

Involvement Strategy

Bringing patients, service users, carers, researchers and the public together for better health and social care

With special thanks to more than a hundred people living or working in south London who co-designed this strategy via questionnaire responses, workshops and discussions from September 2020 to February 2021.



Contents

1. Summary	3
2. What is this strategy document about?	5
3. Our history of involvement	6
4. Equality, diversity and inclusion	8
5. Who is involved and how we report	10
6. How we work: our core principles	13
7. What we want to achieve	14
8. Activities and timing	15
9. Resources	18
10. How will we know we are making a difference?	19
11. Keeping in touch	20

Appendix and further information

1. A note on language	21
2. ARC South London partners and collaborators	21
3. References	22

1. NIHR ARC South London Involvement Strategy (2019 – 2024) – Summary

Involvement and the work of NIHR ARC South London

At the NIHR Applied Research Collaboration (ARC) South London our research covers health and social care for people of all ages and backgrounds. We recognise the value in bringing together people with experience using health and social care services in south London with our researchers. The views and experiences of patients, service users, carers and other local people must inform our research – from choosing what to study, through to how we plan the studies, carry out the research and understand our findings. We also need to let people know what we have found and help research findings to improve health and care services. Our work is funded by the National Institute of Health Research (NIHR) and we use the NIHR’s definition of ‘involvement’ in research, as ‘research being carried out “with” or “by” members of the public rather than “to”, “about” or “for” them.

About our involvement strategy

This strategy sets out how we will involve the public in our work – by public we mean patients, potential patients, carers and people who use health and social care services, as well as people from organisations that represent people who use services. We worked with a wide range of people from diverse backgrounds to develop the strategy and used questionnaires, a series of workshops, as well as looking back at how we involved patients in our work in the previous organisation, the Collaboration for Leadership in Applied Health and Care (CLAHRC) South London. We want this document to be regularly used and updated, informed by the experiences of involving the public in our research and share our learning. We understand that involvement may be challenging because it takes time, especially to develop trust and build relationships. Researchers also need to listen to patients and the public, service users, carers and community groups, and be willing to let this influence research strategy, planning and practice. We also want to establish long-term, collaborative relationships with local people and communities, rather than engaging people just to help with specific tasks.

Equality, diversity and inclusion

Equality, diversity and inclusion is a central theme in the strategy. We aim to work with groups across the nine protected characteristics covered by the Equality Act 2010 (age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation). However, in relation to our core research, we recognise that health outcomes are much worse for people who are Black, Asian and minority ethnic and people with disabilities in particular, and they have been worse affected by Covid-19. We have chosen initially to prioritise involvement from these groups. The killing of George Floyd and the Black Lives Matter movement have highlighted similar issues in the UK as the USA and highlighted structural racism and how this worsens inequalities. These inequalities are magnified locally because of the diversity of our population from Black, Asian and other minority groups.

Who is responsible for putting the involvement strategy into practice?

The senior management of the ARC (the ARC director, on behalf of the ARC Executive and ARC Board) have overall responsibility for putting this strategy into practice. Patient, service user and carer and community members from a wide range of groups will be members of the ARC Executive and Board, reflecting the importance of

involvement in ARC governance and everyday practice. The leads of each research theme are also responsible for effective involvement within their theme. We will also have four new groups to help ensure effective involvement: the Involvement Advisory Group, ARC South London Public Research Panel, Involvement Learning Network and the Equality, Diversity and Inclusion Working Group. These structures including the implementation and involvement team, the involvement coordinator and patient, service user and carer champions within each research theme, will help make sure there is effective co-production, involvement and evaluation across all research activities.

What will we do?

We will provide support for researchers, such as guidance on best practices and how to communicate without clinical or research jargon, and the use of clear language. We will also offer training and opportunities for shared learning. We will support patients, service users, carers and local people who contribute to our research with training and guidance, enabling them to gain more knowledge to support research applications. We will also find out the best ways of supporting and working with diverse communities who are not usually involved in research, so they can help shape our work. Involvement activities can be extremely time consuming and require a specialist set of knowledge and skills. The ARC researchers are supported by the core Implementation and Involvement Team, and all themes (research and cross-cutting) are required to adequately resource their own involvement activity.

How will we know we are making a difference?

Involvement activities will be monitored by the ARC Executive and ultimately the ARC Board. Each theme will report on their activities through their progress reports and through case studies. We will provide 'best practice' examples of case studies to help guide themes. We will also seek the views of patient, service user, carer, and public contributors, of community partners and of research staff in a range of projects to identify what has worked well, or not so well from their perspective with regard to involvement, so as to learn continuously and strengthen good practice.

Keeping in touch

Effective communication is essential to the involvement strategy and it has several aspects – for example, the involvement coordinator and research teams need to use different ways to reach out to local people and communities to encourage them to get involved. We will produce materials in plain English to explain research structures and processes. When people have been involved in our research, we will let them know about progress and about the impact they have made. We will do this in plain English or whatever way is most relevant to them, and in a timely manner. We also aspire to lead the way with best practice, and communication beyond our ARC community to wider groups, nationally and internationally.

2. What is this strategy document about?


Bringing patients, service users, carers, researchers and the public together for better health and social care

The NIHR Applied Research Collaboration (ARC) South London aims to improve the wellbeing of people living and working in south London through health and social care research addressing local needs and priorities.

To make sure that the ARC's research delivers positive change, it is essential that patients, service users and carers are involved in the ARC's research and that we engage with the wider public and community.

“I was already aware about some of the issues that we were experiencing in the community... I was able to empathise. I was able [...] to make sure that the researchers were aware of the issues [...] that's what I thought very valuable, was and it certainly made me feel that I was actually contributing effectively.”

A patient and public involvement member at our
Active Involvement in Research Day (AIRD) 2020



The ARC's research is designed to improve health and social care for people of all ages and backgrounds. As a research organisation, we recognise the vital importance of bringing together people with direct lived experience with our research teams. The unique perspectives of patients, service users, carers and other local people must inform our research – from choosing what to study, how to design and carry out research, understanding our findings, through to letting people know what we found and helping to make sure that research findings are used to improve practice.

Our approach to involving the public in our research is informed by a report published by the ARC's funders, the National Institute for Health Research (NIHR): [Going the extra mile: Improving the nation's health and wellbeing through public involvement in research](#)¹ (2015). In that report, the NIHR set out their vision that by 2025, people using health and social care and increasing numbers of the public, should be able to contribute to research, helping to identify priorities and questions and informing the design and development of innovations. The [UK Standards for Public Involvement](#)² were produced to help identify and strengthen good practice, with co-production of research encouraged, and more emphasis on equality and diversity.

This strategy document highlights the importance of public involvement in research and how we will make sure it is prioritised and valued at NIHR ARC South London. We want to work with local people to strengthen the involvement of patients, service users, carers and wider public, and to increase community trust and interest in taking part in research. Ultimately, we want to make sure that through this involvement our research is carried out “with” or “by” members of the public, rather than “to”, “about” or “for” them.


We have worked with a wide range of people from across south London's diverse communities to develop the strategy. They identified three core principles (see section 6) as being particularly important:

- i. Equality, diversity and inclusion
- ii. Relationship building
- iii. Willingness to change

This strategy is framed around those three principles. We want this strategy to meaningfully influence our work at the ARC. We want it to be a 'live' document, which will be used, regularly updated, debated, and shaped by people with lived experience. We will evaluate how effective it is in helping us achieve our aims.

“Working with organisations to involve people completely changed our research question... They have been fantastic in terms of thinking through how we’re going to analyse our data. And together, we put in a submission... about how voices had not been heard... I would never do research again without having a partnership and collaboration with organisations and all the representatives that they can bring... It’s been an absolute joy.”

A researcher who helped to co-produce this strategy



A note on language and accessibility

This strategy is written for anyone interested in our approach to involvement at the ARC. However, it is a detailed document and uses terminology specific to this area. We will therefore develop a plain English summary of the strategy’s aims for the ARC’s website. In discussing involvement in health and social care research, it can be difficult to find words that everyone feels comfortable with or understands in the same way. For an explanation of the language and key terms used in this strategy, please see the appendix.

3. Our history of involvement

The ARC South London builds on the work of a previous NIHR-funded research organisation, the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London, which ran between 2014 and 2019. At the CLAHRC, there was a strong culture of researchers working with local people. There were many active public and patient contributors working within the research themes, and researchers working to champion involvement. The research themes were supported by a small public and patient involvement team. This team included service user researchers who combined knowledge based on their lived experience with academic skills, and undertook research on public and patient involvement. They worked alongside a coordinator, whose main role was to support the research themes with involvement, offering guidance on matters such as payment, good practice, and involvement resources.

Involvement was part of the CLAHRC’s governance, with a public and patient Strategic Oversight Group bringing together public and patient members and research staff. Other involvement activities at the CLAHRC included an annual Active Involvement in Research Day and a public and patient newsletter.

At the ARC South London, which launched in 2019, we are building on these strong foundations and now have an important resource in a theme dedicated to patient and public involvement (PPI) research. These ‘enablers’, plus a wider environment in which

the value of public involvement is increasingly recognised, give us a great opportunity to deliver meaningful and innovative involvement, with more emphasis on equality, diversity, and inclusion. In addition, a new area of enquiry at the ARC is social care research, an academic area with a tradition of involving people who use care services and carers (family and friends) in research.

New resources to help day care centres reopen safely after lockdown

During the first lockdown in 2020, most social care day centres had to close. When they were allowed to re-open, they were faced with the task of making their services safe for service users and staff. Working closely with local providers, service users and the public, the ARC's social care researchers produced a new resource to support day centre managers, [Helping adult day centres to 'unlock lockdown'](#). The team also worked with the Social Care Institute for Excellence (SCIE) to produce national guidance.

“Day care services in south London provide a vital service in helping people with significant care and support needs to remain living at home – for example, people with severe dementia, people with significant medical equipment needs, and people with severe mental health problems. It was vital that they were to open again, and to do so safely.”

Professor Jill Manthorpe, the ARC's social care theme lead



The Green, Nunhead
Community Centre

In 2019, at the start of the ARC South London, the new implementation and involvement (I&I) team commissioned an external rapid review of involvement and diversity and inclusion activities. This review considered how effective involvement had been in the CLAHRC, and how that could be built upon and adapted for the new ARC. The review explored the experiences and views of those with key roles within the CLAHRC and provided a discussion document to inform the development of this strategy. One of the main outcomes of the review was that we recognised we needed to further increase the role of patient, service user and public involvement in our governance. Another was that our involvement activities needed to span the lifetime of each research project (from start to finish), rather than just at particular stages in the research process.

The ARC started the engagement and consultation phase of the involvement strategy development work in the summer of 2020, beginning with questionnaires distributed widely among our service users, carers and community groups. More than 40 responses were received. The outputs from the questionnaire responses were then fed into a series of online workshops with the public, researchers and involvement experts in the autumn of 2020, and taken forward by the strategy working group.

During this time, we recognised the difficulties in safely involving people who could not easily communicate online (except through groups and networks to which they might already belong). There were others, though, who had found it hard to get to meetings physically and preferred phoning in or using the internet. Across the ARC, we will continue to look at ways to involve more people with varied communication, language and access needs.



Some of the participants at our online Active Involvement in Research Day 2020

4. Equality, diversity and inclusion

Since the start of the ARC in October 2019, issues related to equality and diversity have been at the heart of public debate around the world. In the UK, the Covid-19 pandemic has disproportionately affected certain groups in society. In addition, after the killing of George Floyd, the Black Lives Matter movement has highlighted similar deaths in the USA, UK and elsewhere. Both have highlighted the continuing existence of structural racism and how this worsens inequalities. In south London, these inequalities are magnified because of the diversity of our population from Black, Asian and minority ethnic groups³.

In the ARC's application for NIHR funding, equality, diversity and inclusion (EDI) were highlighted as key priorities, to be supported by a new dedicated lead for equality, diversity and inclusion. Our EDI strategy has two areas of focus:

- To make sure that at an organisational level, the ARC is prioritising EDI
- To make sure that EDI is a central component of this involvement strategy.

This reflects our aim of building broad community involvement with diverse communities in south London. To achieve this, we aim to work with groups across the

nine protected characteristics covered by the Equality Act 2010 (age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation).

However, in relation to the ARC's core research, we recognise that health outcomes are much worse for people from Black, Asian and minority ethnic groups and people with disabilities in particular. We have chosen initially to prioritise involvement from these groups.

How the ARC has responded to EDI issues and the pandemic

Early in the Covid-19 pandemic, it became clear that the disease and its effects on society were having a disproportionate impact on Black, Asian and minority ethnic groups and deprived communities, and intensifying ongoing health inequalities. To understand and document these health, social and economic impacts, the ARC held an online event in April 2020 on how Covid-19 affected under-served groups. A report from the event was submitted to UK Parliamentary Women & Equalities Committee and [key findings were published in the BMJ](#).

We then established an EDI working group (co-chaired by the EDI Lead and the ARC Director) in June 2020. This has:

- Established a Covid-19 Public Research Panel to give people who are less likely to be involved in research a much greater say in our work (pictured below)
- Reviewed how ARC themes are collecting data relating to people from Black, Asian and minority ethnic groups, soon to be extended to other protected characteristics
- Developed equality monitoring tools for the ARC's Board and Executive members and agreed to increase the diversity of both governance structures through greater community involvement
- Ensured diverse community engagement in new seminar series (February 2021 onwards).



The online event in April 2020 provided a template for involvement taken up by other ARC researchers. For example, our maternity and perinatal mental health researchers organised two online events bringing together patient and public involvement and engagement leads, researchers and service users from diverse ethnicities to identify key issues, including the racism and 'postcode lottery' faced by some pregnant women, and exploring the impact of the pandemic on services. Findings were shared in BMC

Public Health and a blog was co-produced by service users and researchers for the ARC website.

“Early in the discussion, researchers were asked [...] ‘How are you going to hear the real issues from those living in the most disadvantaged areas or being discriminated against?’ The clear message was that researchers need to involve these groups in order to hear how it really is. Peer research using participatory methods was recommended as a way to empower communities and enable them to have a voice.”

Mary Newburn et al in Engaging local women in maternity research during the Covid-19 pandemic

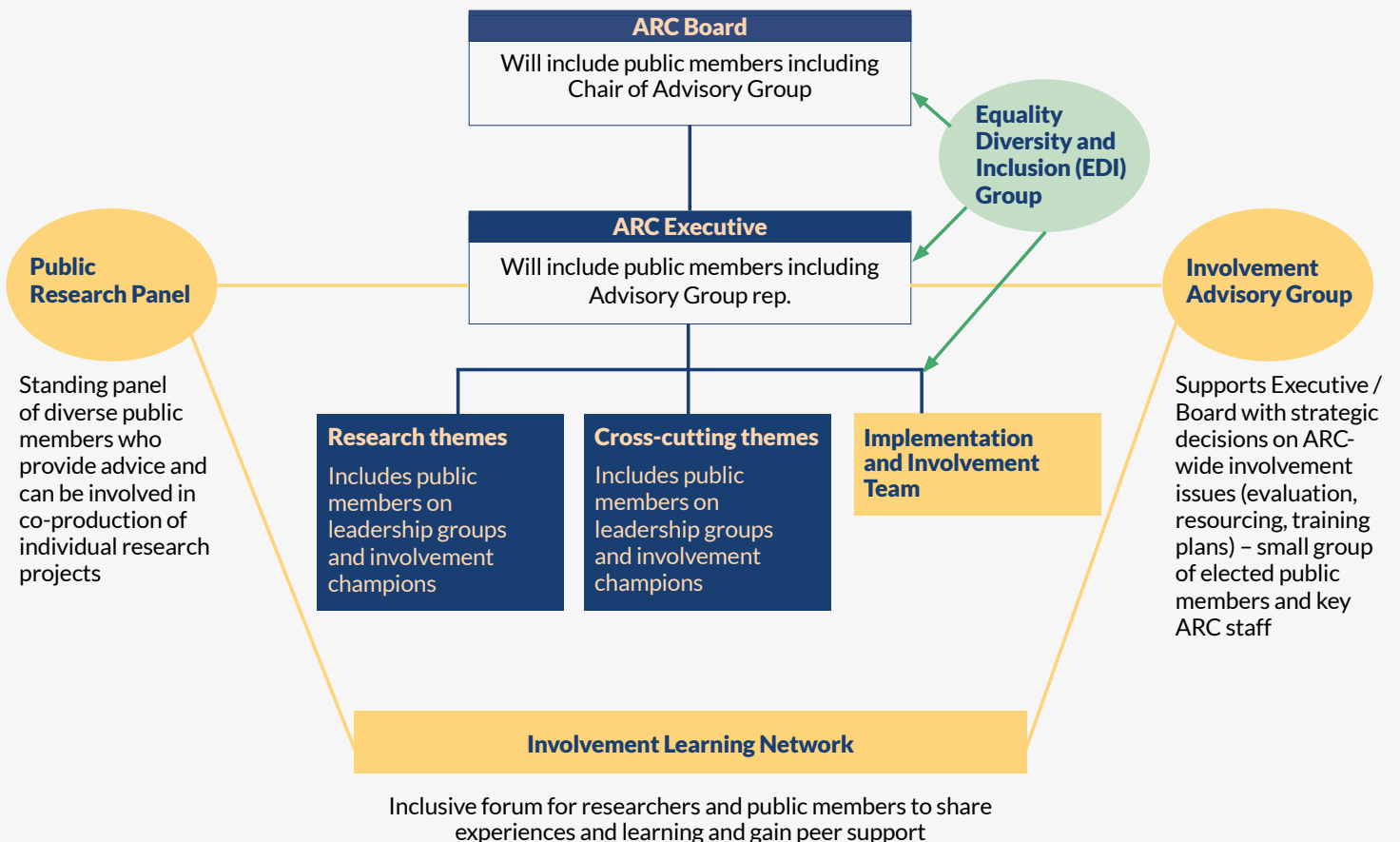
“What needs to be understood is that Black mothers are out there. Black mothers want to be engaged. And we want to be engaged in a way that leads to actionable outcomes and an uplift in our communities. What we don’t want is to be exploited.”

Agnes Agyepong, ARC South London Covid-19 Public Research Panel member in Service user involvement in maternity and perinatal mental health research

5. Who is involved and how we report

Involving patients, service users, carers, and the public is integral to the ARC’s work. In order to deliver this involvement strategy, we need effective leadership and clear accountability across the organisation.

ARC South London – proposed involvement structures



ARC governance structures

The ARC director, on behalf of the ARC Executive and ARC Board (the key governance and oversight bodies of the ARC), has overall responsibility for putting this strategy into practice.

The responsibility for effective involvement among the ARC's themes sits with each theme lead. Support structures, including the cross-cutting implementation and involvement team, and patient, service user and carer champions within the research themes (and cross-cutting themes where appropriate), will help make sure there is effective co-production, involvement and evaluation across all the ARC's research activities.

How involvement will work at ARC South London

We expect all ARC researchers to be leaders in involvement. However, we recognise the importance of the ARC senior management's influence on this work. ARC Executive and Board members will therefore act as 'involvement sponsors'. We also plan that an ARC Executive member and Board member will lead a discussion on involvement every six months. There will be patient, service user and carer and community members from a wide range of groups on the ARC Executive and Board, reflecting the importance of involvement in ARC governance and everyday practice. These new members of the Board and Executive will not be staff employed by any of the ARC's partner organisations (see appendix for list of partners).

Our governance meetings will ensure that involvement is actively sought and taken up, not just a 'tick box' exercise. For example, sufficient public, patient, service user and carer members or community stakeholders will be invited to the meetings so that people do not feel isolated. We will consult on the time and format of meetings to offer more opportunities for active participation and personal stories. The decisions and work of the ARC Board and Executive will be fed back to the public and available via our website and newsletters.

The ARC Board and Executive meetings will lead on:

- Priority setting – ensuring research theme priorities continue to represent important areas for local people (for example, we have seen priorities change in relation to the Covid-19 pandemic)
- Monitoring and evaluation – ensuring all themes have effective involvement mechanisms in place, which are leading to greater impact
- Dissemination and communication of research findings
- How involvement can inform the translation of research into local health and social care practice
- Training to ensuring all members have a clear understanding of the role of involvement and the need for equality, diversity and inclusion with minority group representation in governance.

Research theme leads should provide strong leadership on involvement.

This includes making sure:

- Diverse contributors are represented in the theme's leadership group
- A diverse set of involvement champions support the theme to promote best practice

- Involvement reflects equality, diversity and inclusion among service users, carers, patients, and communities
- Involvement and engagement, including EDI considerations, are a standing agenda item in all theme meetings
- Involvement is built into all aspects of the research process – including project planning, costing, monitoring and evaluation, schedules of work and allocation of staff time
- Funds for payment of public, patient, service user and carer contributors are available. Involvement-related training and development needs are addressed, for all theme members.

Dedicated involvement structures

(see proposed involvement structures diagram above)

As part of this strategy, we are proposing three key structures (see proposed involvement structures diagram above, coloured in yellow) to support involvement in the ARC:

- **An Involvement Advisory Group** – a small group who will advise the ARC Executive and Board on best practice in ARC-wide involvement activities, including capacity building, and evaluation. Members will also help themes to explore how involvement might be strengthened, but will not advise on individual research studies (see ARC South London Public Research Panel below).
- **ARC South London Public Research Panel** – to provide expert, diverse input and advice, and to support co-production for individual research studies from start to finish, and to propose new ideas for research. This panel was formed as the Covid-19 Public Research Panel in 2020 to support the ARC with Covid-related research. We anticipate that it will evolve into a permanent resource.
- **An Involvement Learning Network** open to all ARC researchers, public contributors and collaborators with the ARC (see appendix for ARC partners) – this will provide an inclusive space to share experiences of involvement, learning, good practice, engagement, challenges and suggestions. It will also join up and strengthen relationships with other involvement activities in south London, for example those in university departments and the NIHR Biomedical Research Centres.

These three structures will interconnect with each other, and with the ARC's EDI working group, and will be continually evaluated. They will also work closely with the ARC Executive and Board public members.

Providing support for involvement activities

The ARC's implementation and involvement (I&I) team is responsible for delivering and coordinating involvement across the ARC, and for promoting good practice and a culture that embraces involvement. It will work with the communications team to help share information and ideas with local communities.

An involvement coordinator, Savi Hensman, will support this work across all ARC themes, through developing and sharing guidance, responding to requests for advice or information, and supporting researchers in deepening relationships with local service users, carers, patients, and communities. They will also arrange ARC-wide involvement-related events, including an annual Active Involvement in Research Day, maintain a

database of relevant south London groups, produce a quarterly e-newsletter, and assist in monitoring and evaluation.

An equality, diversity and inclusion (EDI) lead, Dr Josephine Ocloo will help to embed equality, diversity and inclusion in involvement-related and other aspects of the ARC's work. This includes jointly leading an EDI Working Group with the ARC Director and facilitating the ARC South London Public Research Panel (outlined above).

Each ARC research theme will have an involvement champion – a member of staff or paid public consultant who will champion involvement within the theme. In this role they will: support involvement contributors, be a point of contact for people interested in being involved, make sure that documents provided to public contributors are clear and understandable, encourage good practice, and help to resolve difficulties.

The involvement champion role will be properly valued – with time allocated, and a clear role description – to make sure that they can build long-term trusting relationships with public contributors to strengthen research. As with all other roles, the champions should reflect diverse communities in south London.

6. How we work: our core principles

We have worked with a wide range of people from across south London's diverse communities to develop this strategy. Through a series of co-production workshops, three core principles have emerged:

● **Equality, diversity and inclusion:** everyone's lived experience is unique, and is informed by multiple characteristics. Making sure that communities who are under-served by research and who face inequalities in health and care are properly represented in the research process is vital. At the ARC, it is essential that we involve and learn from diverse groups. We will support all ARC's themes by helping them to involve a broad range of individuals and communities, to enrich their research activities.

● **Relationship building:** meaningful public involvement takes time, especially to develop trust and build long-term relationships. Researchers need to listen to patients, the public, service users, carers and community groups, and be willing to let this influence research strategy, planning and practice.

Engagement should be based on long-term, collaborative relationships with local people and communities, not specific short-term tasks. We will need to work to sustain such relationships and a collaborative culture. This will provide a firm foundation for strengthening involvement.

As such, involvement input will be prioritised, respected, and remunerated. It is also our responsibility to respect this relationship by putting in place structures and governance/oversight/evaluation arrangements to make sure involvement activities are effective and deliver desired goals.

● **Willingness to change:** ARC researchers should be willing to change plans and adapt research in response to what people say and be flexible on how people may want to be involved, even if this is not what was expected or wanted. This is real involvement. We will use shared learning networks and case studies to show how research processes, directions and outcomes have been improved, to demonstrate the positive impact

of meaningful involvement. This needs to happen across the ARC research agenda. Our ARC will encourage research ethics committees and funders to adopt a flexible approach, which strengthens involvement and co-production.

We will continuously evaluate our progress and develop an Involvement Advisory Group (see above) to make recommendations to the ARC Executive and Board on developing a measurement framework. We will also introduce end-of-project reports for all research studies to demonstrate the role of involvement.

Ultimately, we need to consider changes to the way in which the ARC operates, such as adapting the working of Executive and Board to be more inclusive and open to diverse views and perspectives.

Evaluating involvement in palliative and end of life care

Through focus groups and interviews with public members and researchers, the ARC's palliative and end of life care research theme evaluated their involvement strategy. This identified a number of issues including building long-term relationships, being aware that emotional support may be needed when talking about sensitive topics, and being able to work flexibly with people living in unpredictable circumstances. Staff and public members shared their findings in the journal Palliative Medicine.

7. What we want to achieve

The ARC's implementation and involvement team will lead the involvement and EDI strategies, and provide support, guidance, training, monitoring and evaluation. They will also co-ordinate peer-support, sharing and learning across the ARC and work closely with ARC's capacity building theme, responsible for training activities, to offer a framework for involvement that can be tailored by ARC research themes and projects.

Support for ARC researchers:

- Providing guidance – for example on best practices, research findings on involvement and EDI, how to communicate without jargon and using clear language. Signposting to wider support available from the NIHR Centre for Engagement and Dissemination, other ARCs and national networks
- Developing / ensuring access to training for researchers and others in the themes (including generic training for all researchers, and more in-depth development for theme leads and involvement champions)
- Supporting the role of involvement champion – with time allocated as well as bespoke training and role description
- Access to professional development opportunities, including conferences
Involvement Learning Network – a network for peer support and shared learning
Developing short courses or other innovative participatory methodologies for working with the public and diverse communities.

Support for patient, service user, carer and public members / contributors:

- Providing guidance – on being involved in various stages of research, including preparing plain English summaries

- Enabling public, patient, service user and carer contributors to gain knowledge to support research applications when needed, for example signposting to background reading and to experts
- Clear recognition of the work of involvement contributors / members – including letters of engagement/recruitment, written reports on their activities, acknowledgement of development of research skills
- Training for people to become expert “participatory” or “peer researchers” – in addition to valuing a broad range of diverse experiential knowledge, we may want to complement this with contributors who themselves have knowledge and skills in research practice – for example, service user/carers researchers. This will require the development of robust processes for identifying, training, supporting and funding people to develop their skills and expertise
- Involvement Learning Network – a network for peer support and shared learning
- Exploring the best ways of supporting and working with diverse and under-served communities so they can help shape ARC research.

8. Activities and timelines

Area of activity	Specifications	Due by
1. ARC strategy development	1.1. Plan and begin co-design process for involvement strategy: <ul style="list-style-type: none"> ● EDI listening exercise (see 1.2 below) ● Survey (completed in Sept 2020) ● Active Involvement in Research Day (held in Sept 2020) ● Involvement workshops (held in Oct-Nov 2020) ● Involvement working group (established in Dec 2020) 	April 2020
	1.2 Hold online listening event to identify key issues for ARC and beyond arising from from unequal impact of pandemic on diverse groups	April 2020
	1.3 Final involvement strategy to be approved by ARC Board & submitted to NIHR	March 2021
	1.4 Strategy to be evaluated and updated at east every 12 months	March 2022
	1.5 ARC leadership team to conduct a listening exercise / refresh of the “research needs articulation” exercise involving a diverse range of local people and communities, in order to determine potential future research priorities for the ARC and its themes, and broader local research activities.	Sept 2022

	1.6 ARC leadership team to plan for diverse involvement in future ARC or similar (post-2024 research) applied health and care research proposals	Sept 2023
2. Governance and accountability arrangements	2.1 EDI working group set up	July 2020
	2.2 Identify sponsor for involvement at Board level (Ray Chaudhuri)	Dec 2020
	2.3 Identify involvement sponsor at Executive level (Natasha Curran)	Jan 2021
	2.4 Board and Executive meetings to have EDI and involvement as standing items	June 2021
	2.5 Establish involvement and community stakeholder member representation on both Board and Executive	Sept 2021
	2.6 All themes to have outlined their own involvement governance arrangements, including local champion and mechanisms to ensure diversity	Sept 2021
3. Establishing new PPI structures	3.1 Establish implementation and involvement team	April 2020
	3.2 Set up (Covid) Public Research Panel	Jan 2021
	3.3 Complete Terms of Reference (ToR) for Involvement Learning Network and Involvement Advisory Group	June 2021
	3.4 Begin recruitment for Involvement Advisory Group	July 2021
	3.5 Establish Involvement Learning Network	July 2021
	3.6 First meeting of Involvement Advisory Group	Sept 2021
	3.7 Business plan for continuation of public research panel	Sept 2021
4. Capacity building	4.1 Provide guidance and links to resources on involvement during pandemic	June 2021
	4.2 Develop role description for involvement champion	June 2021

	4.3 Survey theme leads and involvement members re: current involvement practices, needs and requirements	Sept 2021
	4.4 Understand current best practice and identify and develop guidance, resources and training on involvement for: i) Theme leads ii) all ARC researchers, and iii) involvement members	Dec 2021
	4.5 Co-design development pathways for public contributors to develop more in-depth expertise, for example in developing grant applications	Jan 2022
	4.6 Further strategy for capacity building to be developed and benchmarked / approved by Involvement Advisory Group	Jan 2023
5. Resourcing	5.1 Recruit to new involvement and implementation manager post (based at the Health Innovation Network)	March 2021
	5.2 All themes to have identified dedicated time for involvement champion role, and resource to remunerate public members	Sept 2021
6. Monitoring and evaluation	6.1 Advisory / expert group to make initial recommendations to ARC Executive & Board re: a measurement framework	Oct 2021
	6.2 Involvement measurement framework to be signed off by ARC board	Dec 2021
	6.3 Introduce “end of project reports” for all research studies to demonstrate how involvement has strengthened the research	Oct 2021
	6.4 Use impact case studies to support evaluation – including learning from failures, and present at our Active Involvement in Research Day	March 2022
	6.5 Evaluate overall involvement throughout life of ARC	June 2024
7. Communications	7.1 Regular involvement newsletters to be produced	Dec 2019
	7.2 I&I team and communications team to identify bestpractice involvement case studies and impact examples	Sept 2021

7.3 Communications team to work with themes and I&I team to expand dissemination of research findings to our diverse communities using a range of channels and engaging formats of materials in order to reach national and international audiences

March 2022

7.4 Develop regular feedback mechanisms between our ARC involvement structures, Executive, Board and diverse communities to further develop understanding and best practice (linked to evaluation framework)

March 2022

9. Resources

Current resources

ARC South London has an implementation and involvement team which will oversee the implementation of this strategy. This has two co-leads, both with substantive roles at the Health Innovation Network, south London's Academic Health Science Network, and two posts: a 0.8 patient and public involvement coordinator and 0.4 EDI lead. The team is also supported by a senior researcher helping to strengthen equality, diversity and inclusion at King's College London. The team are:

- Dr Natasha Curran, implementation co-lead, medical director, Health Innovation Network
- Zoë Lelliott, implementation co-lead, deputy chief executive, Health Innovation Network
- Savitri Hensman, involvement coordinator, ARC South London, King's College London
- Dr Josephine Ocloo, equality, diversity and inclusion lead, ARC South London, King's College London
- Professor Ann McNeill, Vice Dean (Culture, Diversity & Inclusion), Institute of Psychiatry, Psychology & Neuroscience, King's College London.

There is a non-pay allocation (£10,000 in 2021) to support activities, such as payment for involvement. Each theme also has a dedicated budget to support involvement activities, including payment.

Resourcing enhanced involvement

Involvement activities can be time consuming and need a specialist set of knowledge and skills. To deliver its ambitious vision for involvement, the implementation and involvement team will need to work to secure extra resources to support delivery, for example of the ARC South London Research Panel, but it is recognised that this will be challenging.

In the CLAHRC when extra funding was secured it was held centrally. Research themes could then bid for this funding to support involvement activities. This helped to generate creative approaches to involvement such as:

- The maternity theme developed networks led by service users using Facebook and hosted events. Service users and carers evaluated public involvement in the palliative care theme and were involved in grant applications.
- We held workshops for service users, carers, public representatives and PPI champions, to develop their skills.

The implementation and involvement team will explore ways to continue this approach at the ARC.

10. How will we know we are making a difference?

Our public collaborators must be able to answer the question: ‘What’s the point of my involvement?’ People getting involved in health and social care research are often sharing experiences from vulnerable times in their lives, on matters close to their hearts. Demonstrating real change, not only in research, but also on delivering improvements in health and social care-related practice, can encourage future involvement.

“When you’re bringing people in to say why you should be involved as a PPI member, say “Our work is aiming to make it better for other people.” That simple reference point will help people understand that their role will serve a purpose. And it doesn’t happen overnight, but it will contribute to change for everyone.”

A patient and public involvement member involved in developing this strategy

Monitoring involvement activities and performance at the ARC

Monitoring involvement activities and performance should be integral to management and oversight within the ARC, and therefore overseen by the ARC Executive and ultimately the ARC Board.

The implementation and involvement team will report to the Executive annually on progress in putting the strategy into practice, addressing monitoring and evaluation at theme and ARC-wide level, and providing examples of how involvement has made a difference.

At the research theme level, theme leads will be responsible for ensuring plans, structures and resources relating to involvement are in place and are regularly reviewed in ARC’s bi-annual theme progress reports.

In addition, the ARC’s annual report to the NIHR includes feedback on involvement activities and outcomes. This must be provided at theme level, as well as for the ARC as a whole, and include the use of impact case studies. Individual end-of-project reports must also cover how diverse involvement was achieved.

Developing a robust measurement and evaluation framework

We propose that the Involvement Advisory Group will lead on developing a robust measurement and evaluation framework, with input from the PPI research theme. We will draw on the [NIHR National Standards for Public Involvement](#), as well as emerging knowledge in this field, while adapting to local needs, to avoid a ‘tick-box’ approach.

We will use appropriate quantitative measures to monitor involvement across the ARC. These include the:

- number of research projects with public, patient, service users or carer, or community involvement
- number of grant applications with public members
- number of public members involved
- number of public members who participate in training.

However, we do not want to emphasise increasing the numbers involved for its own sake, as then involvement will become superficial. Instead, we want to emphasise the quality of involvement – for example, the depth of our listening, our responsiveness and the sustainable nature of the relationship.

For this reason, we will seek the views of patients, service users, carers, public contributors, community partners and research staff in a range of projects to identify what has worked well, or not so well from their perspective on involvement. The aim is to learn continuously and strengthen good practice across the ARC.

How we will show that we have made a difference

We will use compelling case studies to demonstrate the impact of diverse involvement to our funders and the public. These case studies will highlight how research has been informed and shaped by the insights and experiences of patients, carers and the public, and how this benefits health and social care.

Understanding care preferences following acute illness among frail older people
Drawing on the advice of patient and public involvement contributors, the ARC's palliative and end of life care theme initiated new research exploring what frail older people who have been acutely ill regarded as priorities for their care and how this might change. The [findings](#) showed that improving quality of life, remaining independent, being comfortable, supporting those closest to them and staying out of hospital were often rated as more important than extending life. This underlines the importance of listening closely to understand each patient's preferences for care.

11. Keeping in touch

Communications activities underpin the involvement strategy, and the work of the implementation and involvement team. For example, the involvement coordinator and research teams need ways of reaching out to local people and communities to encourage them to get involved. They also need materials to explain the aims of the ARC and how it works. These activities are closely supported by the ARC's communications team.

In relation to the dissemination of research findings, it is critical that we tell those who have been involved in a timely manner what impact they have made. We must do this in plain English (or whatever way is most relevant to those involved). We also aspire to lead the way with best practice, and communication beyond our ARC community to wider groups, nationally and internationally.

Contact us–email: arc-communications@kcl.ac.uk

1. A note on language

In discussing involvement in health and social care research, it can be difficult to find words that everyone feels comfortable with or understands in the same way. Using the core principles that emerged during the co-design of this strategy, we will make sure that throughout the ARC, people are sensitive to what individuals and groups prefer.

In this strategy we have used these words and definitions, but this does not mean these are the only 'right' words.

- **Involvement:** we have chosen involvement rather than patient and public involvement (PPI), which we know can exclude some people with lived experience of health and social care and their communities. We use NIHR's definition (from INVOLVE⁶) of 'involvement' in research, as 'research being carried out "with" or "by" members of the public rather than "to", "about" or "for" them.
- **Engagement:** where researchers share and disseminate information and knowledge about research and creating a dialogue with the public.
- **Participation:** people taking part in research (i.e. the subjects of research).
- **Co-production of a research project** is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge (NIHR Involve 2019⁴).
- **Researcher:** any member of research staff within the ARC.
- **Public member or contributor:** a service user, carer or member of the wider public actively involved in a project, theme or advisory or governance role in a research organisation which does not employ them.
- **Patient:** people with a wide range of health conditions; includes social care and mental health service users.
- **Carer:** people who provide unpaid support to family members or friends with care needs, and distinct from paid careworkers or personal assistants.
- **Community:** to describe a setting or group where people have something in common but do not necessarily share the same views and interests (and a person can be part of several communities).
- **Under-served groups:** to describe different population groups to whom the research community ought to be providing a better service.
- **Black, Asian and minority ethnic groups:** we use this term, and no acronyms, to describe different minority ethnic groups but acknowledge that such terminology does conflate groups of very diverse peoples and can hide disparities between groups. In our research programmes we therefore will refer to individual ethnic groups or communities directly where that is appropriate.

2. ARC South London partners and collaborators

- ARC South London's host trust is King's College Hospital NHS Foundation Trust. The other core partners are King's College London, Kingston University and St George's, University of London, Health Innovation Network (Academic Health Science Network

for south London), King's Health Partners (Academic Health Science Centre for south London), Guy's and St Thomas' NHS Foundation Trust, South London and Maudsley NHS Foundation Trust, and St George's University Hospitals NHS Foundation Trust.

● Some of the ARC themes are connected with involvement forums or networks, which also cover other research, while NHS foundation trusts have a membership, from which governors are elected, and sometimes service user networks or advisory councils.

● ARC South London also works with other NIHR bodies such as NIHR Clinical Research Network (CRN) South London, NIHR Biomedical Research Centres (BRCs), NIHR Schools, and NIHR Policy Research Units, which also have their own involvement advisory groups, and ARCs elsewhere in England, as well as community and voluntary organisations and other groups and individuals. Groups and organisations linked with particular ARC themes or which are sometimes represented at ARC-wide events range from small peer support or community groups to large charities, which sometimes undertake research as well as delivering services. Some specialise in particular conditions such as stroke, diabetes or mental health problems or use adult social care or children's social care services; others reflect broader concerns among people facing disadvantage and discrimination. Meanwhile local authorities (which have a key role in social care and public health) and are part of local democracy, and primary or integrated care coordinating bodies involve people in many activities. Most adult social care is provided by the independent sector and ARC South London also works with this large workforce and its volunteers. See lists of our [partners and collaborators](#).

3. References

[1.] NIHR. [Going the extra mile: Improving the nation's health and wellbeing through public involvement in research](#) [Accessed online January 2020]

[2.] UK Public Involvement Standards Development Partnership (2019) – [UK Standards for Public Involvement](#) [Accessed online January 2020]

[3.] [Ethnic groups by area, England and Wales, 2011](#) [Accessed online January 2020]

[4.] INVOLVE (2019) [Co-production in Action: Number One](#). Southampton, INVOLVE.