

The word "EMBED" is written in large, bold, blue capital letters. It is overlaid on a dark grey silhouette of the Fife region in Scotland.

EMBED

Experiences of Multimorbidity at the End of life

*Embedding public involvement in
Palliative Care PhD research in Fife*



PhD Fellow on the Multimorbidity Doctoral Training Programme for Health Professionals, which is supported by the Wellcome Trust (223499/Z/21/Z)



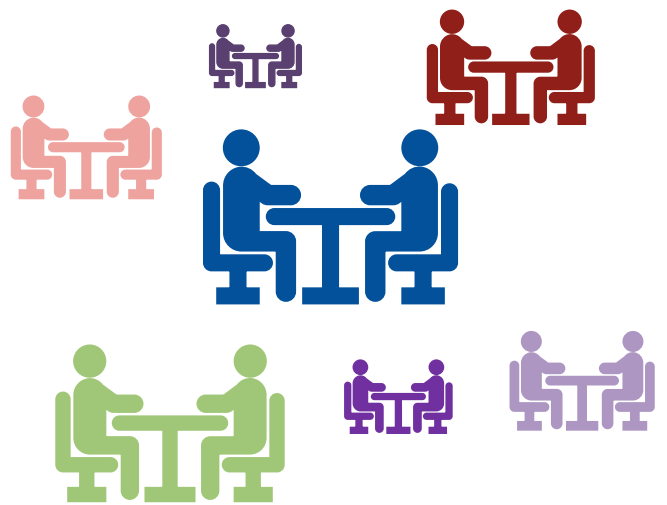
Public Advisory Group member, part of Fife Community Advisory Council

How are we defining advanced multimorbidity?

How do those with multimorbidity use healthcare at the end of life?

What are the experiences of those with multimorbidity + carers?

syndromes
practitioner
nutrition
treatment
age
tools
functional
healthcare
benefits
conditions
caregiver
symptoms
self



*the issues we came up against were not always age related yet sometimes felt **uncoordinated, system and process focused**, with the patient's wellbeing almost an **afterthought**. They had to fit into the system rather than the system working with them.*

*I feel if healthcare professionals had openly discussed my father-in-law's conditions, and how they interacted with each other and impacted on quality of life and end of life care, it would have been **easier to navigate** and planned end of life care could have been discussed rather than reactive to events.*

Fife Community Advisory Council

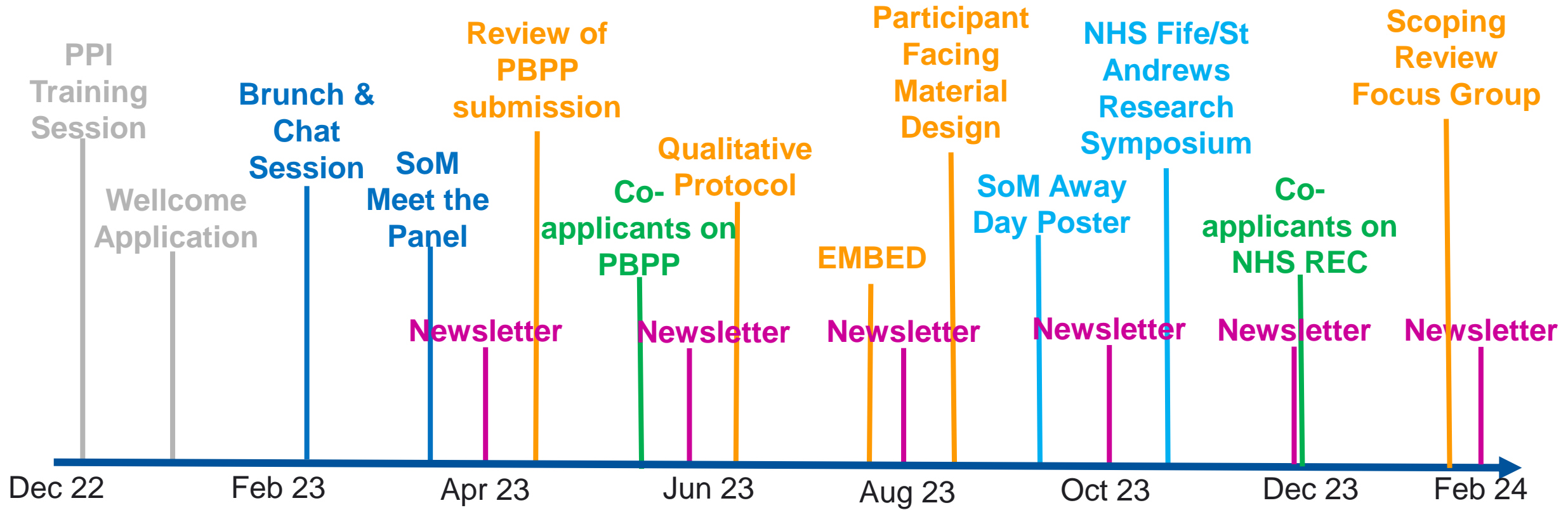
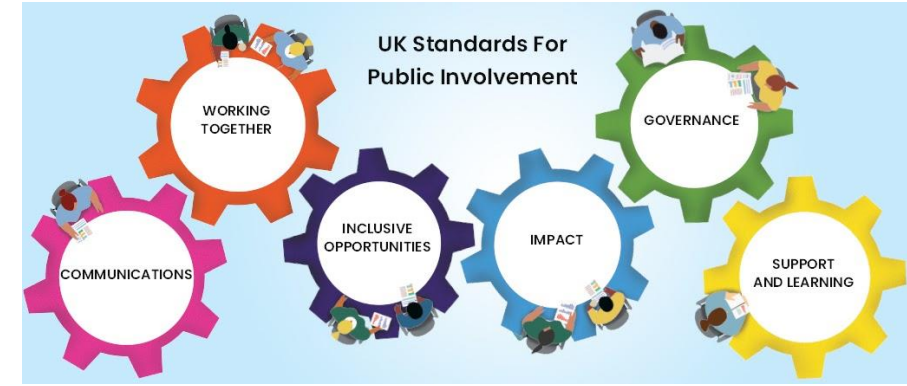
Helping improve healthcare research across Fife



*End of life, death and dying **will come to us all** yet continue to be sensitive topics, so **breaking down barriers** by investigating the surrounding healthcare and welfare issues in all their forms can only help in my view*

*Am concerned with **single problem approach** of doctors rather than consideration of whole person.*

*We all have to die and if **we can contribute to improving that passage** for others and ourselves by being involved in your project and others like it, then **I believe we should accept that privilege**.*



Participant Information Video

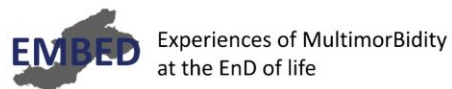
IRAS: 332826

EMBED – Experiences of Multimorbidity at the End of Life
Experiences of healthcare and support for people with multiple long-term health conditions in the last year of life and their caregivers

Dr Sarah Bowers, Professor Frances Quirk, Dr Jo Bowden



www.st-andrews.ac.uk



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Public Advisory Group



The Public Advisory Group for this project is made up of 6 public advisors and is supported by the Fife Community Advisory Council. Many of our public advisors have personal experience of caring for loved ones at the end of their life and it is through these reflections they are able to help us shape our research. The Public Advisory Group is involved at every stage of our research from design, implementation, analysis and dissemination. They are integral to our work and ensure this research is meeting the needs of the public. Our Public Advisory Group strives to meet the UK Standards for Public Involvement.

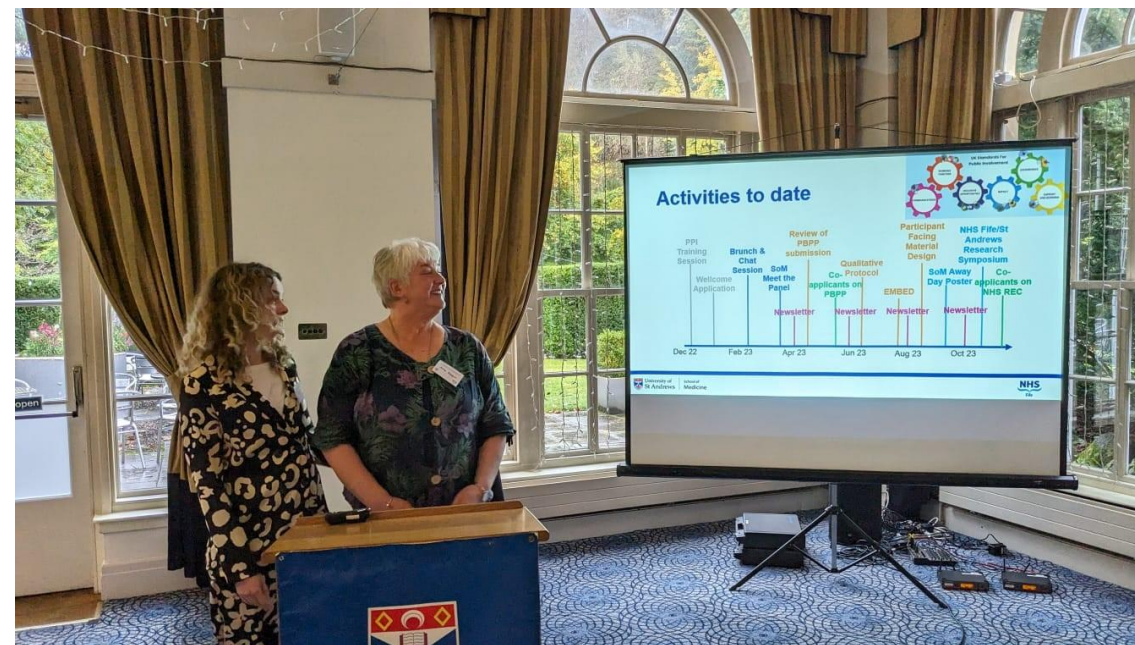
Fife Community Advisory Council

Helping improve healthcare research across Fife



Multimorbidity at the End of Life February Update

February 2024 Newsletter



What's gone well?



Regular
communication &
feedback



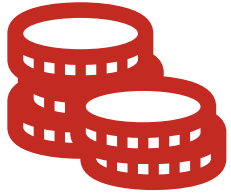
Respect within the
group



Using participants
to their personal
strengths



Focus on personal
experiences



Clarifying processes
for payments



Sharing opportunities
equally



Ensure clarity
between projects



Training in research
skills

What can we do better?

Benefits to early career researchers





The Tammy Prescott Patient and Public Involvement Award 2024 Runner Up

Project lead: Dr Sarah Bowers

‘How do people with multiple long-term conditions use and experience healthcare in the last year of life?’

