processes are set out in the School's Business Plan at <https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-Phase-III-Business-plan.pdf>.

Some members of the Research Advisors Group will also be members of the Three School's Dementia Research Group.

Links with the DHSC/NIHR

Links between the three Schools and NIHR will be maintained throughout the programme, including attendance by DHSC and NIHR representatives at Group meetings.

3.3 Administration

SSCR's Director will be funded at 0.05 FTE to manage the overall Programme. He will be supported by a 0.40 FTE Research Programme Officer who will support the day-to-day operational planning and organisation of the Programme, manage commissioning and reporting processes, and facilitate representation from the Programme's Research Advisors.

Additional support will be provided through SSCR's existing administrative processes, particularly for financial and contractual management, and communications support.

3.4 Monitoring and reporting

The Programme's performance will be reviewed by the Three School's Dementia Research Group biannually.

Annual progress reports will be provided by the Three School's Programme to NIHR.

Reporting processes will follow SSCR's processes for award-holders. These include biannual progress reports, regularly monitoring of knowledge exchange and impact arrangements, and a final report within 30 days of the end of the project. Any substantive variations to research projects will need to be approved by the Three School's Dementia Research Group following discussion with the Director of the relevant School hosting the project.

All award-holders will be expected to adhere to all appropriate monitoring and reporting requirements, including within each School and those of organisations hosting the research. Wherever possible, these processes will be aligned to avoid additional bureaucracy.

A contractual requirement for all research projects will be preparation an End-of-Project report consisting of:

- a short administrative report, including a financial statement;
- one or more peer-reviewed paper(s) submitted to top quality journals (in pre-submission manuscript form) with appropriate funding disclaimers;
- a short note reflecting on the methods used and any issues/lessons that arise (things that did and did not work); and
- a brief, accessible 'Findings' report for publication by the three Schools.

The End-of-Project report will be peer-reviewed. Amendments may be requested before publication of specific parts of the report. In addition, projects will be required to confirm feedback has been provided to all participants in studies as appropriate. Final payment will be contingent on satisfactory delivery of all of these outputs.

3.5 Regulation and transparency

The three Schools will comply with guidance issued from the DHSC and other statutory bodies such as EU regulations on clinical trials, the Mental Capacity Act 2005 and the Mental Health Act 2007 with regard to the conduct and administration of research. All research will need to comply with the UK Policy Framework for Health and Social Care Research (2017) and with the requirements of equality and human rights legislation. All research will need to follow requirements set out in the Data Protection Act 2018.

Intellectual Property agreements will be drawn up in accordance with standard NIHR procedures and detailed in individual project contracts. Requirements around access to data and data archiving will also be set out.

The three Schools will continue to implement NIHR's Open Access policy to support transparency of research findings. Every journal article and every other form of dissemination based on work commissioned under this Programme will be required to acknowledge funding from the Three Schools and NIHR.

Everyone involved in this Programme is expected to comply with guidance with regard to the conduct and administration of research set out by the institutions hosting the research. Where guidance from an individual institution differs from that of the lead partner, the lead partner's internal guidance will be deemed applicable.

The three Schools will adhere to the Freedom of Information Act as applicable. Requests for information will be dealt with in line with LSE's Freedom of Information principles, on behalf of SSCR.

3.6 Contractual arrangements

The main contract with NIHR will be held with the London School of Economics and Political Science and will apply across all three Schools.

For research projects commissioned, an agreement will be issued covering the requirements of the individual funded project based on SSCR's Standard Terms and Conditions.

3.7 Financial arrangements

A proportion of funding (5%) will be allocated towards management and operational costs for the Programme, including director's time (0.05 FTE), administrative time (0.40 FTE), governance processes, public involvement (0.10 FTE lead and research advisors time) and knowledge exchange. It is expected that 95% of the budget will be allocated to research and related-activities (including capacity-building) carried out collectively across the Three Schools.

Decisions on funding will be taken by the Three School's Dementia Research Group in relation to individual projects after full consideration of the current state of evidence in that field, the type of research to be undertaken, the best design for that type of research, the expected value for money of that work and its relevance to the improvement of dementia-related practice in England and independent peer-review. The Group will closely monitor expenditure patterns and the consequences for research quality and the distribution of resources, and make recommendations for change if necessary.

FEC/overheads

Funding for all projects, reviews and other research-related activities will be on the basis of value for money.

This Programme does not provide full economic costs. Universities, HEIs and others can request up to 25% of total salary costs in overheads as long as these are fully justified as part of the full proposal. The Programme will provide resources for items traditionally associated with full economic cost charges where these are relevant to the proposed project and are fully justified (such as administrative support time, equipment, some consumables (telephone calls, printing), staff training).

It is expected that discussions around research support costs and excess treatment costs will take place with the relevant parts of NIHR, and studies are expected to make full use of the support from local Clinical Research Networks where appropriate.

Resources should include all relevant costs, including payments or salaries for those involved in the project from non-academic settings (such as local authorities involved in providing data or recruiting participants for a project). The Programme will pay justifiable costs to ensure that

projects are as inclusive as possible.

Financial management and regulations

The financial arrangements for the School, including the allocation of funding to projects, will be overseen by the Three School's Dementia Research Group. SSCR's Finance and Impact Manager will provide regular expenditure information to the Group to support these discussions.

Records of leveraged funding will be maintained.

Invoicing

Payment for commissioned research will be made quarterly from the LSE upon receipt of invoices detailing actual expenditure. Payment schedules will be set out in individual subcontracts.

Project contracts will stipulate requirements to submit timely invoices to support the Programme's financial management processes.

Regular meetings will take place of finance managers across the Three Schools to support management of the Programme.

Auditing

LSE, on behalf of SSCR, may be required to appoint an independent chartered or certified public accountant to examine all relevant books and records of the Three Schools. Where required, reasonable prior written notice will be given.

All members of the Three Schools involved in this Programme are expected to follow the audit principles set out by their host institutions.

Indemnity and insurance

Issues of indemnity and insurance will be set out in the individual contracts with host universities. It is the responsibility of the individual host institution to ensure that all staff engaged in programmes have the appropriate indemnity for the conduct of research. Proof of indemnity will be requested upon signature of agreements.

Arrangements for withdrawal

In the event of withdrawal of a Principal Investigator on a funded research project, the Three School's Dementia Research Group will discuss with the host university for that project an acceptable replacement to ensure that the project can continue. Where this is not possible, the Group will make all reasonable attempts to reallocate the committed funding to another university or organisation that can complete the required project. Any reallocation will be agreed with the NIHR.

The process for terminations relating to breaches with commissioned research will be stipulated in the relevant agreements and dealt with accordingly.

4. CONDUCTING HIGH-QUALITY RESEARCH

4.1 Aims

Through this Programme, the three Schools are committed to commissioning primary and secondary research across the spectrum of dementia-related practice, across different groups, settings and using a range of methodologies. Research could involve any aspect of prevention, diagnosis, treatment, support or care, and related health, social care and other services.

The core aim of this Programme is to carry out high-quality internationally leading research to produce new knowledge (including, where appropriate, reviews and syntheses of existing evidence) to improve the lives of people with dementia, their families and other carers, and to reduce the risk of dementia.

The three Schools are committed to commissioning primary and secondary research across the spectrum of dementia-related practice, across different groups, settings and using a range of

methodologies. Research could involve any aspect of prevention, diagnosis, treatment, support or care, and related health, social care and other services.

In planning research and commissioning projects, the Programme aims to spread research activity so that it maps more closely onto the geographical distribution on dementia need.³

4.2 Research themes and projects

Members of the three Schools will be invited to develop proposals by the end of October 2021 for specific projects to start no later than January 2022. Further invitations to submit research ideas and full proposals will follow later in 2021 and thereafter.

The Programme will endeavour to span the most important themes currently emphasised in dementia-related policy and practice in England. Annex B provides further details on possible areas of research.

The Three School's Dementia Research Group will continue to take note of developments beyond the three Schools that might inform studies within the Programme, e.g. James Lind Alliance and other research prioritisation exercises, research commissioned by other NIHR programmes and other funders, and significant policy and practice developments. We will also liaise with other current and potential funders of dementia-related research to ensure complementarity in the research that gets commissioned. A webinar will be held in November 2021 to take stock of dementia research currently underway in order to help prioritise research topics for the second tranche of studies.

The type of research to be undertaken - a review, an initial 'scoping' of the issues, an exploratory study or a full evaluation - will be considered by the Three School's Dementia Research Group before work is commissioned. Research projects funded through this Programme might be, for example, feasibility or scoping research which provides the basis of a further proposal to leverage funding from NIHR or another relevant funder.

4.3 Over-arching principles and cross-cutting considerations

The following principles will be adhered to throughout the Programme's research activities:

- All research activities require collaboration across members of the Schools, with at least two members from different NIHR Schools involved in each research project.
- Proposals should demonstrate a commitment to highlighting inequalities in need, access to support, outcomes, funding and other relevant dimensions, and - where appropriate - making research-based recommendations to address them.
- All activities should appropriately recognise cultural, ethnic, socio-economic and other dimensions of diversity.
- Appropriate and meaningful engagement with people living with dementia, carers and practitioners is required. Efforts should be made to support participation of people for whom standard methods of communication are not possible.
- The highest ethical and research governance standards must be achieved across all Programme activities.
- The pursuit of scientific excellence is imperative, but should be proportionate to the real-world relevance of the question.

³ The [NIHR Highlight Notice on dementia](#) notes: "An analysis of where NIHR supported studies related to dementia have recruited patients and the prevalence of dementia across England indicate that dementia prevalence is highest in the Northwest (Southport and Formby; Fylde and Wyre; Eastern Cheshire), in the West (Shropshire) and South coast of England (East Sussex; South Eastern Hampshire; Isle of Wight). The CCGs with the most research activity in dementia though are in North Central London, Newcastle Gateshead, Oxfordshire, and Cambridgeshire and Peterborough, where the prevalence levels are lower."

- Peer-review processes will be employed to ensure that funded proposals and completed reports are of a high standard and relevant.
- The details of commissioned projects and the findings of completed studies will be highly visible within the public domain, and accessible to all relevant stakeholders.
- All projects will be required to consider their pathways to impact from the outset, and to implement these as far as possible.
- All projects will be required to ensure open-access publications in peer-reviewed journals.

5. COMMISSIONING

The commissioning of activities within this Programme will be managed by the Three School's Dementia Research Group.

5.1 Process

Members of the three School will be invited to submit expressions of interest (EOI) to outline potential projects. These EOIs will be reviewed by the Three School's Dementia Research Group (or a subgroup consisting of at least the three School Directors). If agreed, the project Principal Investigator will be invited to prepare a full research proposal.

For the first round of commissioning the process will be:

- Expression of interests invited on 13 September 2021 with submissions due by 23 September
- Decisions and feedback on EOIs sent to lead applicants by 28 September 2021
- Full proposals due by 19 October 2021
- Decisions by 30 October 2021

For the second round of commissioning, expressions of interest will be due by 16 November 2021.

Further rounds of commissioning will be agreed by the Three School's Dementia Research Group depending on resource availability.

5.2 Commissioning Panel

A Commissioning Panel will be established consisting of the Three School's Dementia Research Group, representatives of the Research Advisors Group and others with relevant topic and methods expertise (from England or elsewhere). The Panel will need to be large enough to manage potential conflicts of interests and to manage the workload of reviewing proposals.

5.3 Peer-review

Prior to commissioning, each project will be peer-reviewed. An extended Commissioning Panel will be established with members of the Panel acting as peer-reviewers. Each proposal will also be peer-reviewed by at least one member of the Research Advisors Group.

Decisions on which proposals will be funded, and any conditions attached to that funding, will be the responsibility of the Three School's Dementia Research Group based on discussion at the Commissioning Panel. These decisions will be informed by the following criteria:

- potential to have an impact on the lives of people living with dementia and their carers;
- relevance to dementia-related practice;
- feasibility;
- methodological excellence;

- originality;
- collaboration across two or three NIHR Schools;
- value for money;
- strength of the research team, including appropriate involvement of service users, carers and practitioners;
- clearly defined and costed plans for involvement, well-defined pathways to impact (through engagement and dissemination, for example) and a commitment to inclusive as possible of research participants;
- clearly defined and costed plans for meeting research ethics and governance requirements.

5.4 Research ethics and governance

All projects must have successfully undergone a form of ethics review. Where required, projects must apply for a favourable opinion from an appropriate research ethics as specified under Health Research Authority (HRA) guidance. Where HRA approval is not required, review by a university ethics committee will be required.

The three Schools acknowledge that time spent on ethics applications is not funded by universities for career-track research staff. However, time spent on ethics preparation itself will not be eligible for funding from this Programme. Funding can be released for activities that do not require ethics approval while ethical processes for other project elements are completed. Where ethical approval is not received, funding for those activities requiring approval will not be released and (if appropriate) the project contract will be terminated.

6. BUILDING RESEARCH CAPACITY

The three Schools place substantial emphasis on capacity-building, particularly for researchers at the immediate postdoctoral stage and early career researchers. This Programme will build on the capacity-building programmes that are already established in each of the three Schools, and to give particular emphasis to cross-School initiatives (shared training, for example). This will include, for example, bringing relevant researchers across the three Schools together to discuss research ideas and related activities.

Practitioners in primary care, public health and social care who may have limited or no research experience will be encouraged to participate in dementia research as a step towards establishing their own longer-term research careers, and hopefully to help develop more 'practitioner-academics' where there are large gaps between research and practice (such as in adult social care).

Another aspect of capacity-building will be to use Programme funding to support the channelling of research ideas and research careers on to further opportunities, for example for Programme Grants or other NIHR awards.

Specific initiatives will be discussed by the Three School's Dementia Research Group. The expectation is that all research funded through the Programme will support capacity-building in some form.

7. PUBLIC INVOLVEMENT

The Three Schools aim to foster an environment of trust and co-production in dementia-related research, building on the existing involvement strategies in place within each School and following guidance and standards from NIHR.

Programme initiatives will focus on four broad groups: i) people living with dementia; ii) unpaid family and other carers; iii) health and social care professionals; and iv) the public. Each of the

four groups has an important contribution to make to the definition of research priorities and the details of individual projects, and in planning how best to achieve impact from research.

Support for the Programme's strategy management will be provided through the Research Advisors Group (see above), which will develop a broad involvement and engagement strategy for the Programme. A dedicated lead (0.10 FTE) on involvement for the Programme will be identified.

All individual research projects will be required to have appropriate and meaningful involvement; proposals that are co-produced with relevant individuals and groups (people living with dementia, carers, practitioners) will be welcomed.

The three Schools will endeavour to develop further links, building on their extensive network of stakeholders, to support further engagement with Programme activities.

8. KNOWLEDGE EXCHANGE AND IMPACT

The implementation of evidence across primary care, public health and social care will be underpinned by appropriate knowledge exchange, impact and engagement (KEIE) approaches for the Programme. These will build on existing infrastructure and strategies within the three Schools, and will:

- view the central role as being facilitative, supportive and focused on linkage across the dementia research sector, with clear opportunities and expectations of KEIE activity to be conducted by each funded project;
- start early and be ongoing throughout the Programme;
- focus on the Programme contributing to existing and emergent dementia sector networks and organisations, not on building its own network;
- ensure internal processes are designed to make the most of the information collated from projects and wider Programme activities; and
- focus on supporting the development of the evidence base for impact and - where possible - implementing evidence directly.

Key priorities will be to:

- strengthen the Three School identity and voice in dementia-related research;
- support the generation of impact from commissioned projects;
- add value to the Programme's commissioned research by drawing together evidence across the Programme;
- develop and enhance a sense of community across the Three Schools;
- effectively engage with relevant and key stakeholders to improve research awareness and uptake;
- Improve understanding of knowledge exchange, impact and implementation science for dementia-related research.

The three Schools will continue to work closely with other organisations with expertise in knowledge exchange, including the NIHR Centre for Engagement and Dissemination and other knowledge translation entities. Considerable efforts will be made to ensure knowledge exchange processes are embedded into all aspects of the Programme's activities and particularly in funded research studies. Proposal leads will be required to respond to comments on their impact review and reflect amendments in their research design, budget and timetable as part of the peer-review and commissioning process.

9. PERFORMANCE REVIEW

We will review the performance of the Programme against its mission and objectives on an annual basis, with annual reports submitted to NIHR.

NIHR will review the Programme’s performance annually and through a final review.

The performance of individual commissioned projects will be reviewed in line with reporting requirements set out above.

10. BUDGET

The Programme will be funded to a total of £3.5 million from September 2021 to 30 April 2024.

	Year 1	Year 2	Year 3	Year 4	Total
	Sep 2021 - Mar 2022	Apr 2022 - Mar 2023	Apr 2023 - Mar-2024	Apr 2024	
Core Management Costs	£30,000	£70,000	£71,000	£4,000	£175,000
<i>Staffing and overheads:</i>					
<i>Director (0.05 FTE)</i>					
<i>Programme Support Officer (0.40 FTE)</i>	26,000	46,000	47,000	4,000	123,000
<i>Involvement lead (0.10 FTE)</i>					
<i>Involvement</i>	2,000	8,000	8,000	0	18,000
<i>Knowledge exchange</i>	2,000	14,000	14,000	0	30,000
<i>Consumables</i>	0	2,000	2,000	0	4,000
Research and related activities (including capacity-building)	£470,000	£1,430,000	£1,425,000	£0	£3,325,000
Total	£500,000	£1,500,000	£1,496,000	£4,000	£3,500,000

ANNEX A: Three Schools Members

SPCR: Bristol, Exeter, Keele, Manchester, Nottingham, Oxford, QMUL, Southampton, UCL; see <https://www.spcr.nihr.ac.uk/>

SPHR: Bristol, Cambridge, Exeter, Fuse (Durham, Newcastle, Northumbria, Sunderland and Teesside), Imperial, LiLaC (Liverpool and Lancaster), LSHTM, PHRESH (Birmingham, Keele and Warwick), Sheffield; see <https://sphr.nihr.ac.uk/>

SSCR: Birmingham, Bristol, KCL, Kent, LSE, Manchester, York; see <https://www.sscr.nihr.ac.uk/>

ANNEX B: 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.^{4,5} 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.⁶

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.⁷ 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.⁸ 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*,⁹ 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)

“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

⁴ 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).

⁵ 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.

⁶ 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).

⁷ 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.

⁸ 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.

⁹ Department of Health (2016) *The Prime Minister's Challenge on Dementia 2020: Implementation Plan*. London: DH.

research.¹⁰ 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^{11 12} and an earlier Lancet Neurology Commission.¹³ The priorities resonate with gaps in the evidence base identified by NICE when it most recently produced dementia guidelines,¹⁴ and also with a very recent collective exercise to describe the impact of COVID-19 on dementia wellbeing and identify directions for future research.¹⁵

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 later-life risk factors for various dementias.^{16,17} These are highly clustered for communities that experience disadvantage, creating conditions in which whole communities are at increased risk of dementia.¹⁸ The fact that many of those risk factors for dementia are also

¹⁰ 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.

¹¹ Livingston G, Sommerlad A, Orgeta V et al. (2017) Dementia prevention, intervention, and care. *The Lancet*. 2017; 390: 2673-2734.

¹² 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.

¹³ 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.

¹⁴ National Institute for Health and Care Excellence (2018) *Dementia - Assessment, management and support for people living with dementia and their carers*. London: NICE

¹⁵ 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.

¹⁶ Livingston et al. (2017, 2020) op. cit.

¹⁷ WHO (2019) *Risk reduction of cognitive decline and dementia: WHO Guidelines*. Geneva: WHO.

¹⁸ 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.

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 conditions¹⁹).

- **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 achieve better health behaviours?
- Approximately 80% of people with dementia in England in 2015 were living in the community.²⁰ 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

¹⁹ Kingston et al. (2018) *Ageing & Ageing* op.cit.

²⁰ Wittenberg et al (2019) *International Journal of Geriatric Psychiatry* op.cit.

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).