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| Host department: Keele |
| Project Title: DEEP END: Dementia prognosis: exploring health, care, and lived experience perspectives. |
| Proposed supervisory team:  |
| Primary supervisor (Host department): Dr Rosie Harrison, SoM Keele - Expertise: Qualitative methods, Social Science, Medical Sociology, Carer ResearchSecond supervisor (Consortium partner): Dr Sarah Griffiths, Senior Alzheimer’s Society Research Fellow, Research Department of Primary Care and Population Health, UCL – Expertise – dementia research, qualitative approaches, intervention development, PPIEOther members of the supervisory team/advisors* Prof Carolyn Chew-Graham, SoM Keele - Expertise: Primary care, clinical research, dementia, qualitative methods
* Dr Paul Campbell, SoM Keele - Expertise: Dementia research, mixed methods, epidemiology, social care
* Dr Michelle Marshall, SoM Keele - Expertise: Dementia research, epidemiological/quantitative, prognosis
* Professor Kelvin Jordan, SoM Keele – Expertise: Statistics, clinical research, dementia research, epidemiology
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| Potential for cross consortium networking and educational opportunities: |
| Aside from the formal and informal training plans this proposal offers excellent opportunities for wider cross consortium networking and educational opportunities. At a local level the candidate will have opportunities to network with other dementia researchers and PhD candidates (Keele, University of Birmingham) as part of the ARC WM DEMCARE programme as well as engage with several dementia-based practitioner groups (psychiatry, social care, primary care) from our links to our local NHS Foundation Trust and Primary Care Network. In the wider sphere our previous MEDDIP project (now moving to its’ second funding application phase) involved collaboration with researchers from universities including UCL, Sheffield, Warwick, and Newcastle with anticipation that the candidate will have opportunities to engage and develop links for future project and academic career pathway development from this work. At UCL SG will introduce the student to relevant research and practice contacts who work across primary and social care (e.g., within social prescribing, dementia support work, Age UK and social enterprises supporting people with dementia) across a wide-ranging network e.g. researchers at King’s College London, Leeds Beckett University and LSE, DemiQual (<https://demiqual.wordpress.com/>), and DEM-COMM (<https://www.arc-wx.nihr.ac.uk/dem-comm-research-fellows>). |
| Project description: |
| BackgroundOver 950,000 people live with dementia in the UK currently, with this number set to significantly increase by 80% over the next 20 years as the UK population ages. Over the previous decades the UK government set initiatives (e.g. National Dementia Strategy, Prime Minister’s Dementia Challenge), and now has continued with the NHS England Well Pathway for Dementia, to ensure that people “live well” with dementia, with a core consideration on preventing or delaying impactful outcomes such as hospitalisation, care home admission, and premature death. Evidence shows variation in the progression rates towards such impactful outcomes within the dementia population, but less is understood on the reasons for this variation. Understanding the course and prognosis of dementia is an important step in our ability to identify potential markers that lead to changes in progression. Having this information confers several clinical and care practice benefits; a) increases clinical and care practice knowledge for population care planning, b) is informative at a patient/service user level (individual care pathway planning), c) informative for individuals who have received a diagnosis of dementia and families/carers in terms of understanding their likely dementia course, and d) it can inform intervention development (i.e. on identified modifiable factors) to change/improve progression.Recent research completed by the proposed supervisory team via the Dunhill Medical Trust funded [MEDDIP - Keele University](https://www.keele.ac.uk/health/fmhsresearchthemes/mentalhealthandwellbeing/meddip/) using routine collected electronic health records identified and validated markers (at the time of diagnosis) as indicators of change (e.g. multi-morbidity, safety, home pressures) in relation to longer term outcomes (hospital admission, palliative care, mortality). A subsequent NIHR School for Primary Care Research funded systematic review has augmented these findings by identifying further prognostic factors (e.g. race, living alone, caregiver issues), measurable in primary care, which predict poorer outcomes. Whilst these results are informative, they are limited due to the incompleteness of recording in primary care records, particularly with regard to the lived experience of progression of dementia. There is now a need to compliment these findings by exploring how people living with dementia and caregivers experience change in progression (and what they regard as the points of significant change), how information on prognosis might be used in health and care services, particularly care planning, and how information on prognosis may be best used within the interactions between health and care practice and persons living with dementia and their families.Objectives1. Review current qualitative and case study evidence on the course of dementia to understand key points and narratives that contribute to prognosis and outcomes (cognitive decline, hospitalisation, formal care, palliative care, death)
2. Use qualitative approaches to explore the lived and health and care experience/perspectives across the course of dementia, how is change in the course experienced and understood, what is the experience of engagement with health and care services in times of change, what value does information on prognosis provide for persons who live with dementia and their families/carers and exploration of clinical and practice perspectives on the points and circumstances that may lead to a change in status (e.g. hospital admission, formal care placement, death).
3. Exploration of how prognostic information can best be used/applied in practice, and how viable interventions could be developed to address these identified key change points and circumstances.

Methods1.Establishing a Patient Advisory Group (PAG) and Practitioner group to advise on the planned research.2. Two reviews utilising scoping/systematic methods (one for lived experience, the other for health and care experience) employing standardised review processes (e.g. CRD, PRISMA, JBI) to map/assess current evidence informing topic guides. 3.Primary qualitative research using semi-structured interviews/focus groups, with people with dementia and their carers/families and those involved in dementia-based health and care. Data will be analysed thematically using the principles of constant comparison. 4. Develop a framework for intervention suitable for evaluation in future programme funding (i.e. as part of the candidate’s continued academic pathway development).5. Dissemination (co-produced with PAG), at least two manuscripts in peer-review journals, presentations at academic and clinical/practice conferences, development of lay outputs for local disseminations (via networks at Keele and UCL). |
| Indicative project costs:  |
| In addition to the candidate’s salary and supervisory costing, it is anticipated that additional costs will include:Fees (currently £4,786pa for a home student), External courses (£2500), Review costs including interlibrary loans (£250), Interview transcription (£1500), Focus groups (£500), Relevant software packages, e.g. Covidence, NVivo (£1000), Travel expenses, e.g. for interviews, visits to UCL (£2000), Open Access Publication (£3000), Conference attendance (£1000), PAG/Practitioner groups (£500, though candidate will be encouraged to apply for appropriate NIHR PPIE grant support). |
| Training and development provision by host: |
| ***Formal training:***A formal training plan (Development Needs Plan) will be fully completed at Keele once the candidate is selected, the content of needs will be based upon the candidate’s skills and previous research experience. It is anticipated that the candidate will access the following training: systematic review/meta-analysis training sessions (Keele), registration at to Keele relevant Masters-level modules (e.g. Research Methods, Advanced Qualitative Methods), the candidate will alsobenefit from the wealth of multidisciplinary expertise and doctoral training opportunities for PhD candidates at UCL including training in qualitative research methods (e.g. UCL Qualitative Research Methods in Health), and attendance at departmental methodology workshops and seminars, including those on co-production and PPIE. The candidate will also be supported to identify relevant external training courses if required (informed by the Development Needs Plan). |
| *Informal training:* The doctoral candidate will attend seminars/journal clubs within the School of Medicine and at Keele University as well as have engagement with our local university NHS Foundation Trust to secure links to dementia practice settings. At Keele the candidate will join the Keele Mental Health and Wellbeing Faculty Research Group (led by CCG), will engage with the wider NIHR ARC WM DEMCARE (and national DEMCOMM) programme and Dementia Research Group (Keele and MPFT, via PC) and will be encouraged to link with dementia-based PhD candidates (at Keele and UCL). The candidate will also engage with the MEDDIP team (led by MM and KJ) who are progressing the quantitative work that will compliment this PhD proposal, and will work with our colleagues within the Keele Research User Group who can advise on the setup of the advisory groups. At UCL the candidate will be given the opportunity to shadow SG in her qualitative and codesign work on the [**CAPPD**](https://www.ucl.ac.uk/epidemiology-health-care/research/primary-care-and-population-health/research/ageing/centre-ageing-population-studies-1) study and get involved in department public involvement group meetings and activities. We envisage that the candidate, aside from regular supervisory meetings, will travel to UCL at least once every 6 months to ensure an immersive engagement. |
| ***PPIE*:** PPIE will be a core component of this project. Initially the candidate will develop their proposal via access to the NIHR ARC WM DEMCARE PPIE group (inclusive of those living with dementia and caregivers) to inform on lived experience perspectives. If successfully funded the candidate will then engage fully with the Keele Research User Group to set up a dedicated Dementia PPIE group over the course of the doctoral study, and to facilitate PPIE membership to the Project Advisory Group (PAG), this activity will also involve engagement with UCL PCPH PPIE networks (including the “Dementia studies lived experience group”). To support this the candidate will apply for a NIHR patient and public involvement and engagement (PPIE) grant (£600) to support a PAG panel to support the project. |