



Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS)

Handbook for Public Advisors & Public Contributors

Our Public & Community, Involvement & Engagement (PCIE) Vision:

Where meaningful public and community involvement and engagement is a central part of ARC KSS' health and social care research activities

We aim to use clear language in this guide, but you may like to refer to the [NIHR Glossary](#) while reading this guidance.

Who we are:

The Applied Research Collaboration, Kent, Surrey and Sussex (**ARC KSS**) is a group of organisations that **collaborate** (work together) to develop research ideas and turn them into projects. Our research is **Applied Research** which means it seeks to solve a practical problem using knowledge from established research or examining practises and experiences of health, social & community care. (It is different from clinical research which focuses on improving the prevention, diagnosis, treatment and delivery of health & care service). The most important part is making sure any information we find out (evidence) is shared with those that can use it and put it into practice quickly to make positive changes to services in real-world settings (**Knowledge Mobilisation**).

Who do we work with?

We work with a number of organisations and individuals whose goals are to improve the health and social care of people in Kent, Surrey & Sussex. These include:

- Academics from local universities or medical schools
- Professionals from NHS or Local Council services
- Service Providers (NHS & Voluntary Sector)
- Communities
- Local people
- Voluntary organisations

How are we funded?

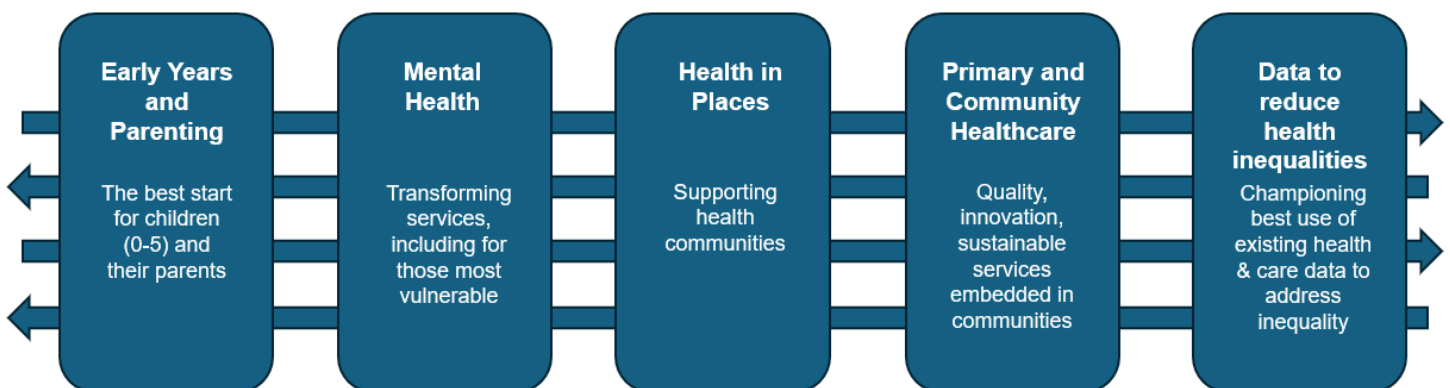
There are currently 10 ARCs across England and they are all funded through the **National Institute for Health & Care Research** (NIHR). The NIHR is funded by the Department of Health & Social Care (DHSC) to support and deliver applied health & social care research that improves people's health and wellbeing and promotes economic growth. There are a number of research organisations funded by the NIHR, such as, the Research Delivery Network (RDN) and the Research Support Service (RSS), and we all have different functions.

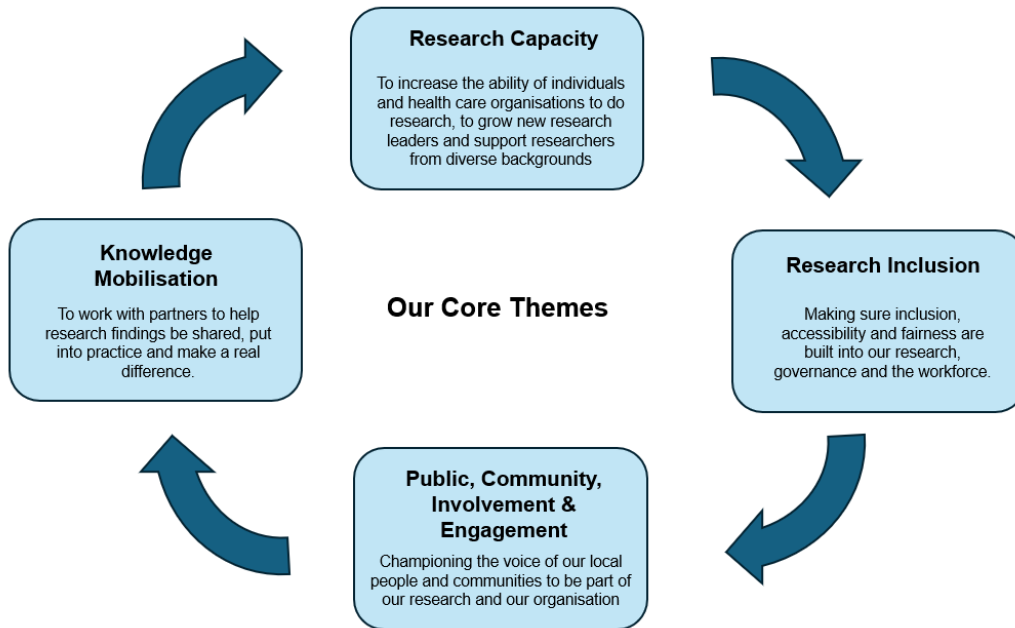
We also work closely with Health Innovation Kent, Surrey, Sussex, (HIKSS) which is part of the wider Health Innovation Network (HIN). Funded by the NHS and Office of Life Science (part of the British government), HIKSS helps us to get our research findings shared and used (implemented) for the benefit of people who receive and who deliver health and social care services.

How we focus our research:

There are many possible topics for health and social care research. At ARC KSS, we focus on the areas that matter most across Kent, Surrey and Sussex. By exploring the key challenges in our region and working closely with partners and public members to understand the needs of health and care services and local communities at local, regional and national levels, we agreed our research priorities. These priorities have shaped our five Research Themes and four Core Themes.

Our Research Themes





Why do we value public involvement?

It is important to us that those who are the focus of our research in health and social care have a say in how that research is identified, designed and carried out.

We aim to make sure our research is relevant and responds to the issues that are important to our public and communities, as well as those who deliver the health and social care services across our regions.

Your views and opinions are important. You can offer a point of view that academics or service providers may not have considered. When everyone's ideas and views are brought together, they can result in high quality, relevant and useable research evidence, which can improve the health, care and wellbeing of others in our region.

What is Public Involvement?

At ARC KSS we refer to Public & Community, Involvement & Engagement (PCIE) but others may call it PPI (Patient and Public Involvement), PPIE (Patient and Public Involvement & Engagement), Lay involvement or similar. This all refers to asking and listening to public members or community groups so we can hear their perspectives about our research.



Engagement

Information and knowledge about research is shared and disseminated (circulated)

- This can help to explore, discuss and shape research.
- A two-way process that includes talking to each other and listening.
- It involves building relationships with communities
- Its goal (aim) is to be helpful to all of us.



Involvement

Where members of the public are actively involved in research projects and in research organisations.

Examples include:

- Reviewing of documents
- Working with those who fund our research to decide the most important research to carry out
- Offering advice as a member of a project steering group
- Helping researchers to consider how their projects might be viewed by those taking part in the research.
- Carrying out interviews as part of the research team.



Participation

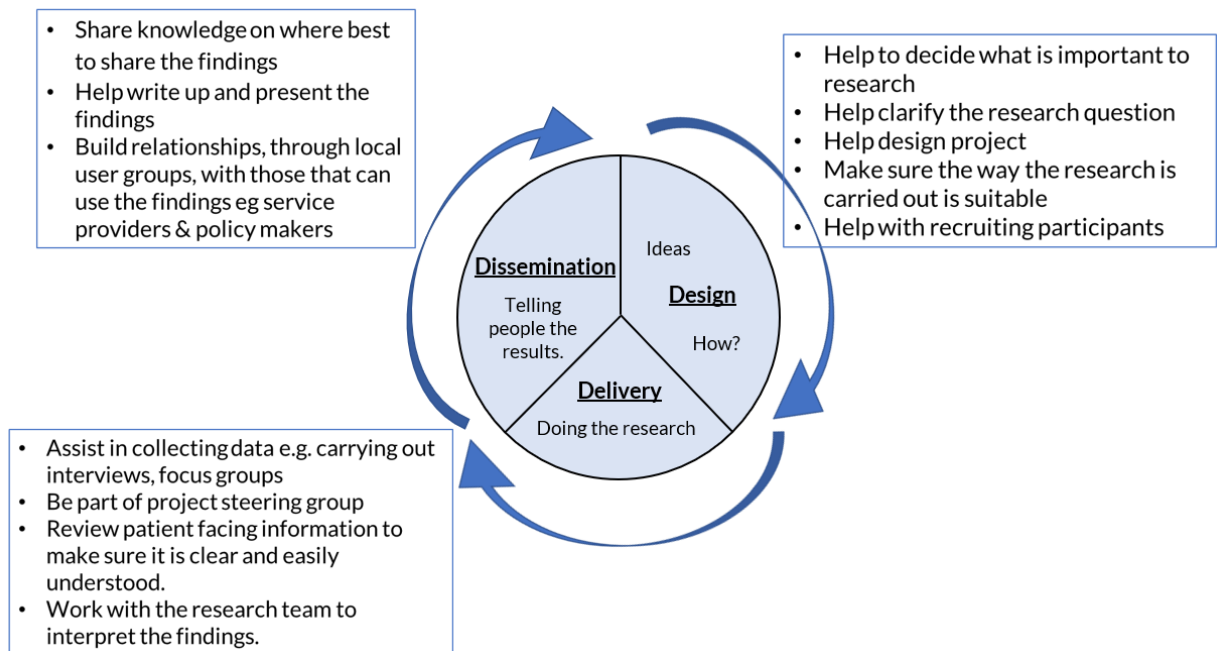
Where people take part in the research study itself

Different public member roles:

At ARC KSS we have two public member roles:

1. **Public Contributors** - someone who has agreed to be part of our research family. We let them know when opportunities to get involved become available via email and through the newsletter. Public Contributors are able to pick and choose the involvement opportunities as they are offered, depending on their interests and availability. There is no minimum or maximum commitment, all offers of help are welcome.

Here are some examples of where public contributors might help support our research within the journey of a research project:



2. **Public Advisors** - As well as being involved in the same way as the Public Contributors, Public Advisors take on the additional role of supporting the organisational work (governance) of ARC KSS, making sure the research we support is relevant to our local communities and meets our objectives (aims/ goals).

Two **Theme Public Advisors** are aligned to each of the following themes:

- 5 research themes (as previously described)
- Knowledge Mobilisation
- Research capacity Development (ORCA)
- Research Inclusion

Their role is to:

- work closely with the theme teams to bring a public point of view to the overall direction of the theme and the work they are doing.
- be members of our organisational public members oversight group (Public Involvement Network - **PIN**). This group meets quarterly (every three months) with the aim of supporting each other; finding out what work is going on across the ARC KSS and working together to raise the profile of public involvement in ARC KSS activity.

We have three **Board Public Advisors** who, as members of the ARC KSS Board, share overall responsibility for the management and oversight of the collaboration, particularly representing the view of our local communities and populations at Board level.

We have one **Executive Public Advisor** who, as a member of the ARC KSS executive committee, provides a public perspective to the Senior Leadership Team, helping to ensure plans, funding and priorities stay on track.

Payment:

ARC KSS values the experience, knowledge and skills that service users and the public can bring to research. Being a public member with ARC KSS is not an employment role, it is voluntary. However, where possible, we aim to offer payment for your expertise and time when contributing to our activities such as meetings, focus groups, reviewing documents, recruitment panels or similar.

Being part of a collaboration means working with a number of different research organisations who may use different payment policies for paying public members.

Payment falls into two main processes:

1. Payment through our partner universities. The Universities we work with may follow the [NIHR public payment guidance](#) but each one determines their own payment policy.
2. Payment made through ARC KSS's host organisation, Sussex Partnership Foundation Trust, using its Service User and Carer Payment Policy. We follow national NIHR guidance on payment rates. This follows a process of signing up to the payroll system. If you are a UK taxpayer, tax and pension contributions will be taken off automatically (unless you choose to opt out). At the end of the tax year, you will receive a P60 form showing what you earned and what was deducted.

Our aim for each involvement opportunity is to describe clearly:

- the activities and level of commitment for the involvement
- the amount being offered
- conditions for reimbursement of travel and subsistence expenses
- to whom payment claims must be submitted

- the payment terms according to the supporting organisation's policies
- Please be aware, as these are official payments they may affect benefits you might be receiving. The NIHR have guidance on their website for [members of the public considering involvement in research](#) including information about a free and confidential service available to support members of the public whose welfare benefits may be affected by payment for involvement.

Code of Conduct:

We work hard to make sure that everyone feels welcome and included when they are working with us at ARC KSS and therefore ask that public members agree to the following ways of working

Respect and Inclusion

- Treat everyone with dignity, courtesy and respect.
- Value different views, experiences and backgrounds.
- Do not discriminate or harass anyone on any grounds, including age, disability, race, religion or belief, sex, gender identity, sexual orientation, or family status.

Working Together

- Prepare for meetings and take part openly and constructively.
- Share your views respectfully and listen to others.
- Support group decisions, even where you may have held a different view.

Representing the Public Voice

- Try to represent a wide range of patient and public perspectives, not only your own personal experience.
- Be open-minded, fair and objective.

Confidentiality and Trust

- Keep information shared in meetings confidential.
- Do not share ARC KSS information outside the group unless permission has been given.

Openness and Integrity

- Declare any conflicts of interest as soon as they arise.
- Complete feedback or evaluation activities when requested.

What you can expect from ARC KSS in return:

As a Public Advisor, ARC KSS will:

- Provide an induction and a named contact person.
- Offer advice, guidance and training to help you carry out your role.
- Ensure payment and expenses are agreed in advance
- Keep your personal information safe and confidential and not share it without your permission.
- Communicate with you regularly and offer opportunities for feedback.
- Share meeting information and agendas in advance where possible.
- Work with you to understand and support any needs you have, so you can take part fully and comfortably. Let us know early if something is not working so we can support you.

If things go wrong:

We are committed to providing a respectful, inclusive and supportive environment. If something does not feel right, please raise it as early as possible so we can address it. We value feedback and concerns as opportunities to learn and improve. We can only do better in the future with your help.

Raising a concern

- We aim to resolve issues quickly and fairly. Most concerns can be resolved informally through one-to-one discussion, supported conversations with those involved, or additional guidance.
- Speak first to your named theme/project contact
- If you prefer, or if the concerns involve this named contact, you can contact any member of the PCIE team including the Strategic PCIE Lead.

When expectations are not met

- We will always try to resolve issues informally first, where appropriate
- In more serious cases (such as harassment, discrimination or confidentiality breaches), or where informal steps have not worked, a **formal process** may be required.
- Formal action may include:
 - Temporary pause of involvement while concerns are reviewed
 - An oral or written warning
 - In serious cases, ending involvement in the programme

- Any formal process will be explained clearly, handled fairly, and managed by someone not directly involved in the issue. You will be kept informed throughout and given the opportunity to respond.
- Concerns about staff behaviour will be managed in line with the organisation's complaints and disciplinary procedures. We will explain the process and, where appropriate, share the outcome with you.

Staying in touch with what is going on at ARC KSS:

We don't want you to feel alone in your role with ARC KSS and want to make sure you are able to connect with other members of the public and to know what research is going on across the organisation. We aim to do this through a variety of means (most of which are not remunerated, unless there is some specific and agreed role for the participant, such as preparing a presentation).

Website - <https://arc-kss.nihr.ac.uk/>

There are individual pages for each theme highlighting their research, there are also pages for Public, Community, Involvement & Engagement news and events as well as summaries from projects that are reporting on their findings.

AR KSS Spotlight newsletters delivered straight into your inbox. An electronic newsletter allows you to quickly scan through recent reports and read those that interest you.

If you have not already signed up, you can do this by following [this link](#).

Email - Once you have agreed to become a public contributor or advisor your email will be added to our mailing list. This remains private and only information about public involvement opportunities will be sent to you.

Research Symposiums - Throughout the year ARC KSS host publicly accessible conferences (hybrid, online or in person) where you will be given the opportunity to hear about some of the great projects and the ways in which their findings are being used locally and nationally. These will be shared via our newsletter, on our website and on Padlet.

Most of these activities are voluntary and generally not remunerated, unless there is some specific and agreed role for the participant, such as preparing a presentation.

Padlet - An online interactive platform accessible to ARC researchers, partners and public members where information about upcoming events, training and involvement opportunities are posted. Please ask for details.

Useful resources:

Starting Out Guide - Why and how to get involved in research (nihr.ac.uk)

This Starting Out Guide has been written to help and advise members of the public who would like to get involved or have recently become involved in research. In this guide you will find key information and principles about getting involved in research, whatever your experience or prior knowledge.

A research handbook for patient and public involvement researchers

This handbook is written for patients and members of the public who want to understand more about the approaches, methods and language used by health-services researchers.

What is patient and public involvement ('PPI') in research? Why does it matter?

A series of video interviews with public members about why they think involving public members in research is important.

NIHR Glossary

A glossary of words containing the definitions of some of the terms commonly used in research.

Co-Production: Together we are better - a leaflet for the public

A leaflet produced by ARC KSS as a way of introducing the key ideas behind co-production to members of the public who may be new to working in this way.

Payment guidance for members of the public considering involvement in research. (NIHR)

This guide is for members of the public thinking about getting actively involved in research and you are being offered expenses and/or payment for your involvement. It offers answers to some frequently asked questions and suggests where you might get advice about your particular circumstances.

Plain English Campaign - tools for writing in plain English.

A series of free guides to get you started writing in plain English.

Hear from two of our Current Theme Public Advisors about why they got involved and what they hope to achieve

Public Member video cskvcxjk

To contact us:

We welcome your comments, questions or general feedback. To contact us:

email: [**spft.publicinvolvementarckss@nhs.net**](mailto:spft.publicinvolvementarckss@nhs.net)

Phone: **0300 304 0125**

PCIE team members:

Dr Anna-Marie Bibby Jones - Strategic Lead

Pippa Shaw - PCIE Operational Team Lead

Louise Lacey - PCIE Research Manager

The original version of this guidance document was reviewed with ARC KSS public advisors: Janice Clark, Paul Burchett & Sarah Giles. It has been updated May 2026 with support from public advisors Hasu Ramji, Sarah Giles, Eleanor Levy.