Involving people with experience of dementia in a systematic literature review about accessing urgent care.

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People living with dementia supported the literature review by highlighting which aspects were most relevant for them.

7 Alzheimer’s Society Service User Review Panels helped set the search strategy

Initial research question: “How are decisions made in out-of-hours primary care?”

- “What is out of hours?”
- “Normal GP is more important”
- “We say ‘doctor’, not ‘GP’”

Final research question: “What factors affect decision making in urgent care?”

- “We just go to A&E”
- “We’ve had good and bad experiences”
- “Understanding’ is key in decision making”

Researchers followed the strategy to search databases, include/exclude papers and extract results

Factors from the literature affecting decisions in urgent care

- “Is this because hospitals are bad for people with dementia, or because hospitals find people with dementia too challenging?”
- “Adequate social care will prevent emergencies”
- “Professionals don’t have dementia specific training”
- “There’s no alternative to A&E”

Topics of discussion in evidence synthesis

- Avoiding hospital admissions
- Carer as patient advocate
- Carer burnout can cause emergencies
- Communication challenges
- Service barriers
- End of life planning

“Professionals find dementia difficult, carers can help.”
“People with dementia can get confused in emergencies.”
“Continuity between services is so important, but rare”
“Sore subject”
“The most important thing to do when you get a diagnosis”