UKRI Ideas to Address COVID-19 – Proposal Form

Once completed please combine this form, along with optional max 1xA4 page of figures/data tables, and required CVs and proof of lead organisation support, into a single pdf for submission.

Section 1: Proposal Summary

1.1 Title (max. 150 characters)

DETERMIND-C19: Impact of COVID-19 on people newly diagnosed with dementia and their family carers, a mixed method study nested in DETERMIND

1.2 Scientific/technical summary (max. 250 words)

People with dementia are at high risk of adverse outcomes from COVID-19 and may also be adversely affected by the steps taken by society to control the spread of the infection. They have difficulty remembering and understanding restrictions and precautions put in place to protect them and others, and may be distressed that non-resident family and social networks are compromised. In addition, there is currently reduced access to many formal care services. This may cause strain for people with dementia and co-resident and non-co-resident family carers, particularly those with a recent diagnosis who are attempting to come to terms with living with dementia and navigating the complex support landscape. We currently have few empirical data with which to help us to formulate how best to support them. We will address this gap by examining how a group of 266 people newly diagnosed with a range of severities of dementia in the months before the COVID-19 lockdown and their carers have been affected by COVID-19 and the predictors of better and worse outcomes (quality of life, depression, carer burden and physical health). They were recruited as part of the ESRC/NIHR-funded DETERMIND programme and have a rich baseline characterisation of socio-demographics, clinical state, and service use. Using telephone quantitative and qualitative interviews we will investigate what has happened to them and how outcomes vary by clinical and sociodemographic factors such as dementia severity, neuropsychiatric symptoms, service receipt, ethnicity, gender, and place of residence. We will use these data to generate practical guidance for services and families on how best to support people with dementia and carers in this and any future pandemic.

1.3 Project duration*

Proposed start date (dd/mm/yy)	01/06/2020
Proposed duration of award (months)	12
Proposed end date (dd/mm/yy)	31/05/2021

* note max. 18 months

1.4 Project cost (£)	**FY 20/21**	**FY 21/22**	**TOTAL**
Indicative costs	117,283		

1.5 Which councils' remits is your proposal most aligned to?	Primary	Secondary
AHRC	☐	☐
BBSRC	☐	☐
EPSRC	☐	☐

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ESRC	☒	☐
Innovate UK	☐	☐
MRC	☐	☒
NERC	☐	☐
Research England	☐	☐
STFC	☐	☐
Don't know	☐	☐

Section 2: Investigator Details

2.1 Principal Investigator	
Name	Prof Sube Banerjee
PI Organisation	University of Plymouth
PI Department	Faculty of Health
Industry/SME	No
Email address	sube.banerjee@plymouth.ac.uk
ORCID	0000-0002-8083-7649
Administrative authority contact name (email)	robert.fern@plymouth.ac.uk

2.2. Co-Investigators	
Name (Organisation)	Dr Ben Hicks (Brighton and Sussex Medical School)
Name (Organisation)	Prof Martin Knapp (London School of Economics (LSE)) Prof Raphael Wittenberg (LSE and University of Oxford) A/Prof Josie Dixon (LSE) A/Prof Bo Hu (LSE) A/Prof Sanna Read (LSE) A/Prof Nic Brimblecombe (LSE)
Name (Organisation)	Prof Yvonne Birks (University of York) Prof Kate Baxter (University of York) Dr Kate Grindley (University of York)
Name (Organisation)	Prof Jenny Rusted (University of Sussex) Prof Peter Harris (University of Sussex) Dr Eleanor Miles (University of Sussex) Dr Rotem Perach (University of Sussex)
Name (Organisation)	Ms Margaret Dangoor (PPI)
Name (Organisation)	Prof Carol Brayne (University of Cambridge)
Name (Organisation)	Prof Dame Louise Robinson (University of Newcastle) Prof Alan Thomas (University of Newcastle)
Name (Organisation)	Prof Robert Stewart (King's College London)
Name (Organisation)	
Name (Organisation)	

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2.3 Project Partners (unfunded by proposal, if applicable)		
Project partner organisation	Project Partner Contact	Contribution Type (e.g. access to equipment, samples)
Alzheimer's Society	Colin Capper	PPI, involvement in formulation of guidance for support, communication
NHS England	Prof Alistair Burns, National Clinical Director for Dementia	Link with NHS England, involvement in formulation of guidance for support, communication

*Please estimate approximate value of partner contribution

Section 3: Importance, Deliverables, Expertise, and Resources

3.1 Please describe and justify the importance of the COVID-19 related knowledge gap and/or need that you are targeting (max. 250 words)

There are around 750,000 people with dementia in England (7.2% of the population aged 65 and over) two-thirds of whom live in the community outside care homes. They are at high risk of serious outcomes from COVID-19 and in many cases their family carers, most frequently their spouse, are also at similarly high risks due to age and comorbidities. We have little evidence on how lockdown is affecting community dwelling people with dementia and their family carers with different demographic and socio-economic characteristics. Impacts will differ between those with co-resident (where the carer lives with the person with dementia) and non-co-resident carers. Resource mobilisation to acute care in the NHS and social care means that there are reductions/changes in post-diagnostic support and homecare, this project will investigate how these changes are affecting life under lockdown for those with dementia and their carers as a whole and particular populations. The combination of vulnerability to the virus together with reductions in services and the potential exacerbation of dementia symptoms from isolation and lack of occupation makes people living with dementia at home a unique group and as yet we know very little about how they are being affected or what influences this. We will fill this evidence gap by following up a deeply phenotyped sample of people with dementia and carers who were assessed in the months before the lockdown as part of the DETERMIND programme which focussed on equality and equity of care and outcomes in those diagnosed with dementia. This study will provide much needed information on the experiences and outcomes of people with dementia and their carers in this pandemic and guidance on how best to support people with dementia and their carers and how this may need to be tailored to specific groups.

3.2 Please describe how the research impact(s) can be scaled to be useful to the UK as a whole (max. 250 words)

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We will extend the Theory of Change methods used in DETERMIND to synthesise the data collected in DETERMIND-C19 and generate actions for impact. Closely collaborating with stakeholders, we will translate these into practical guidance for services and families on how best to support people with dementia in this and any future pandemic. Our research team is well networked with the NHS and social care nationally and working with our partners the Alzheimer's Society and the National Clinical Director for Dementia at NHS England (Prof Alistair Burns) and the NIHR School for Social Care Research we will make our guidance available nationally for people with dementia, family carers, voluntary organisations, the NHS, and social care. To deliver this nationally we will augment our existing DETERMIND website https://determind.org.uk/ and link DETERMIND-C19 results and guidance with local and national on-line sources of information including Alzheimer's Society's resources. The website has links to our institutional websites and these will be extended. We will prepare interim research findings after half the interviews are completed and issue interim guidance. Outputs will be accessible and will contain a clear summary and infographics. Our target audiences include: the public, people with dementia and family carers, clinicians and care staff, the third sector, health and social care commissioners and policy-makers and NICE. We will specifically target: policy networks and other groups representing older people and their families (eg ADASS, Age UK, Alzheimer's UK, Carers UK, Care and Support Alliance); care provider networks (eg UK Home Care Association, Care England); regulatory and sector-specific bodies (eg Care Quality Commission, Skills for Care); and knowledge brokers/change agents (eg Social Care Institute for Excellence, Think Local Act Personal)

Section 4: Plan of Research including Importance, Deliverables, and Resources

4.1 In this section you should provide an overview of the nature of the proposed research or project (study design, approach and deliverables) (max. 1500 words). To include:
- **How deliverables will provide/lead to benefit(s) relating to the health, social, economic, cultural and/or environmental impacts of the COVID-19 outbreak within 18 months.**
- **How these are unique and value-adding compared to existing COVID-19 related activities targeting the same or similar knowledge gap(s) and/or need(s)**

1.0 AIM

1.1. To examine the experiences of people newly diagnosed with dementia and their family carers (both co-resident and non-co-resident) during the COVID-19 pandemic, and its impact on quality of life, social connection, and psychological and physical health.

1.2. To compare different sub-groups based on clinical and sociodemographic characteristics to identify inequalities in care and support received, outcomes and experiences.

1.3. To use these data to generate, using Theory of Change methodology, practical guidance for services and families on how best to support people with dementia and family carers in this and any future wave of COVID-19 or other epidemic.

2.0 RESEARCH QUESTIONS

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2.1　　How do people with recently diagnosed dementia and their carers perceive, experience and manage the COVID-19 pandemic and the public health restrictions imposed?

2.2　　How do their quality of life, social connection, and psychological/physical wellbeing during the pandemic vary by sociodemographic, carer and clinical factors?

2.3　　How have services changed for people with dementia and how do co-resident and non-co-resident family carers manage and cope with changes in the support and services they receive? What has helped and what has hindered?

2.4　　In this group, does the pandemic result in additional unmet care needs, and how do these differ by clinical, sociodemographic and carer factors?

2.5　　What further support do people recently diagnosed with dementia and their carers require during the pandemic and how does this vary with clinical/sociodemographic factors?

2.6　　How do individuals manage their care requirements if the person with dementia, their family carer or both have receive a diagnosis of COVID-19?

3.0　　METHOD

3.1　　Design

This is a mixed methods study using quantitative measures of quality of life, social connection, care/support patterns, and well-being alongside semi-structured in-depth qualitative interviews to explore in more detail people's experiences of living with dementia during the pandemic. Data will be collected by telephone interview, supported by materials sent by post (technologies familiar to people with dementia)

3.2　　Participants

Existing participants recruited into the DETERMIND cohort (people with dementia (n=266); family carers (n=204)) will be invited to participate in the DETERMIND-C19 sub-study. DETERMIND is a longitudinal study, funded by the ESRC and NIHR, that aims to explore and understand inequalities and inequities in post-diagnostic dementia care and outcomes for people with dementia and their carers. 900 people with dementia (diagnosed in the past 6-months) will be recruited into a cohort and followed up yearly for three years. Recruitment began in August 2019 across the south-east, south London, and the north-east. Recruitment is currently paused until face-to-face interviews are possible. We have a diverse sample from varying sociodemographic backgrounds, who have had extensive baseline face-to-face interviews measuring demographic and clinical status, quality of life, well-being, and service use. They provide an accessible, well-phenotyped cohort for DETERMIND-C19, with the data already collected (high quality with low missingness levels) used as a baseline comparator.

3.3.　　Sample size and statistical power

For at least 80% power at 5% significance (R-squared test=0) with 6 predictor variables, 143 participants would allow us to detect a small-to-medium effect sizes f^2=0.10 (GPower). We estimate there may be 10% attrition between the baseline and DETERMIND-C19 assessments. Given 204 family carers at baseline, we have set a target sample of 184 carer participants. This will allowing for further COVID-19 effects on participation. Given challenges associated with completing capacity assessments by telephone alongside family carers' potential apprehension in engaging people with dementia in research during this period we are also aiming for a target of 184 people with dementia.

Ethics: We will include all carers (n=201) but (given telephone constraints) only interview people with dementia with capacity to consent. For them: (i) those who gave informed consent at DETERMIND baseline will be considered (n=222); (ii) their carers will be contacted first and asked whether the person with dementia would be able to take part in a telephone interview or if there

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are reasons not to contact them; and (iii) a trained Research Assistant (RA) will assess capacity to consent by telephone and those with capacity will be invited to participate. We will seek a substantial amendment to our ethical approvals to allow the DETERMIND-C19 telephone interviews, we are confident that we can obtain this within four weeks.

3.4 Quantitative assessment

All family carers and people with dementia who consent will be assessed with a battery of quantitative measures delivered by an RA by telephone. Alongside bespoke and open-ended questions on whether participants have contracted COVID-19, the resulting impacts, and any changes in their service use or support arrangements, this will include:

•	Person with dementia rating self - disease-specific health-related quality of life (HRQL, DEMQOL), generic HRQL (EQ-5D-5L), cognition (Mini Mental State Examination), impact of Covid-19 (Impacts of Events Schedule, IES), loneliness (De Jong Gierveld 6-item, De6), stress (Perceived Stress Scale, PSS).
•	Carer rating person with dementia – disease-specific HRQL (DEMQOL-Proxy), service use (Client Services Receipt Inventory CSRI), neuropsychiatric symptoms (NPI), physical illness (Cumulative Illness Rating Scale for Geriatrics), proxy rating of generic HRQL (EQ-5D-5L), stress (PSS).
•	Carer rating carer - carer condition-specific quality of life (C-DEMQOL), impact of Covid-19 (IES), carer generic HRQL (EQ-5D-5L); carer burden (Zarit CBI), carer mental health (HADS), wellbeing (ONS4), support provided, loneliness (De6).

3.5 Qualitative assessment

30-40 in-depth semi-structured telephone interviews (or password-protected Zoom or Skype call, if preferred by respondent) will be conducted by a researcher with a purposive sample of the DETERMIND cohort, the number determined by theoretical saturation. This will comprised 15/20 people with dementia and 15/20 co-resident and non-co-resident carers, with the interviews being conducted on dyads or individually. The interviews will be guided by a topic guide and last around 30-40 minutes (shortened if needed). The team has extensive experience in interviewing people with dementia and their carers. This will spot any signs of distress and respond appropriately, for example, asking if the respondents would like to pause or moving to a different topic. The interviews will be conducted after the quantitative measures with participants purposively selected on sociodemographic characteristics, severity of dementia, and experiences of COVID-19. These interviews will enable further exploration of people's experience of the pandemic and the restrictions imposed, their experiences of living with dementia during this period, of changes in usual service provision, and facilitators and barriers encountered to sustain or improve quality of life. Interviews will be audio recorded and transcribed verbatim.

3.6 Analysis

Quantitative analysis will use baseline DETERMIND data collected before the pandemic and the DETERMIND-C19 interview. By comparing the measures between baseline and follow-up, we will identify individuals who report less support and care and who report a decline in their quality of life and wellbeing. We will carry out regressions/path models to investigate to what extent participants' experiences of receiving/not receiving care and support during the pandemic, and their resulting quality of life and psychological wellbeing, differ by sociodemographic/socioeconomic/clinical factors. We will investigate whether people's perceived impacts of COVID-19 mediate or moderate these relationships and outcome measures. Analyses will be adjusted for baseline service use and wellbeing. We will use change models to investigate whether the changes in service use and wellbeing before and during the pandemic differ by the respondents' sociodemographic/clinical factors. The models will use full information maximum

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likelihood estimation to handle missing data. Qualitative data from the interviews and open-ended responses on the questionnaires will be managed in NVivo12 and used to provide further insights into the quantitative findings. The data will be analysed thematically and will examine differences in people's experiences based on respondent characteristics, exploring why and how differential experiences of the COVID-19 pandemic occur. We will use 'triangulation protocols' at a thematic level and 'mixed methods matrices' at the level of individual cases for data integration.

3.7   Patient and Public Involvement (PPI)
We will use DETERMIND's PPI structures to ensure meaningful involvement at all stages. MD is a co-applicant on this and DETERMIND, she is an expert by experience having cared for two people with dementia. She convenes the study reference group.

4.0   OUTPUTS AND IMPACT

4.1   Theory of Change (ToC) synthesis of data and formulation of actions for impact
The DETERMIND programme makes major use of ToC methods to coordinate and co-develop our research and its outputs. We have developed an iterative, collaborative ToC logic model. We will further develop this to synthesise insights from the quantitative and qualitative data collected in DETERMIND-C19 and use them to generate actions for impact. Closely collaborating with stakeholders, including people with dementia, carers, practitioners, commissioners and policy makers, facilitated by our partner the Alzheimer's Society, we will use this process to generate practical guidance for services and families on how best to support people with dementia in this and any future pandemic. The logic model will provide a visual conceptual map of the journey undertaken by people with dementia and carers and the impact of COVID-19. The inclusive, iterative process proposed is of particular value because of the intersection between the complexity of dementia treatment and care and those of COVID-19.

4.2   Deliverables and benefits within 18 months
We will use our unique data to generate practical guidance for services and families on how best to support people with dementia and their family carers in this and any future pandemic. Working with the Alzheimer's Society and the National Clinical Director for Dementia at NHS England (Prof Alistair Burns) and the NIHR School for Social Care Research we will make this available nationally for people with dementia, family carers, voluntary organisations, the NHS, and social care. We will use our DETERMIND website and link with local and national on-line sources of information including Alzheimer's Society's resources. Academic outputs (papers and conference presentations) will complement this and add to the evidence base for national and international action.

4.3   How DETERMIND-C19 is unique and value-adding
•   No other cohort of people with dementia has our detailed set of quality of life/sociodemographic/psychological/clinical variables measured in the six months before the COVID-19 lockdown.
•   The DETERMIND cohort is specifically-designed to be inclusive of people with dementia from Black, Asian and Minority Ethnic groups.
•   The DETERMIND study allows a unique focus on inequalities and inequity in care and outcomes for people with dementia and carers.
•   The three-year follow-up we will carry out in the DETERMIND programme means we can (later) prospectively study the longer-term effects of the outbreak on this population.
•   Repurposing existing DETERMIND investigator resources minimises costs, maximising value for money.

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> • Our sample includes co-resident and non-co-resident carers, the data collected in Understanding Society excludes non-co-resident carers.

4.2 Please provide a brief description of the resources required in the different contributing environments (staff, materials, data, facilities etc.), including whether these are in hand, or if not, what gives you confidence that they will be accessible when required? (max. 250 words). Note here if you are requesting access to shared UKRI facilities including computational facilities.

We have all the resources we need in terms of senior researcher/investigator and project manager (BH) time in the current DETERMIND grant and the participants have already been identified. The investigators will all spend 2.5% of their time on DETERMIND-C19 other than BenH (project manager) who will spend 50% of his time on this and SB (PI) who will spend 10%, but no funds are sought for this since they are repurposed from the DETERMIND grant. Recruitment in DETERMIND has paused and since our RWs in Sussex, London and Newcastle are NHS based they have been redeployed to COVID-19 supporting roles in their Trusts other than 1.0WTE in our Sussex site. To arrange and complete the 368 quantitative interviews and 40 qualitative interviews needed we require a minimum of 4.0WTE RWs if we are to complete the assessments in a five-month period. This amounts to arranging and completing 20 interviews per WTE per month, in addition they will work on data entry, cleaning, and qualitative coding under senior supervision. As in DETERMIND, the RWs will be employed by NHS Trusts to facilitate patient access. We are seeking 100% of the funding for the direct costs of 3.0WTE NHS-employed RAs for 9 months (£94,683) and DETERMIND will provide the other 1.0WTE RA. We are also seeking funding for phone/internet costs since these need to be made from RA's homes due to lockdown (600 calls and project comms £1,000), field data entry tablets (3 @ £300, £900), transcription costs (40 interviews @ £80 per transcript £3,200), Alzheimer's Society and PPI facilitation (£4,500), guidance preparation/formatting/infographics (£5,000), replacement costs for external ToC contributions from stakeholders (£3,000) and communication/dissemination costs (including meetings/conferences (online and face-to-face if possible) and website fees £5,000).

Section 5: Investigators

5.1 Please provide evidence that the team has the necessary expertise, track record and contacts to undertake the proposed work and ensure its impact (max. 250 words). If you are requesting our help in finding support from shared staff pools, note this here.

To deliver DETERMIND-C19 we will use the whole DETERMIND programme team. We are a strong, experienced, multidisciplinary team combining the social, economic and policy research expertise of the Care Policy and Evaluation Centre (CPEC) (formerly the PSSRU) at LSE [MK, RW, JD, BH, SR] and the Social Policy Research Unit at York [YB, KB, KG], with epidemiology and public health at the Institute of Public Health at Cambridge [CB] and KCL [RS], experimental and social psychology at Sussex [JR, PH, EM, RP], primary care and ageing at the Institute of Ageing Newcastle [LR], and clinical research in dementia and the NHS at Newcastle [LR], KCL [RS], Brighton and Sussex Medical School [BH], and the University of Plymouth [SB]. We have deliberately chosen to include in this application our early career researchers embedded in DERTERMIND programme to maximise their possibility for career development. Meaningful PPI is a foundational commitment in DETERMIND and is also fundamental to this application. MD, an expert by experience of being a family carer for

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two people with dementia over a 20-year period is a full applicant on this proposal and therefore has been and will be involved in all stages of the research as an equal partner. The Alzheimer's Society supports this project and has agreed to work with us as an integral element of our PPI strategy throughout the project. Our team includes world-leading clinical [AT, RS, LR, SB], social/economic [MK, RW, YB], and epidemiological [CB, RS] researchers in dementia alongside high level expertise in public health [CB], primary care [LR], psychiatry [SB, AT, RS], and psychology [JR, PH]. All have held major grants and have a strong track record in delivery. SB will direct the project taking ultimate responsibility for it and the delivery of all outputs.

The following should also be provided. **These should be combined with this form into a single pdf for submission** to CV19researchinnovation@ukri.org

CVs - Please provide a CV for the PI and Co-Is/Team members. Each CV to provide relevant key publications/outputs and grants and other relevant information indicating their suitability to lead/support the work as described in the application (no more than 1xA4 page per CV using Arial 11 point).

Institutional approvals Include evidence of approval from the host institution/company/organisation which confirms you are able to carry out the proposed work under any institutional restrictions currently in place.

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Annex 1: Regulatory requirements: Please complete as applicable

A. Legislative/Ethical requirements

Note: Data produced as a result of this funding must be shared in line with the [Joint statement on sharing research data and findings relevant to the novel coronavirus (nCoV) outbreak](#).

Does this programme involve:	
1. Animals? The use of vertebrate animals or other organisms covered by the Animals (Scientific Procedures) Act 1986[1], whether or not it requires licensed procedures.	No
1a. Animal Species? If animals are being used please provide the basic species information e.g. Mouse.	
2. Human Tissue? The use of human tissue as defined in the Human Tissue Act 2004[2]?	No
3. Stem Cells? Does the research involve the use of Stem Cells or regenerative medicine?	No

Note: The MRC will make public information about animal experiments when needed (e.g. as anonymous examples, or in response to direct queries) but will resist all requests for information that might lead to the identification of places or individuals, except with the express permission of the individuals concerned.

B. Additional information for clinical research

Does this programme involve:	
1. Human participation? Research which requires *face-to-face* contact with *patients*, or with *healthy human participants* (by holders of a clinical contract) and may involve use of patient records as a concomitant, e.g. a clinical trial.	Yes
2. Records based studies? Research which requires *access to personal data* on health or lifestyle *without* involving face-to-face contact with any people, e.g. public health interventions, health economic studies, epidemiological studies, health services research and meta-analyses - information may be obtained by telephone, postal questionnaires/surveys or electronic/manual data retrieval.	No
3. Clinical samples? Research which involves *laboratory studies* on *human material* which are specifically designed to understand or treat a disease/disorder. N.B. Basic biomedical research remote from application to a disease/disorder, such as the use of immortalised human cell lines in model biological systems, is excluded.	No

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[1] http://www.homeoffice.gov.uk/science-research/animal-research/
[2] https://mrc.ukri.org/research/facilities-and-resources-for-researchers/regulatory-support-centre/human-tissue/

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4. Technology development for clinical use? Development or adaptation of technologies for diagnosis or therapy, e.g. instrument development for diagnostic or surgical use; development of new techniques, such as photodynamic therapy, for clinical use.	No

Note: This information will not be made publicly available in an identifiable format.

C. Additional Analysis Data

The following data will assist us in scientific and strategic reporting and may be published.	
Research Setting Based on direct patient contact, indicate whether the research involves a particular medical setting such as primary care or secondary care.	Primary care/the community

D. Other ethical considerations

Other Ethical Considerations	
Are there other ethical and/or health and safety issues that have been considered	Yes
If Yes, please outline (max 100 words)	
There are issues of capacity and consent when working with people with dementia. We will include all carers (n=201) but (given telephone constraints) only interview people with dementia with capacity to consent. For them: (i) those who gave informed consent at DETERMIND baseline will be considered (n=222); (ii) their carers will be contacted first and asked whether the person with dementia would be able to take part in a telephone interview or if there are reasons not to contact them; and (iii) a trained Research Assistant (RA) will assess capacity to consent by telephone and those with capacity will be invited to participate. We will seek a substantial amendment to our ethical approvals to allow the DETERMIND-C19 telephone interviews, we are confident that we can obtain this within four weeks.	
Is the ethical approval already in place?	No
Will ethics approval be sought and if so when?	Yes on submission

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DETERMIND-C19: Gantt chart of key tasks and deliverables

Staff and tasks	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr
RWs employed		🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦			
Investigator time (unfunded)	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Ethical approval	🟥											
PPI consultation	🟥											
Send out invitations to participate	🟥	🟥	🟥	🟥								
Quantitative interviews		🟥	🟥	🟥	🟥	🟥						
Preliminary quantitative data analysis				🟥	🟥							
Qualitative interviews			🟥	🟥	🟥	🟥	🟥	🟥				
Analyse qualitative data				🟥	🟥	🟥	🟥	🟥				
Interim report and guidance					🟥							
Final quantitative analyses and synthesis						🟥	🟥	🟥	🟥	🟥		
Generation of papers and guidance						🟥	🟥	🟥	🟥	🟥		
Communication activities						🟥			🟥	🟥	🟥	🟥

Reference list for measures

CSRI: Beecham, J., & Knapp, M. (1992). Client Service Receipt Inventory (CSRI). Database of Instruments for Resource Use Management.

Cumulative illness rating scale: Linn, B. S., LINN, M. W., & Gurel, L. E. (1968). Cumulative illness rating scale. Journal of the American Geriatrics Society, 16(5), 622-626.

C-DEMQOL: Brown, A., Page, T. E., Daley, S., Farina, N., Basset, T., Livingston, G., ... & Bowling, A. (2019). Measuring the quality of life of family carers of people with dementia: development and validation of C-DEMQOL. Quality of Life Research, 28(8), 2299-2310.

DEMQOL, DEMQOL-Proxy: Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R., Foley, B., Smith, P., ... & Mann, A. (2005). Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. Health Technology Assessment (Winchester, England), 9(10), 1-93.

ELSA single item loneliness measure: The Office for National Statistics. (2018) Measuring loneliness: guidance for use of the national indicators on surveys. https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/methodologies/measuringlonelinessguidanceforuseofthenationalindicatorsonsurveys

EQ5D: The EuroQoL Group. (1990). EuroQol-a new facility for the measurement of health-related quality of life. Health Policy. 16(3), 199-208

Hospital and Anxiety Depression Scale (HADS): Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. Acta psychiatrica scandinavica, 67(6), 361-370.

Impact of Events Scale: Horowitz M, Wilner N, Alvarez W. (1979). Impact of event scale: a measure of subjective stress. Psychosom Med. 41(3), 209-218.

De Jong Gierveld Loneliness Scale: Gierveld, J. D. J., & Tilburg, T. V. (2006). A 6-item scale for overall, emotional, and social loneliness: Confirmatory tests on survey data. Research on aging, 28(5), 582-598.

MMSE: Folstein, M. F., Folstein, S. E., McHugh, P. R., & Fanjiang, G. (2001). Mini-Mental State Examination user's guide. Odessa, FL: Psychological Assessment Resources.

Neuropsychiatric Inventory: Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. Neurology, 44(12), 2308-2308.

ONS4: The Office for National Statistics. (2006). Personal well-being user guidance. https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/methodologies/personalwellbeingsurveyuserguide.

Perceived stress scale: Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. Journal of health and social behavior, 24, 385-396.

Relative Stress Scale: Ulstein, I., Bruun Wyller, T., & Engedal, K. (2007). The relative stress scale, a useful instrument to identify various aspects of carer burden in dementia?. International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences, 22(1), 61-67.

Role Captivity Scale: Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The gerontologist, 30(5), 583-594.

UCLA three-item loneliness scale: University of California Los Angeles (UCLA) three-item loneliness scale. The Office for National Statistics. (2018) Measuring loneliness: guidance for use of the national indicators on surveys. https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/methodologies/measuringlonelinessguidanceforuseofthenationalindicatorsonsurveys

Zarit Carer Burden: Zarit SH, Reever KE, Bach-Peterson J. (1980) Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist. 20(6): 649-655.

DETERMIND protocol paper

Farina, N., et al. (2019). DETERMinants of quality of life, care and costs, and consequences of INequalities in people with dementia and their carers (DETERMIND): a protocol paper. International Journal of Geriatric Psychiatry, 35, 1-12.

DETERMIND-C19 CVs (alphabetical order)

Sube Banerjee
Kate Baxter
Yvonne Birks
Carol Brayne
Nicola Brimblecombe
Margaret Dangoor
Josie Dixon
Kate Grindley
Peter Harris
Ben Hicks
Bo Hu
Martin Knapp
Eleanor Miles
Rotem Perach
Sana Read
Louise Robinson
Jennifer Rusted
Robert Stewart
Alan Thomas
Raphael Wittenberg

Name: Professor Sube Banerjee MBE	
Present appointment: Professor of Dementia & Executive Dean, Faculty of Health, University of Plymouth	
Telephone number: 07734681599	**Email address:** sube.banerjee@plymouth.ac.uk

MBBS (University of London)	1987
MRCPsych	1991
MSc (Epidemiology, LSH&TM)	1993
MD (University of London)	1995
FRCPsych	2004
MBA (London Business School)	2012

Appointments

01/11/2019 – date Professor of Dementia & Executive Dean, Faculty of Health, University of Plymouth
01/11/2012 – 31/10/2019 Professor of Dementia and Deputy Dean, Brighton and Sussex Medical School
01/02/2003 - 01/11/2012 Professor of Mental Health and Ageing - KCL, Institute of Psychiatry
01/02/2000 - 01/11/2011 Clinical Director - South London and Maudsley NHS Trust
01/07/2007 - 01/04/2010: National Clinical Lead -National Dementia Strategy - Department of Heath

Selected grants held as PI

- Measurement of health-related quality of life in people with dementia: the development of a new instrument responsive to change. PI 2000-2003. NHS R&D HTA £350k.
- HTA-SADD Study of Antidepressants in dementia: a definitive multi-centre RCT of clinical and cost effectiveness. Chief Investigator (CI). £2.3 million. NIHR HTA. 2006-10.
- MRC-DOMINO. A placebo controlled RCT of Donepezil and memantine combined and alone vs placebo in AD. MRC 2007-10. local PI £2.4 million.
- Generation of preference-based indices from DEMQOL and DEMQOL-Proxy for use in economic evaluation. HTA NIHR Methodology programme. PI 2008-11. £860k.
- MODEM Comprehensive approach to modeling outcome and cost impacts of interventions for dementia. ESRC. Local PI 2013-17. £3.3 million.
- Time for Dementia: development and evaluation of a novel interdisciplinary longitudinal clerkship in dementia. Principal investigator 2014-2020. Health Education England KSS. £2.4 million.
- SYMBAD RCT study of mirtazapine and carbamazepine for agitation and aggression in dementia. Chief Investigator. 2015-2018. NIHR HTA Programme. £1.5 million.
- C-DEMQOL Development of a quality of life measure for carers of people with dementia. Principal investigator. 2015-2018. Alzheimer's Society. £315k
- STRiDE Strengthening responses to dementia in developing countries. Co-applicant. 2017-2022. Research Council UK (RCUK) Global Research Challenges Fund. £7.9 million.
- DETERMIND Determinants of inequalities and inequities in dementia. CI. ESRC 2019-2024 £4.9 million

Selected publications:

- Banerjee S (2009). Use of antipsychotics for people with dementia – time for action. London: DH.
- Banerjee S, Hellier J, Dewey M et al (2011). Study of the use of anti-depressants for depression in dementia: the HTA-SADD Trial. The Lancet 378: 403-11.
- Barnes TR, Banerjee S, Collins N, Treloar A, McIntyre SM, Paton C (2012). Antipsychotics in dementia: prevalence and quality of antipsychotic drug prescribing. BJ Psychiatry; 201(3):221-6.
- Howard R, …, Banerjee S, … Bentham P, Phillips P (2012) Donepezil and memantine in moderate to severe AD. New England Journal of Medicine 366 893-903.
- Romeo R, Knapp M, Hellier J, … Banerjee S (2013). Cost-effectiveness analyses for mirtazapine and sertraline in dementia: randomised controlled trial. *Br J Psychiatry*; 202:121-8.
- Banerjee, S. (2014). Multimorbidity—older adults need health care that can count past one. *The Lancet*. S0140-6736(14)61596-8. doi: 10.1016/S0140-6736(14)61596-8.
- Howard R, McShane R, Lindesay J… Banerjee S, Adams J, Johnson T, Bentham P, Phillips PP (2015). Nursing home placement in the DOMINO-AD trial. Lancet Neurology, (12): 1171-81.
- Donegan K, Fox N, Black N, Livingston G, Banerjee S, Burns A (2017). Secular trends in patterns of diagnosis and treatment for people with dementia in the UK. The Lancet Public Health 2 (3) e149–e156.
- Livingston G; Sommerlad A; Orgeta V; Banerjee S… (2017). The Lancet Global Commission on Dementia Prevention and Care. Lancet S0140-6736(17)31363-6.
- Zuidersma M; Chong K-C; Hellier J; Oude Voshaar R; Banerjee S (2019). Sertraline and mirtazapine versus placebo in depression in dementia. American Journal of Geriatric Psychiatry, 27(9), 920-931.
- Chong K-C, Böhnke JR, Prince M, Banerjee S (2019). Quality-of-life in dementia: Assessment in low-and-middle income countries. Psychological Assessment 31(10), 1264-1277.

CURRICULUM VITAE

Dr. Kate Baxter
Senior Research Fellow, Social Policy Research Unit, University of York

Tel: 01904 321966
Email: kate.baxter@york.ac.uk
ORCHID ID: https://orcid.org/0000-0002-3094-9546

Academic qualifications
2004   Ph.D. in Social Policy, London School of Economics & Political Science
2000   Advanced Certificate in Education, University of Bristol
1991   MSc in Health Economics, University of York
1989   BA in Economics, University of Essex

Employment history
2018-present   Senior Research Fellow, Social Policy Research Unit, University of York
2005-2018   Research Fellow, Social Policy Research Unit, University of York
2000-2003:   Research Fellow, NHS R&D Training Award, Division of Primary Care, University of Bristol
1998-2000:   Lecturer in Health Economics, Department of Social Medicine, University of Bristol
1994-1998:   Research Associate, Division of Primary Care, University of Bristol
1992-1994:   Research Associate, Department of General Practice, University of Manchester

Academic responsibilities
Fellow of NIHR School for Social Care Research
Member of British Society of Gerontology
Member of the Yorkshire and Humber Regional Carers Lead Officers Group

Three most recent grants awarded
Understanding and using people's experiences of social care to guide service improvements: could an effective and efficient co-design approach be translated from health to social care? Ryan, S., Bebbington, P., Martin, A., Locock, L., Barnett, A., Zeibland, S., Baxter, K., Birks, Y. F., Wilberforce, M. R. and Lambert, A. NIHR HS&DR £665k 1/02/20 - 30/11/22

Supporting Adult Social Care innovation (SASCI). Malley J, Knapp M, Fernandez J-L, Wittenberg R, Wistow G, Birks, Y, Baxter K, Manthorpe J, Ferlie E, Boaz A, Carlin J. Economic and Social Research Council (ESRC): £181k 16/09/19 - 15/09/24

Self-funders' preferences for support in navigating community social care. Wilberforce, M. R., Baxter, K., Birks, Y. F., Vass. C., & Tonks, S. NIHR School for Social Care Research: £284k 1/01/20 - 31/03/22

Three most recent publications
Baxter, CR, Heavey, EEL & Birks, YF 2020, 'Choice and control in social care: experiences of older self-funders in England', *Social Policy and Administration*, vol. 54, no. 3, pp. 460-474. https://doi.org/10.1111/spol.12534

Thom, G, Agur, M, Brown, S, Davies, K, Bakri, S, Mori, D, Farrar, P, Birch, A, Barber, J, Meagher, J, Murray, R, Purdon, S, Bryson, C, Fleischmann, P, Gibson, S, Brims, L, Weatherly, HLA, Faria, R, Longo, F, Baxter, K, Niven, B, Bevington, J, Norbury, A & Duff, S 2020, *Evaluation of the Integrated Personal Commissioning (IPC) Programme: Final evaluation report*.

Aspinal, FJ, Stevens, M, Manthorpe, J, Woolham, J, Baxter, CR, Samsi, K, Hussein, S & Ismail , M 2019, 'Safeguarding and personal budgets: the experiences of adults at risk', *Journal of Adult Protection*, vol. 21, no. 3. https://doi.org/10.1108/JAP-12-2018-0030

CURRICULUM VITAE

Professor Yvonne Birks

Current Employment
2013-present. Professor of Health and Social Care, University of York
2019- present. Deputy Director, NIHR School for Social Care Research

2020-present. Associate Dean for Research, Faculty of Social Sciences, University of York

Selected Publications
Hardicre, N.K., Birks, Y., Murray, J., *et al.* Partners at Care Transitions (PACT) - exploring older peoples' experiences of transitioning from hospital to home in the UK: protocol for an observation and interview study of older people and their families to understand patient experience and involvement in care at transitions. *BMJ Open* 2017;**7:**e018054. doi: 10.1136/bmjopen-2017-018054

Gridley, K., Birks, Y., Parker, G. Exploring good practice in life story work with people with dementia: the findings of a qualitative study looking at the multiple views of stakeholders. Dementia 2020;19(2):182-194. doi: 10.1177/1471301218768921. Epub 2018 Apr 24

Heavey, E., Baxter, K., Birks, Y. Financial advice for funding later life care: a scoping review of evidence from England. Journal of Long-Term Care 2019. pp. 51-65. ISSN 2516-9122

Murray, J., Hardicre, N., Birks, Y., O'Hara, J., Lawton R. How older people enact care involvement during transition from hospital to home: a systematic review and model. Health Expectations 2019. 22 (5), 883-893

Baxter K, Heavey E, Birks Y. Choice and control in social care: experiences of self funders in England. Social Policy and Administration. 2019; https://onlinelibrary.wiley.com/doi/full/10.1111/spol.12534

Parker, G., Gridley, K., Birks, Y. Glanville, J. Using a systematic review to uncover theory and outcomes for a complex intervention in health and social care: a worked example using life story work for people with dementia. Journal of Health Services Research & Policy 2020; DOI: 10.1177/1355819619897091

Selected recent grants awarded

Ryan, S., Bebbington, P., Martin, A., Locock, L., Barnett, A., Zeibland, S., Baxter, K., Birks, Y., Wilberforce, M., Lambat A. People's experiences in adult social care services: improving the experience of care and support for people using adult social care services. NIHR HS&DR £6700,00. Feb 2020-Nov 2022.

Bannerjee S, Rusted J, Harris P, Miles E, Knapp M, Wittenberg R, Read S, Dixon J, Dangoor M, Hu B, Stewart R, Thomas A, Robinson L, Birks Y, Baxter K, Brayne C. DETERMinants of quality of life, care and costs IN people with Dementia and their carers after diagnosis. ESRC/NIHR. £4,621,445. 2019-2023

Wilberforce M, Ferris S, Tucker S, Birks Y. Enabling older people to engage effectively with social care: developing a theory of change for specialist mental health support worker interventions. NIHR RfPB. £157,840. September 2019- February 2021.

Baxter K, Heavey E, Overton L, Ryan S, Barnett A, Calline S, Lymer A, Birks Y. Finding and funding social care: a qualitative study of the experiences of self-funders. NIHR RfPB £270,610.00. Sept 2019-Feb 2021

Malley J, Knapp M, Fernandez JL, Wittenberg R, Wistow G, Birks Y, Baxter K, Manthorpe J, Ferlie E, Boaz A, Carlin J. Supporting adult social care innovation (SASCI). ESRC. £1599233.15. Sept 2029- Aug 2024.

Birks, Y: Wilberforce, M; Clegg, A. Increasing sustainability of health and care services for older people with frailty. Within NIHR ARC . £75,423. Oct 2019-Sept 2024.

Professor Carol Brayne CBE MD MSc FRCP FFPH FMedSci
Director, Cambridge Institute of Public Health (2008 -)
Professor of Public Health Medicine, Department of Public Health & Primary Care (2001-)
University of Cambridge School of Clinical Medicine
t: +44 (0)1223 330334   e: carol.brayne@medschl.cam.ac.uk

A medically qualified epidemiologist and public health academic whose main research has been longitudinal studies of older people following changes over time with a public health perspective and a focus on the brain. The lead principal investigator in the MRC CFA Studies and other population based studies.

Selected Awards & Relevant Roles: Platinum Merit Award (2020); Chair, RCP Advisory Group on Health Inequalities (2019-); Chair, Wellcome Trust Population & Public Health Expert Review Group (2016-2018); Alzheimer's Society Dementia Ambassador (2012-); Emeritus Senior Investigator, National Institute Health Research (2012-); Co-chair, Alzheimer's Society Research Advisory Council (2011-)

Selected Grants:

Funder	Title	Amount	Dates
National Institute for Health Research (NIHR)	NIHR Applied Research Collaboration (EoE) – Population evidence and data science theme lead	£9M	2019-2024
EU Horizon 2020 research and innovation programme	PRODEMOS – Mental health and dementia risk	£2.5M (£517K to UCAM)	2018-2022
National Institute for Health Research (NIHR)	School for Public Health Research I & II Cambridge Centre (PI)	£2,500,000 £2,500,000	2017-2022 2012-2017
Alzheimer's research UK (ARUK)	The feasibility and practicality of dementia risk reduction in the older population: A pilot trial	£784,374.66	2018-2020
National Institute for Health Research (NIHR)	CLAHRC East of England – Collaboration for Leadership in Applied Health Research Care	£10.1 million	2013-2019
National Institute for Health Research (NIHR)	Modelling the Potential Population-Level Impact of Modifying Dementia Risk Factors Using Data from the Cognitive Function and Ageing Study	£74,327.00	2015-2016
Economic and Social Research Council (ESRC)	Maintaining Function and Well-being in Later Life: A Longitudinal Cohort Study	£3 million	2010-2016
Medical Research Council (MRC)	Epidemiological neuropathology of dementia – The Cognitive Function and ageing Neuropathology Study	£2.6 million	2010-2016

Total Number of Publications = 801
Selected Publications
1. Richardson C, Stephan BCM, Robinson L, **Brayne C**, Matthews FE; Cognitive Function and Ageing. Two-decade change in prevalence of cognitive impairment in the UK. Eur J Epidemiol. 2019 Sep 5.

2. Matthews FE, Stephan BCM, Robinson L, Jagger C, Barnes LE, Arthur A, **Brayne C**, Cognitive Function and Ageing Studies (CFAS) Collaboration. A two decade comparison of incidence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function Ageing Study I and II. Nature Communications 2016 7:11398

3. Matthews FE, Arthur A, Barnes LE, Bond J, Jagger C, Robinson L, **Brayne C**; on behalf of the Medical Research Council Cognitive Function and Ageing Collaboration Cognitive Function and Ageing Study I and II. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II Lancet. 2013 9902:1405-1412.

Nicola Brimblecombe

Current employment: Assistant Professorial Research Fellow, Care Policy and Evaluation Centre, London School of Economics and Political Science, June 2012-present. Research on unpaid carers; unmet need for services; long term economic impact of childhood emotional and behavioural problems and of childhood bullying victimisation: youth mental health services

Previous employment
Health Information and Policy Officer, Maternity Alliance, 1999-2002
Researcher, School of Geographical Studies, University of Bristol, 1997-1999
Research Assistant/Lecturer, School of Education, Oxford Brookes University, 1993-1996

Education
MSc Comparative Social Research, University of Oxford, 1993
BSc (Hons) 2:1 History and Psychology, Oxford Polytechnic, 1990

Selected publications (see also https://scholar.google.com/citations?user=fsfq2dgAAAAJ&hl=en)

- Manthorpe, J., Moriarty, J., Brimblecombe, N., Knapp, M., Snell, T. & Fernandez, J.L. (2019) 'Carers and the Care Act: promise and potential', in S. Braye & M. Preston Shoot (eds) *The Care Act 2014: Wellbeing in Practice (Transforming Social Work Practice Series).* London: Sage.
- Brimblecombe, N., Fernandez, JL, Knapp, M., Rehill, A. & Wittenberg, R. (2018) 'Review of the international evidence on support for unpaid carers', *Journal of Long-Term Care*, September, pp.25-40.
- Pickard, L., Brimblecombe, N., King, D., and Knapp, M. (2018) ''Replacement Care' for Working Carers? A Longitudinal Study in England, 2013–15'. *Social Policy & Administration*, 52: 690– 709.
- Pickard, L., King, D., Brimblecombe, N., & Knapp, M. (2018) 'Public expenditure costs of carers leaving employment in England, 2015/2016' *Health and Social Care in the Community*, 26(1), 132-142
- Brimblecombe, N., Evans-Lacko, S., Knapp, M., King, D., Takizawa, R., Maughan, B. & Arseneault, L. (2018) 'Long term economic impact associated with childhood bullying victimisation', *Social Science & Medicine*
- Brimblecombe, N., Pickard, L., King, D. & Knapp, M. (2017) '*Barriers to receipt of social care services for working carers and the people they care for in times of austerity'. *Journal of Social Policy* 47(2), 215-233.
- Pickard, L., King, D., Brimblecombe, N. & Knapp, M. (2015) 'The effectiveness of paid services in supporting unpaid carers' employment in England'. *Journal of Social Policy*, 44, 3, 567-590

Grants
Lead Investigator: *What are the effects of unmet need for social care on unpaid carers? Risk factors, consequences and mediators*, NIHR SSCR, May 2019 to April 2021
Lead Investigator: *The role of adult social care in improving outcomes for young people who provide unpaid care*, NIHR SSCR, August 2016 to January 2019
Co-Investigator: *Adult Social Care Research Unit*, NIHR, January 2019 to December 2024
Co-Investigator: *Long term economic impact of childhood emotional and behavioural problems,* ESRC, September 2017 to December 2019
Co-Investigator: *Supporting carers following the implementation of the Care Act 2014: eligibility, support and prevention*, Department of Health, October 2016 to March 2019
Co-Investigator: *Overcoming Barriers: Unpaid Care and Employment Longitudinal Study*, NIHR SSCR, October 2014 to May 2016.

MARGARET DANGOOR

Patient, User and Carer involvement including research – relating to dementia and carer issues.

RGN, DMS, MA (Health Law), Dip.Risk.Man. MCIM, MHSM

Direct personal experience as a carer of a relative with dementia.

Both husband and mother developed Alzheimer's in later life. Husband, 86yrs lived and cared for at home died at the end of January 2018. Mother died in 2013 at the age of 102 following a period in a care home.

Community involvement – Current

Trustee of local charity, normally providing respite and other services for carers. Recently significantly extended services to meet COVID-19 emergency requirements including protected home care, volunteer recruitment, home deliveries and food bank establishment. To replace Caring Café provision for people with dementia and their carers, personal telephone support extended including emergency situation support and carer Zoom sessions. Also trustee of the Centre for Ageing Better and Carers UK and charter member of Independent Age, all organisations working at national level to respond to the COVID-19 national policy issues and individual members support.

Research Involvement – current and recent

DETERMIND – DETERMinants of quality of life, care and costs, and consequences of inequalities in people with dementia and their carers Co-investigator and research involvement manager for this 5-year project. To ensure that people with dementia and their carers have meaningful involvement with the project.

MODEM – Comprehensive approach to modelling outcome and cost impacts of interventions for people with dementia (2014) Co-investigator and research involvement manager for this 4-year project, completed in September 2018.

Current or past involvement as an advisor with various research projects at the CPEC, (previously PSSRU) in London and Kent, also the Open University, the London School of Hygiene and Tropical Medicine, KCL, the James Lind Foundation and the King's Fund. NIHR Collaboration for Leadership in Applied Health Research & Care (CLAHRC) (2009-12).

User Carer Practitioner Group (UCPRG) Member of the National Institute of Health Research (NIHR) School of Social Care Research since 2009 and recently chair of the group. Member of the SSCR Advisory Board representing the UCPRG.

Career history

Qualified as RGN in the 1960s (**Westminster Hospital**). NHS career until 1996, nursing and general management. 1999-2009 executive director of ALARM, a risk management organisation supporting healthcare managers and clinicians. Admitted to Fellowship of the **Royal Society of Medicine in 1999**

Curriculum Vitae: Josie Dixon

Address: Care Policy and Evaluation Centre (CPEC), London School of Economics and Political Science, Department of Health Policy, Houghton Street, London WC2A 2AE, UK
Telephone: 07989 070 777   **Email:** j.e.dixon@lse.ac.uk

Education: London School of Economics and Political Science (LSE)
2020   PhD candidate (pursuing by papers)
1996   MSc Social Research Methods (Social Policy) – Distinction

1993   BSc Economics (Government) - First Class Honours

Appointments

2012 – present	Assistant Professorial Research Fellow, CPEC, Department of Health Policy. London School of Economics and Political Science
2003 – 2012	Research Director, National Centre for Social Research (NatCen), Qualitative Research Unit (QRU)/ Health and Wellbeing Directorate
2000 – 2003	Principal Consultant, Improvement and Development Agency (IDeA)
1997 – 2000	Senior Policy Researcher, Audit Commission

Current research grants

- DETERMIND: DETERMinants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their family carers. ESRC. £4,621,445.40. Co-investigator. January 2019 - December 2024.
- Scaling up the Family Carer Decision Support Intervention: A transnational effectiveness-implementation evaluation. EU-JNPD ? Alzheimer's Society UK. €1,719,962. Co-investigator. March 2019 - March 2022
- PrepareD. Helping people with dementia and their carers prepare for advanced illness and end of life. Alzheimer's Society. £241,238. Principal investigator. September 2018 – August 2023.

Selected publications

- Dixon J, Mays N, Trathen A, Knapp M, Wistow G, Wittenberg R. Funding and planning for social care in later life: a deliberative focus group study. Health and Social Care in the Community. 2019
- Dixon J, Knapp M. Whose job? The staffing of advance care planning support in twelve international healthcare organizations: a qualitative interview study. BMC Palliative Care. May 2018; 17:78
- Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end of life outcomes for people with dementia and their carers: a systematic review and critical discussion. Journal of Pain and Symptom Management. 2017; 55,1: 132-150
- Dixon J, King D, Knapp M. Advance care planning and place of death in England. BMJ Supportive and Palliative Care. Open Access. 2016.
- Dixon J, King D, Matosevic T, Clark M, Knapp, M. Equity in the provision of palliative care in the UK. London: PSSRU, London School of Economics and Political Science/ Marie Curie. 2015.
- Knapp M, Black N, Dixon J (with Damant J, Rehill A, Tan S). Independent assessment of improvements in dementia care and support since 2009 (for UK Department of Health and Social Care). London: Policy Innovation and Evaluation Research Unit (PIRU). 2014.

Kate Gridley
Research Fellow, Social Policy Research Unit/NIHR School for Social Care Research, University of York Tel: 01904 321988 Email: kate.gridley@york.ac.uk
ORCHID ID: https://orcid.org/0000-0003-1488-4516

Academic qualifications
2019 - ongoing: Enrolled to undertake PhD in Social Policy, University of York
2007 - 2009: MRes Social Policy (Distinction), University of York
1997 - 2001: BA Hons Social Studies (1st), University Newcastle Upon Tyne

Employment history
2006 - present: Research Fellow, Social Policy Research Unit, University of York
2004 - 2006: Public Health Development Specialist (Community Involvement), Peterborough Primary Care Partnership
2001 – 2003: Manager/Development Worker, The Volunteer Centre – Chesterfield & NE Derbyshire.

Selected Publications
- Gridley, K., Birks, Y. and Parker, G., (2020). Exploring good practice in life story work with people with dementia: The findings of a qualitative study looking at the multiple views of stakeholders. Dementia, 19(2), pp.182-194.
- Parker, G., Gridley, K., Birks, Y., & Glanville, J. (2020). Using a systematic review to uncover theory and outcomes for a complex intervention in health and social care: a worked example using life story work for people with dementia. Journal of Health Services Research & Policy.
- Brooks, J., Gridley, K., & Parker, G. (2019). Doing research in care homes: the experiences of researchers and participants. Social research practice, 8(Autumn), 19-27.
- Gridley, K., Aspinal, F. J., Parker, G. M., Weatherly, H. L. A., Neves De Faria, R. I., Longo, F., & Van Den Berg, B. (2019). Specialist nursing support for unpaid carers of people with dementia: a mixed-methods feasibility study. Health Services and Delivery Research, 7(12), 1-232.
- Brooks, J., Gridley, K. and Savitch, N., (2017). Removing the 'gag': involving people with dementia in research as advisers and participants. Social Research Practice, pp.3-14.
- Gridley, K., Brooks, J. C., Birks, Y. F., Baxter, C. R., & Parker, G. M. (2016). Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care. Health Services and Delivery Research. ISSN 2050-4357
- Gridley K, Brooks J and Glendinning C (2014) Good practice in social care: the views of people with severe and complex needs and those who support them. Health & Social Care in the Community 22(6), 588–597.
- Gridley, K., Spiers, G., Aspinal, F., Bernard, S., Atkin, K., & Parker, G. (2012). Can general practitioner commissioning deliver equity and excellence? Evidence from two studies of service improvement in the English NHS. Journal of Health Services Research & Policy, 17(2), 87-93.
- Gridley, K., Aspinal, F., Bernard, S., & Parker, G. (2011). Services that promote continuity of care: key findings from an evaluation of the national service framework for long-term neurological conditions. Social Care and Neurodisability. 2(3). 147-157.
- Bernard, S., Aspinal, F., Gridley, K. & Parker, G. (2010) Integrated Services for People with Long-term Neurological Conditions: Evaluation of the Impact of the National Service Framework: Final Report, York: Social Policy Research Unit, University of York, pp. 327.

Peter Harris, AFBPsS, C.Psychol, HCPC registered.
Email: p.r.harris@sussex.ac.uk; **ORCID ID** 0000-0003-4599-4929
Web:http://www.sussex.ac.uk/profiles/10678; https://www.sussex.ac.uk/psychology/sarg/index

Current Appointment: Professor of Psychology, University of Sussex (2012 - current);
Subject Group Lead for Social & Applied Psychology (14 Faculty)
Education:
1992   PhD in Psychology (UCL & LSE).
1977   BSc (Hons), First Class, Psychology, UCL.

Research & Professional activity
I am a social and health psychologist. My principal research focus in recent years has been on the impact of self-affirming (reflecting on core values or personal strengths) on responses to stress and health risk information. At Sussex I lead the *Self-Affirmation Research Group*, a University-recognised research group comprising one of the largest groups of researchers with interests in self-affirmation processes in the world. I am the author of 120+ peer-reviewed papers. I have co-authored 25+ successful grants (£9.1 million from UK funders, CA$690k from Canadian funder, $400k from USA funder, and €160k from EU funders), with funding from the leading UK (ESRC), American (NSF) and Canadian (SSHRC) social science research councils and the UK NHS (NIHR). *Professional activities* include member of the Population Research Committee and vice chair of the Prevention Expert Review Panel of Cancer Research UK, member of the UK Government's Scientific Pandemic Influenza Advisory Committee during the 2009 flu pandemic, and of the DH Pandemic Flu Communications Network - Behavioural Science Advisory Sub-Group.

Current grants
2019-19 Will COVID-19 increase educational inequalities? EASP Covid-19 rapid response funding. €5,000. Co-I with M. Easterbrook (PI, Sussex) and colleagues in Belgium and Poland.

2019-23 DETERMIND: DETERMinants of quality of life, care and costs IN people with Dementia and their carers after diagnosis. ESRC and NIHR. £4.7m. Co-I with S. Banerjee (PI, Sussex) and 17 UK colleagues.

2019-23 Beyond green values: Affirmation processes in consumer decision making about climate change. Social Sciences and Humanities Research Council (SSHRC), Canada. CA$156,450. Co-I with D. Griffin (PI, UBC).

Selected Recent Self-Affirmation Publications (peer-reviewed journals)
Dutcher, J. M., et al. (In press). Neural Mechanisms of Self-Affirmation's Stress Buffering Effects. *Social Cognitive and Affective Neuroscience.*

Harris, P. R., et al. (2019). Individual differences in self-affirmation: distinguishing self-affirmation from positive self-regard. *Self and Identity*, *18*, 589-630.

Farina, N., et al. (2019). DETERMinants of quality of life, care and costs, and consequences of INequalities in people with dementia and their carers (DETERMIND): a protocol paper. *International Journal of Geriatric Psychiatry*, 35, 1-12.

Novakova, B., Harris, P. R., Rawlings, G. H., & Reuber, M. (2019). Coping with stress: a pilot study of a self-help stress management intervention for patients with epileptic or psychogenic non-epileptic seizures*. Epilepsy and Behavior, 94*, 169-177.

Morgan, J. I., & Harris, P. R. (2015). Evidence that brief self-affirming implementation intentions can reduce work-related anxiety in downsize survivors. *Anxiety, Stress, & Coping*, *28*, 563–575.

Harris, P. R. et al. (2014). Combining Self-Affirmation With Implementation Intentions to Promote Fruit and Vegetable Consumption. *Health Psychology, 33,* 729-736*.*

Epton, T, Harris, P. R., et al. (2014). The impact of self-affirmation on health behaviour change: A meta-analysis. *Health Psychology, 34*, 187–196*.*

Ben Hicks
Research Fellow and DETERMIND Programme Co-ordinator Phone: 07881 915776
Centre for Dementia Studies, Brighton and Sussex Medical School Email: b.hicks@bsms.ac.uk
Staff profile: https://www.bsms.ac.uk/about/contact-us/staff/dr-ben-hicks.aspx

Research interests

Ben's is currently the Programme Co-ordinator for DETERMIND, an ESRC/NIHR funded study that seeks to explore and address inequalities in the post-diagnostic care pathway for people with dementia and their care partners. His wider research interests are concerned with supporting the social inclusion and sense of 'self' for people with dementia through creative ecopsychosocial initiatives using mediums such as technology and art.

Representative recent publications

- Farina, N., **Hicks, B**., Baxter, K., Birks, Y., Brayne, C., Dangoor, M., ... & Banerjee, S. (2019). DETERMinants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their carers (DETERMIND): A protocol paper. *International journal of geriatric psychiatry*.
- **Hicks, B**., Innes, A., & Nyman, S. R. (2019). Experiences of rural life among community-dwelling older men with dementia and their implications for social inclusion. *Dementia*, 1471301219887586.
- **Hicks, B**., Innes, A., & Nyman, S (2019). Exploring the active mechanisms for engaging rural-dwelling older men with dementia in a technological initiative. *Ageing and Society*. 1-33.
- Kenigsberg, P.A., Aquino, J.P., Bérard, A., Brémond, F., Charras, K., Dening, T., Dröes, R.M., Fabrice, G., **Hicks, B**., Innes, A. and Nguyen, M., (2019). Assistive technologies to address capabilities of people with dementia: from research to practice. *Dementia*, *18*(4), 1568-1595
- **Hicks, B**. Carroll, D. Shanker, S. & El-Zeind, A. (2017) 'Well I'm still the Diva!' Enabling people with dementia to express their identity through graffiti arts: Innovative Practice. *Dementia. Published Online*
- Cutler, C., **Hicks, B.,** & Innes, A. (2016). Does digital gaming enable healthy aging for community-dwelling people with dementia? *Games and Culture*, *11*(1-2), 104-129.
- Kennedy, F., **Hicks, B.,** & Yarker, J. (2014). Work stress and cancer researchers: an exploration of the challenges, experiences and training needs of UK cancer researchers. *European journal of cancer care*, *23*(4), 462-471.
- Munir, F., Yarker, J., **Hicks, B.,** & Donaldson-Feilder, E. (2012). Returning employees back to work: developing a measure for supervisors to support return to work (SSRW). *Journal of occupational rehabilitation*, *22*(2), 196-208.

Promotional films

- Young at Art: Using graffiti arts to explore identity in people with dementia at an Assisted Living Facility-**https://vimeo.com/280562779**

Funded Grants

- 2018-2020 **Hicks, B.** Using drama and storytelling to support well-being in people with dementia. ERASMUS (37,000 Euros).
- May 2018-July-2018 **Hicks, B.,** Falconer, E., Charles, F. Developing a Virtual Café to support knowledge-exchange amongst dementia practitioners. ACORN (£5,000).
- 2017-2018 **Hicks, B.,** Nyman, S., Thomas, S., Tang, W., & Cutler, C. Developing a Virtual Learning Environment for dementia care home staff and community practitioners. HEIF-6 (£70,000)
- 2017-2019 **Hicks, B.,** Tang., W & Weiner, J. Developing a training program for enhancing the autonomy of people with dementia. ERASMUS (50,000 Euros)
- 2016-2018 **Hicks, B.,** Tang, W., & Wiener, J. ADGAMING Using Serious Games to support the well-being of people with dementia. ERASMUS. (45,000 Euros)
- 2017-2018 **Hicks, B**. & Shanker, S. Public Engagement using Graffiti Arts to engage people with dementia. British Psychological Society (BPS). (£10,000)
- 2012-2013 Innes, A. & **Hicks, B.** Dementia Care Research Mapping Exercise. DeNDRoN. (£7,000)

Dr. Bo Hu

8.01G Pankhurst House, Clement's Inn,   Mobile: 079-7766-5242
LSE, London WC2A 2AE, UK   b.hu@lse.ac.uk

EDUCATION

Department of Social Policy, London School of Economics and Political Science (LSE)
London, UK
- PhD, Social Policy   Oct. 2008 - April 2013

School of Economics, Nankai University   Tianjin, China
- PhD, International Economics   Sep. 2006 - July 2009

School of Economics, Nankai University   Tianjin, China
- MSc, International Economics   Sep. 2004 - July 2006

School of Economics, Tianjin University of Finance and Economics   Tianjin, China
- BSc, International Economics   Sep.2000 - July 2004

EMPLOYMENT

Personal Social Services Research Unit, Department of Social Policy, LSE   London, UK
Research Fellow   May 2019 - Present
Research Officer   June 2013 - May 2019
- Conducting research on long-term care for older people and people with dementia
- Writing up peer-reviewed journal articles, research reports and research proposals
- Reviewing journal articles and research grant applications
- Supervising postgraduate students at LSE

RESEARCH GRANTS

- DETERMIND: DETERMinants of quality of life, care and costs IN people with Dementia and their carers after diagnosis, 2019-2023, Economic and Social Research Council (ESRC) and National Institute for Health Research (NIHR), co-investigator
- Understanding the interactions between state pension and long-term care funding reforms in Great Britain; 2014-2016; Nuffield Foundation, co-investigator, co-investigator

SELECTED RECENT PUBLICATIONS

Peer-reviewed journal articles

Hu, B and L, Li (2020) The protective effects of informal care receipt against the progression of functional limitations among Chinese older people. *The Journals of Gerontology: Social Sciences*, 75(5), 1030-1041. https://doi.org/10.1093/geronb/gby107.

Wittenberg, R., **B. Hu**, C. Jagger, A. Kingston, M. Knapp, A. Comas-Herrera, D. King, A. Rehill and S. Banerjee (2020) Projections of care for older people with dementia in England: 2015 to 2040. *Age and Ageing,* 49(2), 264-269. https://doi.org/10.1093/ageing/afz154.

Hu, B (2019) Is bullying victimization in childhood associated with mental health in old age? *The Journals of Gerontology: Social Sciences*, September, 1-27. https://doi.org/10.1093/geronb/gbz115.

Wittenberg. R., M. Knapp, **B. Hu**, A. Comas-Herrera, D. King, A. Rehill, C. Shi, S. Banerjee, A. Patel, C. Jagger, A. Kingston (2019) The costs of dementia in England. *International Journal of Geriatric Psychiatry*, 34(7), 1095-1103. https://doi.org/10.1002/gps.5113.

Hu, B (2019) Projecting future demand for informal care among older people in China: the road towards a sustainable long-term care system. *Health Economics, Policy and Law*, 14 (1), 61-81. https://doi.org/10.1017/S1744133118000221.

MARTIN KNAPP: Short CV, April 2020

ORCID 0000-0003-1427-0215

Current employment

o Professor of Health and Social Care Policy, Department of Health Policy, London School of Economics and Political Science (LSE); previously Professor of Social Policy (1996 to 2019)

o Professorial Research Fellow, Care Policy and Evaluation Centre (formerly PSSRU); previously PSSRU Director (1996 to 2019)

o Director, National Institute for Health Research (NIHR) School for Social Care Research

Previous employment

o Professor of Health Economics, King's College London, Institute of Psychiatry (1993-2014)

o Professor of Economics of Social Care, Department of Economics & PSSRU, University of Kent

Qualifications

o BA, Economics & Pure Mathematics (First), University of Sheffield, 1973

o MSc, Econometrics & Mathematical Economics, LSE (University of London), 1975

o PhD, Social Policy, University of Kent, 1980

Research activities

PI or Co-I for c.25 current research projects; funders include ESRC, MRC, NIHR, Alzheimer's Society, Alzheimer's Research UK, Health Foundation. Projects include: *STRiDE: Strengthening responses to dementia in developing countries* (PI; £7.8m; UKRI); *Supporting Adult Social Care Innovation* (Co-I; £2.4m; ESRC); *MODEM: modelling outcome and cost impacts of interventions for dementia* (PI; £2.6m; ESRC/NIHR); NIHR School for Social Care Research (grant-holder; £30m, 2009-19; £21m 2019-24). Also Co-I on four current DHSC/NIHR Policy Research Units.

Recent publications (Google Scholar H-index 112)

Knapp M, Wong G (2020) Economics and mental health: the current scenario. *World Psychiatry* 19(1):3-14

Livingston G, Manela M, O'Keeffe A et al (2020) Clinical effectiveness of START psychological intervention for family carers and the effects on cost of care for people with dementia: six year follow-up of a randomised controlled trial. *British Journal of Psychiatry*, 216(1), 35-42.

Comas-Herrera A, Fernández JL, … Knapp M ... (2020) COVID-19: implications for the support of people with social care needs in England. *Journal of Aging & Social Policy* forthcoming

Burley C, Livingston G, Wimo A, Knapp M… (2020)Time to invest in prevention and better care of behaviors and psychological symptoms associated with dementia. *International Psychogeriatrics*

Wittenberg R, Hu B, Jagger C, Kingston A, Knapp M et al (2019) Projections of care for older people with dementia in England: 2015 to 2040. *Age and Ageing* 49(2): 264-269.

Romeo R, Zala D, Knapp M, Orrell M, Fossey J, Ballard C (2019) Improving the quality of life of care home residents with dementia: Cost-effectiveness of an optimized intervention for residents with clinically significant agitation in dementia. *Alzheimer's & Dementia* 15 (2), 282-291.

Dixon J, Knapp M, King D (2019) et al. Advance care planning in England: Is there an association with place of death? *BMJ Supportive & Palliative Care*, 9:316–325.

Wittenberg R, Knapp M, Hu B et al A (2019) The costs of dementia in England. *International Journal of Geriatric Psychiatry* 34:1095-1103.

Rotem Perach

E-mail: r.perach@sussex.ac.uk
Mobile: +44 7983814990

Research Experience

Postdoctoral Research Fellow, School of Psychology, University of Sussex, UK. 2019-current
   Research on emotion regulation, decision-making, and wellbeing in dementia.

Postdoctoral Research Associate, Department of Psychology, Goldsmiths University of London, UK.   2017-2018
   Systematic review and meta-analysis on the wellbeing outcomes of insomnia interventions.

PhD researcher, School of Psychology, University of Kent, UK.   2014-2019
   Quantitative research on self-activation in response to psychological threat.

Research assistant, Herczeg Institute on Aging, Tel Aviv University, Israel.   2009-2014
   Mixed methods research on psychological wellbeing in older persons

Higher Education

PhD in Psychology, University of Kent, UK   2014-2019
MSc in Psychology, Leiden University, Netherlands.   2007-2009
BA in Psychology, The Hebrew University of Jerusalem, Israel.   2003-2005

Selected Publications

Perach, R., J. Rusted, Harris, P. R., Miles, E. (in review). Emotion regulation and decision-making in dementia: A scoping review. (Dementia).

Perach, R., Allen, C., Kapantai, Madrid-Valero, J. J., Miles, E., Charlton, R. A., & Gregory, A. M. (2019). The psychological wellbeing outcomes of nonpharmacological interventions for older persons with insomnia symptoms: A systematic review and meta-analysis. *Sleep Medicine Reviews*, 43, 1-13. https://doi.org/10.1016/j.smrv.2018.09.003

Perach, R., & Wisman, A. (2016). Can creativity beat death? A review and evidence on the existential anxiety buffering functions of creative achievement. *The Journal of Creative Behavior.* doi: 10.1002/jocb.171

Cohen-Mansfield, J., **Perach, R.**, Stern, T. K., Albeck, S., Rotem, D., Arnow, T. L., & Lerman, Y. (2016). Telephone hotline for aging: Information needs, quality of service, and insights. *International Social Work*. https://doi.org/10.1177/0020872816651702

Cohen-Mansfield, J., & **Perach, R.** (2015). Interventions for alleviating loneliness among older persons: A critical review. *American Journal of Health Promotion*, *29*(3), e109-e125.

Public Engagement

University of Sussex, School of Psychology Blog. Can culture beat the coronavirus?, March 19, 2020, shorturl.at/aclBW

Huffington Post. How creative achievement eases your fear of dying, December 22, 2016, https://goo.gl/o3PkrJ

Eleanor Miles: Curriculum Vitae
University of Sussex, BN1 9QH, UK   e.miles@sussex.ac.uk

EDUCATION

2005-2009   Ph.D. Psychology, University of Manchester
2002-2005   B.A. Psychology (1st class honours), University of Manchester

PROFESSIONAL APPOINTMENTS

2013–   Lecturer/Senior Lecturer, School of Psychology, University of Sussex
2011-2013   Research Fellow, Department of Psychology, University of Sheffield
2008-2011   Research Associate, Department of Psychology, University of Sheffield

SELECTED GRANTS

2019-2023   ESRC (£3,787,000, Co-I)
"DETERMinants of quality of life, care and costs, and consequences of INequalities in people with dementia and their family carers"

2014-2015   Richard Benjamin Trust (£10,000, PI)
"Reducing mental health stigma in future doctors: An intervention study"

2011-2014   John Templeton Foundation (£273,000, Co-I)
"Enacting Virtue, Controlling Vice: Testing Three Strategies for Overcoming Unconscious Influences and Translating 'Good' Intentions into Action"

SELECTED PUBLICATIONS

Total number of peer-reviewed journal publications: **30**, Total Cited by: **2679**, h-index: **20**

Farina, N., Hicks, B., Baxter, K., Birks, Y., Brayne, C., et al. (2020). DETERMinants of quality of life, care and costs, and consequences of INequalities in people with dementia and their carers (DETERMIND): a protocol paper. Int. Journal of Geriatric Psychiatry, 35, 290-301 (IF: 3.1)

Sheeran, P., Abraham, C., Jones, K., Villegas, M. E., Avishai, A., et al. (2019). Promoting physical activity among cancer survivors: Meta-analysis and meta-CART analysis of randomized controlled trials. Health Psychology, 38(6), 467. (IF: 3.5)

Miles, E., Sheeran, P., Baird, H. M., Macdonald, I., Webb, T. L., & Harris, P. R. (2016). Does self-control improve with practice? Evidence from a 6-week training program. Journal of Experimental Psychology: General, 145, 1075-1091. (IF: 3.5)

Sheeran, P., Maki, A., Montanaro, E., Avishai-Yitshak, A., Bryan, A., Klein, W. M. P., Miles, E., & Rothman, A. J. (2016). The impact of changing attitudes, norms, and self-efficacy on health-related intentions and behavior: A meta-analysis. Health Psychology, 35, 1178-1188. (IF: 3.5)

Miles, E. & Crisp, R. (2014). A meta-analytic test of the imagined contact hypothesis. Group Processes & Intergroup Relations, 17, 3-26. (IF: 3.5)

Webb, T. L., Schweiger Gallo, I., Miles, E., Gollwitzer, P. M., & Sheeran, P. (2012). Effective regulation of affect: An action control perspective on emotion regulation. European Review of Social Psychology, 23(1), 143-186. (IF: 4.5)

Kellett, S., Oldham, M., Miles, E., & Sheeran, P. (2012). Interventions to increase attendance at psychotherapy: A meta-analysis of randomised controlled trials. Journal of Consulting and Clinical Psychology, 80, 928-939. (IF: 4.5)

Webb, T. L., Miles, E. & Sheeran, P. (2012). Dealing with feeling: A meta-analysis of the effectiveness of strategies derived from the process model of emotion regulation. Psychological Bulletin, 138, 775-808. (IF: 13.3)

Short Curriculum Vitae

Dr Sanna Read

Educational qualifications:
Docent in Geropsychology, University of Jönköping, Sweden, 2005
Doctor in Psychology, University of Jyväskylä, Finland, 2000
Registered Psychologist, Finnish National Authority for Medicolegal Affairs, 1996
Master in Psychology, University of Jyväskylä, Finland, 1996

Posts:
Research Fellow, London School of Economics, UK, 2014-
Lecturer/Senior Researcher, London School of Hygiene and Tropical Medicine, UK, 2011-2014
DL tutor, London School of Hygiene and Tropical Medicine, UK, 2011-
Research Fellow/Method Consultant, Helsinki Collegium for Advanced Studies, Finland, 2010-
Lecturer/Research Fellow, London School of Hygiene and Tropical Medicine, UK, 2008-2009
Research Fellow, University of Surrey, UK, 2007 - 2008
Associate Professor/Assistant Professor, University of Jönköping, Sweden, 2002 - 2007
Researcher, post-doctoral, University of Nijmegen, The Netherlands, 2001 – 2002
Researcher, University of Jyväskylä, Finland, 1997 – 2001

Recent research grants:
2018: ESRC grant for the project *Determinants of quality of life, care and costs, and consequences of inequalities in people with Dementia and their carers (DETERMIND)*. Leader: Sube Banerjee. My role: Co-researcher.
2018: Alzheimer's Society grant for the project *Understanding and improving support to help people with dementia and their carers prepare for advanced illness and end of life.* Leader Martin Knapp. My role: Co-researcher.
2017: LSE RIF funds for developing a grant application on *Inequalities in dementia.* Leader Sanna Read and Raphael Wittenberg.

Key publications:
Read, S., Comas-Herrera, A., & Grundy, E. (2020). Social Isolation and Memory Decline in Later-life. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 75*, 367–376. https://doi.org/10.1093/geronb/gbz152

Farina, N., Hicks, B., Baxter, K., Birks, Y., Brayne, C., Dangoor, M., Dixon, J., Harris, P.R., Hu, B., Knapp, M., Miles, E., Perach, R., Read, S., Robinson, L., Rusted, J., Stewart, R., Thomas, A., Wittenberg, R., & Banerjee, S. (2020). DETERMinants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their carers (DETERMIND): A protocol paper. *International Journal of Geriatric Psychiatry, 35*, 290–301. https://doi.org/10.1002/gps.5246

Read, S., & Grundy, E. (2017). Fertility history and cognition in later life**.** Read, S., & Grundy, E. (2017). Fertility history and cognition in later life. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 72, 1021-1031. https://doi.org/10.1093/geronb/gbw013

Read, S., Grundy, E., & Foverskov, E. (2015). Socioeconomic position and subjective health and well-being among older people in Europe: a systematic narrative review. *Ageing and Mental Health,* 20, 529-42. DOI: 10.1080/13607863.2015.1023766

Read, S., & Grundy, E. (2014). Allostatic Load and Health in the Older Population of England: A Crossed-Lagged Analysis. *Psychosomatic Medicine, 76*, 490-496.

Curriculum Vitae: Professor Dame Louise Robinson

PRESENT APPOINTMENTS
2017-date   Regius Professor of Ageing
2017-2020   National Institute of Health Research (NIHR) Senior Investigator
2009-date   Professor of Primary Care and Ageing, Newcastle University
1996-date   General Practitioner, Saville Medical Group, Newcastle upon Tyne

MAJOR GRANTS (Current) - Total funding to date £54 million (£31 million as PI)

1. £2,001,242. **Policy Research Unit** – Older People and Frailty. 2019-2023. Hanratty B, (PI), **Robinson L et al.** Co-applicant.
2. £2,477,935. **NIHR Programme Grant.** Dementia Person Aligned Care Team. 2018-2022. Byng R (PI), **Robinson L et al.** Co-applicant.
3. £784,374. **Alzheimer's Research UK**. The feasibility and practicality of dementia risk reduction in the older population: A pilot trial. Grant Ref: ARUK-PRRF2017-008. 2018-2020. Brayne C (PI), **Robinson L et al.** Co-applicant.
4. £1,680,224. **Alzheimer's Society – Centre of Excellence.** Primary and Community care based post diagnostic Dementia care (PriDem). **Robinson L et al** 2018-2022. **Principal Investigator**
5. £1,928,468. **NIHR** Global Health Group on Dementia Prevention and Enhanced Care – (De-PEC). Project number 16/137/62. 2017-2020. **Robinson L** et al. **Principal Investigator.**
6. £45,000. **NIHR Senior Investigator Award.** 2017-2020. NF-SI-0616-10054.
7. £2,803,331. **NIHR Programme Grant.** REducing and preventing COgnitive impairment iN older age groups (the RECON Programme). Little P (PI), Robinson L et al. 2017-2022 RP-PG-0615-20014. Co-investigator.
8. £353,923. Dementia undetected or undiagnosed in primary care: the prevalence, causes and consequences. PI Savva G (UEA), Brayne C, Barnes L, Arthur A, **Robinson L**, Stephan BCM, Matthews F et al. **NIHR HS&DR**. 2016-2019. Co-investigator.
9. £20,000,000*. National Centre for Ageing Science and Innovation. **Robinson L**, Day C, Brink C, Watson P, Oliver P et al. **Government Office** 2016-2018. **Principal Investigator**.
10. £2,400.000. NIHR School for Primary Care Research membership. **Robinson L** et al. 2015-2021. **Principal Investigator**.

Recent publications

Amador S, Sampson EL, Goodman C, **Robinson L**. A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia. *Palliative Medicine* 2019 https://doi.org/10.1177/0269216319834227

Magklara E, Stephan BCM, **Robinson L.** Current approaches to dementia screening and case finding in low- and middle-income countries: Research update and recommendations. *International Journal of Geriatric Psychiatry* 2019 34:1, 3-7

Bamford C, Lee R, McLellan E, Poole M, Harrison-Dening K, Hughes J, **Robinson L,** Exley C. What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders. *BMC Geriatrics* 2018 18:302 https://doi.org/10.1186/s12877-018-0983-0

Tang E, Price C, Stephan BCM, **Robinson L,** Exley C. Post-stroke memory deficits and barriers to seeking help: views of patients and carers. *Family Practice,* 2018, cmy109, https://doi.org/10.1093/fampra/cmy109

McGrattan M, Barry HE, Ryan C, Cooper JA, Passmore AP, **Robinson L,** Molloy GJ, Darcy CM, Buchanan H, Hughes CM. The development of a core outcome set for medicines management interventions for people with dementia in primary care. *Age and Ageing*, 2018; 0: 1-7 DOI: 10.1093/ageing/afy172

Stephen B, Birdi R, Tang EYH, Siervo M, **Robinson L.** Secular trends in dementia prevalence and incidence worldwide: A systematic review. *Journal of Alzheimer's Disease* 2018; 66: 2. JAD18-0375

Pink J, O'Brien J, **Robinson L,** Longson D. Dementia: assessment, management and support: summary of updated NICE guidance. *BMJ* 2018;361:k2438 DOI: 10.1136/bmj.k2438.

Bennett H, Norton S, Bunn F, **Robinson L,** Rait G, Goodman C, Brayne C and Matthews FE. The impact of dementia on service use by individuals with a comorbid health condition: a comparison of two cross-sectional analyses conducted approximately ten-years apart. *BMC Medicine* 2018, 16:114 https://doi.org/10.1186/s12916-018-1105-8

Jennifer Mary Rusted, Ph.D., A.B.P.S., C.Psychol.

Current Position: Professor of Experimental Psychology
Address: School of Psychology; University of Sussex; Brighton BN1 9QG
                        Tel: Work (01273) 678325
                        Email: j.rusted@ sussex.ac.uk

Employment History
1980-1982   Postdoctoral Research Fellow, Dept. of Psychology, University of
                        Nottingham
1982-1984   Lecturer in Psychology, Goldsmiths' College, University of London.
1985   Research Officer, Merrill Palmer Institute of Child Development,
1985-1986   Research Fellow, Psychology, Wayne State University, Detroit, USA
1986   Career break (maternity absence)
1987-1988   Senior Research Fellow, Human Psychopharmacology Unit, Reading
University
1988- 1997   Lecturer in Experimental Psychology, University of Sussex
1997- 2006   Senior Lecturer /Reader in Experimental Psychology
2006-present   Professor of Experimental Psychology

Professional Activities
Alzheimers Society: Specialist Review Panel / Scientific Advisor
Co-Theme Lead – Dementia and Older Peoples Mental Health – Sussex Partnership Trust 2006-2017
NIHR Chair of the Trials Steering Committee for RADAR trial (to 2018)

School/University boards
Sussex University Chair of Research Degrees Exam Board 2017-present
Co-Director: Alzheimers Society Doctoral Training Centre, School of Psychology
Sussex University Deputy Springboard Champion for Academy of Medical Sciences
Sussex University MRC Confidence in Concept Initiative panel member

RESEARCH interests
Psychopharmacology of Human Memory; APOE e4 in cognition across the lifespan; Dementia

Publications SYNOPSIS
H index: 25; GS i10-index: 59

DPhil students successfully graduated to date: 29

Current GRANTS
2019-2024: ESRC: DETERMIND: DETERMinants of quality of life, care and costs IN people with Dementia and their carers after diagnosis. (co-I; lead: Banerjee, S)   £4M
2018-2023: Alzheimer Society: Improving the experience of dementia and enhancing active life: a longitudinal perspective on living well with dementia (the IDEAL-2 study) (**co-I**; lead: Clare)   £2M
2015-2020 Alzheimer Society: Of Molecules, Mice and Men: exposing and understanding APOE effects across the lifespan. Co-PI with Louise Serpell   £350,000
2014-2019: ESRC-NIHR: Improving the experience of dementia and enhancing active life: a longitudinal perspective on living well with dementia (IDEAL-1)(Co-I; Lead: Clare) £5M

Selected Recent Publications:
Evans SL, Dowell NG, Prowse F, Tabet N, King SL, Rusted JM. (2020) Mid age APOE ε4 carriers show memory related functional differences and disrupted structure-function relationships in hippocampal regions. Scientific Reports. 10: 3110. doi: 10.1038/s41598-020-59272-0
John A, Rusted J, Richards M, Gaysina D (2020) Accumulation of affective symptoms and midlife cognitive function: The role of inflammation. Brain, Behavior and Immunity, 84**,** 164-172.
Lancaster C, McDaniel M, Tabet N, Rusted J. (2019) Prospective Memory: Age related change is influenced by APOE genotype. Ageing, Neuropsychology and Cognition.
DOI: 10.1080/13825585.2019.1671305

Professor Robert Stewart

ORCID ID   0000-0002-4435-6397
Current post: Professor of Psychiatric Epidemiology and Clinical Informatics, King's College London; Consultant Psychiatrist, South London & Maudsley.

Qualifications:

From	To	Degree	Class	Institution	Subject
10/1999	12/2001	MD	-	University of Leeds	Medicine
10/1998	09/1999	MSc	-	London School of Hygiene & Tropical Medicine	Epidemiology
08/1993	06/1996	MRCPsych	-	Royal College of Psychiatrists	Psychiatry
09/1986	08/1991	MBChB	-	University of Leeds	Medicine and Surgery

Selected current grants:

Start Date	Duration (months)	Amount	Title	Funder	Role
2019	60	£3,952,066	Determinants of quality of life, care and costs, and consequences on inequalities in people with dementia.	ESRC	Co-applicant, KCL Lead
2018	24	£1,497,000	Mental Health Data Pathfinder award to KCL	MRC	Lead Applicant
2018	48	£360,000	Senior Investigator Award	NIHR	Lead applicant
2018	60	£1,497,000	Health Data Research UK, London site	MRC	Co-applicant
2017	60	£6,857,498	SLAM/KCL Biomedical Research Centre for Mental Health - Clinical and Population Informatics Theme.	NIHR	Theme Lead
2017	36	£867,365	eLIXIR, Early Lifecourse data Cross- Linkage in Research; a multidisciplinary partnership.	MRC	Co-applicant, Informatics Lead

Selected recent publications

1. Soysal P, Perera G, Isik AT, Onder G, Petrovic M, Cherubini A, Maggi S, Shetty H, Molokhia M, Smith L, Stubbs B, Stewart R, Veronese N, Mueller C. The relationship between polypharmacy and trajectories of cognitive decline in people with dementia: a large representative cohort study. *Experimental Gerontology* 2019; 120: 62-67.
2. Sommerlad A, Perera G, Mueller C, Singh-Manoux A, Lewis G, Stewart R, Livingston G. Hospitalisation of people with dementia: cohort study using English electronic health record data from 2008 to 2016. *European Journal of Epidemiology* 2019; 34: 567-577.
3. Leniz J, Higginson IJ, Stewart R, Sleeman KE. Understanding which people with dementia are at risk of inappropriate care and avoidable transitions to hospital near the end-of-life: a retrospective cohort study. *Age and Ageing* 2019; 48: 672-679.
4. Perera G, Pedersen L, Ansel D, Alexander M, Arrighi HM, Avillach P, Foskett N, Gini R, Gordon MF, Gungabissoon U, Mayer M-A, Novak G, Rijnbeek P, Trifirò G, van der Lei J, Visser PJ, Stewart R. Dementia prevalence and incidence in a federation of European electronic health record databases: the European Medical Informatics Framework resource. *Alzheimer's & Dementia* 2018; 14: 130-139.
5. Kim J-M, Stewart R, Lee Y-S, Lee H-J, Kim MC, Kim J-W, Kang H-J, Bae K-Y, Kim S-W, Shin I-S, Hong YJ, Kim JH, Ahn Y, Jeong MH, Yoon J-S. Effect of escitalopram vs placebo treatment for depression on long-term cardiac outcomes in patients with acute coronary syndrome: the DEPACS randomized clinical trial. *JAMA* 2018; 320: 350-358.

Present Appointment
Professor of Old Age Psychiatry at Newcastle University and Director of Brains for Dementia Research; Honorary Consultant in Old Age Psychiatry at Gateshead Health NHS Trust (Tenured Post, NHS Funded, from November 2002)

Contact Details

Department: Translational and Clinical Research Institute
Institution: Newcastle University
Address   Biomedical Research Building, Institute for Ageing and Health, Newcastle University, Campus for Ageing and Vitality, Newcastle upon Tyne, NE4 5PL
               Telephone: 0191 445 5212; Email: alan.thomas@ncl.ac.uk

Previous Appointments
May 1999 to Oct 2002   Clinical Lecturer in Old Age Psychiatry, Newcastle University
Nov 2002 to Aug 2013   Clinical Senior Lecturer in Old Age Psychiatry, Newcastle University

Qualifications
BSc (first class), MB ChB, MRCPsych, PhD

Selected Current Research Grants
Co-applicant: 2020-2023: Brains for Dementia Research Stem Cell and Fibroblast Resource. **Alzheimer's Brain Banks UK, £200,804.**
Co-applicant: 2020-2023: A study of neuroimaging and magnetoencephalography biomarkers for prodromal dementia with Lewy bodies. **The Lewy Body Society, £198,767.**
Lead Applicant: 2018-2021: Brains for Dementia Research Programme. **ABBUK, £2,658,281.**
Co-applicant: 2019-2024: DETERMIND: DETERMinants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their family carers. **Economic and Social Research Council, £3,952,066.**
Lead Applicant: 2019-2022: Understanding the Contributions of Multiple Pathologies to Dementia in the BDR Programme. **Alzheimer's Research UK, £71,209.**
Co-Applicant: 2018-2021: Developing a novel eletrophysiological cholinergic biomarker in Lewy body dementia CREED-WESTERN. **The Selfridges Group Foundation, £298,557**.
Co-Applicant: 2018-2022: Problem solving therapy for depression in older adults with dementia. **NIHR HTA, £1,597,688.08.**
Lead Applicant: 2015-2020: 123I-MIBG Scintigraphy Utility as a biomarker for Prodromal DEmentia with Lewy Bodies (SUPErB). **Alzheimer's Research UK, £492,273.**.

Selected Publications (Current H Score = 54 (Citations: 11,180)
Taylor, J. P., I. G. McKeith…..**A. J. Thomas**, and J. T. O'Brien. (2020). 'New evidence on the management of Lewy body dementia', *Lancet Neurol*, 19: 157-69.
McKeith, I. G., T. J. Ferman, **A. J. Thomas**…and P. Tiraboschi (2020). "Research criteria for the diagnosis of prodromal dementia with Lewy bodies." *Neurology* 17:743-755. doi: 10.1212/WNL.0000000000009323.
Schumacher, J., **A. J. Thomas**…and J. P. Taylor (2020). "EEG alpha reactivity and cholinergic system integrity in Lewy body dementia and Alzheimer's disease." *Alzheimers Res Ther* **12**(1): 46
Thomas, A. J., …and J. T. O'Brien (2019). "Diagnostic accuracy of dopaminergic imaging in prodromal dementia with Lewy bodies." *Psychol Med* **49**(3): 396-402
King, E., O'Brien, J.T….and **Thomas, A.J.** (2018) 'Peripheral inflammation in prodromal Alzheimer's and Lewy body dementias', *J Neurol Neurosurg Psychiatry*, 89(4), pp. 339-345
Thomas, A.J., Taylor, J.P ….and O'Brien, J. (2018) 'Revision of assessment toolkits for improving the diagnosis of Lewy body dementia: The DIAMOND Lewy study', *Int J Geriatr Psychiatry*, 33(10) pp1293-1304

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E-mail: Raphael.wittenberg@phc.ox.ac.uk

Education:
MSc in Economics, London School of Economics, 1987
MA in Politics and Philosophy (second class), University of Oxford, 1977

Current and recent appointments:
2013-date: Associate Professorial Research Fellow (from July 2019 Deputy Director), Care Policy and Evaluation Centre, London School of Economics (p/t)
2012-date: Senior Researcher Fellow, CHSEO, Nuffield Primary Health Care Sciences Department, University of Oxford (p/t)
2000-2012: Senior economist, Department of Health and Social Care (p/t)

Main current research projects:
DETERMinants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their carers (DETERMIND), funded by ESRC+NIHR, 2019-2023, co-leader of 2 work-packages

Policy Innovation Research Unit (PIRU), funded by NIHR, 2011-2023, co-applicant

Economics of Social and Health Care Research Unit (ESHCRU), NIHR funded, 2011-2023

Adult Social Care Research Unit (ASCRU), funded by NIHR, 2019-2023, co-applicant

Older People and Frailty Research Unit (OPRU), funded by NIHR, 2019-2023

Multi-morbidity, Services and Costs in Later Life (MuSeCoL) Study, funded by the NIHR School for Primary Care Research, 2018-2019, principal investigator

Main recent relevant publications:
Wittenberg R, Hu B, Jagger C, Kingston A, Knapp M, Comas-Herrera A, King D, Rehill A and Banerjee S, Projections of care for older people with dementia in England: 2015 to 2040, *Age and Ageing,* Volume 49, Issue 2, March 2020, pages 264–269,

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* 2019; 34: 1095–1103.

Wittenberg R, Knapp M, Karagiannidou M, Dickson J and Schott J (2019) Economic impacts of introducing diagnostics for MCI Alzheimer's disease patients, *Alzheimer's & Dementia Translational Research & Clinical Interventions,* 2019: 5, 382-387

Anderson R, Knapp M, Wittenberg R, Handels R and Schott J (2018) *Economic Modelling of Disease-Modifying Therapies in Alzheimer's Disease*, report for Alzheimer's Research UK

Wittenberg, R., Hu, B. and Hancock, R., (2018). *Projections of demand and expenditure on adult social care 2015 to 2040*, Personal Social Services Research Unit

University of Plymouth

9 May 2020

To whom it may concern,

Confirmation of Lead Organisation support DETERMIND-C19 – Prof Sube Banerjee

I am pleased to offer my support and confirmation of approval for Prof Sube Banerjee and his team's application for funding for: *DETERMIND-C19: Impact of COVID-19 on people newly diagnosed with dementia and their family carers, a mixed method study nested in DETERMIND.*

The University is delighted to support this work which will receive all necessary commitment from our Faculty of Health. I confirm that the work is achievable under current constraints and that we are satisfied that the work can begin within four weeks of confirmation of funding.

Yours faithfully

Professor Jerry Roberts
Deputy Vice-Chancellor Research and Enterprise

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