

Dementia Research - What Do Different Public Groups Want? A Survey by the Scottish Dementia Clinical Research Network

Law et al. (2013)
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For which topic were research priorities identified?

dementia

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

The benefits of involving patients and carers in research cannot be overemphasized. Benefit include researchers having a focus for their research, getting the approach and language appropriate to the target group, higher quality data and reaching a wider audience (Blackburn, Hanley, & Staley, 2010), therefore increasing the overall impact of the research. This, in turn, leads to a consequently higher public health impact on the subject of study. There is a paucity of research into what people actually want as research topics in dementia. no one has specifically sought the opinion of people with dementia, their carers and clinicians working in the field of dementia on what type of dementia research they would value.

What was the objective?

to identify the dementia research priorities of people with dementia and their carers

What was the outcome?

a list of 4 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: survey: participants were asked to choose four priority themes for clinical research from a list of 15 by forced-choice questions asking to identify topic with highest priority from the 15 topics, duration of dementia on which studies should be focused, their preferred type of study and whether or not they would be willing to volunteer for such studies

Which stakeholders took part?

People with dementia and their carers who may or may not be participating in research and those who are directly participating in research. 514 participants.

How were stakeholders recruited?

For the stakeholder group of people with dementia and their carers in general the project team, in collaboration with Alzheimer Scotland Action on Dementia (the principal dementia-related voluntary organization in Scotland), distributed the questionnaire with their general mailing of the Alzheimer Scotland Newsletter to 6000 recipients comprising Alzheimer Scotland members and members of the public who have an affiliation with that organization. For the stakeholder group of people with dementia and carers directly participating in research the project team mailed the questionnaire to participants on the Scottish Dementia Research Interest Register (SDRIR). This is a case register. For the stakeholder group comprising the general public with an interest in dementia research, the project team provided an online version of the questionnaire which could be filled in on the SDCRN website.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.