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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?”

“Normal GP is more important”

“What is out of hours?”

“We say ‘doctor’, not ‘GP’”

“We just go to A&E”

“We’ve had good and bad experiences”

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

6 people living with dementia and 5 carers helped synthesise the findings

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

Factors from the literature affecting decisions in urgent care

“Adequate social care will prevent emergencies”

“Is this because hospitals are bad for people with dementia, or because hospitals find people with dementia too challenging?”

“Professionals don’t have dementia specific training”

“There’s no alternative to A&E”

Avoiding hospital admissions

Carer as patient advocate

Carer burnout can cause emergencies

Communication challenges

Service barriers

End of life planning

Topics of discussion in evidence synthesis

“Professionals find dementia difficult, carers can help.”

“We really value our carers”

“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”

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