

Re-
~~Co-~~Designing for
Better Dementia
Research

Rasa Mikelyte & Dawn Horne





Dawn

- ✦ Diagnosed with Alzheimer's disease and vascular dementia at 77
- ✦ Author of Dawn's Dementia Field Guide
- ✦ NHS Dementia Envoy
- ✦ Member of East Kent Forget-Me-Nots (DEEP group)
- ✦ Trustee for a dementia arts charity Bright Shadow
- ✦ Researcher
- ✦ Tailor
- ✦ Psychiatric nurse
- ✦ Business owner
- ✦ Mother of four

Rasa

- ✦ Researcher in Applied Health and Social Care since 2012
- ✦ Care worker in a dementia care home for 15+ years
- ✦ Assistant psychologist in an NHS memory clinic... many years ago!
- ✦ Trustee for a dementia arts charity Bright Shadow
- ✦ Likes meddling in co-design and co-production with people living with dementia



**A story of
Dawn's
research
journey...**



**... with a few
provocations
along the way!**

The beginning:

1. Co-design of an easy-read version of an adult social care toolkit



This project is funded by the National Institute for Health and Care Research (NIHR) Research for Social Care Call (RfSC), under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number NIHR202974).

The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.



- ♥ The Adult Social Care Outcomes Toolkit (ASCOT) is an outcome measure, capturing social care-related quality of life.
- ♥ This means it measures the aspects of QoL most impacted by social care:
 - ♥ Control over daily life
 - ♥ Personal cleanliness and comfort
 - ♥ Clean and comfortable home
 - ♥ Food and drink
 - ♥ Personal safety
 - ♥ Relationships with family and friends
 - ♥ Occupation (doing things you value and enjoy)
 - ♥ Dignity
- ♥ <https://www.pssru.ac.uk/ascot/>

What tools does ASCOT offer?

SCT4

4-level self-completion tool

INT4

4-level interview tool

CH4

4-level mixed-method tools in care homes

- Residents' view
- Structured observation
- Staff and family member view

Carer SCT4

4-level self-completion tool for family/friend carers in community settings

Carer INT4

4-level interview tool for family/friend carers in community settings

SCT4 Proxy tool

4-level proxy-report version for completion by someone who knows the person well

CWRQoL

4-level self-completion tool for people working in adult social care

SCT4 Easy Read

4-level self-completion tool for people with intellectual disabilities

Used internationally:



Why was an easy-read version for older people needed?

Some older people find the standard questionnaire difficult to complete, this might be due to:

- ♥ Mild-to-moderate dementia
- ♥ Cognitive impairment
- ♥ Unfamiliarity with surveys
- ♥ Other age-related needs

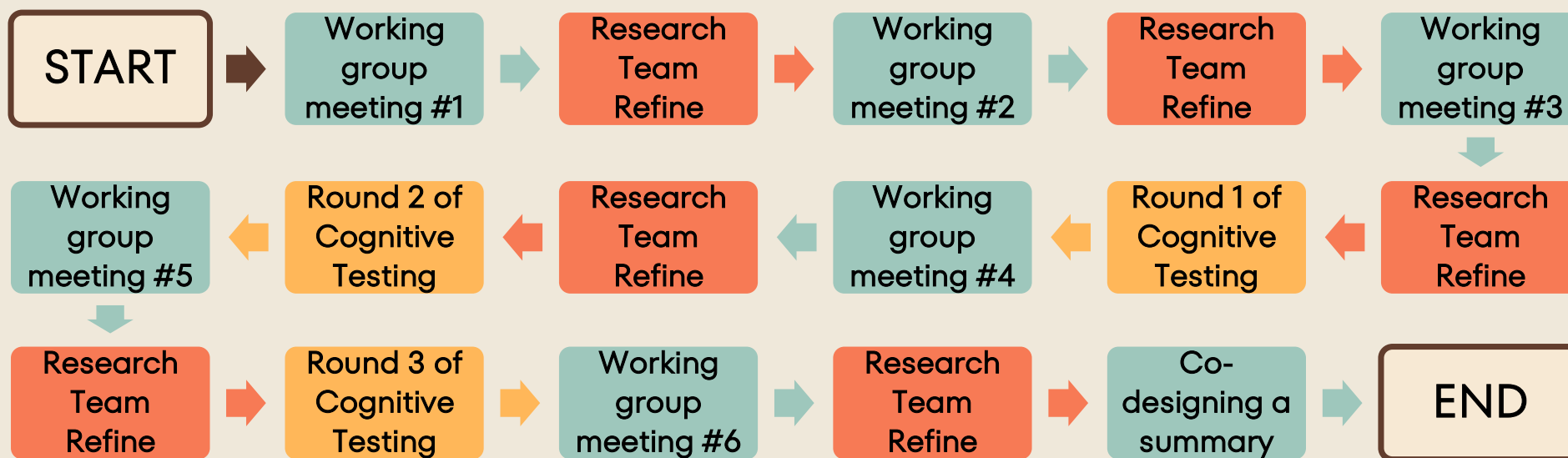


There already was an 'easy-read' ASCOT tool for adults with intellectual disabilities

- ♥ The ASCOT team had many requests to use this with older people living in the community



Why was an easy-read version for older people needed?

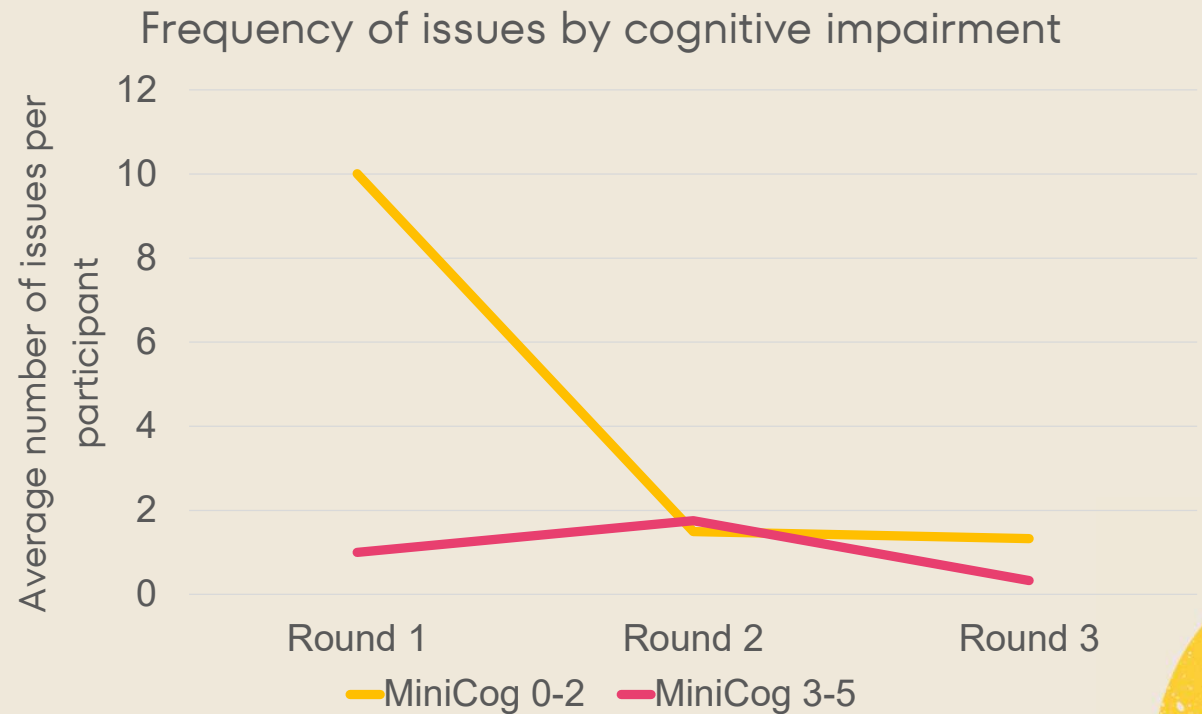


Working group: 8 older people (many living with dementia, some did not have personal experiences of social care input), 6+1 meetings. Cognitive testing: 25 older social care users (each person tested once only), latter rounds focussed on increasing ethnic diversity

Issues assessed:

- 👉 Comprehension
- 👉 Recall
- 👉 Judgement
- 👉 Response Mapping
- 👉 Prompt required

Cognitive Testing Results



NB: small sample size!

What is different about the new version?

- ✦ Many elements of the tool have changed because of the iterative refinements:
 - ♥ Use of images
 - ♥ Re-ordering of, or addition of (more relevant) prompts for questions
 - ♥ Changes to the wording of response options
 - ♥ Removal of qualifiers in response options ("It is ok.")
- ✦ The tool is more relevant, more understandable and easier to respond to than ever before for this group of people.



Tool Iterations



This question is about what you eat and drink. Think about if:

- You can have the food and drinks you like.
- You have enough food and drinks to keep you healthy.
- You can eat and drink as often as you need to.

What do you think about what you eat and drink?

Please tick (✓) 1 box

- I get all the food and drink I like when I want. 😊
- I get enough of the food and drink I like when I want. 😊
- I get some of the food and drink I like when I want, but not enough. 😞
- I do not get any of the food and drink I like so I might get ill. 😞



This question is about what you eat and drink. Think about if:

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Please tick (✓) 1 box

- I get all the food and drink I like when I want. 😊
- I get enough of the food and drink I like when I want. 😊
- I get some of the food and drink I like when I want, but not often enough. Sometimes I'm hungry or thirsty. 😞
- I do not get any of the food and drink I like. I am often hungry or thirsty. 😞



This question is about what you eat and drink.

Think about if:

- You can have the food and drinks you like.
- You have enough food and drinks to keep you healthy.
- You can eat and drink as often as you need to.

What do you think about what you eat and drink?

Please tick only 1 box

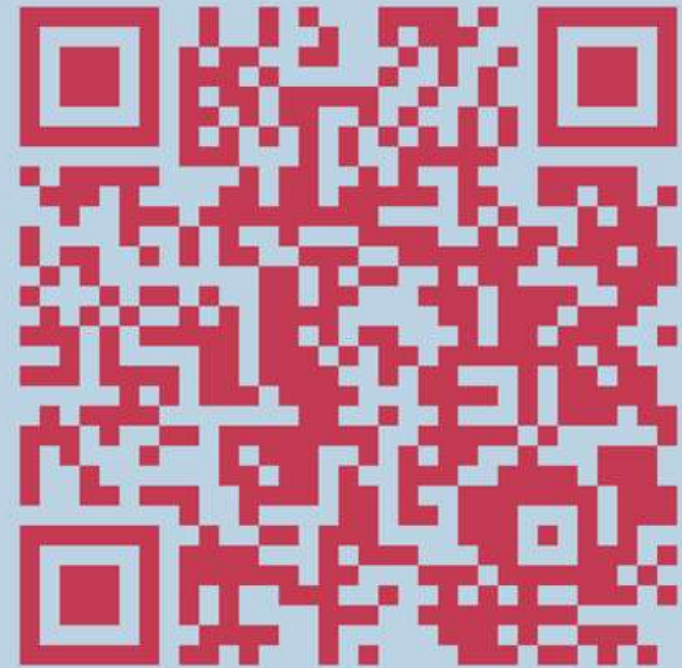
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- I do not get any of the food and drink I like. I am often hungry or thirsty.

Watch our project videos:

Project Overview

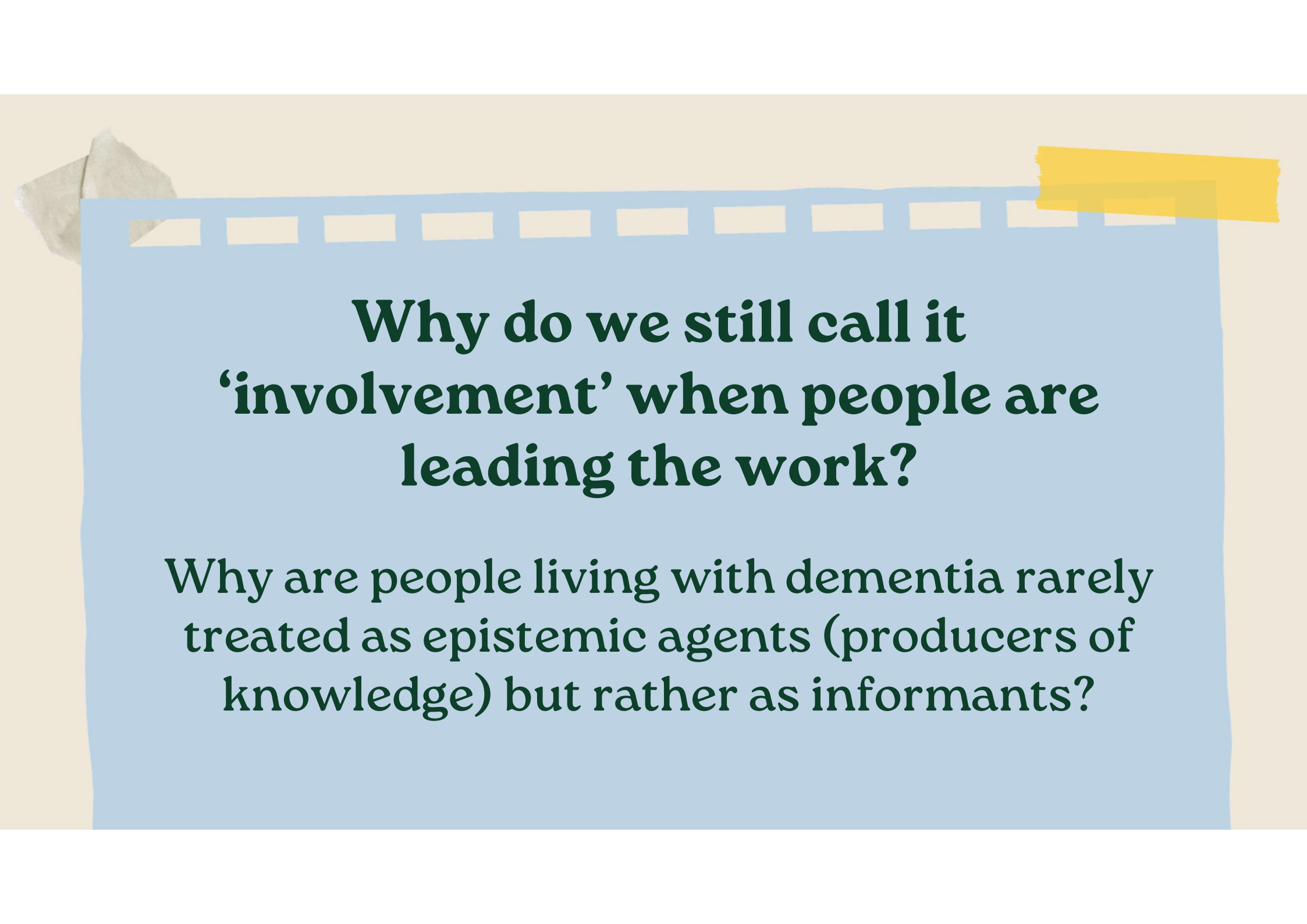


**Reflections from
the working group**



What difference do we hope this will make?

- ✿ ASCOT is an internationally used outcome measure for social care.
- ✿ This co-designed easy-read toolkit will enable more people to report the impact of services on their quality of life.
- ✿ Care providers and commissioners can use the tool to assess how well services are meeting people's needs.
- ✿ The tool has already been licensed for use by the British Red Cross to evaluate the impact of their services across the UK with 10,000 older people.



**Why do we still call it
'involvement' when people are
leading the work?**

**Why are people living with dementia rarely
treated as epistemic agents (producers of
knowledge) but rather as informants?**

Taking a step back in the research cycle



2. Co-development and Application of a Priority- Setting Approach for Dementia Research

Funded by:

NIHR | School for Social
Care Research

Supported by:



This presentation is based on independent research funded by the National Institute for Health and Care Research (NIHR) School for Social Care Research (SSCR).

The views expressed in this presentation are those of the authors and not necessarily those of the NIHR SSCR, the NIHR or the Department of Health and Social Care.

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

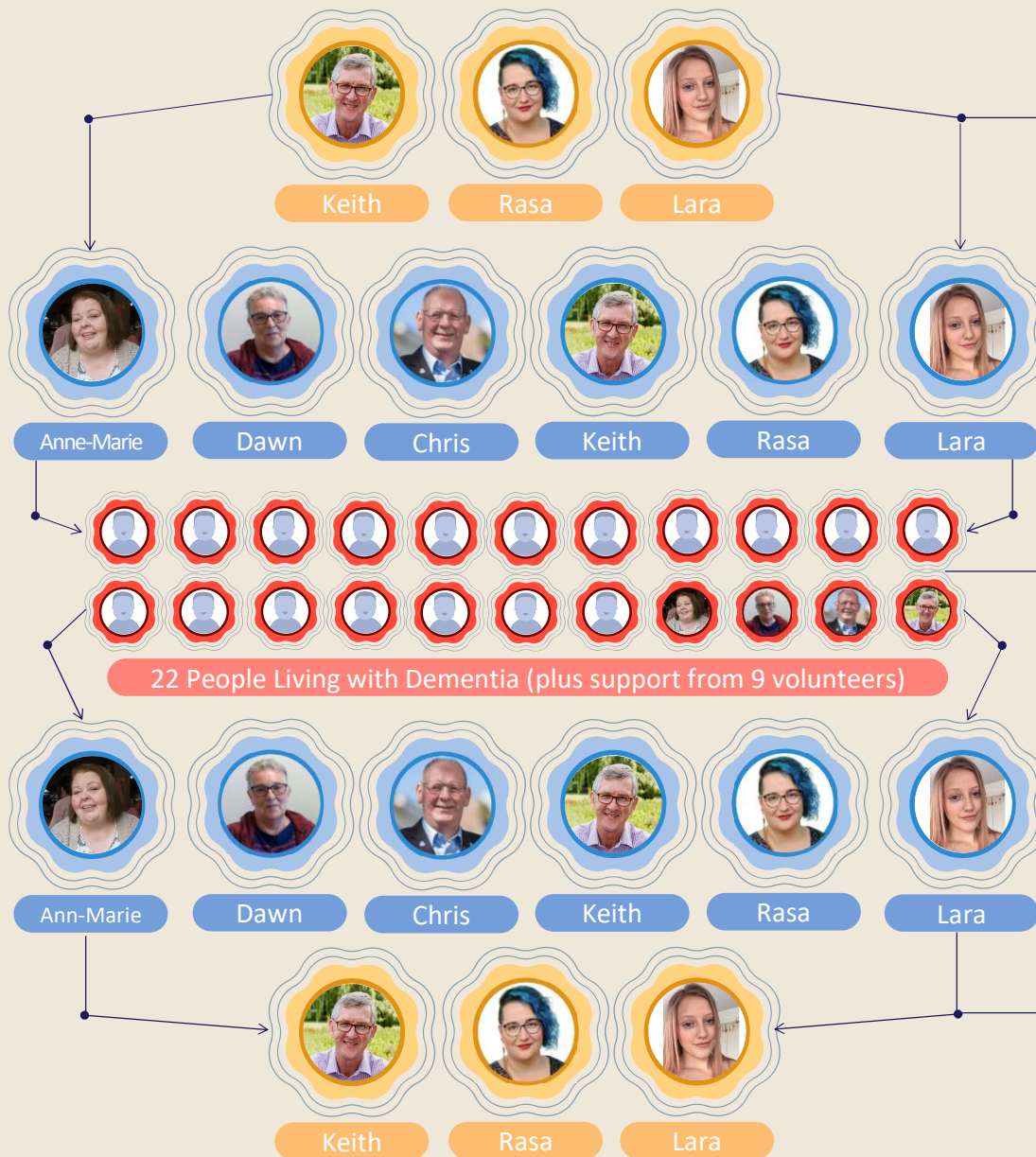


To set research priorities for living with dementia in Kent

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 top3 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



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?

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?

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?

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?

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)

write in your own research priority

Other suggested priorities:

- Creativity and/or 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

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Other suggested priorities:

- Creativity and/or 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)

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:



WHAT have people living with dementia said?



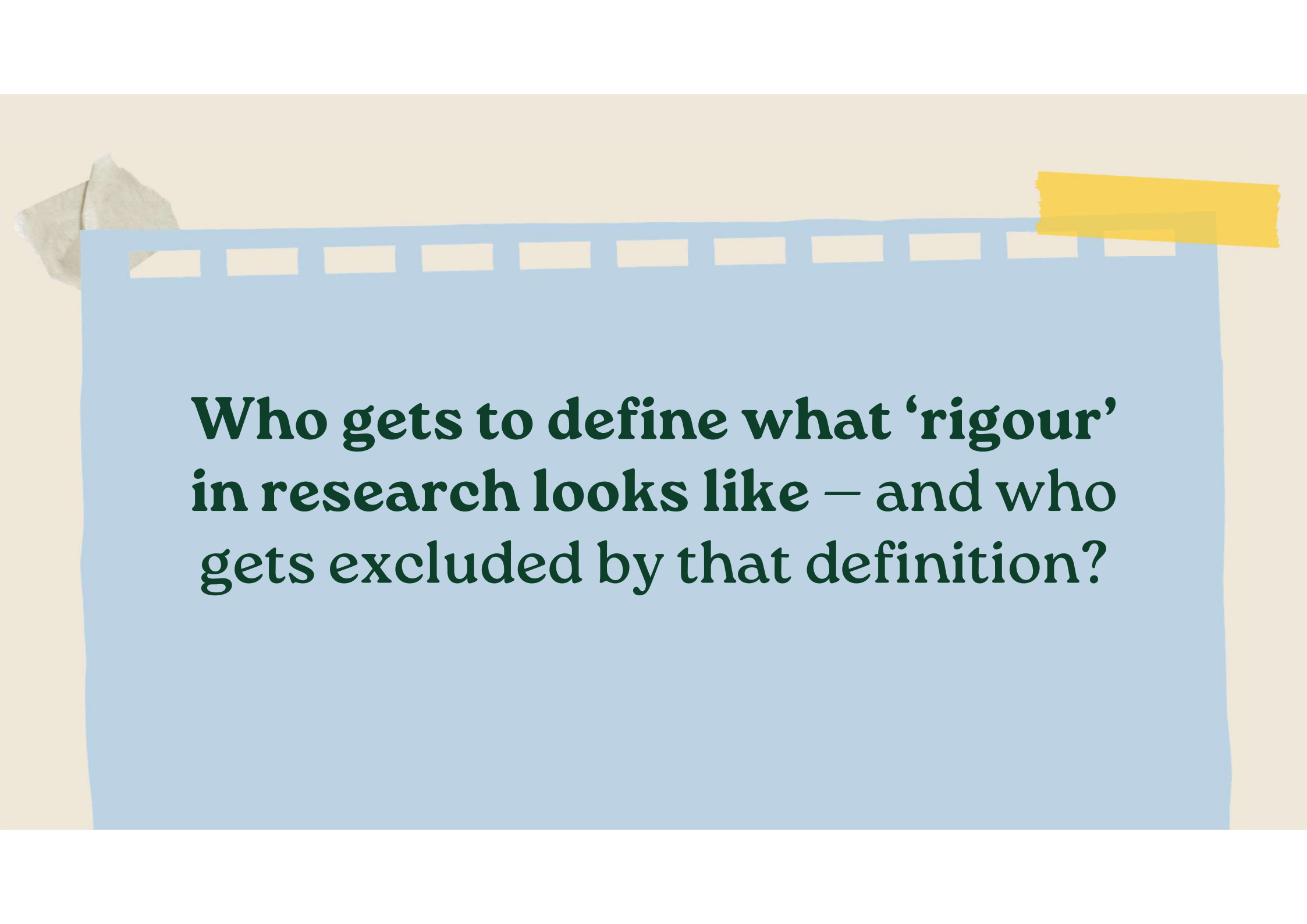
This summary was written by Keith Oliver, Anne-Marie Norris, Dawn Horne, Chris Norris, Lara Stenbridge and Rasa Mikelyte. The work was funded by NIHR SSCR. Images and infographics by Slidesgo and Freepik.



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!**





Who gets to define what 'rigour' in research looks like – and who gets excluded by that definition?

Taking another step back in the research cycle

3. Applying for Research Funding



Marie Curie and Alzheimer's Society joint funding call to transform end of life care for people living with dementia

Coproducing best practice guidance for the end-of-life care of people who live alone with dementia: A knowledge exchange and co-design study

Chris Poyner, Fiona Aspinal, Jennifer Brooks, Pippa Collins, Dawn Horne, Caludio di Lorito, Annabel Farnood, Rasa Mikelyte, Tomasina Oh, Sarah Polack, Hannah Wheat, & Lesley Williamson

Failed at post-final application stage rebuttal. Changed and resubmitted elsewhere.

Dawn's role as co-applicant:

Pre-application

- Shaped initial idea; attended full team and smaller meetings
- Co-wrote PPI sections
- Consulted East Kent Forget-me-nots on the merits of the proposal and ways to disseminate and have influence

If successful

- Jointly responsible for delivery
- Co-lead of the PPI advisory group
- Part of the dissemination team



**Why do we stop at one or two
lived-experience co-applicants?**

**Is it tokenism, or are we afraid of
sharing power?**

Stepping into the spotlight

1. The Webinar



DEMENTIA RESEARCH

Webinar

13 MAY 2024
11AM-12PM
ON ZOOM

SETTING RESEARCH PRIORITIES FOR LIVING WITH DEMENTIA IN KENT

BY KEITH OLIVER AND RASA MIKELYTE



HEALTHY YOU - KEEPING YOURSELF HEALTHY WHILE SUPPORTING SOMEONE LIVING WITH DEMENTIA

BY MIKE PARISH, WINNIE HENRY, DAVID ROSS AND BARBORA SILAROVA



ADAPTING A TOOLKIT FOR OLDER PEOPLE USING SOCIAL CARE SERVICES

BY DAWN HORNE AND JAMES CAIELS



MEASURING THE QUALITY OF LIFE OUTCOMES OF PEOPLE WITH DEMENTIA AND THEIR CARERS

BY STACEY RAND



REGISTER:

www.tinyurl.com/dem1305

HOSTED BY

PROF ANN-MARIE TOWERS



This
DEMENTIA AWARENESS WEEK
hear from people living with dementia, carers and researchers!

CHSS PSSRU NIHR Applied Research Collaboration Kent, Surrey and Sussex



Being part of a research project

Adapting A Toolkit For Older People Using Social Care Services

HOW DID THE RESEARCH STUDY COME ABOUT?
Over half a million older people in the UK are supported by publicly funded social care services. These services help with day to day living or people's own homes, in care homes and other settings. The Adult Social Care Outcomes Toolkit (ASCOOT) has been widely used to measure the impact of social care on the quality of life of people supported. However, some older people find the questionnaire difficult to complete. This study aimed to enable more older people to complete the questionnaire themselves, so that they can tell care providers, policy makers and researchers how they feel about social care services they receive.

WHAT WE DID:
A group of older people, primarily those living with dementia, and their support/careers care together as a working group to adapt an existing version of the ASCOOT toolkit for this age group. The new version was then tested with people who find questionnaires difficult to complete. We had several meetings to refine the tool. The working group met for a total of 20 hours, reviewing all aspects of the toolkit in detail and were keen to ensure that different opinions and experience were taken into account. This key summary was also co-developed by the working group. You can watch a video of working group members sharing their experience on OOH.

START → Working group meeting 01 → Research Team Review → Working group meeting 02 → Working group meeting 03 → Working group meeting 04 → Research Team Review → Working group meeting 05 → Research Team Review → Working group meeting 06 → Research Team Review → Working group meeting 07 → Research Team Review → Working group meeting 08 → Research Team Review → Working group meeting 09 → Research Team Review → Working group meeting 10 → Research Team Review → Working group meeting 11 → Research Team Review → Working group meeting 12 → Research Team Review → Working group meeting 13 → Research Team Review → Working group meeting 14 → Research Team Review → Working group meeting 15 → Research Team Review → Working group meeting 16 → Research Team Review → Working group meeting 17 → Research Team Review → Working group meeting 18 → Research Team Review → Working group meeting 19 → Research Team Review → Working group meeting 20 → Research Team Review → END

WHAT WE FOUND:
The working group collectively reviewed the questionnaire. They made changes to the wording of the questions and response options, the amount of content on each page and its layout, and the overall style. After each 'round' of changes, working with older people supported by social care services, findings were brought back to the working group. The working group then discussed the findings and agreed to further changes. These included illustrations being removed, thought to be distracting, further clarifying some of the wording and others. The final version of the adapted toolkit is substantially different from the standard version and the easy read version primarily designed for people with learning disabilities.

CONCLUSIONS:
This work shows the importance of designing outcome measures together, or consulting with older people living with dementia or sensory difficulties, and with their carers/supporters. Future research should investigate how this co-designed easy read toolkit may enable more people to independently report the impact of social care services on their quality of life.

ASCOOT CHSS PSSRU NIHR



**Do researchers tasked with
inclusion often block inclusion?**

**(the language, the structure, the
timing, the funding)**

Stepping into the spotlight

2. The Support that Matters Exhibition



FUNDED BY
NIHR | National Institute for Health and Care Research

 Alzheimer's Society

NIHR | Applied Research Collaboration Kent, Surrey and Sussex

 BRIGHT SHADOW

 **impact**
THEHOP50+

The Workshops



The Workshops



The Exhibitions





*"Support means help to
live an independent life
while coping with my
dementia."*



Dawn Horne

Born 1944

Lives with dementia



Watch the exhibition



Artwork only

Full event



A blue notepad with a perforated top edge is centered on a light beige background. A yellow sticky note is attached to the top right corner of the notepad. A piece of brown paper is tucked under the top left corner. The text is written in a bold, dark green font on the notepad.

What would it look like to fund dissemination as co-creation?

Stepping into the spotlight

3. Writing for Publication



Assisted dying: thoughts from someone living with Dementia

By Dawn Horne, supported by Pippa Collins, Annabel Farnood, Elizabeth Grey, Rasa Mikelyte, Tomasina Oh, Chris Poyner, and Lesley Williamson (NIHR ARC Dementia Community Fellows)

...and hopefully more to come!





**Can academic publishing ever
be(come) inclusive of authors or
co-authors living with dementia?**

**Can we get it
right?**

**Is reimagining
influence and power
in dementia research
possible?**



What You *Think* You Should Fear (But Maybe Don't Need To)

- Uncertainty and lack of control
- Involving people living with dementia specifically
- Conflict during the involvement process
- Clash of the academic and lived perspectives

What You *Really* Should Be Afraid Of

- Doing harm
- Not being realistic about expectations
- Goal overtake (delivery vs involvement)
- Lack of support for PPI
- Making people feel used
- (Two-way) tokenism
- Institutional undermining

Increasing the involvement of people living with dementia in research and diversifying types of that involvement will be **messy!**

But it offers **tangible impact on people's lives – if not through large scale changes in society, policy or service provision, then **in the lives of researchers living with dementia.****



THANK YOU!

sylviadawnhorne@gmail.com

r.mikelyte@kent.ac.uk