

USER, CARER & PRACTITIONER INVOLVEMENT



STRATEGY FOR PHASE 3 OF THE SCHOOL 2019–24
13 JULY 2020

GLOSSARY OF KEY TERMS

PPI – Public and Public Involvement, is the term more generally used by the National Institute for Health Research (NIHR) to cover wider involvement of those members of the public with an interest in research. This is a term more widely used across NIHR rather than specifically within NIHR SSCR. Within NIHR SSCR we use the following terms for this strategy:

Involvement – people being supported to have an active role in shaping research and related activities.

Engagement – where information and knowledge about research are provided and shared, and where there is a broader dialogue about the use of research evidence, generally to and with wider audiences than those directly involved in research projects.

Participation – being involved in research by providing information/data related to the focus of the project. This strategy is not focused on this aspect of working with the public in research, but it is noted that NIHR SSCR requires all its research to be conducted to the highest ethical and research governance standards, and to comply with the *UK Policy Framework for Health and Social Care Research*¹.

The people we want to engage with and involve are defined in the following definitions:

Service user – a term generally used in adult social care for someone who is receiving care and support. This support may be located in the statutory, third or private sectors, and may be funded by the state and/or paid for by the person themselves (or by family/friends) (known as self-funders) and/or subsidised/funded by charities. The needs of the service user and the support being received can vary considerably across populations, including support for mental and physical health needs, and learning, physical and sensory disabilities. Sometimes people in these circumstances are also referred to as survivors or people with lived experience. We use all these terms in the work of the School, but generally use the terms service user or user in our core documentation and work. Recent critiques of the phrase 'service user' prompt us to revisit our terminology in this area across the lifetime of the School's third phase. Other preferred terms include, for example, people with lived experience or public advisors.

Carer – someone who provides unpaid care and support to a service user or someone who is not in receipt of social care. Often it is a family member of the service user, though not always.

Practitioner – someone who works in delivering adult social care. This can mean managers and commissioners as well as frontline care workers such as care assistants, social workers, and occupational therapists.

¹ www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research

INTRODUCTION

The National Institute for Health Research (NIHR) established the School for Social Care Research (SSCR) (also, 'the School') in 2009, and has (re)commissioned it for three phases of 5 years each (2009–14, 2014–19, and now 2019–24). The seven current core member universities of NIHR SSCR are the London School of Economics and Political Science (lead for the NIHR SSCR), King's College London, and the universities of Birmingham, Bristol, Kent, Manchester and York.

Our remit is to contribute to developing the evidence base to help improve practice in adult social care in England. The School's Business Plan sets out its aims and objectives, its research priorities and operating procedures. This strategy document concerns how involvement across NIHR SSCR will be developed to support this work.

From its inception, we have worked to ensure that the School sets and lives up to high standards with regard to the involvement of service users, carers and practitioners in its activities. During its second phase, the School's Executive Group (EG) requested the User, Carer, Practitioner Reference Group (UCPRG), a key advisory body in NIHR SSCR, to draft a strategy for involvement in the work of the School of people who use adult social care services, carers of those people, and practitioners working in the sector. The agreed strategy was published in 2015 and its

implementation was reviewed by the UCPRG in 2016, with the review informing ongoing evolution of the our approach to involvement up to 2019.

As we began our third phase in May 2019, the EG worked with the UCPRG to review our involvement strategy and refresh it in the light of lessons learnt from previous work, the new Business Plan for this phase, and other developments, notably the publication of the UK Standards for Public Involvement. We say more about how this strategy has evolved later.

This strategy's focus is on the direct *involvement* of people in the work of the School, but also overlaps with a wider process of public *engagement* in adult social care research. The strategy set out here should therefore be read in conjunction with our Business Plan to understand our principles and proposals in the round, and our full commitment to develop an inclusive community for adult social care research. We will work with others, notably across NIHR, to support public engagement work.

We note that key elements of the first involvement strategy are still within this refreshed strategy, and that this is an evolution building on our previous high-quality practice and lessons learnt from across the School and more widely. We remain committed to:

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- developing an environment of trust and collaboration in our research
 - ensuring the relevance of our research to the priorities and lives of people using services, their family and other unpaid carers (hereafter 'carers') and those responsible for adult social care practice
 - developing excellence in knowledge exchange, mobilisation and impact through involvement to inform practice and further research.
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2 <https://www.nihr.ac.uk>

3 <https://sites.google.com/nihr.ac.uk/pi-standards/home>

4 <https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-Phase-III-Business-plan.pdf>

The practices developed in the first ten years of the School with regard to service user, carer and practitioner involvement continue as building blocks to this new strategy. Significant examples include:

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- establishing, building and developing the User, Carer, Practitioner Reference Group (UCPRG) as a key component of the School's governance structure and processes
 - ensuring representation from the UCPRG and beyond on the School's Advisory Board as another significant element of governance
 - reviewing of research applications to NIHR SSCR by service users, carers and practitioners as a norm
 - reviewing of research reports and scoping & methods papers by service users, carers and practitioners as a norm
 - ensuring representation from UCPRG on the commissioning panels of NIHR SSCR
 - ensuring the culture of the School is supportive of the principles of wider involvement and of individuals who are involved in our work
 - expecting high standards of service user, carer and practitioner involvement in all the research commissioned by the School
 - engaging service users, carers and practitioners in other activities of the School, such as workshops and the Annual Conference
 - highlighting examples of involvement in our research projects, including of coproduction and user- led research
 - linking across NIHR and Involve for sharing good practice in involvement in research.
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This strategy builds on these foundations and adds to them, based on our experience of involvement work to date. It recognises that involvement and inclusion are not without their challenges, but sets out the

highest aspirations for this work. It also plans to develop and share the knowledge-base for how to do it well.

STRATEGIC AIMS FOR INVOLVEMENT IN NIHR SSCR

Our over-arching ambitions are captured in points 1–7 below. We then set out specific aims and tasks using the *UK Standards for Public Involvement* as our framework (see below).

Our over-arching ambitions for involvement in this third phase of NIHR SSCR are to:

- 1 continue to provide a focus for best practice in User, Carer and Practitioner (UCP) involvement in adult social care research
- 2 continue to have UCP involvement embedded throughout the School's activities, including our
- 3 governance and building capacity programme
- 4 expect high standards of involvement in all of our research commissioned
- 5 continue to explore how to improve involvement in NIHR SSCR and its research
- 6 share good practice on involvement with NIHR and other interested groups, networks and individuals beyond the NIHR SSCR
- 7 enmesh this involvement strategy and work in our newer research capacity development programme of work
- 8 continue to learn about good practice, develop the evidence and evolve our practice and strategy for involvement in research.

Our strategy is now presented in line with the structure of the *UK Standards for Public Involvement*. These standards provide a framework for planning and undertaking effective involvement work in research. They are not intended to be prescriptive of practice for every context but as a basis for thinking about '*what does good involvement look like in our context?*'. As the UK Standards are being more widely adopted in this way it makes sense for NIHR SSCR to develop this strategy in line with that framework. One good reason is to allow easier read across between involvement work of the School and that of other groups and organisations, which will facilitate development of the evidence base for, and sharing, excellent practice in involvement.

The UK Standards were written from the perspective of involvement in health research, and this is reflected in some of the language used in that document, such as discussing the work of *health professionals*, *health conditions* and *health state*. However, the standards can mostly be readily and helpfully read to the context of adult social care research, as we have done below. Being a multi-layered framework for involvement, many elements are interlinked and overlap. Consequently, some examples of what the School intends to do are relevant to more than one of the UK Standards. We have sought to avoid excessive repetition of specific action points across standards.

Standard 1: INCLUSIVE OPPORTUNITIES

We will offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

For example, by:

- ensuring the Executive Group of NIHR SSCR (and our colleagues involved in our commissioning panels) and our documentation for funding applications provide a clear steer that early involvement is built into the design and execution of research
- encouraging and supporting, where appropriate, pre-submission collaborative work between researchers and collaborators so as to make early involvement effective (in conjunction with, for example, the NIHR Research Design Service (RDS) and wider NIHR work in this area)
- continuing involvement in the governance of the School, including setting its strategic direction (through the UCPRG and the School's Advisory Board) and in operationalising the School's overarching business plan and involvement strategy, such as involvement in key meetings, workshops and plans, reviewing research proposals and as equal members of panels for commissioning research proposals
- supporting activities to ensure good involvement of a diversity of people in the School's research as appropriate to the context of individual studies, including allowing for funding for work to support people with additional communication or other needs to be involved
- monitoring the equality, inclusivity and diversity 'reach' of the School's involvement activities, noting gaps in relation to marginalised voices and communities. This will relate to research topics and applicants but also School governance, for example reviewers, conference keynotes, members of commissioning panels and Advisory Board

- paying proactive attention in research applications and related activity to the proper funding of activities which involve people with a range of diverse support needs, including but not limited to, for example, costs of translation, British Sign Language, easy-read, accessible venues, supporter costs
- working with the NIHR communications team and other relevant organisations to promote involvement and engagement in adult social care research.

Standard 2: WORKING TOGETHER

Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

For example, by:

- ensuring effective dialogue and collaboration between the UCPRG and the School Executive Group.
- ensuring UCPRG members receive continuing support to conduct their roles
- improving the collation of involvement work across the School by improving liaison with the EG lead on involvement and the core members to provide narratives re involvement, good practice examples and evidence of any barriers/challenges to involvement
- using end-of-project reports to review lessons learnt about roles and expectations with regard to involvement. These will be reviewed by the EG lead for involvement who will produce an output (format to be decided) which sets out achievements, issues and barriers related to involvement across the SSCR research portfolio
- liaising with other relevant parts of NIHR (including RfPB and RfSC) to share ideas, good practice and opportunities to improve involvement in social care research across NIHR.

Standard 3: SUPPORT & LEARNING

Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

For example, by:

- having a budget to support involvement in the core activities of the School
- ensuring that there is a budget for involvement plans in all research projects funded by NIHR SSCR
- having resources for, and actively expecting attention to, addressing barriers to involvement, such as the additional costs of support needs/inclusion, to ensure as wide a diversity of involvement as possible
- having robust procedures for monitoring and reporting the financial activities of the School as a whole and of all projects, including spending on involvement activity
- continuing to include some focus on involvement in our annual conferences and other events as a way to stimulate dialogue and to highlight the work of the School
- being active members of NIHR, Involve and any other relevant networks to share with others the experiences of involvement in adult social care research and learn from the involvement work of others in aligned fields of research. This includes close dialogue with the two other research schools of the NIHR
- accumulating from, and sharing with, our adult social care research community experiences of involvement including opportunities and barriers.

Standard 4: COMMUNICATIONS

Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

For example, by:

- sharing news about involvement in our work, in line with the overall communications plan of the School. This will be based on two-way communications about experiences of being involved in the work of the School
- providing budgets for inclusive and appropriate communications in all NIHR SSCR activities.
- active work with and support for those with additional communications and other needs to be involved in the work of the School
- sharing this strategy across our research community and more publicly, along with other documents we may develop, to help those leading our research projects to understand the expectations of the School with regard to their roles and involvement activity
- participating in activities that respond to regular NIHR requests for reports about our work, in expectation that these are publicly reported
- participating in NIHR involvement networks and events to share lessons from our involvement work.

Standard 5: IMPACT

Seek improvement by identifying and sharing the difference that public involvement makes to research.

For example, by:

- the UCPRG & Executive Group reviewing implementation of this strategy
- collecting, through our project reports and other means, lessons about involvement
- expecting our core member universities, Senior Fellows and Fellows and all those whose research we commission to identify and share learning about activities to support involvement.

Standard 6: GOVERNANCE

Involve the public in research management, regulation, leadership and decision making.

For example, by:

- promoting leadership and role-modelling for involvement across the School and exemplary involvement in its governance
- supporting the UCPRG to be an active voice in the delivery of this strategy and the NIHR SSCR Business Plan
- supporting representation from the UCPRG on the School's Advisory Board.



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