

Public Involvement Impact Review

The public members act as “critical friends”, bringing expertise and lived experience to the research.

Project - Planning for Future Care During the COVID-19 Pandemic

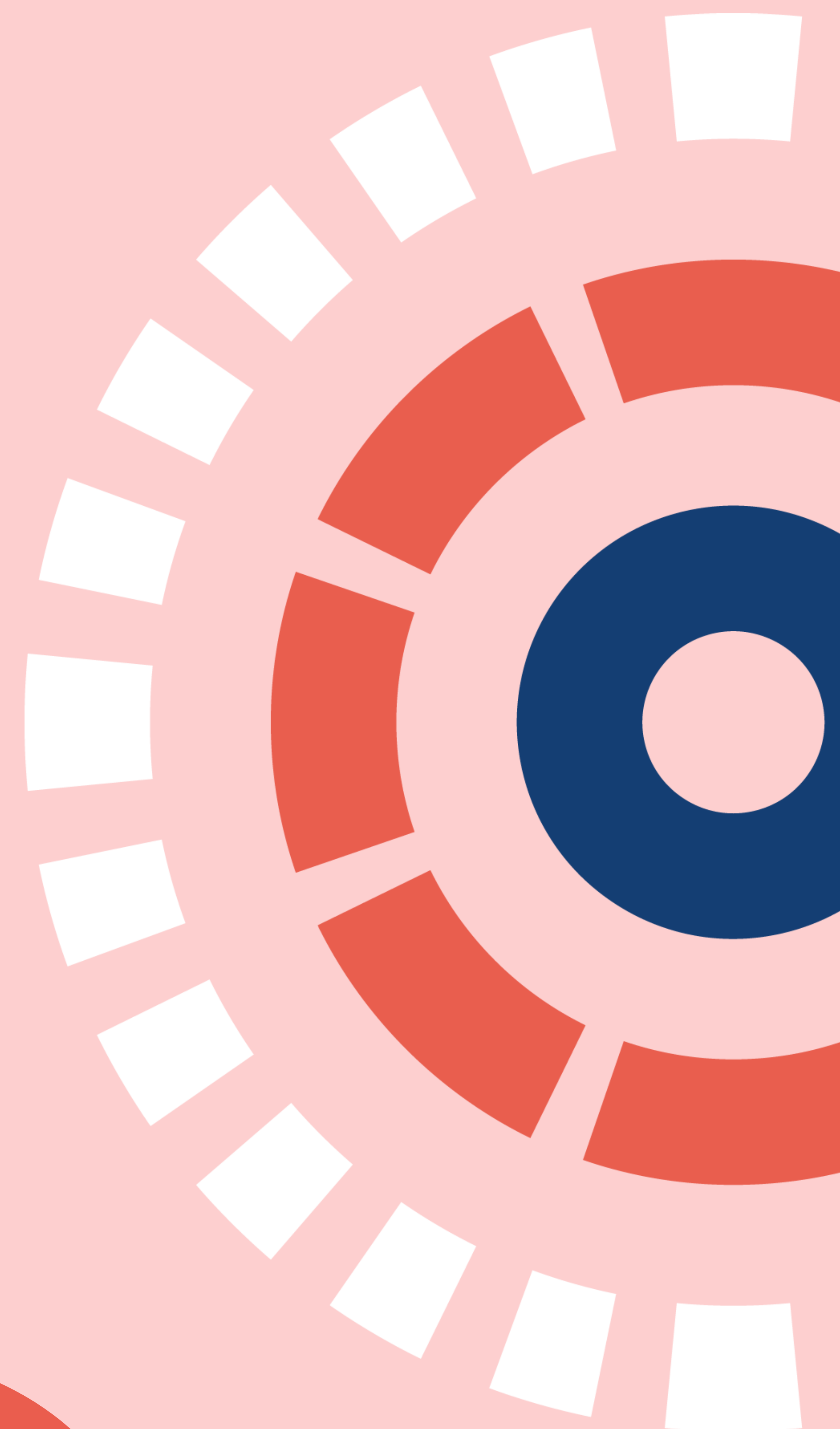
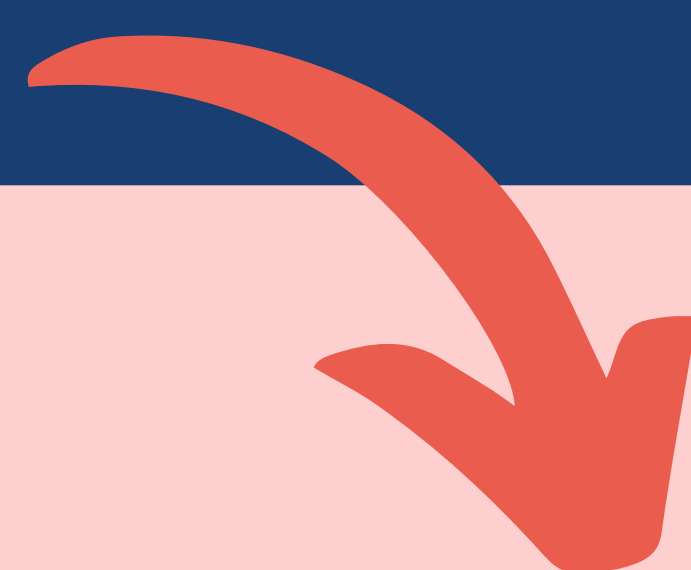
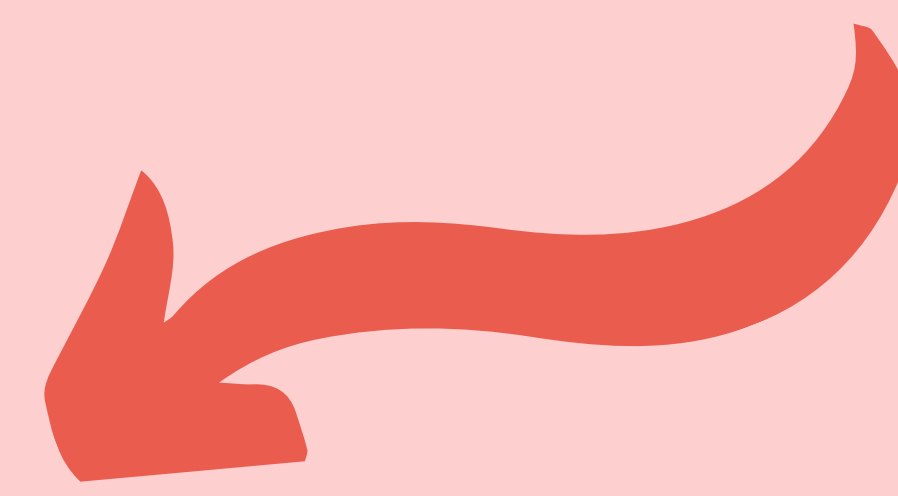


The saying ‘nothing about us without us’ has been used to give voice to the idea that those who are affected by research have the right to influence what is researched and how this is done. People’s lived experiences are invaluable to researchers, helping them to understand things from another perspective, as well as ensuring that the research answers questions that communities care about.

Ensuring that patients, community members, and researchers work together in partnership is at the core of all the research done by ARC KSS. All funded studies work in partnership with members of the local community to design and shape the research questions and data collection tools and share the findings. ARC KSS aims to combine lived experience (‘insider’) and academic (‘outsider’) perspectives to enhance the validity and relevance of the research findings, and lead to greater opportunity for successful implementation.

One of the ARC KSS funded research studies which successfully brought together the different perspectives is the Planning for Future Care During the COVID-19 Pandemic project. The study aims to explore the implementation of an Advanced Care Planning Intervention, that was introduced during COVID-19, to help patients on the End of Life pathways to plan for their care with their health and social care practitioners.

The research team are working in partnership with people who have had a connection with palliative care services, either as a patient, a family member or through working in a voluntary sector organisation. Not only do the public members work with the research team to co-write the research questions, design the data collection tools, and find meaningful ways of working and effective approaches to share research findings, they also help keep the research team on track and improve accountability.



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“For me it keeps the research grounded, knowing that I have to feed back to the public members group. And, knowing that I need to involve them also keeps the research grounded in what is important to our communities. I love getting involved in theory and philosophy and you can go off in your research and forget what's actually needed.” [Jo Bayly, lead researcher]

Working with (the research team) has been a very interesting experience. With full induction of the study and guidance as needed, ensured I could understand and give the input from the patient perspective. [Public Member]

“Our public members support with everything. They added new questions that I hadn't thought of to address, to elicit information on issues that they thought were important to the topic. They changed words in questions to improve the clarity of meaning. And they changed the order of the questions to improve the flow.” [Jo Bayly, lead researcher],

A legacy from this project has been the establishment of a public and community group where there previously had been none. This has already resulted in some of the public members becoming involved with another NIHR partner project team showing how networks and relationships created during one project can go on to inspire and impact on public involvement in another project. The members of the newly formed public and community group are all passionate about sharing their experiences to improve things for others and are now able to support the hospice with their work on other research studies and are being used in planned future research projects.

Our input is being listened to and we are seen as equal partners in every aspect and at all times [Public Member]

