Research: What is the value of working with people and communities?

Health Innovation Kent Surrey Sussex

Part of the Health Innovation Network

Office for Life Sciences

NHS

We know that there are challenges with patient, public involvement and engagement (PPIE) in research…We have the expertise to help you!

- **Resource:** Delivering meaningful involvement with the public requires additional capacity, specialist knowledge and time - particularly with co-design and co-production.

- **Engaging with diverse groups:** It is hard to find public contributors and effectively involve underrepresented communities.

- **Tokenism:** Involving patients and the public with the sole purpose of meeting funding requirements can result in poor experiences and this negatively impacts on public trust in a research study.

- **Lack of evaluation**: Lack of public involvement and evaluation of the impact of public contributors negatively impacts the value of the study.

How we can help: From gathering lived experience through co-production and crafting PPIE and NIHR inclusion plans, to making your communications inclusive and accessible — we can support you in involving diverse voices and applying proven PPIE methods in your research.

KSS Health Innovation Kent Surrey Sussex

We champion the active involvement of the public, patients, carers and staff in shaping research and innovation.

As a dedicated team of **involvement specialists**, we bring expertise in embedding **community insights** and **lived experience** at every stage of the research and innovation journey. Our knowledge of the statutory duties in Working with People and Communities, enables partners to fulfil their **legal**, **social** and **moral** obligations for genuine community involvement.

Through strong partnerships across Kent, Surrey and Sussex we support our partners to **co-produce inclusive, meaningful** and **community-led** research and innovation that benefits all.

NHS Sussex Digital and Data People's Panel
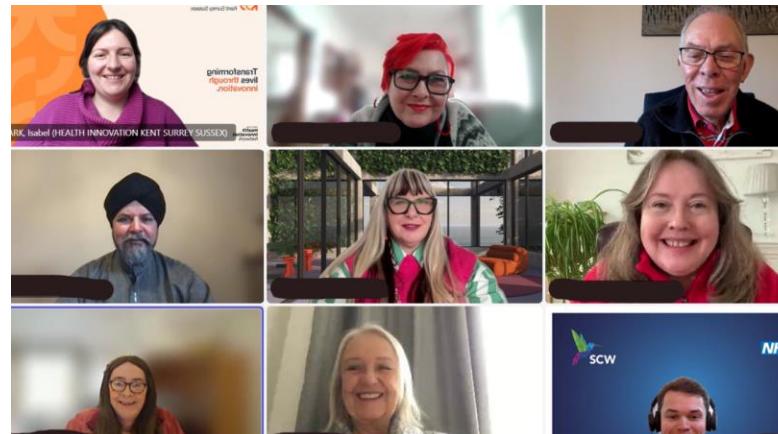
NHS Kent, Medway and Sussex Secure Data Environment Public and Patient Advisory Group

"I found it very encouraging how our group moved in the same direction while debating a complex topic. It's almost fluid how the ideas and concepts evolve. I've been in groups in other environments, and it's got confrontational at times" - **Public Member**

KSS Health Innovation Kent Surrey Sussex

3

Research

By listening to insights from people and communities, we help our research partners to:

- **Improve relevance and quality:** Insights from patients, carers, and the public help shape research that matters to real people, making studies more useful and impactful.

- **Enhance study design and delivery:** Working with communities builds trust, transparency, and accountability - making it more likely that people will engage, participate, and stay involved.

- **Boost dissemination and impact:** Involving people in sharing results and shaping messaging ensures findings are accessible, meaningful, and more likely to be used.

- **Meet funder and policy expectations:** Many funders, including the NIHR, now require a clear PPIE plan as part of the application process.

We do this by:

- Seeking and embedding lived experience through **co-production** and **co-design** at **every stage of the research journey**.

- Developing tailored **PPIE plans**, [NIHR Inclusion Plans](#) and budgets that align with your research goals.

- Using a range of **tested PPIE methods** to define roles, track progress, and share the value of PPIE with funders and communities.

- **Communicating clearly** by ensuring your materials are inclusive, accessible, and written in plain language.

- **Involving underrepresented** communities and people living with health conditions in research projects.

- Partnering with **VCSE organisations** to reach and involve marginalised communities and tackle health inequalities.

KSS Health Innovation Kent Surrey Sussex

Case study: Connecting Children and Young People Digitally to Improve Mental Health Wellbeing

Challenge: During coronavirus, mental health services for young people moved online – leaving many struggling to find the information they needed – while practitioners raised concerns about delivering care safely on digital spaces.

What we did:

- **Partnered with children and young people**, via YMCA DownsLink Group, to **co-evaluate** and **co-review** the e-wellbeing website (www.e-wellbeing.co.uk) for children up to age 18 and their families.

- **Co-produced** a series of digital ambitions through workshops to support the mental health of children and young people.

- **Co-produced and co-facilitated** digital training with *e-wellbeing's youth ambassadors*.

Impact:

- **Relevance & Quality:** Partnered with NIHR ARC KSS, YMCA DownsLink Group, and the University of Sussex to ensure the platform and evaluation reflected real needs — making the research more relevant and impactful.

- **Design & Delivery:** Over 15,000 young people used the site in one year (53,000+ page views), and 200+ Sussex professionals were trained to engage young people digitally. Strong community uptake and feedback drove platform improvements, building trust and real-world relevance.

- **Funder Expectations:** The evaluation secured follow-on funding from Health Education England to develop a practical toolkit and training — demonstrating real-world impact and alignment with NIHR PPIE priorities.

KSS Health Innovation Kent Surrey Sussex

# Case study: Research with people living with Dementia

Challenge: People with Dementia face unique challenges, including lack of information following a diagnosis and struggle to access health and care services.

What we did:
- Worked in partnership with the NIHR Applied Research Collaboration Kent Surrey Sussex to create **two new evidence-based resources** for people living with dementia, **co-designed** with people living with dementia:
  - **Co-Cog:** a new smartphone app which offers new ways to monitor health and facilitate timely interventions for people with Dementia.
  - **My Choice:** an evidence-based, accessible resource helping people live well with dementia.
- Led **outreach**, **involvement**, and **co-design** with people living with dementia
- Held **safe**, **trusted sessions** to understand and design around real-world challenges

Impact:

- **Relevance and quality:** Direct input from people with **lived experience** of dementia has ensured Co-Cog reflects **real-world needs**, making the research more relevant and impactful.

- **Design and delivery:** Co-Cog is continuously shaped by people with dementia and their carers - building trust, deepening engagement, and keeping the **innovation real-world ready**.

- **Wide-scale adoption:** My Choice has been **widely adopted** across the UK and gaining international interest (6,000 downloads in one year) - demonstrating how **working with communities drives meaningful, far-reaching impact**.

KSS Health Innovation Kent Surrey Sussex
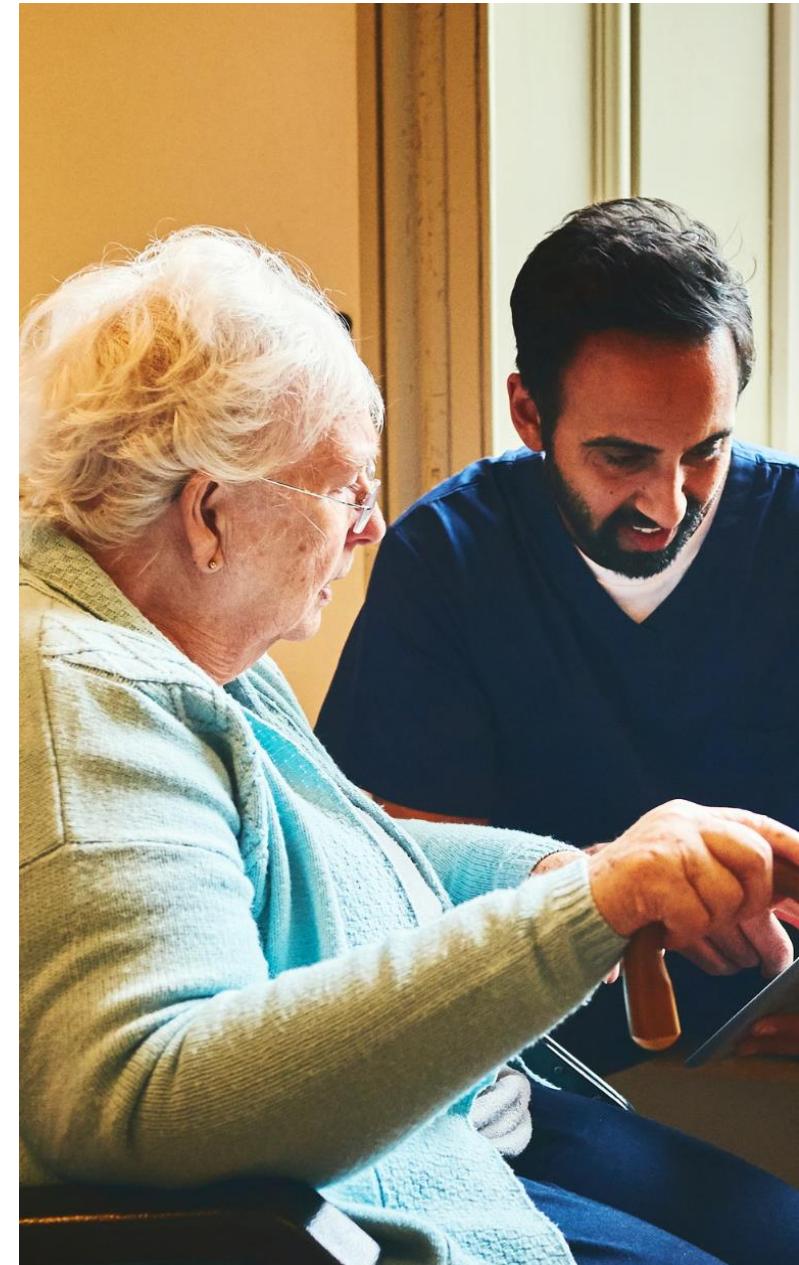
Contact us

We encourage anyone who wants to involve people and communities in research and innovation to contact the team today.

Email: isabel.clark3@nhs.net