ARC KSS - Public and Community Involvement and Engagement (PCIE) Strategy 2021

1. Background

The purpose of the Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS) is to improve the health and social care of people living in the region through developing research partnerships and the implementation of research into practice. A core activity of the ARC is to engage with and involve local communities and the public in its work. Based on a scoping of local need there are 8 research themes:

- Social care (person-centred, community based)
- Starting well (mental health and children and young people)
- Dementia (living well with dementia)
- Primary and community care (sustainable and integrated care for chronic conditions and marginalised groups)
- Co-production
- Public health
- Digital innovation
- Health and social care economics

Unlike other areas in England, ARC KSS is the first of its type in this region which has given the challenge of setting up from scratch but also the opportunity to think as innovatively and flexibly as possible with regard to embedding Public Involvement in the newly forming ARC KSS. This strategy has built on the work started in the ARC's original submission to the National Institute for Health Research (NIHR) and covers a 5-year period from October 2019 to October 2024. Our first year was a set up phase with implementation planned from October 2020, however challenges from the restrictions of working virtually due to the Covid 19 pandemic restrictions have caused some delay.

Our focus has been to develop the PCIE strategy using the INVOLVE principles. We set up a working group of 20 people. Through three working group meetings we have refined a vision and aims for the strategy, a programme of activities through which we hope to achieve these aims, and identification of measures of success. These ideas have been shaped into this document, presented here as our Public & Community Involvement & Engagement Strategy.

2. Definitions

In the past few years there has been a growing awareness of the relevance and advantages of ensuring the public voice is heard in research or in-service development. As a consequence, there has been a confusingly large number of terms that have appeared which all refer to using the public voice or perspective in some way. In our strategy we have defined what we mean by public and community, involvement and engagement.

When using the term *public* we include patients, potential patients, carers and people who use health and social care services, and people from organisations that represent people who use services or members of the public with an interest in research. This is distinct from those who have a professional role in health or social care services.

We use the term *community* to define a social unit with commonality such as norms, religion, values, customs or identity. Communities may share a sense of place situated in a geographical area or in a virtual space through communication platforms.

involvement is defined as research carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them. It does not refer to the recruitment of patients or members of the public as participants in research. (INVOLVE @ http://www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/.)

engagement is providing the opportunity to share information and knowledge about research, in order to explore, debate and shape research. It is by definition a two- way process, involving interaction and listening, with the goal of generating mutual benefit (National Coordinating Centre for Public Engagement).

3. Vision

The vision for the ARC KSS is to be a place:

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

4. Aims

- Promote inclusive opportunities & establish a supportive culture
- Build capacity for coproduction
- To strive to be as innovative and responsive as possible in our approach to PCIE, recognising that it is a developing and organic process.
- To support the gathering of evidence of the impact and value of PCIE
- Collaboration, networking and shared learning.
- Promote awareness and understanding of PCIE and provide the skills required.

5. Programme of projects and activities

Our strategy is based on the 6 UK Standards for Public Involvement - a framework for what good public involvement should look like. We have used the standards as a guide to co-design our programme of activities through our working group and so we could learn from others and from their experience around how best to ensure success.

We will be measuring the success of the different indicators using a number of different means, including:

- Feedback from involvement opportunities (public advisors and researchers)
- Feedback about training & support
- Monitoring of PCIE activity
- Minutes of meetings
- Reports, articles & other communication
- Surveys/ad hoc interviews for more in-depth look at experiences & impact (as well as trialling co/peer research, with the public undertaking interviews)

For the purposes of the activity table below any member of the public involved or engaged with ARC KSS activities are referred to as **public members**.

Public Advisors are members of the public who have formally signed up to work with ARC KSS on an ongoing basis – see structure below

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Standard 1. Inclusive opportunities

What do we want to achieve (indicators)?	Activity (how?)	Success criteria	Monitored by (including timeline)
i. Involve the public at the earliest stage.	Development and delivery of training package & resources for researchers. Develop effective ways of ensuring opportunities are offered widely and equitably at the earliest opportunity – newsletter, website, social media, partner organisation websites, community information hubs.	Increase in public involvement at project planning stages. Feedback from public members on their experiences of being included in early discussions and feeling valued.	PCIE Group Training lead (annually) Years 1-2 (on-going)
ii. Identify and address barriers	To gain knowledge on what those barriers are to the communities in KSS through networking and research into best practice. To ensure accessibility is considered for all. This will include open and sensitive conversations about any accessibility needs and use of a clear remuneration policy.	Increase in engagement and collaboration with diverse groups across KSS as a result of identifying and reducing those barriers Public report no accessibility issues or those that arise are dealt with quickly. (see standard 4)	PCIE Group Years 1-2 (on-going)
iii. Information about opportunities available by range of methods	Create a regional network/database of individuals & organisations. Develop links with community groups, GP practices, Trust websites to promote opportunities.	Number of public and researchers linked together increases year on year. Information outlets for opportunities increased year on year.	PCIE Group Years 1-2 (on-going)
iv. Fair and transparent processes	Promote opportunities to engage with local community groups working alongside other members of the ARC Team. Raise ARC KSS profile. Promote opportunities through use of social media, newsletters, website.	New community groups are signed up each year. New members of the public are signed up each year.	PCIE Group

v. Choice and flexibility in opportunities	Develop a database of individuals experience and knowledge so people can be involved in a way that suits them and can be identified for appropriate opportunities.	Public members report appropriate matching with projects. Review of ARC KSS PCIE activity log	Years 1-3 (ongoing) PCIE Team
vi. Ensure our community of public contributors accurately reflects the diverse nature of the population we serve.	Actively recruit from groups/organisations that represent under represented areas/groups through building partnerships and engaging with their representative communities and organisations Arising issues around inclusion are acted upon within one month.	Effective processes to gather and maintain demographic data on PCIE. Increase number of diverse community organisations and support groups that are regularly contacted by PCIE team year on year. Maintain or increase diversity of public advisors across all themes.	PCIE Group (quarterly) Year 1-2 (ongoing)

Standard 2. Working Together

What do we want to achieve (indicators)?	Activity (how?)	Success criteria	Monitored by (including timeline)
i. Researchers and the public jointly define & record the purpose of PCIE activity in research projects	Production of guidance for researchers about how to work with the public – (see standard 1:i)	Public members report being involved & engaged in plans. Research plans contain details of planned PCIE activities.	Oversight Executive Committee PCIE Group Years 1-2 (on-going)
ii. A shared understanding throughout ARC KSS as to the Purpose and value of PCIE	For the inclusion of Public Members to be considered in all working groups across ARC KSS	Feedback of Public Members involvement and impact in working groups	PCIE group Years 2-3
iii. Develop project plans & activities together (researchers and public members)	Production of guidance about project planning including identifying individual needs from outset (See standard 1:i)	Range of options covered for working together	PCIE team Years 1-2 (ongoing)

iv. Ensure there is a shared understanding of roles, responsibilities & expectations, within research projects, which may evolve over time	Production of template role descriptions & responsibilities of researchers Joint researcher and public advisor training when appropriate	Research teams & public advisors report use of role descriptions. Increase in opportunities for joint training and monitoring of feedback.	
v. Recognise individual ideas & contributions & uphold decisions together	Guidance to be develop around the principles of coproduction and for these to be demonstrated and role modelled throughout ARC KSS.	The Public report change as a result of their contributions (see Standard 5 The public included as co-authors & co-presenters	PCIE group Year 1-2

Standard 3. Support & learning

What do we want to achieve (indicators)?	Activity (how?)	Success criteria	Monitored by (including timeline)
i. Designate & monitor resources to ensure & support effective PCIE	Set up a clear and simple payment process for public advisors Researchers training and resources to include: • Adequately budgeting for PCIE in their projects – use of INVOLVE PPI budget calculator Identify resources within region for pre-application funding for involvement	PCIE funding is clearly marked and ring fenced within the ARC KSS budget and funds are used appropriately throughout the financial year. Payment offered for all Public Involvement activities PCIE adequately budgeted for in projects List of sources compiled	PCIE Team Lead, Programme manager reporting to exec committee. PCIE group through feedback from prioritisation panel. Year 1-2 (ongoing)
ii. Offer a range of support to address identified needs	Individual objectives & package of training/support for each public advisor Mechanisms for supporting researchers established	All public advisors have package set up with an identified named contact – usually a PCIE coordinator. Public advisors report individual needs addressed Number of researcher/teams supported increases year on year Member of PCIE team attached to each ARC theme	PCIE Team lead reporting to PCIE group Year 2-3

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iii. Have a clearly identified point of contact for information & support	Establish generic PCIE email address PCIE team members identified as first point of contact for public advisors & research theme PCIE section developed on website For each research project to develop their own designated PCIE point of contact.	Clears lines of contact identified in project proposals. Positive feedback from public members following involvement.	PCIE group Year 1-2
iv. Develop, deliver & monitor learning opportunities in partnership	Induction sessions for new public members and advisors PCIE resources for public advisors & researchers Identify regional & national training opportunities for public advisors & researchers – to collaborate with colleagues across NIHR organisations in region. Analysis of researcher survey to identify training needs in the region Co-produced training sessions for researchers and public members.	All public members and advisors take part in induction session(s) Training & resources co-produced. Number of times resources accessed. Regional resource established Number of researchers trained in PCIE and coproduction Researchers report increase in knowledge & confidence with PCIE	PCIE Team Building Capacity Training Lead Year 2-3
v. Actively learn from others, build on & share learning	Support systems for new Public Members and Advisors to be co-designed with public advisors. For public members to be included in Early Career Researcher mentorship programme Public advisors involved in induction of new members of the public members. Opportunities for engagement with Action Learning sets across the region. Regional forum to share learning & problem solve	For new members and advisors to report feeling supported and valued. Number of times Public Advisors involved as co-facilitators of training sessions. Examples of good practise shared across region as result of regional forum. Levels of PCIE in research increases year on year.	PCIE team Year 2-3

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	PCIE panel involved in review of PCIE in research		
	Research teams monitor PCIE within their projects		

Standard 4. Communications

What do we want to achieve (indicators)?	Activity (how?)	Success criteria	Monitored by (including timeline)
i. Develop & deliver a communication plan for our involvement activities and opportunities	Co-produce a PCIE communications plan to: • promote opportunities for PCIE involvement • raise profile of ARC leading to increased trust and involvement of public and communities • promote training opportunities Develop a range of methods for communication Development of website & social media pages in conjunction with the public.	Summary of plan available Key messages are delivered in plain language & methods & routes that will reach them in good time	PCIE group Comms manager Year 1-2 ongoing
ii. Inclusive & flexible in our communication methods to meet the needs of different people	Information produced in different formats, methods, languages, thinking about accessibility at all times PCIE team supports and advises on communication between public members, ARC staff and researchers	Public members report information access needs met Public members are involved in communication outputs. Feedback from the public via website/email is positive	PCIE group Comms manager Programme Manager Year 1-2 ongoing
iii. Gather, offer & act on feedback	Information gathered & fed back about impact of involvement. Method of reporting to be co-produced with public members, researchers and ARC core team	Number of researchers, public advisors and public members asked to provide feedback increases year on year Public advisors and wider public report regular contact from research teams	Exec committee. Year 2-3

Standard 5. Impact

What do we want to achieve (indicators)?	Activity (how?)	Success criteria	Monitored by (including timeline)
i. Involve the public in the assessment of PCIE in research	Set up a Public & Community Group to review work Co-production of evaluation process for PCIE including development of feedback forms & other mechanisms for feedback Co-production of annual PCIE report	Regular collection & reporting of activities & impact shared at all Public and Community Group meetings Annual report produced	PCIE Group reporting to Programme Manager and Executive Group Year 1-2 ongoing
ii. Record agreed purpose for PCIE and its intended outcomes and revisit yearly	Co-production of PCIE strategy Project teams co-produce PCIE objectives & outcomes for their projects	PCIE Strategy produced and revisited yearly Audit of funding proposals and project outcomes with regard to the intended use of PCIE	Year 1-2 (ongoing)
iii. Collect information that will help us assess the impact of PCIE across ARC KSS	Development of indicators for impact Development of range of methods for collecting information on process and impact including doing a sample of interviews/survey for a more in-depth look	Public advisors & researchers complete interim & final report on PCIE for each project/Theme. Examples of impact recorded (including professionally & personally)	PCIE team PCIE Group Year 2-3
iv. Reflect, learn and report the extent to which the activity met intended purpose & outcomes	Publication of annual report of PCIE Annual event to celebrate PCIE Inclusion of description of PCIE in outputs Production of case studies & reports	Public Members report that their contribution was acted upon in a meaningful way	PCIE team report to Programme Manager and Executive group. Year 2-3

Standard 6. Governance

What do we want to achieve (indicators)?	Activity (how?)	Success criteria	Monitored by (including timeline)
i. Public voices are heard, valued and included in decision making.	Public contributors are involved in decision making groups	Public advisors included in Terms of Reference for relevant decision-making groups as members. Public advisor views included in decision making process in a meaningful way	Senior management reporting to executive committee. Year 1-2 (ongoing)
	The public co-design projects/become co-applicants	Projects with public co-applicants increases year on year	
	Guidance developed to ensure wider public voice is heard at Board meetings.	Increase in number of members of public attending Board and proposing questions	
	Public members participate in review of ARC research proposals through involvement in prioritisation process	Public members review each research proposal	
ii. Responsibility for PCIE is visible and accountable throughout our management structure	PCIE strategy made publicly available System for raising issues or complaints in place	Clear process for audit and accountability through PCIE group, Coproduction Theme Lead, executive committee, Board, NIHR,	PCIE group, Coproduction Theme Lead, executive committee, Board, NIHR, Year 1-2
iii. Clear and transparent process for allocation of money and other resources for PCIE	PCIE identified in the ARC budget Public advisors involved in budget allocation for PCIE	That PPIE funding is clearly marked and ring fenced within the ARC KSS budget and funds are used appropriately throughout the financial year.	Programme manager
iv. To develop a clear and transparent process for recruitment of Public Advisors	System in place to appoint public advisors reflecting inclusivity, diversity, support, training (see standard 1:iv & vi, standard 3:ii, iii & iv, standard 4:ii)	Public advisors report good experience of recruitment & appointment process	Annual review.

6. Our Structure

The NIHR **Applied Research Collaboration Kent, Surrey and Sussex Board** is the main accountable body of the ARC. It provides guidance on the overall vision of ARC KSS, including appropriate governance and management and monitors activities against the objectives. Three public advisors are board members responsible for ensuring that the strategy is an integral part of the over-arching vision and direction of the ARC.

Operational responsibility is delegated by the ARC KSS Board to the **ARC KSS Executive** which is directly accountable to the Board (reporting through the Director) and has direct control of the NIHR and co-funding resources. The Executive ensures that ARC KSS delivers its objectives, and monitors the progress of research, implementation and capacity building activities. Three panels have been established to oversee the three underlying objects of ARC KSS; Capacity Building, Implementation and Public Involvement. The panel for public involvement (The ARC KSS **Public and Community Group)** consists of **Public Advisors** who have been recruited by ARC KSS for a mixture of their wealth of lived experience, professional knowledge, professional skills, connections with local connections and their willingness to speak up for others. It is envisioned they will support the work of ARC KSS by a) providing a public perspective to the core workings of the ARC organisation mainly through the Public & Community Group and b) providing a public perspective to the aligned Theme Team helping to identify and develop research priorities. There will be 16 members (2 aligned to each Theme) and will be representative of our local population and identified priority groups. Future plans include representation from local community groups and organisations to join this group.

Each ARC Theme has a small co-ordination group including clinicians, commissioners, public advisors and the research team to co-ordinate and monitor theme activities. Theme Leaders are accountable to the Director and we will establish standardised reporting mechanisms, including for PCIE, to ensure that the ARC Director and Executive Group receive timely and appropriate information.

7. Partners and Collaborators

A unique characteristic of ARCs across the country is their focus on working collaboratively with academics, health and social care providers and the public to produce quality, relevant and ready to use research. This focus provides the infrastructure and the culture in which Public Involvement has the opportunity to be a real partner in the work of ARC KSS. This started at the application process stage by consulting with public and community groups, along with service providers and academics, on the priorities for the area and the subsequent development of our Research Themes and has extended into members of the public becoming partners with the Research Theme Teams as Public Advisors.

We have worked to develop positive working relationships with other NIHR research bodies in the region, and are now a co-contributor in the Regional PPIE Forum along with RDS-SE (Research Design Service – South East) and KSS-CRN (Kent, Surrey, Sussex- Clinical Research Network). This forum aims to ensure a joined-up approach to public involvement, engagement and co-production across the region, through sharing ideas and best practice, offering a coordinated approach and working together to develop solutions to issues and challenges that are common across the region. Membership includes other research organisations in the region, community bodies such as Healthwatch, Public Involvement specialists from other organisations,

researchers from Higher Education Institutes (HEI's) and public members. One outcome from this regional collaboration is the development of a Regional Research Interest Group for BAME communities.

The Academic Health Science Network (AHSN) has been a significant contributor to ARC KSS, offering access to specialist teams as well as funding four Implementation Leads. These roles have been able to seek out and engage with potential partners across the region, specifically service providers and community groups, who they can link up with researchers from the HEI's. Through having these feet on the ground to seek out potential collaborations it is planned this will lead to a wider group of public members and communities being approached to be involved in our research.

Working collaboratively with the wide range of partners across the region that have stated their support of the ARC, gives us the opportunity to share opportunities and connections together. Through sharing these networks, we can extend the reach of our learning and development opportunities, our ability to reach more diverse communities, access professional skills of those within our networks and the inclusion of a greater number of public contributors. The ARC performs the function of facilitating and connecting these opportunities.

Our partners include:

- Health Service Providers
- Local Authority providers
- Commissioners
- Academic Institutes
- ASHN
- Service users/Patients/Carers/Public
- Community Groups
- Clinicians
- Independent Health or Care Providers

7. Resources

The ARC KSS Public and Community Involvement and Engagement is led by the Strategic Academic lead of Nadia Brookes, Theme Lead for Coproduction. However, the day to day operational function is led by a dedicated PCIE Team resourcing of which is as follows:

Public & Community Involvement Team Leader	0.8 wte	Leads ARC KSS PCIE operations; coordinates and implements strategy; KSS point of contact for regional, national forums, NIHR Centre for Dissemination
Public & Community Involvement Coordinator	1.0 wte	Helping to support and embed Public Involvement activities throughout ARC KSS and all its projects
Public & Community Involvement Coordinator	0.2 wte	National social care
Programme Manager	0.1 wte	PCIE operations management
Research Theme Lead	xx	Strategic PCIE

The PCIE Team have recruited and support a panel of 13 Public Advisors (to increase to 19). 3 are Public Advisors to The Board and 16 will be Public Advisors to the eight Themes (2 per theme). The PCIE budget is split between resourcing the Core PCIE elements, resourcing the Public Advisors in their Theme roles and training needs.

In line with the National Standards for Public Involvement we believe it is good practice for public contributors to be offered remuneration for their involvement as this reflects that their time, knowledge, connections and experiences are valued. We follow our host Trust's service users and carers payment policy. This details levels of activity payments, travel expenses, and other expenses such as carers time or child care fees. Using the Trust's payroll system to process the claims allows us to be clear and transparent about the implications for tax, national insurance and pension contributions.

8. Review and monitoring

It will be the responsibility of the Public & Community Group to review this strategy on an annual basis. This will feed into the annual reporting to NIHR about Public involvement activity in the annual report.

One of our aims is to be innovative and responsive. Responsive to the pressures and demands of the community we represent. To this end, part of the reviewing process will be to ensure that we are still responding to the current needs of the local public and community along with the needs of our local health and social care providers.

Changes to the policy will be referred to the executive Group for agreement and implementation.

Glossary

AHSN	Academic Health Science Network
ARC KSS	Applied Research Collaboration Kent, Surrey and Sussex
HEI	Higher Education Institutes
KSS-CRN	Kent, Surrey, Sussex- Clinical Research Network
NIHR	National Institute for Health Research
PCIE	Public and Community, Involvement and Engagement
RDS – SE	Research Design Service – South East

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