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Stembridge, Lara, Oliver, Keith and Mikelyte, Rasa (2024) *Co-Creating and Applying a New Method to Set Research Priorities with People Living with Dementia in Kent.* In: 18th UK Dementia Congress, 27-28 Nov 2024, Coventry, UK. (Unpublished)

Research Priorities Set by People Living with Dementia in Kent:
Training, Support, and Information Accessibility

Co-Creating and Applying a New Method to Set Research Priorities with People Living with Dementia in Kent

Lara Stembridge, Keith Oliver, and Rasa Mikelyte

Why did we do it?

The voice of people living with dementia (PLwD) is crucial in dementia care research. However, people living with dementia often become involved after researchers have already determined the topic of their research.
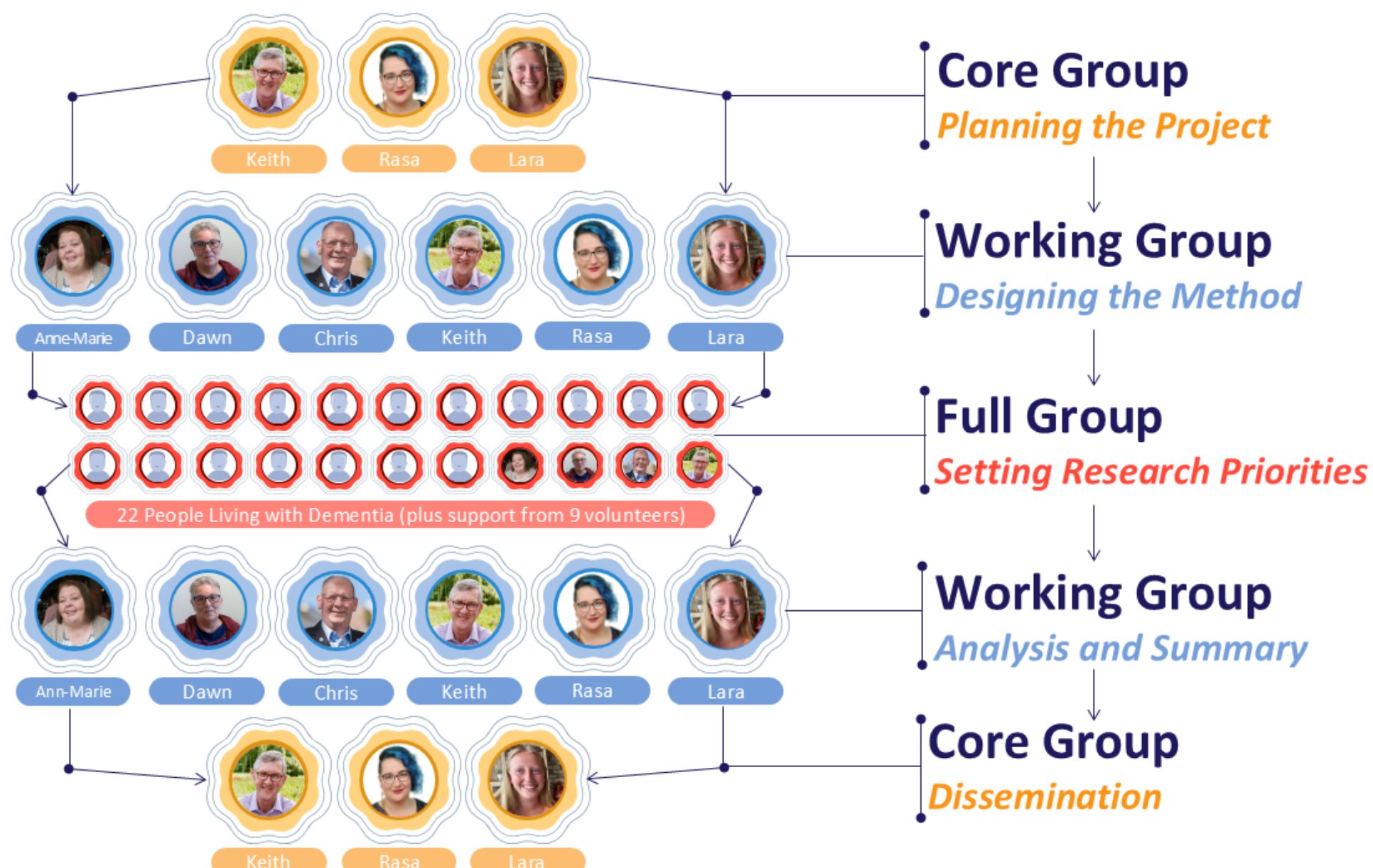
While various approaches, tools, and methods have been developed for setting priorities in health and social care research, few have been successfully applied in priority-setting work with people living with dementia. The aim of our priority-setting work was to exclusively amplify the perspectives of PLwD. Opinions of all stakeholders involved in dementia care are important, but there has been a tendency for family/friend carer and service provider perspectives to considerably outnumber those of PLwD when research priorities are set.

How did we do it?

To ensure that priority-setting methods are inclusive and accessible, we adopted a three-step approach. Our work began with a collaboration between a university-based researcher, a co-researcher living with dementia, and a volunteer supporter. This ensured that all aspects of the work were informed by lived experience.

Next, a 'working group' of PLwD came together to develop the prioritisation approach. This group focused on determining how best to facilitate a larger group of PLwD in setting research priorities for dementia care.

Finally, the co-produced approach was used during a priority-setting event involving 22 people living with dementia from Kent-based dementia empowerment and involvement groups. 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.

Core Group
Planning the Project
Keith · Rasa · Lara

Working Group
Designing the Method
Anne-Marie · Dawn · Chris · Keith · Rasa · Lara

Full Group
Setting Research Priorities
22 People Living with Dementia (plus support from 9 volunteers)

Working Group
Analysis and Summary
Ann-Marie · Dawn · Chris · Keith · Rasa · Lara

Core Group
Dissemination
Keith · Rasa · Lara

What were the Top 3 priorities?

1st Training & Awareness
E.g. The involvement of People Living with Dementia 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 (including via digital technology)

3rd Support
E.g. Evaluating benefits of peer support (to those being supported and to People with Dementia providing peer support)

What makes this approach novel?

Everything from the concepts to be captured by priority setting, to the method and the practicalities of the priority-setting event were determined by people living with dementia (with support from a researcher and a volunteer student). The new method combines the following features:

- It is **group-based**, where people living with dementia can bounce ideas off each other and discuss them

- It uses an **initial list of priorities**, which people living with dementia find easier to critique compared to starting with a blank sheet. These initial priorities are developed by a smaller group of PLwD – not researchers

- It incorporates **anonymous voting**, allowing honest, equitable participation that can be easily quantified

- The voting is followed by an **in-depth discussion of top 3** priorities. This ensures priorities are not just broad topics but are followed by specific suggestions that can be translated into research questions.

Download our summary:

Find out more about the project: