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| Host department: QMUL |
| Project Title: |
| Defining opportunities for timely and equitable dementia diagnosis |
| Proposed supervisory team:  Dr Charles Marshall (Clinical Senior Lecturer and Honorary Consultant Neurologist)  Prof Claudia Cooper (Professor of Psychological Medicine)  Prof Fiona Walter (Professor of Primary Care) |
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| Potential for cross consortium networking and educational opportunities: |
| This project brings together a network of perspectives on dementia from primary care, psychiatry, neurology, and the lived experience of patients from a diverse population. There will be educational opportunities in terms of both qualitative and quantitative methods, participatory research, PPIE, and clinical aspects of dementia assessment and diagnosis. |
| Project description:  Background  People typically wait over three years from symptom onset to dementia diagnosis, and only around two-thirds of those living with dementia have received a diagnosis. Timely diagnosis empowers people living with dementia to understand their symptoms, plan for the future and access current, symptomatic treatments. In future, timely diagnosis could improve access to disease-modifying treatments.  Groups that are typically underrepresented in dementia research, including people living in less affluent areas and from ethnic and other minoritized groups, face barriers to accessing care, for example due to variations in linguistic background and health literacy. They are typically diagnosed with dementia later and with processes characterised by less accuracy and precision. A typical pathway to dementia diagnosis in the NHS begins with a presentation with memory symptoms in primary care that triggers referral to a memory clinic, or in some localities consideration of a dementia diagnosis in primary care. However, dementia is associated with a range of prodromal symptoms that may precede memory problems (including sleep disturbance, weight loss, low mood, anxiety, social withdrawal, declining blood pressure, hearing difficulty).  Diverse groups have highly heterogeneous attitudes and help-seeking approaches, suggesting that this narrow pathway to dementia diagnosis may be one explanation of the lower rates of timely diagnosis reported in people from diverse ethnic, cultural and linguistic backgrounds. In diverse patients’ views, there is a need to understand how people evaluate and articulate changes in themselves and at which point these become symptoms of illness: this important knowledge gap needs elucidation.  This project will use a mixed methods approach to understand patterns of mental, cognitive and bodily changes and associated health care seeking in the years prior to dementia diagnosis in diverse populations in East London, who have high rates of socio-economic adversity. The research will be grounded in the lived experience of PPI participants, and take a participatory, co-designed approach. The findings will influence primary care approaches to memory clinic referral and dementia diagnosis through greater awareness of the heterogeneity of presentations.  Aims and objectives  This project will use a mixed-methods approach to identify opportunities in the care pathway for more timely and equitable dementia diagnosis. We will do this by examining patterns of changes described by patients and their families from diverse backgrounds through (1) in-depth qualitative interviews, and (2) a big data study, to analyse patterns of symptoms in the years preceding the development of dementia. PPI representatives have informed the development of this study, and will be involved in key decisions, including study design, interpretation and dissemination approaches. The main objectives of the project are:   1. Qualitative study:    * To use qualitative methods to explore, in diverse populations served by East London primary care, lived experiences of prodromal dementia; considering how symptoms initially present, are understood and lead, or not, to primary care consultation and diagnosis. 2. Quantitative study:    * To compare in a large primary care dataset the frequencies of risk factors and prediagnostic presentations to primary care between people diagnosed with dementia <2, 2-5 and 5-10 years later, and matched controls.    * To establish the predictive value of prodromal symptoms for subsequent dementia diagnosis in a diverse population, accounting for age, gender and other potential confounders and stratifying by ethnic group 3. PPIE and dissemination    * To use participatory methods to inform quantitative analyses, to ensure the project is grounded in the lived experiences of people experiencing dementia symptoms and their carers    * To explore what the findings tell us about how primary care strategies for dementia detection might be more inclusive, to reduce disparities in dementia diagnosis rates.    * To develop training materials, patient engagement activities, and policy recommendations that are acceptable to people with dementia and their supporters who are the intended beneficiaries of the research.   Method(s)  Stream 1: Lived experience of prodromal dementia - qualitative methods  We will explore in depth how people present to health and social care services prior to a dementia diagnosis, in an ethnically diverse area with high levels of deprivation, where rates of timely dementia diagnosis are low. The student will work with PPI collaborators from Hackney Caribbean Elderly Organisation and the Darul Ummah Mosque to develop a sampling frame that is representative of older people (aged 60+) living in East London, and reflects diversities of culture, gender, ethnicity, disability, and other experiences (migration, deprivation). They will recruit people with dementia and their family members to explore how people make decisions on the pathway to dementia diagnosis, including circumstances where diagnoses are delayed or missed. The project will use an adapted thematic analysis approach, strengthened with a theoretical framework on pathways to treatment previously developed by FW. Themes will be defined and refined, exploring divergences between interviews of people with dementia and their supporters, and across other diverse experiences.  Stream 2: Predictive value of prodromal features of dementia in primary care – quantitative methods  In parallel with the qualitative study, the project will quantify the importance of a range of symptoms and signs of prodromal dementia routinely recorded in primary care. The student will conduct a nested case-control study using electronic health care records (1990-2018) from primary care practices in East London, which contains records for over 1 million inhabitants (98% of all adults in the region), around 5,000 of whom have a dementia diagnosis. The dataset is unique in its diversity (<50% White and around 25% each Black and South Asian) and ethnicity data completeness (<5% missing). We have previously used it to show that ethnicity and deprivation are the most important risk factors for dementia in this population, and to define early presentations of Parkinson’s disease in primary care. Potential prodromal markers of dementia will be defined using the recently updated Lancet Commission literature review, and a Delphi consultation exercise of clinicians, supplemented by findings from Stream 1 interviews and a PPIE workshop. Exposures will include symptom presentations (e.g. memory problems, low mood, fatigue, pain), comorbidities (e.g. depression, hearing difficulty), and clinical measurements (e.g. blood pressure, BMI); and recorded diagnoses of MCI (Mild Cognitive Impairment). For the periods <2, 2 to <5, and 5-10 years before the date of diagnosis (index date for controls), they will first calculate the overall occurrence of prediagnostic symptoms as the absolute number and percentage. This categorization will be used to estimate the odds ratio (OR) for subsequent dementia and 95% CI for each variable of interest in each period and in all 3 periods combined. They will then draw on established methods developed by FW and colleagues for improved cancer detection in primary care, to calculate positive predictive values for subsequent dementia diagnosis of specific features both individually and in combination.  Impact  The goal is to improve equality of opportunity of access to dementia diagnosis using data that are already routinely recorded by GPs, for example through education of primary care clinicians and/or the development of dementia risk alerts.  The findings will allow the development of early versions of candidate interventions for dissemination and evaluation, including:   * An educational tool for primary care clinicians * A public awareness campaign targeted towards the groups participating in the study * A dementia risk alert system for primary care   The student will publish findings as first-author papers in peer review journals. They will work with us to write a policy report outlining implications of the work for national strategies to improve timely and equitable diagnosis of dementia. We will develop this policy report in partnership with NHS England Dementia Clinical Network and Alzheimer’s Society, and we will aim to incorporate the findings into their guidance on national policy for dementia diagnosis, and explore how it might inform their recent work on a symptom checklist. Evidence acquired during this project will support planning of further research to evaluate the impact of and refine our candidate interventions. |

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| Training and development provision by host: |
| Formal training:  The student will have access to formal training in qualitative and quantitative methods, as well as a programme of generic research skills training through the doctoral school at QMUL. |
| Informal training:  The student will be mentored by experts in these methods at the Wolfson Institute of Population Health. They will also participate in monthly PhD workshops hosted by the Preventive Neurology Unit. They will have opportunities to develop clinical skills and a special interest in dementia assessment through participation in memory clinics with the supervisors. |
| PPIE:  The student will work with our PPIE partners at Hackney Caribbean Elderly Organisation and Darul Ummah Mosque to recruit a group of PPIE participants to take part in two workshops. In the first workshop, they will present the emerging analysis and discuss how they included findings from stream 1, inviting participants to suggest additional ways in which stream 1 findings and their lived experiences can inform the work. The second workshop will aid interpretation and integration of findings from the two streams, and the development of a dissemination plan. |