



Involving people with dementia in research

Dr Jemima Dooley

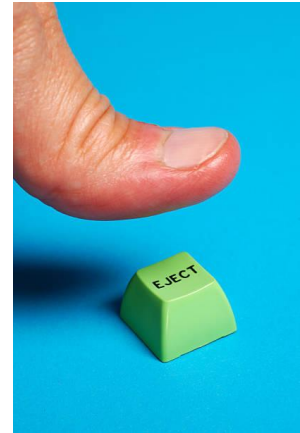
Initial words from John



Why involve people with dementia?

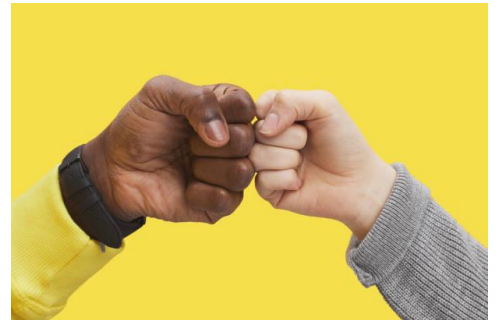
As John says, helps people who have this life-changing diagnosis

- Stop banishing people to “a remote town”
- “Keeps brain cells oiled”
- “Validate our worth”



People with dementia can help us

- Make research more relevant (impactful)
- Increase research participation
- Validate our worth



Example 1: Literature Review

Reviews help us find out what research has been already been done (and what needs doing)

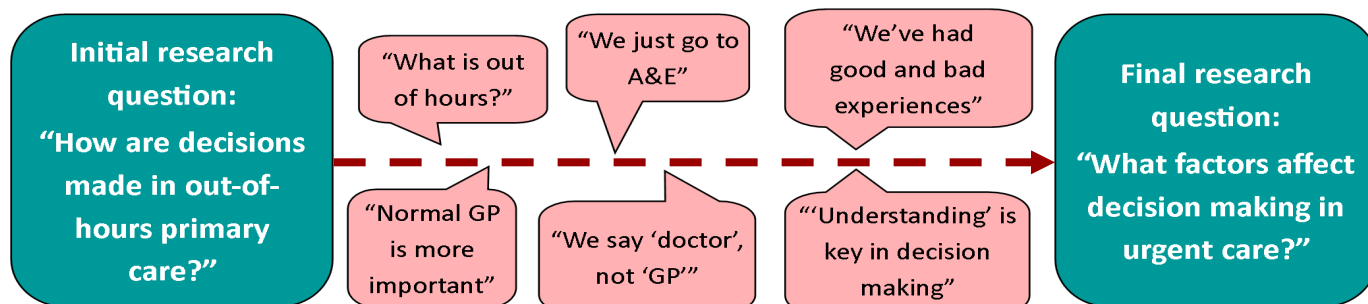
1. 'Search strategy': a specific research question and particular words to use
2. Search different academic databases
3. 'Extract' relevant information from a final list of publications
4. 'Synthesise' all the different findings into one paper.



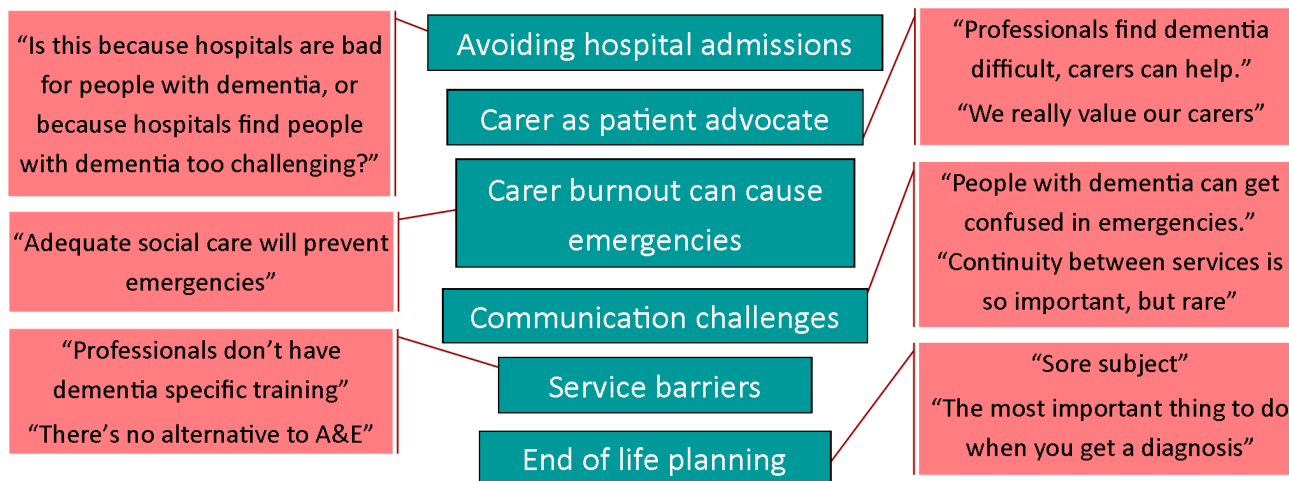
Example 1: Literature Review

Fellowship PPI panel and Alzheimer's Society Service User Review Panels (SURPs)

Search strategy:

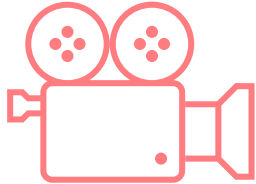


Synthesis:

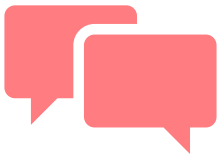


Example 2: Conversation Analysis

Fellowship study: Exploring communication in urgent care in dementia



- Video recording GP home visits to people with dementia



- Analyse the communication – training points.



- CA 'data sessions' with PPI panel and two local SURPs (11 people with dementia and 5 companions)

Example 2: Conversation Analysis

1. Dr: let's have a look at this bruise now:.
2. (2.5)
3. Pt: ↑m ↓mm: [↑mm ↑↑mmm
4. Cr: [you certainly bruise easy don't you:ǃ
5. (.)
6. Pt: ↑m hm:,
7. Cr: you do that you bruise
8. (.)
9. Pt: do I:?
10. Cr: yeah
11. Pt: oh never mentioned it (0.5)
12. Cr: mm ↑hm
13. (0.3)
14. Pt: oh (1.4) got to uh (1.1) get that blood flowing
[↑↑do:n't you:
15. Dr: [↑it ↑looks like [per:pura more than it looks like
anything

Example 2: Conversation Analysis



Clip 4

- 1 Doctor: Let's have a look at this bruise now
- 2 Patient: (humming)
- 3 Carer: You certainly bruise easy don't you?
- 4 Patient: Mhm
- 5 Carer: You do that, you bruise
- 6 Patient: Do I?
- 7 Carer: Yeah
- 8 Patient: Oh never mentioned it
- 9 Carer: Mm hm
- 10 Patient: Oh, got to uh, get that blood flowing don't you?
- 11 Carer: Yes
- 12 Doctor: It looks like peripura more than it looks like anything
- 13 else, I'm not sure it's true bruising
- 14 Patient: Yes well I mean, what about uh
- 15 Doctor: She's not remotely bothered by that
- 16 Carer: No no okay

Dementia Research Meeting – 19th September 2019

We are going to watch a selection of video recordings of
GP home visits with people with dementia.

We'll watch each video twice and then talk about them.

Questions to think about:

- What are the good things about the communication?
- What challenges are there?
 - Are these different for the doctor, patient or carer?
- Why do you think people say things in different ways?
- What do you think about their body language?
- What would make the conversation run more smoothly?
- Have you had experiences like this, and what did you feel at the time?

Please feel free to say anything that comes to mind when
watching the videos, don't hold back!

If you have any questions after the meeting, contact me
(Jemima) on 01179287330 or jemima.dooley@bristol.ac.uk

Example 2: Conversation Analysis

Spoke about their own experience:

- *“it must be so frustrating for the doctor, and for the carer, when the patient isn’t communicating... That’s what I dread, getting into that situation”*

And areas of improvement:

- *“I reckon he could have moved the chair up alongside of her. It would be the easiest thing to do”*

But also made ‘conversation analytic’ observations:

“The carer says, “no it’s for, she vomits”, then the doctor “okay”, then the carer, then the doctor. [The patient]’s out of it then, there’s nothing she can do, she’s not part of the conversation.”

Example 3: Co-produced photography

- Co-produced from conception with the Forget Me Nots – a group of researchers living with dementia

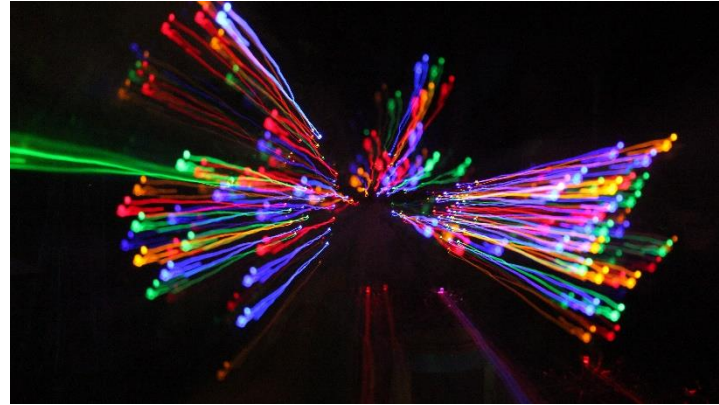


- Encourage people to take part with a photography lesson
- Take photos of life with dementia to discuss as a group (facilitated by the Forget Me Nots)



Example 3: Co-produced photography

Contrasting past and present



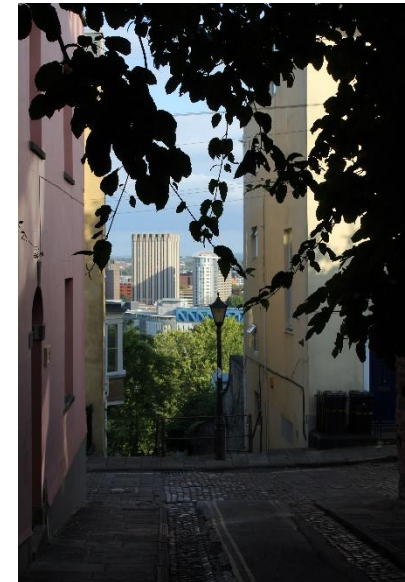
Representations of dementia



Reassurance from the outside world



Facilitators of joy



Emotional states

Example 3: Co-produced photography

The Forget Me Nots were the key to the project's success

Chose photography as a method:

- *“It gave me an excuse to express myself, and it was a way of opening up”*
- *“He went and bought [a camera] because it done him so much good. It was better for him than medicine.”*

Their presence inspired participants:

- *“They were sort of a connection between us and you... they were sort of translators.”*
- *“They were examples of how.. even if you have still got some mild cognitive impairment, or even more severe in some cases, you can still have a good quality of life.”*

Reflections: Challenges in dementia

Impact on communication, memory and behaviour

- DEEP and Alzheimer's Society have amazing resources for how to include people with dementia in research

DEEP Guide



The Dementia Engagement
and Empowerment Project

Involving people with dementia as members of steering or advisory groups

Key messages

- It is important that people with dementia can have direct influence
- This kind of role does not suit many people with dementia
- There are many adjustments that can be made to support people to be part of steering or advisory groups

Dementia-Friendly Focus Groups

Holding a focus group is one way to gather feedback from people who have dementia, but there are considerations to keep in mind.

1. [Group activities](#)
2. [Recruitment and ethical considerations for groups](#)
3. Dementia-Friendly Focus Groups
4. [Service User Groups](#)
5. [Round-table workshops](#)
6. [World cafe method](#)
7. [Electronic voting](#)
8. [Mystery shopping, 'walk through' or audit](#)
9. [Tips for dementia-friendly group discussions and activities](#)

Reflections: Role of companions

Much PPI work in dementia involves just companions or people with dementia alongside companions

Always involve people with dementia!

- ✓ Companions can support those who are less confident
- ✗ Companions inhibit freedom of expression

People with dementia can support each other



Reflections: Extending our 'pool'

Existing dementia groups provide a structure for researchers to work with just people with dementia

- More equal power dynamic at the start
- Saves on time and resources

We need new faces, more ethnic diversity, older people, people with more severe dementia

Make time (+ money!) to address barriers

- Reach out to local community groups
- Talk to other researchers
- **Talk to people with dementia!**



Final words from the Forget Me Nots



“When you are diagnosed with dementia, you are told what you are not capable of doing.

The key thing is that there are things you can do, not endless things you cannot.”

“Through research we’ve been able to make our feelings felt, and we’ve met other people. We feel empowered.

We’d want to say to everyone that research can give you confidence, to be able to talk... It’s our time to be opinionated”



Involving people with dementia in research

Dr Jemima Dooley



Thank you for listening!

@DrMimaDooley @capcbristol

John's video: https://www.youtube.com/watch?v=vfVTtJff9_Q

DEEP: <https://www.dementivoices.org.uk/>

Alzheimer's Society: <https://www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/research-methods>

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