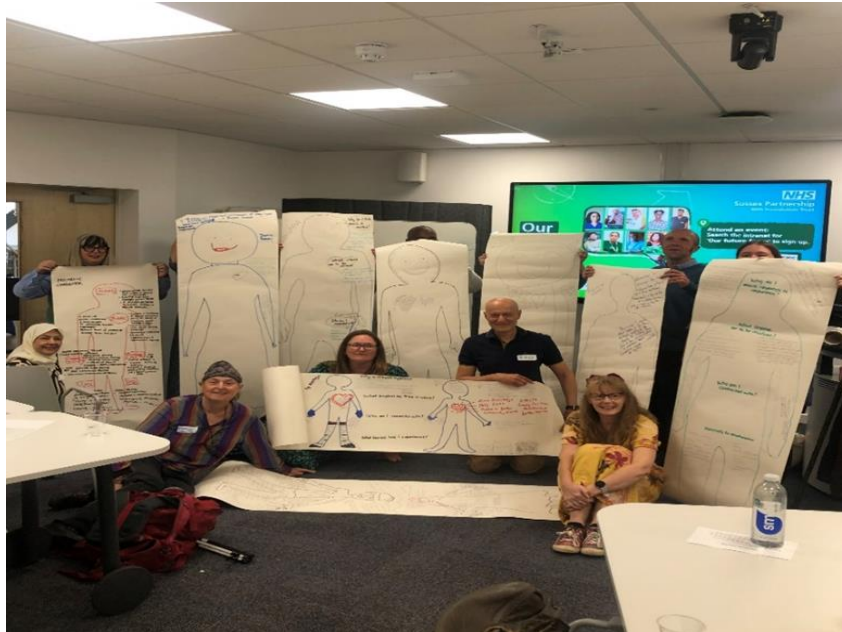




## Applied Research Collaboration Kent, Surrey, and Sussex (ARC KSS) Public and Community, Involvement and Engagement (PCIE) Body Mapping Summary



To support the applied research that ARC KSS fund, public involvement is integral, and the National Institute for Health and Care Research (NIHR) makes clear that it values knowledge, with expectation that members of the public will be involved as research partners in research. ARC KSS has a dedicated Public and Community, Involvement and Engagement (PCIE) team who work together with public members as equal partners to ensure the voices of the populations across Kent, Surrey and Sussex are at the forefront of everything they do. To ensure that public involvement is effective and meaningful the PCIE team have created a dedicated public involvement infrastructure known as the Public Involvement Network (PIN), which has seventeen public members, with the purpose of; being part of the organisational governance, sharing information and practices across ARC KSS research themes, a space for reflection and constructive feedback, to develop the knowledge and confidence for members to be a critical friend and to support the implementation and monitoring of the PCIE strategy. The PIN meets bi-monthly



throughout the year, hosted by the PCIE team, and chaired by a PIN member. Whilst meetings are mainly hosted online via Zoom, the PCIE team value the importance of meeting with public members face-to-face and yearly they host a PIN away day.

In June 2024, the PCIE team came together face-to-face with PIN members to connect in a way that would be relaxed, enjoyable and engaging to promote conversation, working together and information sharing. As an alternative to the usual reviewing and development of wordy documents the PCIE team took a more creative approach with a participatory research method activity known as body mapping to explore topics of interest and appreciate how practices or thoughts relate to specific parts of the body. PIN members share with us a variety of lived experiences and skills along with a wide range of perspectives on our research and using this creative method to draw upon these were welcomed by all.

Working together in pairs, PIN members were provided with marker pens and sheets of paper, with space to either draw around each other or draw freehand the shape of a body. They were asked to write on the body in the areas of the head, heart, hands and legs, answering questions, as shown in the image on the right. There was much hilarity, creative thinking and some inspirational insights into the experiences and passions of each PIN member. The PCIE team valued this time and space to collectively reflect on the questions we asked during this activity with PIN members.





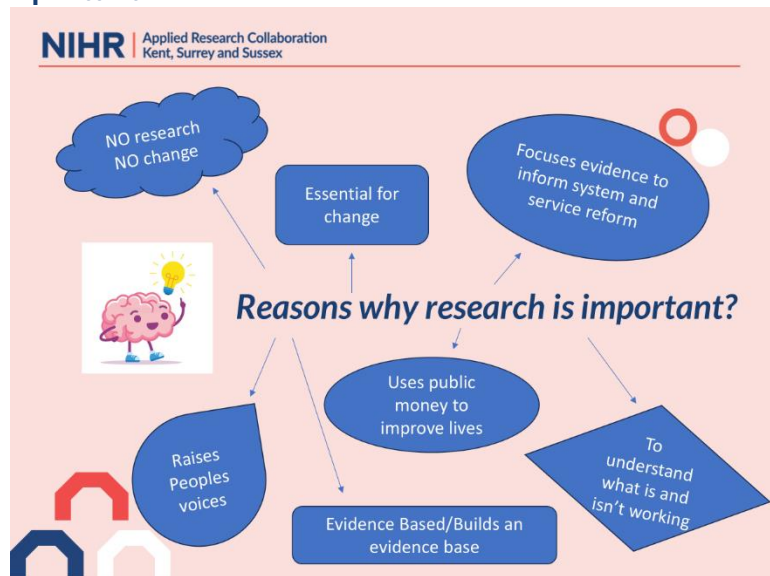
Here is a collection of photos taken on the day showcasing the body mapping activity and how public members worked together.



*What were the findings from the body mapping exercise and how were the PCIE team going to use this information?*

**Why did they think research was important?**

The predominate commonality in the thoughts of why research is important was the notion that it is evidence based; the more research carried out generates innovation and creativity, building an evidence base which is essential for change. It raises people's voices and empowers lived experience, lending confidence and authority to an idea. Greater information allows for solutions to be found, especially when informed by lived experiences; it can decrease the impact of illness, save lives and help people to feel heard and seen.



PIN members on the day said: *“Research is Hope!”* and *“You can never have a true understanding of something through academics if lived experience is missing.”*

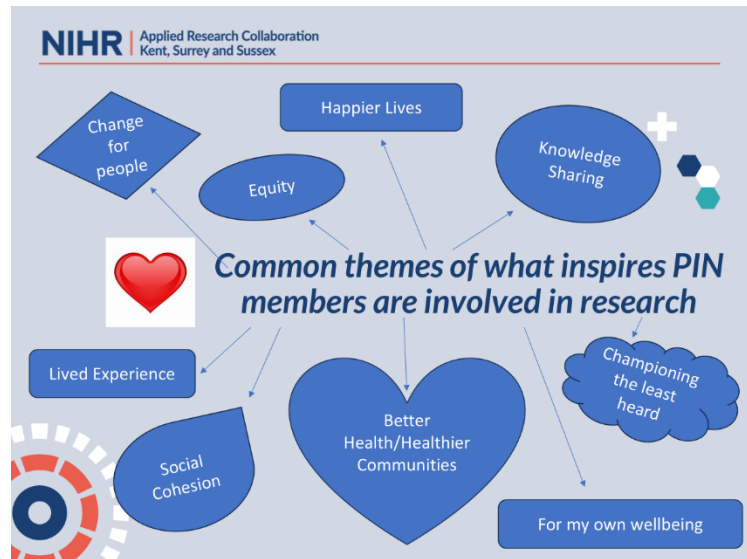


## What inspired them to be involved in research?

Common themes were lived experience, community, equity and improving things for others with the intention of championing the least heard and creating opportunities for others to lead healthier, happy lives; a sense of social cohesion and a commitment to deprived society.

Championing the ethos of **“Nothing about us without us”**, reminding decision-makers of their responsibilities to listen and

learn from and be accountable to those most impacted by decisions they make. Moreover, the resonation of feeling part of something bigger than themselves, meeting new and interesting people, utilising, sharing and building upon their skills.



PIN members reflections on the day:

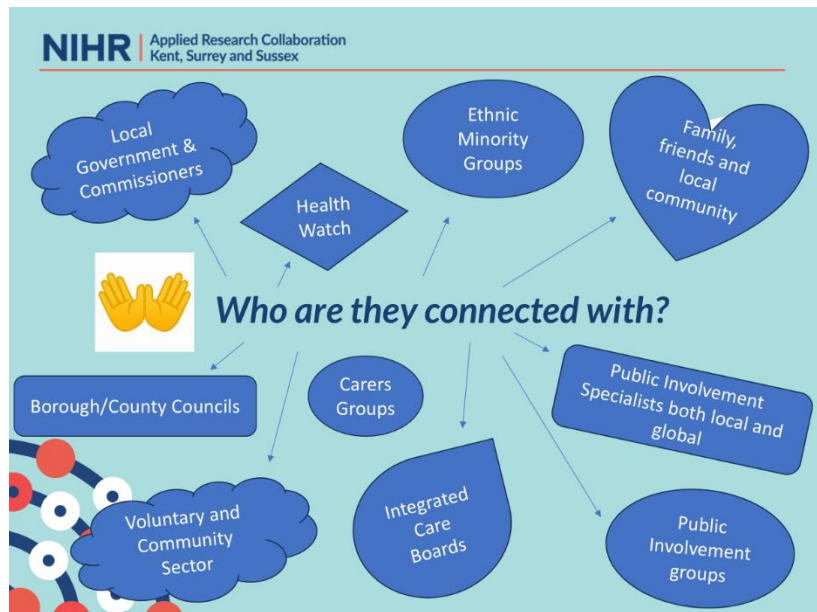
*“I hear about too many bad experiences of young people support for their mental health, I am desperate to see a change, and research can influence and feed that change.”*

*“My own adversity motivates me to support improvements, especially because my lived and learned experience is what we can do things better and do better things.”*



### Who are they connected with?

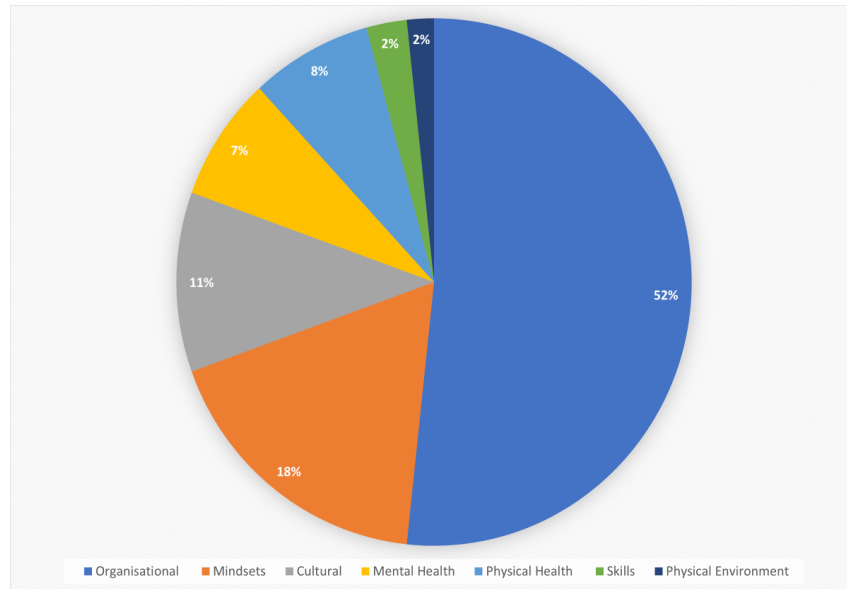
Our public members support as boundary spanners in our research, playing an important role in bridging the gap between the community and researchers. Facilitating the exchange of knowledge, ensuring our research findings are relevant and accessible to the public. The image to the right reflects a small proportion of the rich



diversity of connections held across our public involvement network. From personal connections of family, friends, colleagues and neighbours, local community running and sea swimmers' groups to the voluntary and community sector to Intergrated Care Boards, Councils, other patient & public advisory groups, ethnic minority groups and migrant communities; fostering these strong relationships and maintaining the willingness of public members in boundary-spanning positions is crucial. They enable communication, build relationships and enhance relevance to ensure that research addresses the issues across Kent, Surrey and Sussex, alongside supporting implementation. Their connections are essential to the continuous cross-sector collaboration to enrich the research being carried out across ARC KSS.

### Barriers to being involved in research?

Barriers were categorised as shown in the pie chart below, with the highest percentage as organizational at 52%. Closely followed by mindset at 18%, which on a tangible level is akin to the development of the organisation's cultural growth.



We revisited these barriers with PIN members, contextualising the key organisational barriers to bring them to our focus, framing the initial step to improving the public involvement infrastructure and welcomed any ideas of how they might like to see these barriers being changed.

The table below highlights three core barriers that were identified and what the PCIE team will focus on across 2024/2025, linking where applicable with the PCIE strategy, its objectives and potential next steps.

PCIE team to focus on	PCIE Strategy	Potential next steps
<p><b>Operational ways of working:</b> Jargon, communication, accessibility of information and meeting culture</p>	<p><b>Inclusive Opportunities:</b> Continue to identify and address barriers of equitable, accessible and inclusive involvement, including sensitive conversations about any accessibility requirements.</p>	<p>PIN members to consider producing ‘top tips’ for researchers?</p>



<p><b>Continued development and confidence.</b></p>	<p><b>Support and Learning;</b> Where required individual objectives and identified training/support for each public advisor.</p>	<p>To think creatively about how this could be offered within limited resources e.g.</p> <ul style="list-style-type: none"> <li>• Use of PIN time for learning &amp; development i.e. guest speaking and workshops.</li> <li>• Development of online resources</li> <li>• Individual keeping in touch sessions to highlight positives and to discuss any issues and learning required.</li> </ul>
<p><b>Attitudes towards public involvement as experienced public members.</b></p>	<p><b>Strengthen the input of the public in our ARC KSS structures:</b> Ensure that the public voice is given a meaningful place within the organisation and the opportunity to work collaboratively with ARC KSS colleagues at all levels.</p>	<p>Respect and acknowledgement; Reciprocal, we can focus on this from ARC KSS perspective. Develop and support fruitful conversations between public members and ARC KSS colleagues/researchers; understanding each other's roles, experiencing the value that public members can add. Building and sustaining relationships. Gathering and sharing feedback and impact.</p>

We, the PCIE Team valued this time and space to connect and reflect on all the information that everyone kindly shared with us, strongly reinforcing that public members are still experiencing barriers with involvement to applied research and as we move



forward with next steps, we are committed to meaningfully ongoing dialogue with a collaborative ethos at the heart of what we do. Importantly we gained valuable insights that are within our capacity to change, and we can take these with us each time we champion for a shared understanding throughout ARC KSS as to the challenges, purpose and value of PCIE.

“You can never have true understanding of something through academics if lived experience is missing.” (ARC KSS Starting Well Theme Advisor)

The Public and Community, Involvement & Engagement Team would like to express thanks to the Public Involvement Network for making space to attend this event and for their continued support.

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The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

If you have any questions or would like to get in touch, please contact [Louise Lacey](#) and/or the [PCIE team](#).