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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:

- Creativity and/or 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"