Co-Creating and Applying a New Method to Identify Dementia Care Research Priorities

With People Living with Dementia in Kent

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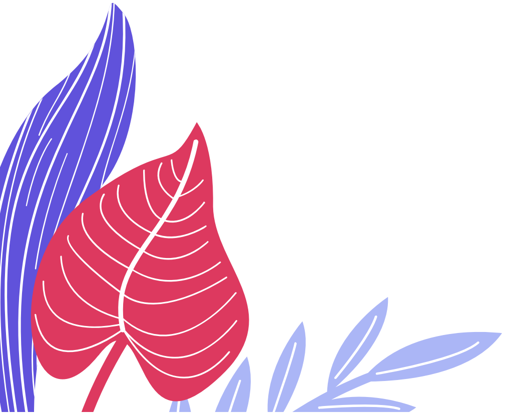


Who gets a say on what dementia research should focus on?

- Usually… researchers themselves!
- When ‘stakeholder’ prioritisation is carried out, the voices of people living with dementia are often in the minority
  - E.g. Dementia Priority Setting Partnership with the James Lind Alliance (Kelly et al, 2015) had:
    - **4.1%** people living with dementia
    - 76.0% family carers/relatives
    - 14.4% health and care professionals

Why don’t we consult people living with dementia more?

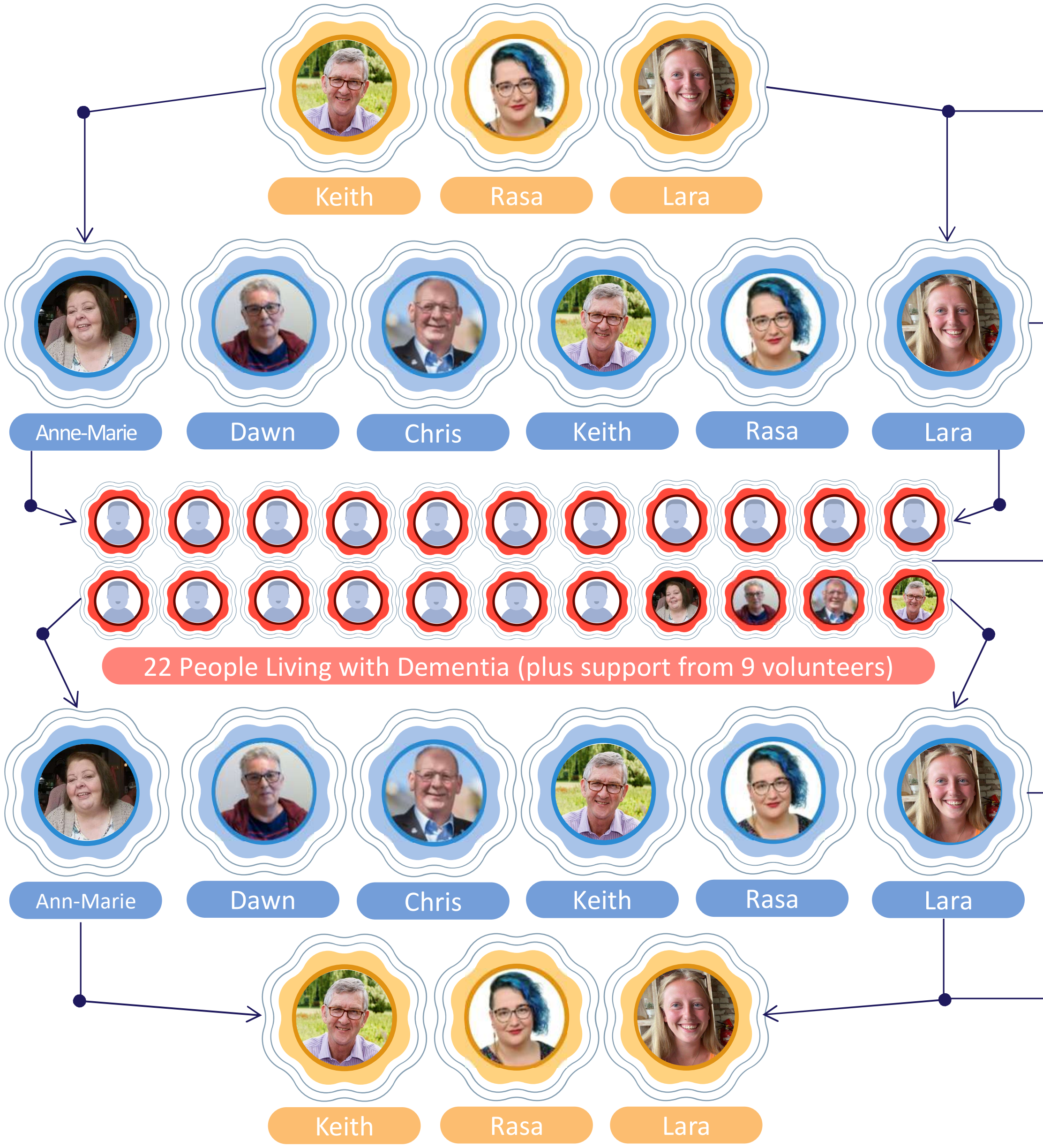
- Funding for public involvement usually starts when research is already funded, not at bid development or earlier
- Methods / tools used to set priorities are not sufficiently inclusive
- Researchers are not very good at explaining in lay, inclusive ways what research is…
- Prejudices about who *should* have a say on research priorities may play a role, too…

Original aim:

To set research priorities for living with dementia in Kent

Amended aim:

To set research priorities for living with dementia in Kent by first co-designing a dementia-inclusive prioritisation approach



Core Group

Planning the Project

Working Group

Designing the Method

Full Group

Setting Research Priorities

Working Group

Analysis and Summary

Core Group

Dissemination

Working Group Co-Design of the Priority Setting Approach

What **CONCEPT** are we capturing?

What are research priorities for living with dementia?

What **METHOD** are we using to prioritise?

- Group-based
- Using an initial list of priorities
- Adding to these and voting anonymously
- Discussing top 3 areas to discern research questions

What do we do about the **PRACTICALITIES**?

- Kent-based dementia groups
- One-off meeting, in-person
- Time to socialise after; catered


Choose 3 top priorities for you
I want to speak please
STORE 4
STORE 5
Toilet
Lipton
RASPBERRY
CIAO!
FIRE EXIT

Fairness

- who is at most risk of dementia?
- who is likely to get a timely diagnosis?
- who is likely to get better support
- who does available support suit best?

Help-Seeking

- why do some people living with dementia look for support themselves and others don't?
- how can people living with dementia be encouraged to accept existing support?

Information

- what information do people need?
- is currently available information suitable for people living with dementia?
- when is the best time to provide information, where, and how much of it?

Support

- who is best-placed to provide different kinds of dementia support?
- is there a way to encourage more peer and inter-generational support?
- support at critical periods (diagnosis, crisis)

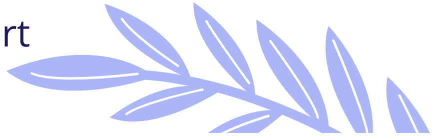
Training / Awareness

- how much dementia training do different professions have?
- what aspects of dementia are people particularly unaware of?
- how can people living with dementia be involved?

write in your own research priority

Other suggested priorities:

- Creativity and/for dementia
- Living alone and dementia progression
- Living alone and/vs isolation
- Expanding participation in research
- Integrated care
- Social care
- Continuity of support
- Media representation
- Stereotypes and Stigma
- Learning environments/experiences
- Rare dementias
- Education of medical doctors
- Opportunities to inform professionals
- Accessibility
- Dementia and (other) disabilities
- Staying in employment with dementia
- Financial support



(1) Fairness

- who is at most risk of dementia?
- who is likely to get a timely diagnosis?
- who is likely to get better support
- who does available support suit best?

(2) Help-Seeking

- why do some people living with dementia look for support themselves and others don't?
- how can people living with dementia be encouraged to accept existing support?

(3) Information

- what information do people need?
- is currently available information suitable for people living with dementia?
- when is the best time to provide information, where, and how much of it?

(4) Support

- who is best-placed to provide different kinds of dementia support?
- is there a way to encourage more peer and inter-generational support?
- support at critical periods (diagnosis, crisis)

(5) Training / Awareness

- how much dementia training do different professions have?
- what aspects of dementia are people particularly unaware of?
- how can people living with dementia be involved?

write in your own research priority

Other suggested priorities:

- Creativity and/for dementia
- Living alone and dementia progression (1)
- Living alone and/vs isolation (1)
- Expanding participation in research
- Integrated care (4)
- Social care (4)
- Continuity of support (4)
- Media representation (3)
- Stereotypes and Stigma
- Learning environments/experiences (5)
- Rare dementias (1)
- Education of medical doctors (5)
- Opportunities to inform professionals (5)
- Accessibility
- Dementia and (other) disabilities (1)
- Staying in employment with dementia
- Financial support (4)

Top Research Priority Areas

1st Training & Awareness

- **E.g.** PLwD involvement in dementia training for health and social care professionals, especially medical doctors

2nd Information

- **E.g.** Increasing information accessibility for people with a more advanced dementia (incl via digital technology)

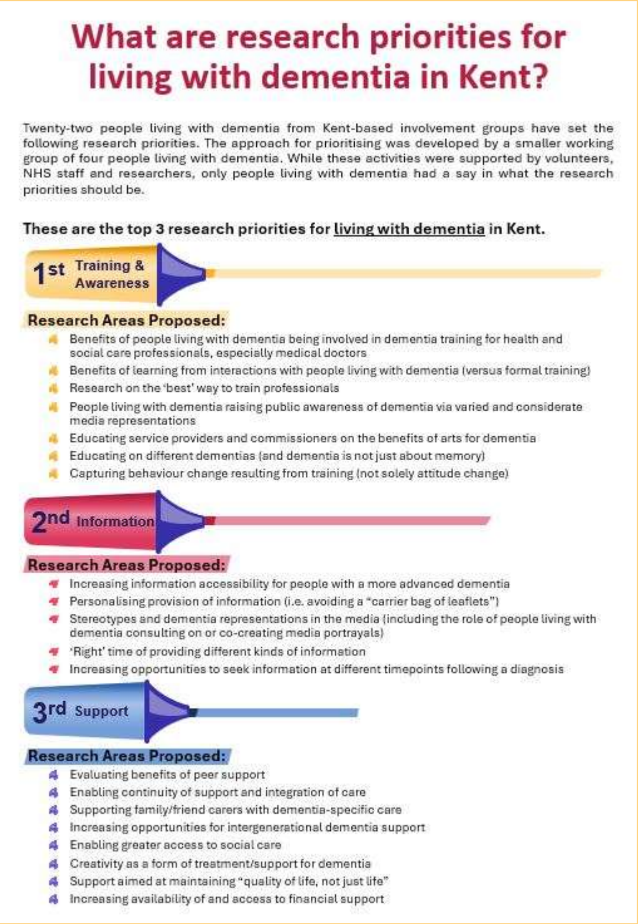
3rd Support

- **E.g.** Evaluating benefits of peer support (to those being supported and to PLwD providing peer support)

So what?

- We are not suggesting everyone should use our approach – quite the opposite!
- We are demonstrating that **people living with dementia can be meaningfully involved at any point of the research cycle**:
  - setting priorities AND
  - deciding the approach for doing so
- **Our method** may be useful as a starting point for co-producing yours!
- **Our Kent-based dementia research priorities** will likely be applicable outside of Kent
- But **the main point we are making is that people living with dementia should be central in deciding what research focusses on!**

Download our Summary



What are research priorities for living with dementia in Kent?

Twenty-two people living with dementia from Kent-based involvement groups have set the following research priorities. The approach for prioritising was developed by a smaller working group of four people living with dementia. While these activities were supported by volunteers, NHS staff and researchers, only people living with dementia had a say in what the research priorities should be.

These are the top 3 research priorities for living with dementia in Kent.

1st Training & Awareness

Research Areas Proposed:

- Benefits of people living with dementia being involved in dementia training for health and social care professionals, especially medical doctors
- Benefits of learning from interactions with people living with dementia (versus formal training)
- Research on the 'best' way to train professionals
- People living with dementia raising public awareness of dementia via varied and considerate media representations
- Educating service providers and commissioners on the benefits of arts for dementia
- Educating on different dementias (and dementia is not just about memory)
- Capturing behaviour change resulting from training (not solely attitude change)

2nd Information

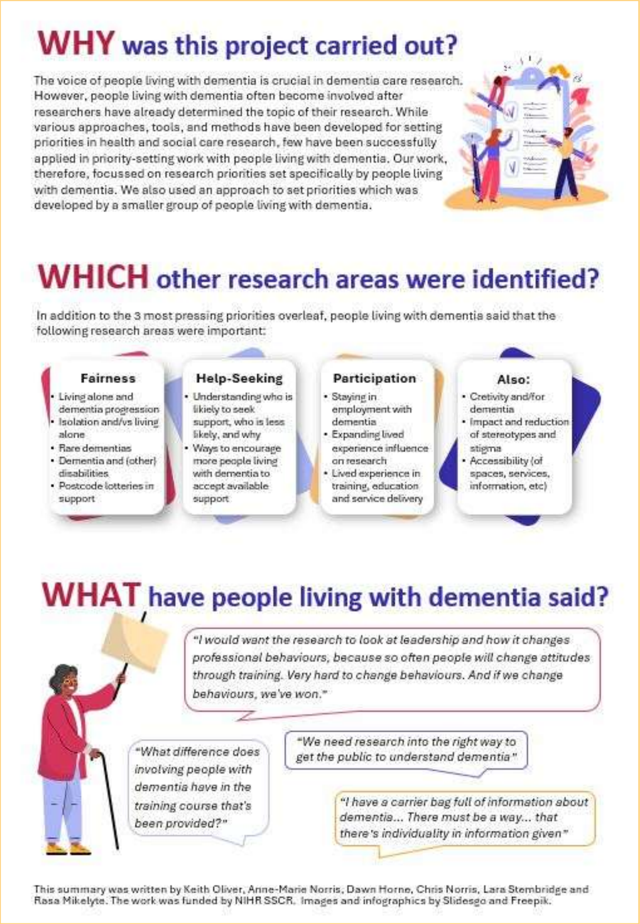
Research Areas Proposed:

- Increasing information accessibility for people with a more advanced dementia
- Personalising provision of information (i.e. avoiding a "carrier bag of leaflets")
- Stereotypes and dementia representations in the media (including the role of people living with dementia consulting on or co-creating media portrayals)
- 'Right' time of providing different kinds of information
- Increasing opportunities to seek information at different timepoints following a diagnosis

3rd Support

Research Areas Proposed:

- Evaluating benefits of peer support
- Enabling continuity of support and integration of care
- Supporting family/friend carers with dementia-specific care
- Increasing opportunities for intergenerational dementia support
- Enabling greater access to social care
- Creativity as a form of treatment/support for dementia
- Support aimed at maintaining "quality of life, not just life"
- Increasing availability of and access to financial support



WHY was this project carried out?

The voice of people living with dementia is crucial in dementia care research. However, people living with dementia often become involved after researchers have already determined the topic of their research. While various approaches, tools, and methods have been developed for setting priorities in health and social care research, few have been successfully applied in priority-setting work with people living with dementia. Our work, therefore, focussed on research priorities set specifically by people living with dementia. We also used an approach to set priorities which was developed by a smaller group of people living with dementia.

WHICH other research areas were identified?

In addition to the 3 most pressing priorities overleaf, people living with dementia said that the following research areas were important:

Fairness

- Living alone and dementia progression
- Isolation and/vs living alone
- Rare dementias
- Dementia and (other) disabilities
- Postcode lotteries in support

Help-Seeking

- Understanding who is likely to seek support, who is less likely, and why
- Ways to encourage more people living with dementia to accept available support

Participation

- Staying in employment with dementia
- Expanding lived experience influence on research
- Lived experience in training, education and service delivery

Also:

- Cretivity and/for dementia
- Impact and reduction of stereotypes and stigma
- Accessibility (of spaces, services, information, etc)

WHAT have people living with dementia said?

"I would want the research to look at leadership and how it changes professional behaviours, because so often people will change attitudes through training. Very hard to change behaviours. And if we change behaviours, we've won."

"What difference does involving people with dementia have in the training course that's been provided?"

"We need research into the right way to get the public to understand dementia"

"I have a carrier bag full of information about dementia... There must be a way... that there's individuality in information given"

This summary was written by Keith Oliver, Anne-Marie Norris, Dawn Horne, Chris Norris, Lara Stembridge and Rasa Mikelyte. The work was funded by NIHR SSCR. Images and infographics by Slidesgo and Freepik.

Thank You!

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