

# Lessons from a research partnership in southwest England to understand community palliative care needs in rural, coastal and low-income communities

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## Plain language summary

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# Plain language summary

## What did we want to improve?

England's South West Peninsula (Cornwall, Devon, Somerset) has high levels of poverty and an ageing population. There are some community groups which enable individuals to support each other at the end of life. However there has been little local palliative (i.e. end-of-life) care research to understand people's needs in rural and coastal areas.

## What did we do?

We created the South West Peninsula Palliative Care Research Partnership including four universities, voluntary and community organisations (including hospices), health research agencies, and a group of individuals interested in palliative care. We wanted to build a sustainable partnership that would identify what communities need to support each other at end of life and help individuals and organisations to plan and participate in research. We reviewed existing research evidence and ran a programme of training events and community activities (an interactive display, focus groups, one-to-one conversations and 'storytelling'). Finally, we came together to discuss the findings and plan next steps.

## What did we find?

Getting support at the end of life can be difficult in the region because of poor transport, distance from services, isolation from support networks, and patchy palliative and social care services.

We found that using creative ways to involve people, like the interactive display, helped clinicians and researchers better understand local needs. Our experience of partnership working showed that palliative care organisations, academics and community organisations working alongside each other can help services reach these areas, and make it easier for people to be involved in research.

## What does this mean?

We hope that continuing this partnership will help communities share and develop expertise in supporting patients and families with palliative care needs, and help clinical services and universities involve people in rural, coastal and low-income areas in planning, delivering and participating in research that addresses their priorities.