DETERMINants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their carers
Overall aim

To investigate inequalities and inequities in care and outcomes for people with dementia and their carers
Partners

- London School of Economics
- Newcastle University
- York University
- Cambridge University
- Kings College London
- Sussex University
Background - Intersectionality

Hulko (2009)
Hicks et al. (2019)
Reagan (2016)
Innes et al. (2011)
Carone et al. (2016)
Background

IDEAL Study- Clare et al. (2014)

- inequality - uneven distribution of health or health resources
- inequity - unfair, avoidable differences arising from differential provision, poor governance, or cultural exclusion

DETERMIND allows us to go beyond a simple input-output model of dementia care (here is a service, people get it, and here are the outcomes)

We will unpick causal chains and build understanding of contextual factors. Focus on modifiable mediating factors that generate unequal access and experiences, leading to inequities in outcome
WS1 - Recruitment and follow-up of DETERMIND cohort

WS2 - Inequalities in use of dementia care

WS3 - Relationship between use and costs of services and outcomes

WS4 - Experience of self-funders of care

WS5 - Understanding decision-making by people with dementia and carers

WS6 - Effect of diagnostic stage and services on outcomes

WS7 - Programme management and Theory of Change-guided research development and coordination

WS7 - Theory of Change-guided generation of conclusions and promotion of impact
Participants

- Newcastle/North-east (Gateshead Trust/Newcastle)
  - White working class
- London (SLAM/KCL)
  - BAME
- South East (Sussex Trust/BSMS)
  - LGBTQ+

PARTICIPANTS NEEDED

- Memory Assessment Service
- GP Practices
- Community groups
- Online sites such as JDR
DETERMIND design

**WS1 - Recruitment and follow-up of DETERMIND cohort**

- 900 people with dementia diagnosed in the last 6 months – baseline assessment
- South East
- South London
- North East

- One-year follow-up
- Two-year follow-up
- Three-year follow-up

BSMS
Newcastle
KCL
• Participants (the person with dementia and their carer) will be asked to complete a series of questionnaires that will last around 120 minutes.
  • Participants then contacted annually for 3 years to arrange follow-up visits.
• Assessments include measures of quality of life, cognitive function, neuropsychiatric symptoms, use of services, activities of daily living, medication, and physical illnesses.
• Qualitative interviews will supplement this work, to gain a more experiential understanding of living with dementia and the care processes
How to Refer – example Sussex

• There are several ways you can refer to us:
  • Email determind@bsms.ac.uk
  • Hand out our flyers (either on their own or as part of your diagnosis pack)
  • Display our posters
  • We are also happy to attend any clinics
Are there inequalities in access to health and social care?

WS2 - Inequalities in use of dementia care

What happens if people with dementia and their carers receive unequal treatment?

Which populations experience inequalities?

WS3 - Relationship between use and costs of services and outcomes

Do these unmet needs and inequalities change over the course of the condition?

Why do inequalities occur and what are the barriers and facilitators to good well-being for disadvantaged populations?

What populations access what services and why?

Does increase in the use of services result in better health outcomes?
Methods
Mixed methods comprising

(i) analyses of existing datasets ELSA, CFAS, MODEM
(ii) analyses of new DETERMIND cohort data
(iii) qualitative interviews of DETERMIND cohort members.
NYorks

WS4 - Experience of self-funders of care

Mixed methods
(i) Self-funders’ experiences of navigating care systems and arranging care post-dementia diagnosis
(ii) Patterns of self-funders’ journeys over time and how these differ from those funded by councils
(iii) How interactions with key people and services affect self-funders’ choices and decision-making
(iv) Characteristics of self-funders and their role in decision-making and experiences of care and support
(v) What social science theories facilitate understanding of self-funders’ experiences
DETERMIND
design

Sussex

Emotional regulation
Cognitive control
Self reflection

WS5 - Understanding decision-making by people with dementia and carers
WS6 - Effect of diagnostic stage and services on outcomes
WS1 - Recruitment and follow-up of DETERMIND cohort

WS2 - Inequalities in use of dementia care

WS3 - Relationship between use and costs of services and outcomes

WS4 - Experience of self-funders of care

WS5 - Understanding decision-making by people with dementia and carers

WS6 - Effect of diagnostic stage and services on outcomes

WS7 - Programme management and Theory of Change-guided research development and coordination

WS7 - Theory of Change-guided generation of conclusions and promotion of impact
Thank you!

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