

Dementia in Rural and Coastal Communities

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Outline of today

- Background to this project
- What I did and what I found
- Engagement event findings
- What next?



What I wanted to find out

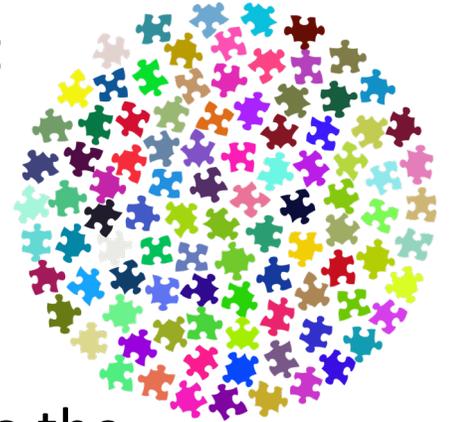
- What support do people living with dementia and families **currently access** in rural and coastal communities?
- What support are they **missing**?
- What **difficulties** do people face in getting support?
- How does the **voluntary sector** support people living with dementia and their families?
- How can we help more people access our **LivDem** course?



Fostering collaborations

Developing relationships with voluntary organisation partners:

- Initial meetings to share the project idea
- Further discussion with partners to:
 - Understand each others' motivations for getting involved
 - Get a deeper understanding of areas of concern for partners - fed into the interview guide
 - Agree together what they can reasonably do to support the research:
 - Handing out or sending out info sheets prior to a visit
 - Arrange a venue to hold interviews
 - Identify particular people who may have interesting experiences and are willing to share



The findings – in no particular order



Carer Experience and Support

- **Carer experience and support:**

“[carer] doesn't seem to have had a lot of help and I don't know if that's because he doesn't know where to find it? You have to push to get help”



Health and Social Care Coordination

- **Health and social care coordination:**

“I mean a variety of different people visited different times and questioned us both...it's a bit confusing who does what...There's probably 5 different places that I have to think now which one of these is the right one to go to with the problem”



Activities and Engagement

- **Activities and engagement:**

General feeling that people want a variety of in-person activities and that they are age appropriate. More physical activity options



Animation link:

<https://www.youtube.com/watch?v=LEbgDJDVb6s>

12 small groups across the three events worked together to prioritise the nine topics



Diagnosis and Post-Diagnosis Support



Health and Social Care Coordination



Information and Signposting



Diagnosis and Post-Diagnosis Support

- **Diagnosis and post-diagnosis support:**
“it seems like people get their diagnosis and that's that. You know, they're not told what their next steps should be”



Community and Social Connection



Transport and accessibility



Carer Experience and Support



Health and Social Care Coordination

- **Health and social care coordination:**
“I mean a variety of different people visited different times and questioned us both...it's a bit confusing who does what...There's probably 5 different places that I have to think now which one of these is the right one to go to with the problem”



Volunteer Involvement



Activities and Engagement



Digital Inclusion and Technology



Information and Signposting

- **Information and signposting:**
“we weren't really offered anything ...just being given some leaflets. And it's sort of almost down to the individual”

Reflections on the project

- Don't underestimate the time to invest in collaborative partnerships
- Budget appropriately for VCSE involvement in research
- Connection the main theme of the findings.
 - What about the voices of those not connected?



Following engagement...what next?



- Sharing findings:
 - Somerset dementia network events x 2
 - Carers event in Watchet
 - Dementia awareness week event
 - Somerset Older Person's Mental Health Steering Group re: pathway review
 - Only Connect symposium in Cornwall

- Co-creating new research
 - Call for public involvement to shape research ideas in the priority areas identified



