Please explain who you are nominating for this award and briefly why

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I am jointly nominating our research team (myself as the lead researching PhD student and my supervisors - Professor Frances Quirk, Dr Jo Bowden, Dr Sarah Mills and Dr Linda Williams) and Public Advisory Group jointly for this award. The Public Advisory Group have been an essential part of what has allowed both this research to happen in the format with which it has been developed and both myself, as a PhD student, to grow and learn. We have implemented innovative ways to integrate this public involvement as a key part of this work and our Public Advisors have shown invaluable commitment, passion and expertise to allow us all to continue to develop this work together.

Project Title

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

Summary

This nomination is for the Public Advisory Group who are an integral driving force to this PhD – "How do people with multiple long-term conditions use and experience healthcare in the last year of life?". The PhD is part of the Multimorbidity PhD Programme for Health Professionals, supported by the Wellcome Trust, which in itself has been supported by public involvement since its inception.

An initial focus group with the Fife Community Advisory Council introduced the project and established interest from potential public members. Immediately, this focus group shaped key decisions in the research. The group highlighted and emphasised the important, reflective insights bereaved caregivers bring to research which shifted our qualitative work. The group disliked the term multimorbidity instead preferring multiple long-term conditions. Furthermore, the group disliked 'PPI' ("it sounds like an insurance scam!") choosing instead to be the 'Public Advisory Group' (PAG). From this initial session, 6 public advisors were recruited who have remained with the project throughout.

The PAG have been involved across all aspects of this mixed-methodologies PhD through a variety of activities including co-development of research concepts and aims, co-application for data access, co-design of the qualitative study, including associated patient-facing materials (see video-link below), and co-presentation at research events. A public facing website has been collaboratively designed to showcase and promote our research and PAG activities. Regular feedback and suggestions are sought on how we can improve PAG activities through bi-monthly newsletters and surveys, through which the PAG shared their personal passion for this work:

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

• "They had to fit into the system rather than the system working with them."

• "…if healthcare had been more open to discuss the healthcare challenges my father-in law was experiencing it would have potentially eased the burden and the guilt surrounding his end of life, on him and his family."

• "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."

Our PAG activities continue to grow and evolve, based on this regular feedback, to meet the needs of both the research projects and our PAG. Future plans include undertaking joint PAG-researcher qualitative analysis, connecting public advisors across different projects and co-planning dissemination events.

By nominating the PAG for this award we wish to highlight the importance of public involvement,

particularly for early careers researchers, and some novel approaches to researcher-public collaborations. Integrating public advisors throughout the work has been transformative – not only to the project itself, but also in enhancing the skills and experience of myself as an early-careers researcher. The passion that the PAG has for the work is powerful, inspirational and a real driving force on tough PhD days. The PAG's passion for the project highlights the importance of this work and we are thrilled to be working with them through to study completion and beyond.
Who is the project lead?
Dr Sarah Bowers
Who was the funder for this project?
The Wellcome Trust (223499/Z/21/Z)
Are there any links or resources you want to share to support your nomination?
Multimorbidity PhD Programme for Health Professionals – University of Glasgow - Colleges - College of Medical, Veterinary & Life Sciences - Graduate School - Multimorbidity PhD programme for Health Professionals Project website – Experiences of Multimorbidity at the end of life (st-andrews.ac.uk) Participant Information Video – https://universityofstandrews907-my.sharepoint.com/:v:/g/personal/sb461_st-andrews_ac_uk/ET4A3DQ3Xk9GkjhHinzMjjIB_u1jXzY_iZtTyfaT4o3ckw?e=kh2JD5