



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

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### Welcome Guide 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:

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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 rather than research such as a clinical trial. The most important part is making sure any information we find out (evidence) is used to make positive changes to services for our local population. We call this implementation.

The purpose of ARC KSS is to improve the health and social care of people living in our region of **Kent, Surrey & Sussex**.

## Who do we work with?

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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?

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There are 15 ARC's 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 Clinical Research Network (CRN) and the Research Support Service (RSS), and we all have different functions.

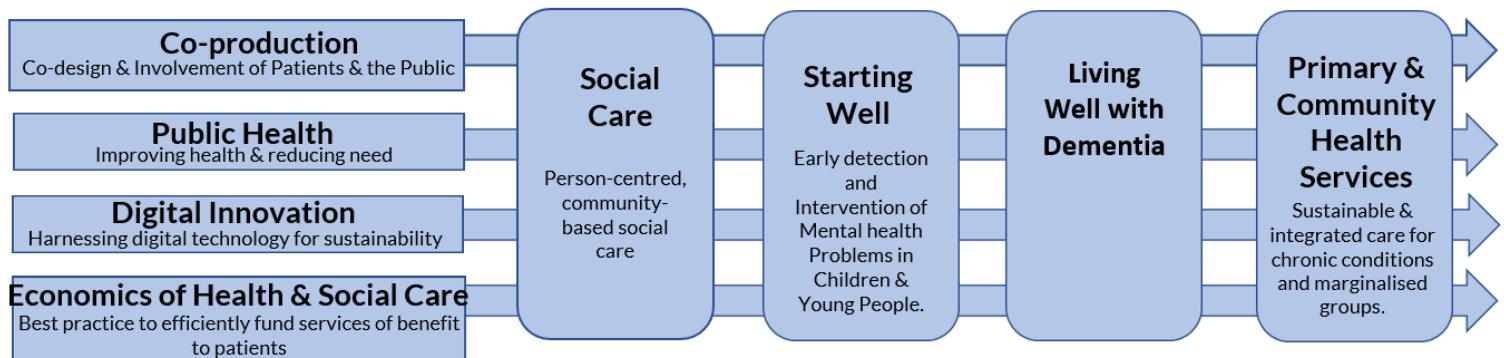
We also work closely with Health Innovation Kent, Surrey, Sussex, (HIKSS) part of the wider Health Innovation Network (HIN). Funded by the NHS and Office of Life Science (part of the British government), HIKSS helps us to get out research findings shared and used (implemented) for the benefit of people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



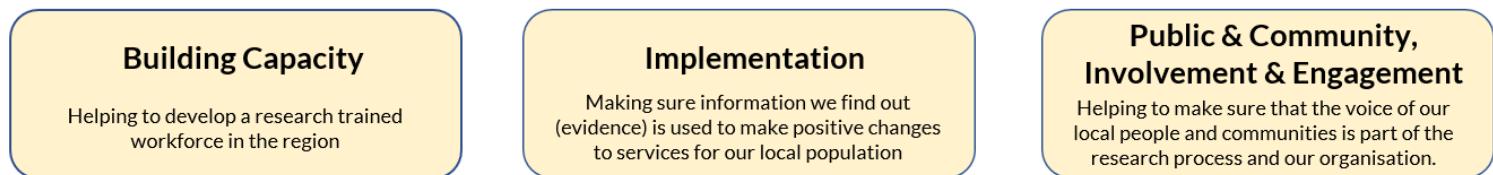
## How we focus our research:

There are a vast number of topics that could be focused on for health and social care research. At ARC KSS we have aligned our research to areas of need that are important across Kent, Surrey & Sussex. A number of particular challenges were identified for our region and along with a public survey to identify research priorities, we developed our 8 research themes along with our 3 supporting teams (pillars).

## Our Themes



## Our Supporting Teams (Pillars)



## 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. 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

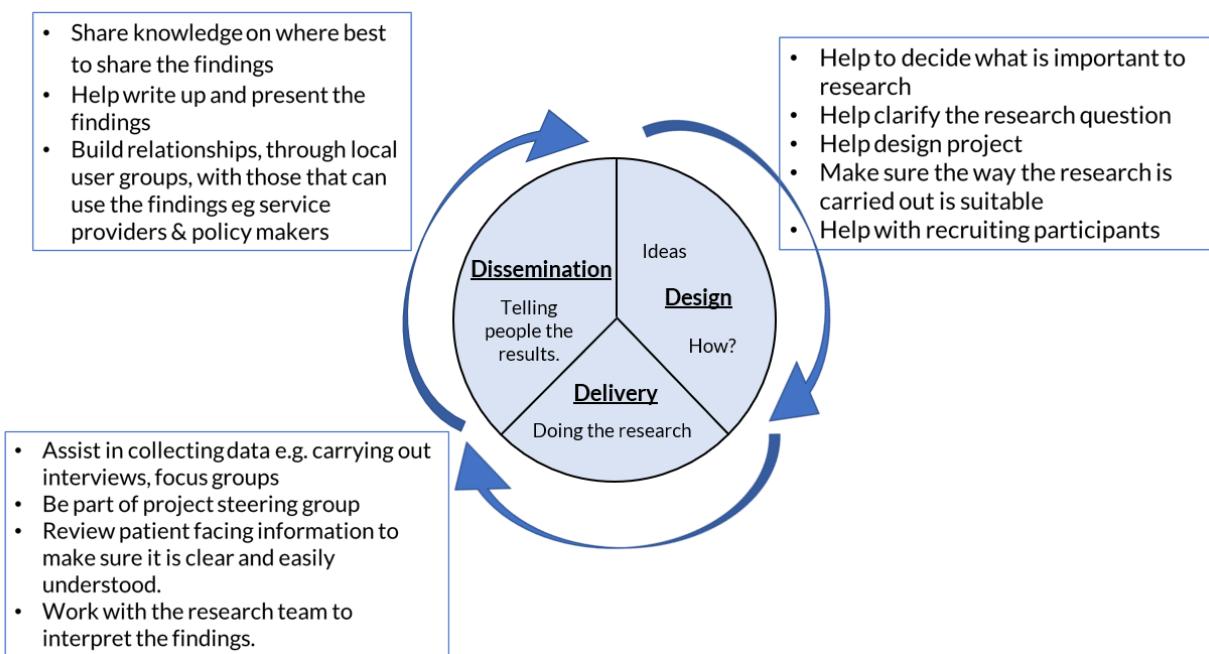
## Different public member roles:

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). We have public advisors who work with our themes as **Theme Public Advisors** and public advisors who work with our Board as **Board Public Advisors**.

Two **Theme Public Advisors** are aligned to each of our 8 themes, 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 bimonthly (every two months) with the aim to support each other, find out what work is going on across the ARC KSS and work 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.



## Payment:

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ARC KSS values the experience knowledge and skills that service users and the public can bring to research. In recognition, and 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 through ARC KSS host NHS Trust (Sussex Partnership NHS Foundation Trust, SPFT) which follows a process of signing up to the payroll system. If you are a UK tax payer, tax will be deducted from your payment before you receive it, and at the end of the financial year you will receive a P60 form of tax deducted.

Our aim is to make it clear at the beginning of each involvement opportunity; the terms of payment (according to the supporting organisations payment policy), the amount being offered and who you will need to submit payment claims to. This includes the reimbursement of any relevant travel or subsistence expenses.

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:

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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 code of conduct:

- Treat everyone with respect.
- Discrimination (or harassment) will not be tolerated. This includes sex, gender reassignment, marriage and civil partnership, pregnancy and maternity, race (including ethnic origin, colour, nationality and national origin), disability, sexual orientation, religion or belief or age.
- Observe collective responsibility for group decisions.
- Prepare for meetings, contribute in meetings and complete opportunity feedback forms.



- Be able to understand and represent the broader range of patient and public perspectives beyond your own experiences, and the ability to be objective.
- Respect the confidentiality of group members, research projects and other ARC KSS business that is discussed at ARC KSS meetings. Information will not be shared outside the group without prior agreement.
- To declare any conflicts of interest.

## What you can expect from ARC KSS in return:

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- An induction and named contact.
- Advice and training to carry out the role and activities.
- Expenses and payment
- Information, including personal details, will be confidential, safeguarded, and will not be shared without express permission.
- Ongoing communication and feedback
- Meeting information and agendas (where required) will be made available prior a meeting.
- If support is needed to help you to take part in our activities we will work with you to understand your support needs to make sure you are fully included.

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

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We don't want you to feel alone in your role of public member with ARC KSS and want to make sure you are able to connect with other public members and also to know what research is going on across the organisation. We aim to do this through a variety of means:

### **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 allowing you to quickly scan through recent reports and read those that take your interest.

If you are 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 Symposia** - Four times a year. 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 across Kent, Surrey and Sussex.

**PACS** (Public Advisor & Contributor work Space)- a virtual workspace on our Glass Cubes platform where public members have direct access to share information, ideas, challenges and connections with other ARC KSS public members - a virtual self-accessing bulletin board. If you would like to sign up to join this virtual space please click this [link](#)

## Useful resources:

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### **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 cxkvcxjk

### To contact us:

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We welcome your comments, questions or general feedback. To contact us please email us at:  
[PublicInvolvementARCKSS@spft.nhs.uk](mailto:PublicInvolvementARCKSS@spft.nhs.uk).

#### **PCIE team members:**

Pippa Shaw - PCIE Team lead

Louise Lacey - PCIE Coordinator

This guidance document was reviewed with ARC KSS public advisors: Janice Clark, Paul Burchett & Sarah Giles.

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