NIHR | Applied Research Collaboration Kent, Surrey and Sussex

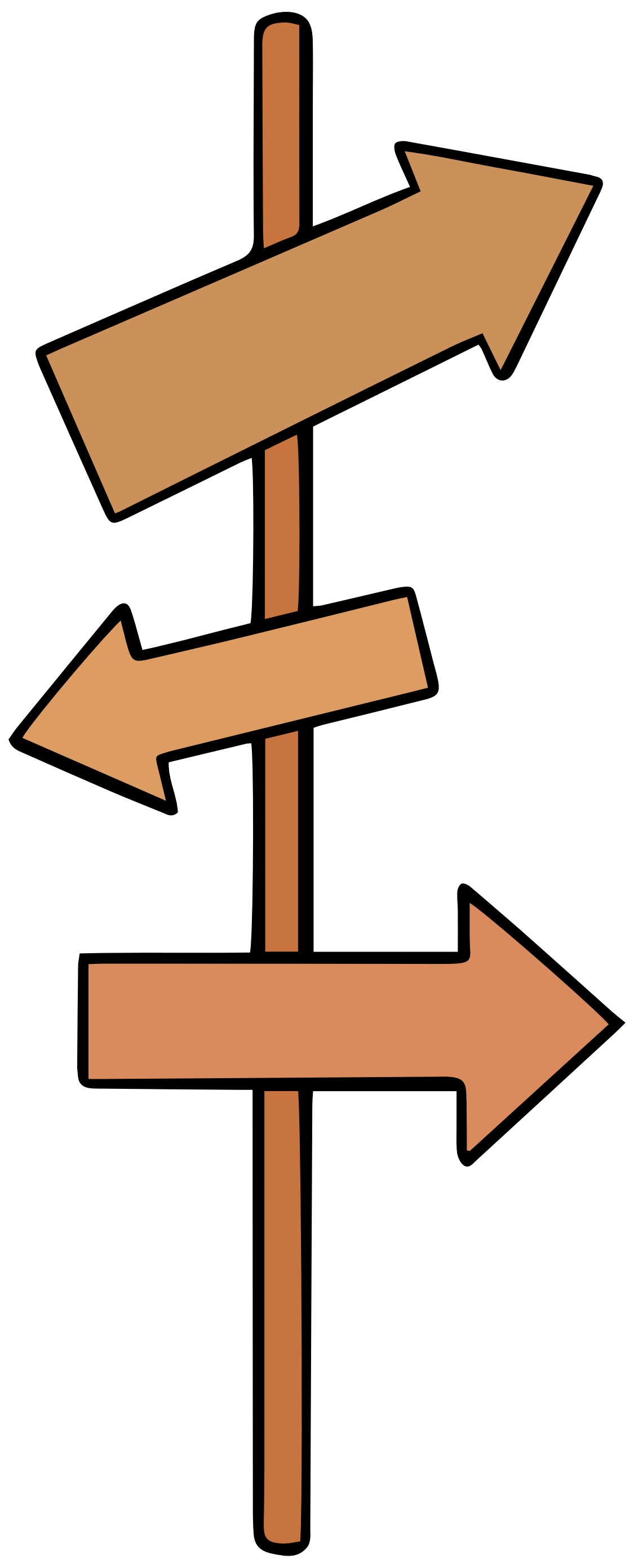
Public Involvement Impact Review

Mapping New Routes: How People Learn to Live Well with Chronic Pain

Background

Ethel is an Advanced Practice Physiotherapist and part-time PhD student specialising in the care of people living with complex and chronic (or persistent) pain. Her doctoral research is exploring the experience of reaching and maintaining a place of living well with chronic pain from the perspective of those with lived experience and those healthcare professionals who support them.

25% of the adult population in the UK lives with chronic pain - pain that persists for longer than three months and which for many affects every aspect of daily life. Most of the research in the field has focused on those who are struggling to cope, identifying, treating or managing symptoms that contribute to disability. Some, however, manage to find a way forward in life, despite living with persistent pain. Less is known about how these people can live well in the presence of pain and whether strategies they adopt could be helpful for those who do not.



Involving People with Lived Experience

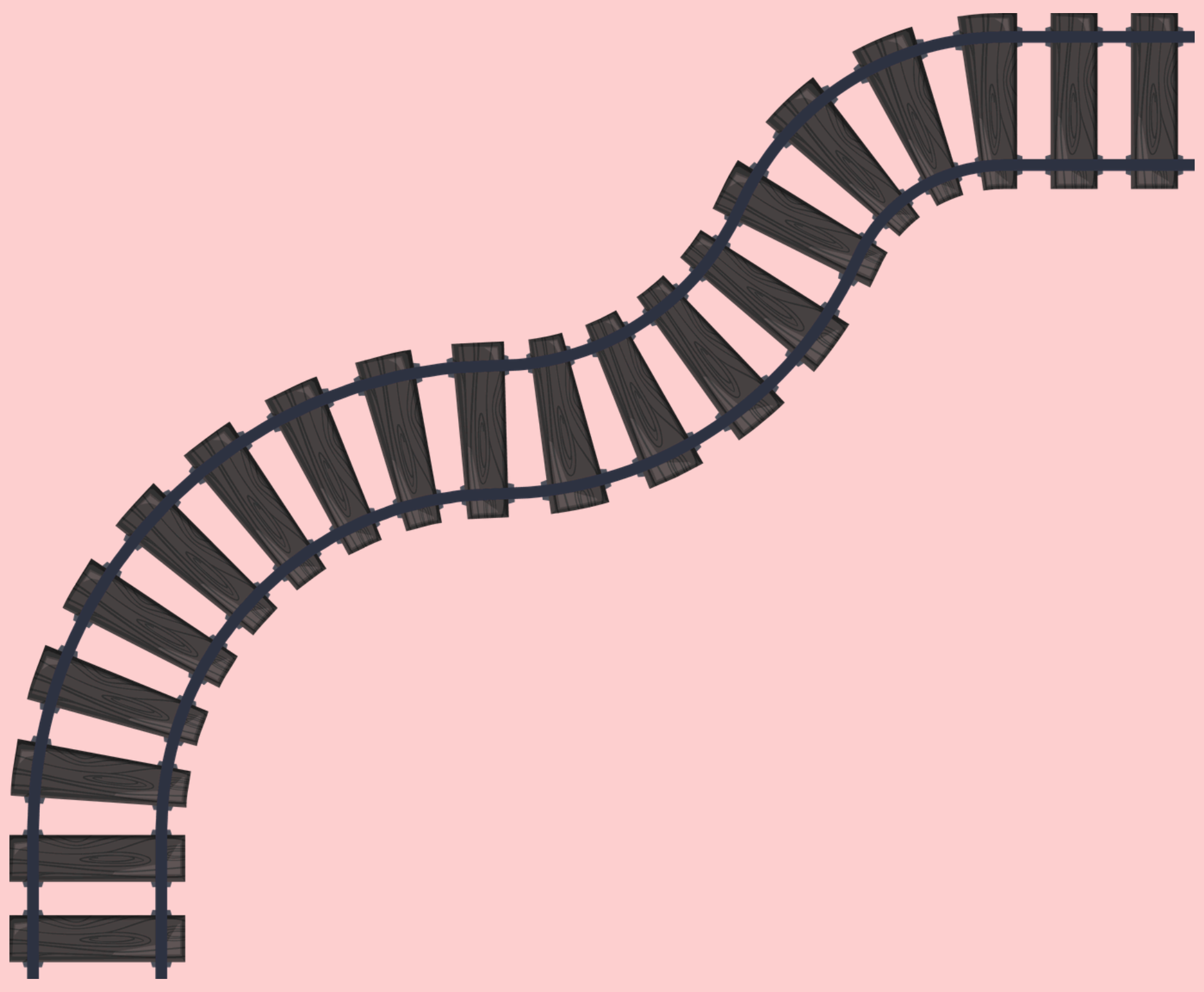
A **Public Advisory Group** of six people living with chronic pain was organised through the University of Kent's Opening Doors to Research group and the ARC KSS PPIE database. In the initial session, the group reviewed the study aims, planned activities, validated tools, and the interview topic guide. They responded positively to the project's focus on living well with chronic pain. Because participants were interested in examining the proposed questionnaires, a second session was held. In this follow-up meeting, they stressed keeping questionnaires brief while still allowing space for free-text responses, and offered guidance on designing appealing recruitment adverts. Additionally, one volunteer took part in a practice interview to help me prepare for data collection.

Recommendations:

- Online interviews preferred.
- Capture study participants' working status.
- Interview participants given choice of a preferred time for their interview (e.g. AM/PM/evening).
- Questions provided beforehand.

Future Activities:

A further activity is being planned with the study's interviewees in order to share the findings from data analysis and request their opinion about the proposed output.



What I have learnt

Involving a PPIE group in my research has shown me how essential lived experience is for creating a study that is both meaningful and accessible. The group helped me see that my focus on living well with chronic pain genuinely resonated with participants, validating the direction of the project. Their feedback led to clearer, more acceptable study materials—including a refined interview topic guide, more manageable questionnaires, and more inviting recruitment adverts—reminding me that what seems straightforward to a researcher may not feel that way to those living with the condition. I learned how important it is to minimise participant burden by keeping questionnaires brief while still offering space for personal expression. The opportunity to conduct a practice interview with a volunteer also strengthened my skills and confidence ahead of data collection. Overall, this experience has reinforced that PPIE is not a tick-box exercise but an ongoing, reciprocal process that enhances both the ethical quality and real-world relevance of research.

What Changed ‘IMPACT’

Refined the study focus to reflect what really matters.

Made my study materials clearer and more people-friendly.

Reminded me to always consider participants’ time, energy, and comfort.

Strengthened my recruitment approach and boosted my confidence.

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