Conference or Workshop Item:

Gridley, Kate orcid.org/0000-0003-1488-4516 (2021) Dementia care for social care self-funders now and in the future::Insights from the DETERMIND study. In: British Society of Gerontology, 07-09 Jul 2021.

Dementia care for social care self-funders now and in the future:

Insights from the DETERMIND study

BSG, 9th JULY 2021

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FUNDED BY

Acknowledgement

The DETERMIND study was supported by the Economic and Social Research Council (UK) and the National Institute for Health Research (UK) through grant number ES/S010351/1 ‘Determinants of quality of life, care and costs, and consequences of inequalities in people with dementia and their carers’ (Investigators: S. Banerjee, K. Baxter, Y. Birks, C. Brayne, M. Dangoor, J. Dixon, P. Harris, B. Hu, M. Knapp, S. Read, L. Robinson, J. Rusted, R. Stewart, A. Thomas, R. Wittenberg).

The support of the ESRC and NIHR is gratefully acknowledged.

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Background

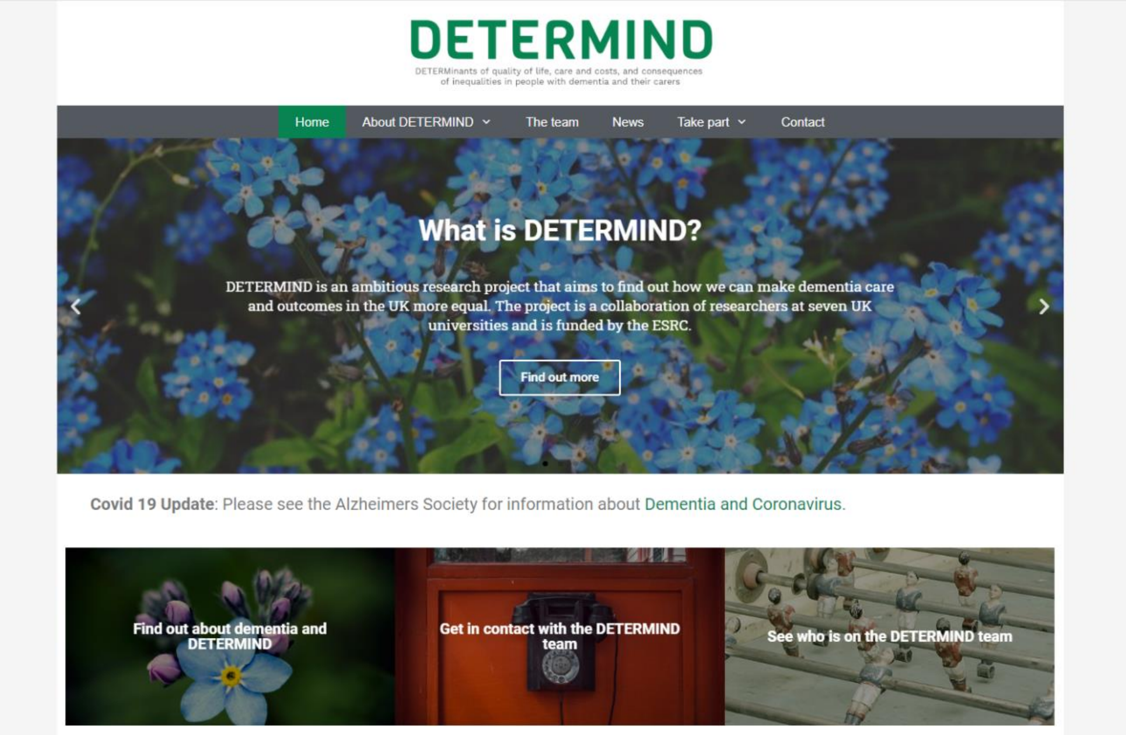
- 7 universities
- 5 years
- 900 people with dementia (and their carers)

Focus is inequalities

7 different streams of work (see Farina et al. 2020)

<u>Work stream 4: </u>Experience of self-funders of care: Investigating the experience of people with dementia and their carers who fund their own care

https://determind.org.uk/



DETERMinants of quality of life, care and costs, and consequences of inequalities in people with dementia and their carers

What is DETERMIND?

DETERMIND is an ambitious research project that aims to find out how we can make dementia care and outcomes in the UK more equal. The project is a collaboration of researchers at seven UK universities and is funded by the ESRC.

Covid 19 Update: Please see the Alzheimers Society for information about Dementia and Coronavirus.

DETERMIND stands for:
DETERMinants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their carers

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Social-care self-funders

- People who pay for all of the social care services they receive themselves because:

'…either they do not meet tight eligibility criteria for access to services and/or their financial means place them above the threshold for local authority-funded care.' (Tanner, 2018)

<u>Includes paying for:</u>

- Day care (attending resource centres, lunch clubs etc.)
- Home care (e.g. personal care in the home)
- Residential care (care home or nursing home)

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Self-funding ≠ unproblematic




- Having sufficient financial resources to self-fund does not guarantee greater control – often decision are made during crisis
- Self-funders say looking for information about care services can be 'exhausting' and 'upsetting'
- They want assistance in making choices from professionals

Despite Care Act (2014) giving local authorities responsibilities to self-funders, in practice many either:

- Don't approach the local authority
- Do approach the LA, but receive little support once it becomes clear they will be self-funding

(Baxter et al. 2019; Baxter et al, 2017; Putting People First, 2011)

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DETERMIND WS4: Research Questions:

In the context of living with dementia:

- *What are self-funders' experiences of navigating care systems and arranging care post dementia diagnosis?*
- *What are the patterns of self-funders' experiences over time, and how do these differ from those of people funded by councils?*
- *What social science theories facilitate understanding of self-funders' experiences?*

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Possible theory – the capability approach

- It's insufficient to look only at the means (commodities) a person has at their disposal
- Also need to consider the conversion factors that enable or prevent a person from utilising resources to achieve outcomes (functionings).

Conversion factors include:

- personal circumstances: such as health, ability and experience
- social and cultural factors: such as policies and cultural norms and the physical environment

Tanner et al. 2018: multiple variables influence ability to purchase care - not just a product of individual purchasing power:

'*an older person might be relatively affluent but severely disabled, confined to the home and have no knowledge of care services or how to purchase them*.' (2018, p 265)

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Methods

- Identify self-funders within the DETERMIND cohort who:
  - Use home care
  - Have or are making transitions into care homes
- Explore processes through qualitative interviews at baseline, 12 and 24 months looking at :
  - interactions with service providers, councils, family and friends
  - sources of information
  - experiences of choice and control
- ‘Follow the thread’ back and forth through the qualitative and quantitative data sets

Following the thread

‘…*a focused iterative process of data interrogation which aims to interweave the findings that emerge from each dataset. The value of this integrative analytic approach lies in allowing an inductive lead to the analysis, preserving the value of the open, exploratory, qualitative inquiry but incorporating the focus and specificity of the quantitative data*’ (Moran-Ellis et al., 2006, p54)

Progress to date…

Time 1: Feb - Aug 2020

T1 interviews mainly remote due to COVID

16 dyads interviewed

- 12 carers
- 6 people with dementia

Time 2: Jun - Aug 2021

T2 recruitment & selection ongoing

7 dyads interviewed so far

- 7 from T1 followed-up
- 6 more from T1 to follow-up
- 24 to recruit

Time 3: Jun - Aug 2022

T3 selection dependent on T2 insights

- 30 dyads to follow up

Example hypotheses:

Example hypothesis:

Self-funders are left on their own to navigate the system without the benefit of a social worker or other care coordinator to tell them what would be a 'good route to take'

Sources:

- Previous literature - but not dementia specific (Putting People First 2011; Baxter et al. 2019; Baxter et al, 2017)
- Qualitative interviews

From DETERMIND (self-funding) carer:

‘…*I think when you’re self-funding, from a carer’s point of view you’re a little bit left on your own basically to, to navigate your own way through and, you know, make the decisions, there’s no sort of person there saying, “well yes, you’ve got to fund it but this would be a good route to take”, or, “that would be an idea, ideal way to go”. So it, it, it’s tricky, I mean, but my mum, yes, she has more options, yes.*’

GATE D (sf-carer)

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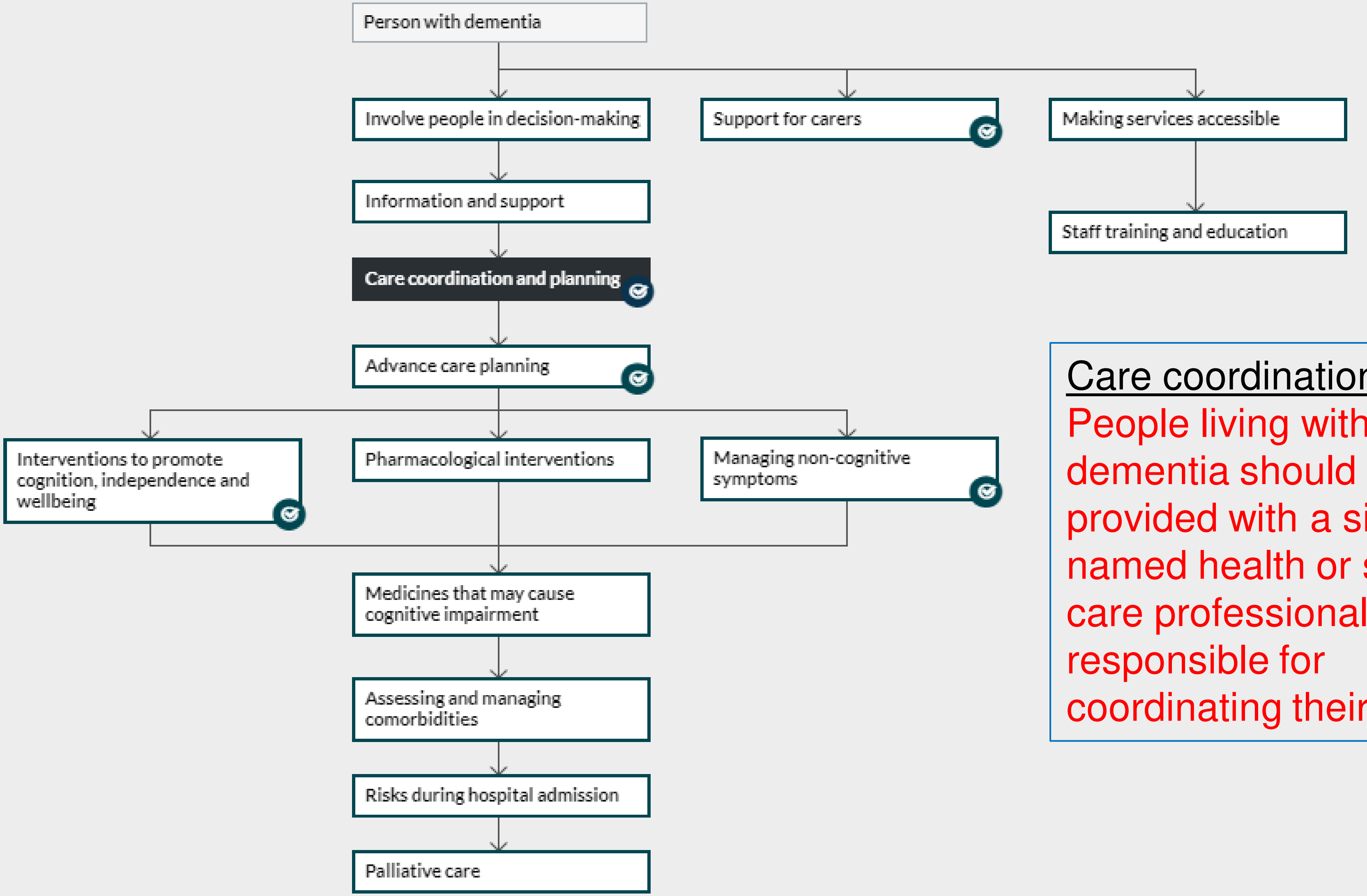
NICE pathway on dementia management



Person with dementia

Involve people in decision-making

Support for carers

Making services accessible

Information and support

Staff training and education

Care coordination and planning

Advance care planning

Interventions to promote cognition, independence and wellbeing

Pharmacological interventions

Managing non-cognitive symptoms

Medicines that may cause cognitive impairment

Assessing and managing comorbidities

Risks during hospital admission

Palliative care

<u>Care coordination:</u>
People living with dementia should be provided with a single named health or social care professional who is responsible for coordinating their care

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Evidence from T1 qualitative data

- Most of the self-funders in our sample did not have any designated professional or service helping to coordinate care (despite this being recommended in NICE dementia guidelines)
- Only two participants had regular contact with adult social care (one was a self-funder, the other council funded)

Actions for T2:

- Recruit more council funded participants for comparison
- Add questions on care-coordination and contact with social care to the quantitative questionnaire

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Importance of social capital

Example hypothesis: Self-funders who are supported by family or friends (social capital) with relevant knowledge and/or experience are in a better position

'I think if you, if you're supported by family that are quite clued up you're in, you're in a much stronger position. I mean if you, I mean my, my husband used to be a social worker so, you know, we are aware of the support that's out there…'

SUSS E (SF – carer)

Evidence from T1 and T2

- Heavy use of family and friends from most participants for information, advice and recommendations
- Hint from T2 that for dementia it might be more nuanced than number of contacts (whose responsibility to act?)

Case study: SLAM C

T1 July 2020: interview with person with dementia	Had an extensive social network, but said he was unaware of what services were available to him. Lived alone with no named carer and no named care coordinator.
T2 June 2021: interview with niece	Rapid decline (not initially picked up by family, friends or services). **No-one's top priority.** Discharged from hospital without support. Moved into a care home.

To follow up in the quantitative dataset

Possible conversion factors:

Care coordination:

- Do they have a named care coordinator?
- Do they have a social worker (and have they had any contact with them?)

Social capital (quality as well as quantity)

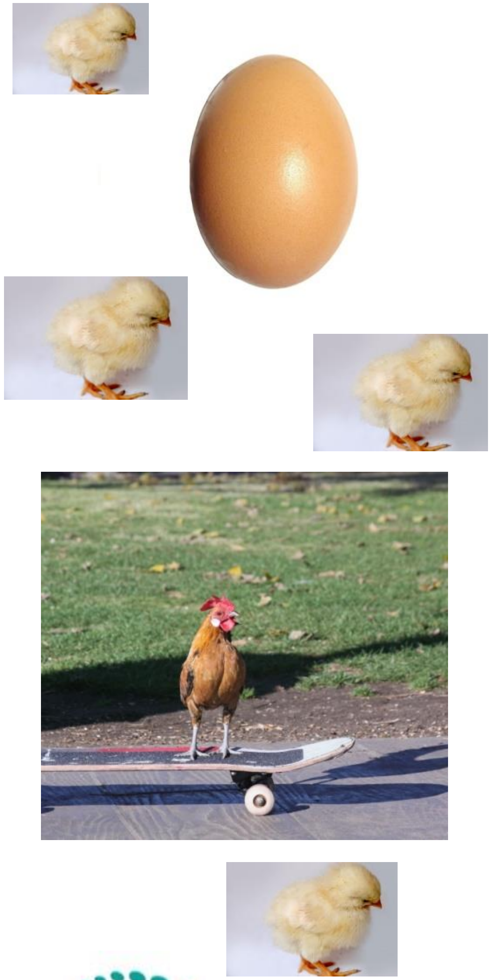
- Do they have any family living with them or nearby?
- Previous career of carer
- Types of support identified (list includes professionals, family and friends)

Mixed method longitudinal approach

Pros and cons: Quantitative and qualitative analysis are concurrent so…

- *We don't* yet have findings of quantitative analysis to guide qualitative interviews
- *But we can* add questions to questionnaires for future time points
- And suggest hypotheses for qualitative and quantitative investigation

Interviewing the same people multiple times gives an extra dimension – can identify key triggers/turning points. Not just about static factor but dynamic processes.



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Questions?

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