

Patient and Public Involvement, Engagement, Participation Strategy (PPIEP) – 2024 - 2029

Introduction to the NIHR HealthTech Research Centre (HRC) in Accelerated Surgical Care

NIHR HealthTech Research Centres (HRCs) work with medical device, diagnostic and digital health technology companies to develop, evaluate and validate new medical technology and diagnostics.

HealthTech Research Centres (HRC) are centres of excellence located in leading NHS organisations across England that accelerate the development of healthcare technologies to improve the effectiveness and quality of health and care services. HealthTech Research Centres (HRC) can help medical device, digital technology and diagnostic companies (collectively known as HealthTech) to develop new innovative medical technologies. This includes help to generate the evidence to demonstrate financial value (health economics) or improve operational efficiency in the NHS (real-world evidence generation).

The **HealthTech Research Centre in Accelerated Surgical Care** aims to drive HealthTech innovation for patients and healthcare systems to deliver socio-economic benefit through quicker diagnosis and treatment of surgical conditions with safe, early recovery in the community.

We are hosted by the Leeds Teaching Hospitals NHS Trust (LTHT), working closely with the University of Leeds, a leading UK University with strengths in biomedical research.

NIHR HRC in Accelerated Surgical Care

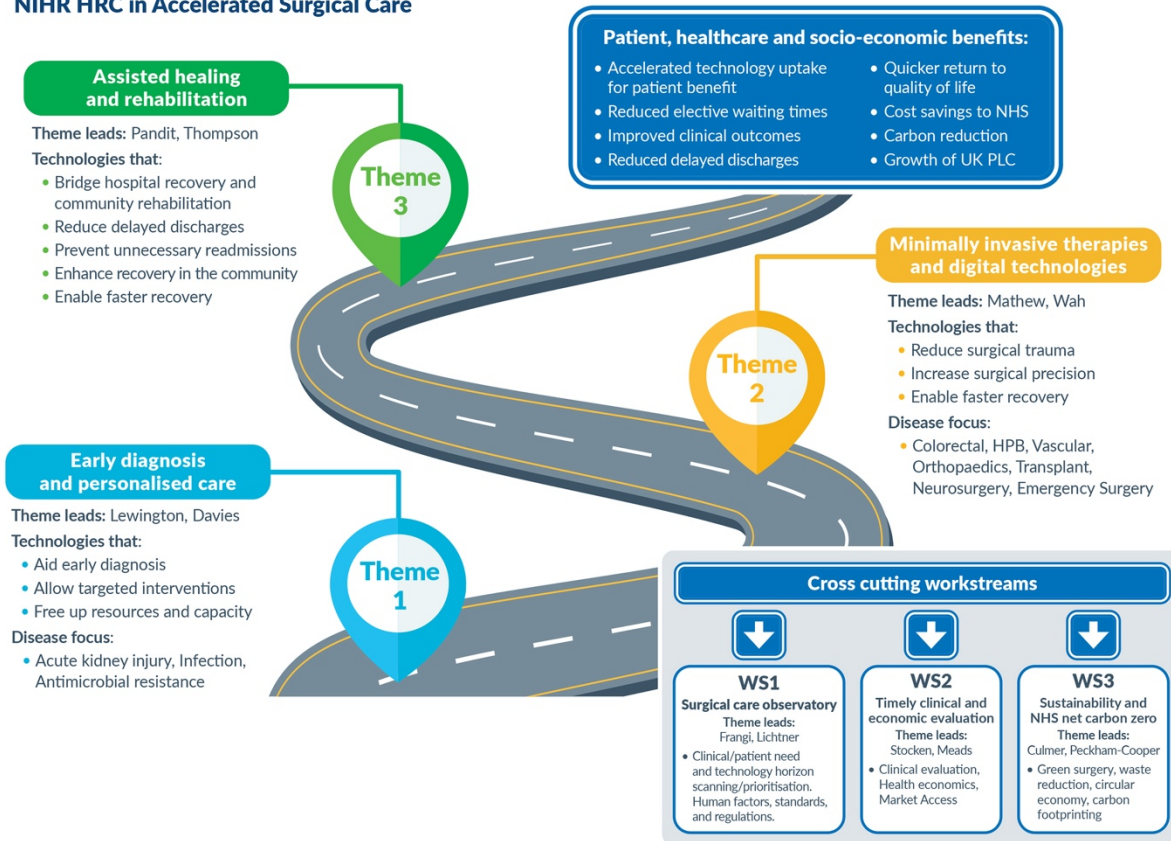


Figure 1.0 Overview of the HealthTech Research Centre in Accelerated Surgical Care

About Surgical Care

One in ten people need surgery each year, but waiting times are at an all-time high with 7.2 million people awaiting routine treatment. This means people are living with prolonged symptoms, added anxiety and employment issues, in addition to paying for additional care. This affects the quality of life for patients, carers, and their families.

Demand for hospital care is limited by the availability of acute care beds with over 13,000 patients occupying beds (one seventh of total NHS bed capacity) who are medically fit but do not have access to suitable community and social care support. Technology can help to address these problems by making surgical care pathways more efficient. But uptake of technologies into routine care is slow with only a small number making it and benefitting patients.

We are based in an area of the country with a strong regional HealthTech cluster linked to the West Yorkshire HealthTech strategy. This will allow fast access to knowledge and expertise to overcome barriers that slow uptake of new technologies and ideas into the NHS. We will provide a supportive and inclusive environment with opportunities for multidisciplinary teams to work together.

Patient and public involvement and engagement will be part of all our activities to make sure our research is relevant to all patients. We will make sure equality, diversity and inclusion are the at the centre of our strategy so that the use of technology works for every patient.

NIHR HRC in Accelerated Surgical Care Patient and Public Involvement, Engagement, Participation Vision

- To ensure our activities and reach are inclusive and reflective of the needs of underserved groups.

Vision: To ensure our activities and reach are inclusive and reflective of the needs of underserved groups

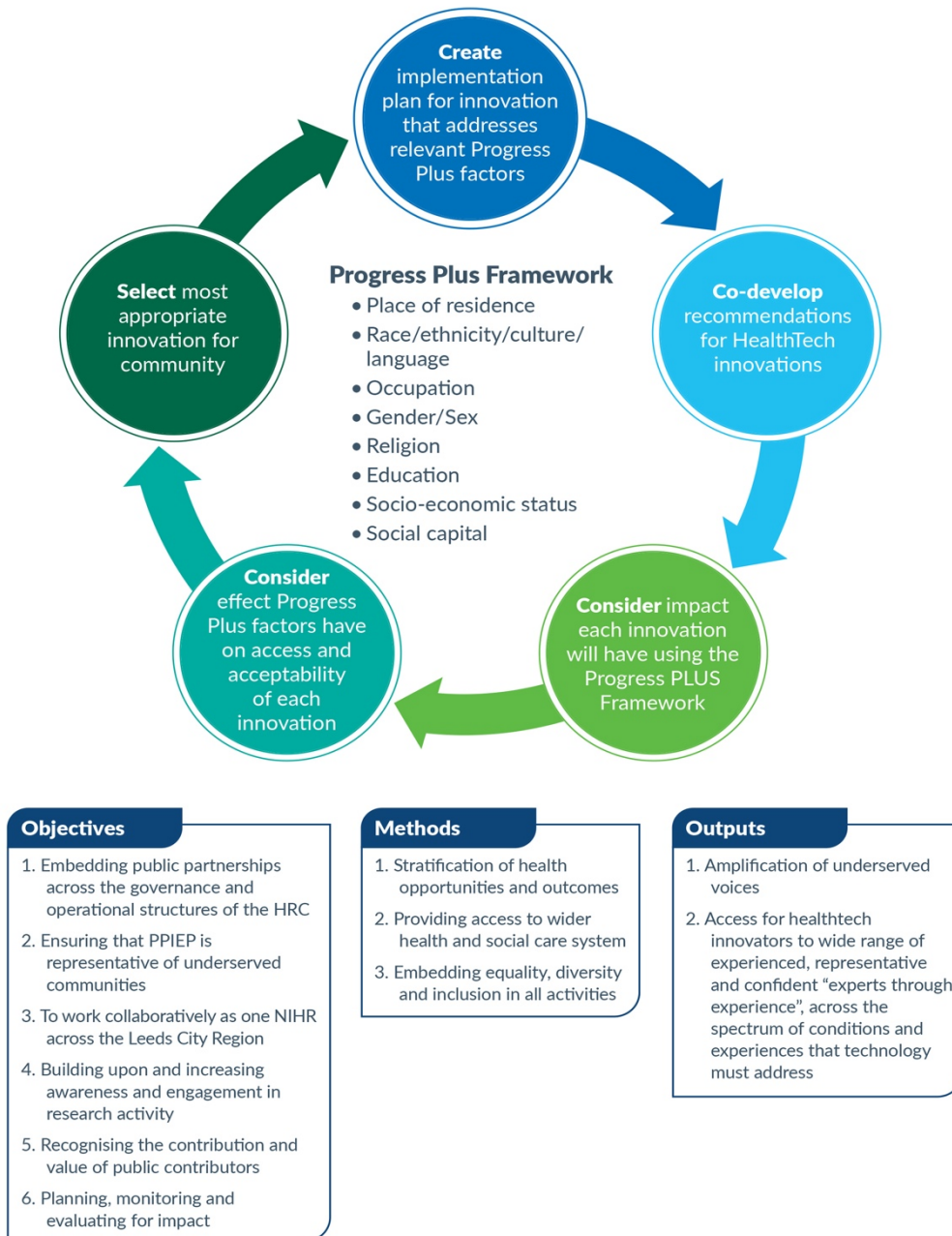


Figure 2.0 Accelerated Surgical Care HRC PPIEP Vision

NIHR HRC in Accelerated Surgical Care Leadership, Management and Governance

Professor David Jayne – Clinical Director



David is Bowel Cancer UK & Royal College of Surgeons of England Chair of Surgery at the University of Leeds and Honorary Consultant Surgeon at the Leeds Teaching Hospitals NHS Trust. He is Associate Dean at the Leeds School of Medicine and Director of Leeds Institute of Medical Research with responsibility for >350 research and support staff. He has over 20 years' experience in progressing surgical technologies along the innovation pathway.

PPIEP plays a central role in all David's research. He works closely with patient and lay member groups to ensure that studies are designed and delivered with and by public and patients, and that research addresses real world needs and healthcare burden. He is cognisant of the importance of research inclusion having co-developed the Equality, Diversity and Inclusion strategies for the previous Surgical Technologies MedTech Co-operative and the School of Medicine.

Ms Varaidzo (Vee) Mapunde – Operational Director



Vee has held NHS professional and management roles, gaining extensive experience of cross-sector working to accelerate the translation and uptake of innovation into the NHS. She was Programme Director for the NIHR Surgical MedTech Co-operative (Surgical MIC) between 2018 and 2024; and has served on various innovation panels and is a judge for the annual global Super Connect for Good competition. She supports start-ups and small and medium sized enterprises (SMEs) at the Advanced Wellbeing

Research Centre Mentorship Accelerator, Sheffield AI Accelerator, the African Academy of Sciences, and Black Valley, to foster an environment where entrepreneurs and start-ups from all backgrounds can thrive.

She has driven the growth of the Surgical MedTech Co-operative through engagement with >350 industry partners, raising >£50m in direct and leveraged income for its partners. She played a key role in developing the Surgical MedTech Co-operative Equality, Diversity and Inclusion strategy and leading the Patient and Public Involvement, Engagement, Participation diversity workstream.

The two proposed Directors (Senior Clinical Academic & Senior Operations Director) bring complementary expertise and leadership skills, with a proven track record of working cohesively to build interdisciplinary partnerships and training networks to accelerate the translation of innovation into the NHS.

Management and Governance

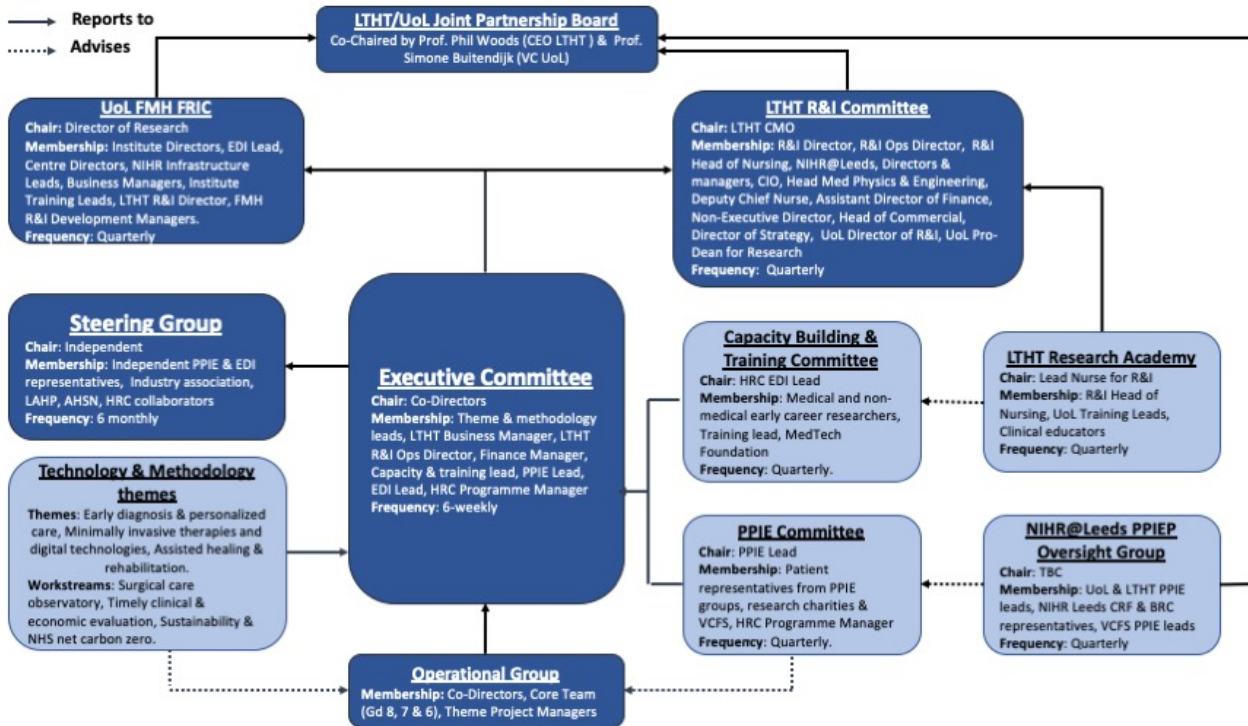


Figure 3.0 Accelerated Surgical Care HRC Management and Governance Arrangements

The **HRC Steering Group** will provide external, independent oversight and strategic guidance. It will be chaired by a high-profile individual renowned as a leader in MedTech innovation and comprise the HealthTech Research Centre (HRC) Co-Directors, national Patient and Public Involvement, Engagement, Participation (PPIEP) representative, MedTech stakeholders, Funders, professional bodies, and the charitable sector.

The **HRC Executive Committee** will be chaired by the Co-Directors with membership from theme leads, Capacity Building and Training Lead, and Patient and Public Involvement, Engagement, Participation (PPIEP) & Equality, Diversity & Inclusion (EDI) lead, with other members co-opted as necessary. This Committee will monitor progress against objectives, share intelligence, review strategic priorities, and plan events.

The Executive will report to both partner organisations. It will report to LTHT Trust Board via the **LTHT R&I Committee**, chaired by the Chief Medical Officer, and to the University via

the **Faculty Research and Innovation Committee**: both committees have joint Trust and University membership. To promote joint partnership working, given the priority of infrastructure funding, LTHT and University of Leeds (UoL) have created NIHR@Leeds, an umbrella group for all NIHR infrastructure to maximise NIHR investment through shared strategies, such as Patient and Public Involvement, Engagement, Participation (PPIEP), Equality, Diversity and Inclusion (EDI) and Communications, in conjunction with joint operational processes.

The **Capacity Building and Training Committee** will develop and implement an HealthTech Research Centre (HRC) training strategy for all our research community. The Chair will sit on the HealthTech Research Centre (HRC) Executive Committee and will be a member of the Joint Clinical Academic Training Committee, which facilitates academic capacity development of medical and healthcare professionals.

Day-to-day activities will be coordinated by an **HRC Operational Group** consisting of the two Co-Directors, Programme Managers and Theme Project Managers. Responsibilities will include project management across the themes, organisation of events, and general administration. Advised by the HealthTech Research Centre (HRC) Executive and Patient and Public Involvement, Engagement, Participation (PPIEP)/Equality, Diversity, Inclusion (EDI) members, the team will be responsible for communication and dissemination. Each HealthTech Research Centre (HRC) theme will have a Patient and Public Involvement, Engagement, Participation (PPIEP) sub-group that will be focused on the activities of that theme. The Patient and Public Involvement, Engagement, Participation (PPIEP) sub-group will work closely with the Theme Project Managers on matters related to event planning, project prioritisation and involvement. Any common issues, opportunities or challenges regarding Patient and Public Involvement, Engagement, Participation (PPIEP) and research inclusion will be discussed at the HealthTech Research Centre (HRC) Operational Group.

The **Patient and Public Involvement, Engagement, Participation (PPIEP) Committee** will be chaired by an appointed Patient and Public Involvement, Engagement, Participation

(PPIEP) member, with extensive NIHR Patient and Public Involvement, Engagement, Participation (PPIEP) experience with national roles, and will review progress against Patient and Public Involvement, Engagement, Participation (PPIEP) strategy, including research inclusion (equality, diversity and inclusion) policy. Membership will include local Patient and Public Involvement, Engagement, Participation (PPIEP) groups, research charities, voluntary, community and faith groups, and LTHT and University of Leeds Patient and Public Involvement, Engagement, Participation (PPIEP) leads. The Patient and Public Involvement, Engagement, Participation (PPIEP) committee will work closely with the Operational Group to ensure that the patient voice, and that of underserved communities, is central to all activities. The Patient and Public Involvement, Engagement, Participation (PPIEP) Chair will sit on the **HealthTech Research Centre (HRC) Executive Committee**.

Aim 1: Embed public partnerships in everything we do

Aim 1: To embed public partnerships in everything we do		
Impact Expected	Research is reflective of the main areas of concerns and interests for those with lived experiences of conditions and leads to surgical treatments and interventions that make a difference to people’s lives.	
Alignment to HRC Research Inclusion Strategy	Objective 5: Embed research inclusion in the way we work, so that we can attract the best people and take forward the best ideas and the best research.	
Involvement Standards	Governance	
Action Plan:		
Short Medium Long Term	Action	Responsible Person/Group
Short Term	<p>Ensure PPIEP representation within the governance of the HRC</p> <ul style="list-style-type: none"> • Appoint PPIEP members to HRC Executive Committee, Capacity Building and Training Committee and NIHR@Leeds PPIEP Oversight Group for duration of HRC. • Secure community representation within governance structures by providing shadowing and other alternative methods of participation as identified by the community organisation. 	HRC Directors
Short Term	<p>Ensure accountability against PPIEP strategy</p> <ul style="list-style-type: none"> • Set up PPIEP sub-groups for each HRC Theme to report activities and progress to HRC Executive Group and support PPIEP members 	HRC Theme Managers, Operations Programme Manager
Medium Term	<p>Ensure equality, diversity, and inclusion is embedded at a senior level to support management of realistic expectations and transparency</p> <ul style="list-style-type: none"> • Involve PPIEP members in the assessment of proposals and grant funding applications for research inclusion principles • Adopt host organisation research inclusion promotion strategy 	HRC Theme Managers, Operations Programme Manager

Aim 2: Ensure that PPIEP is representative of underserved communities

Aim 2: To ensure that PPIEP is representative of underserved communities		
Impact Expected	HealthTech implementation is reflective of a broad range of communities and involvement and participation to research projects is inclusive and diverse.	
Alignment to HRC Research Inclusion Strategy	<p>Objective 5 - Embed research inclusion in the way we work, so that we can attract the best people and take forward the best ideas and the best research.</p> <p>Objective 2: Represent the patient community we serve in our research activities by ensuring our communications and range of activities are fair and free from bias.</p>	
Involvement Standards	Inclusive Opportunities, Communications and Governance.	
Action Plan:		
Short Medium Long Term	Action	Responsible Person/Group
Medium Term	<p>Build relationships with voluntary and community sector organisations</p> <ul style="list-style-type: none"> - We will work together with NIHR@Leeds to establish relationships with community sector organisations to improve reach into communities who are often underserved in research, by developing meaningful and sustainable relationships and co-produced approaches. - We will work together with NIHR@Leeds to facilitate community events where industry and researchers can learn about addressing complex health and care needs in underserved communities. - Identify training and support requirements with underserved communities. 	HRC Directors, NIHR@Leeds, HRC Strategic Programme Manager
Medium Term	<p>Deliver a range of outreach engagement activities in communities whom we don't currently reach.</p> <ul style="list-style-type: none"> • Work with NIHR@Leeds to create a programme of engagement activities led by community interest and need, in a way that is accessible, meaningful and impactful 	HRC Theme Managers, NIHR@Leeds, Operations Programme Manager
Medium Term	<p>Develop a small grant programme to support community and voluntary sector organisations to raise awareness of research within their communities including providing resources and expertise</p> <ul style="list-style-type: none"> - Appropriately act on identified research priorities from underserved communities 	HRC Directors, Strategic Programme Manager

	<ul style="list-style-type: none">- Work with a designated community or third sector organisation to manage the small grants scheme	
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Aim 3: To work as ‘one NIHR’ in the Leeds City region

Aim 3: To work as “one NIHR” in the Leeds City Region		
Impact Expected	PPIEP across the Leeds research partnership is consistent, accessible, efficient, and clear for all those involved in increasing the opportunity for impactful engagement and involvement activities.	
Alignment to HRC Research Inclusion Strategy	Objective 3 - Provide accessible infrastructure by enhancing physical and digital accessibility to increase opportunities to participate and improve experiences.	
Involvement Standards	Working together, Governance	
Action Plan:		
Short Medium Long Term	Action	Responsible Person/Group
Medium Term	<p>Develop the capacity to deliver best practice PPIEP activity across research in Leeds.</p> <ul style="list-style-type: none"> Work collaboratively with NIHR@Leeds to provide a ‘one-stop-shop’ for all PPIEP needs for researchers and industry. 	NIHR@Leeds, HRC Strategic Programme Manager
Medium Term	<p>Cost in PPIEP activity to NIHR@Leeds grant applications to build in additional capacity for beyond grant support.</p> <ul style="list-style-type: none"> Develop a clear costing approach to PPIEP activities and resources in partnership with University of Leeds and Leeds Teaching Hospitals NHS Trust. Develop PPIEP facility to support researchers and industry with post grant and dissemination activity. 	HRC Theme Managers, NIHR@Leeds, HRC Operations Programme Manager
Medium Term	<p>To pool PPIE resources across the NIHR@Leeds partnership to increase capacity, reduce duplication and streamline PPI recognition and payment.</p> <ul style="list-style-type: none"> Develop a common and consistent approach to PPIEP expenses and reward and recognition for PPIEP members, researchers and industry. 	HRC Strategic Programme Manager, HRC Operations Programme Manager, NIHR@Leeds
Long Term	<p>Provide branding for PPIEP excellence in line with the UK Standards for Public Involvement which can be achieved by researchers who excel in PPIEP activity.</p> <ul style="list-style-type: none"> Develop “kite mark”, ideally accredited Promote PPIEP excellence through awards to acknowledge contributions. 	NIHR@Leeds, HRC Strategic Programme Manager

<p>Long Term</p>	<p>Provide a package of support and learning for researchers, industry and patient/lay members.</p> <ul style="list-style-type: none"> • Launch online accredited PPIEP training for the public, researchers and industry. • Provide new public contributors with PPIEP induction training. • Provide clear, consistent guidance and information available on our website which is updated regularly. • Offer patient/lay member mentors for each project. • Co-develop structured, certificated training and support resources for public contributors from underserved communities. 	<p>NIHR@Leeds, HRC Operations Programme Manager</p>
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Aim 4: To build upon and increase awareness and engagement in research activity

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Impact Expected	Increase in diversity of public contributors participating in our research.	
Alignment to HRC Research Inclusion Strategy	<p>Objective 3 - Provide accessible infrastructure by enhancing physical and digital accessibility to increase opportunities to participate and improve experiences.</p> <p>Objective 4: Host and support inclusive events by promoting diversity of attendance and inclusivity of participation.</p>	
Involvement Standards	Communications	
Action Plan:		
Short Medium Long Term	Action	Responsible Person/Group
Medium Term	Set up PPIEP Immersion events for public contributors to learn about the different themes – e.g. research centre tours.	HRC Theme Project Managers
Medium Term	Participate in PPIEP-led conferences and events to celebrate and acknowledge contributions.	HRC Theme Managers, NIHR@Leeds, Operations Programme Manager
Medium Term	<p>Identify and build upon key Leeds based relationships beyond NIHR partners including the Patient Experience team based at LTHT, Patient Experience Team based at mental health and community NHS Trusts, Patient Engagement and Participation Team at UoL, Healthwatch Leeds and Communities of Interest (Forum Central)</p> <ul style="list-style-type: none"> Collaborate with Health Innovation Yorkshire and Humber on their citizen panels and PPIEP Groups for social care. 	HRC Strategic Programme Manager, HRC Operations Programme Manager
Medium Term	<p>Improve accessibility of language used by other stakeholders during PPIEP activities.</p> <ul style="list-style-type: none"> Prepare researchers and industry on working with underserved communities. Assess accessibility in terms of language used during patient engagement activities (i.e. plain language, translation) via surveys, or explored 	NIHR@Leeds, HRC Theme Project Managers

	<p>qualitatively in focus groups, reflection sessions or interviews.</p> <ul style="list-style-type: none">• Facilitate research presentation sessions for academics and healthcare professionals to obtain feedback from PPIEP members on accessibility.	
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Aim 5: To recognise the contribution and value Public Contributors

Aim 5: To recognise the contribution and value of public contributors		
Impact Expected	Increased capacity and growth in PPIEP membership	
Alignment to HRC Research Inclusion Strategy	<p>Objective 1 - Build diverse leadership capacity to ensure diversity in our leadership and governance structures.</p> <p>Objective 2: Represent the patient community we serve in our research activities by ensuring our communications and range of activities are fair and free from bias.</p>	
Involvement Standards	Training, Working Together	
Action Plan:		
Short Medium Long Term	Action	Responsible Person/Group
Short Term	<p>Develop a clear rewards and recognition policy.</p> <ul style="list-style-type: none"> Implement NIHR@Leeds Partnership Rewards and Recognition policy that considers specific groups (e.g. asylum seekers & refugees) whose process of reward and recognition can be more complex than that of others. 	NIHR@Leeds
Medium Term	<p>Provide mentorship and short induction to research for new Public Contributors.</p> <ul style="list-style-type: none"> Facilitate the provision of peer-to-peer support/mentorship to enable new PPIEP members to benefit from experienced PPIEP members. 	HRC Theme Managers, NIHR@Leeds,
Medium Term	<p>Ensure activity and grant application impact/outcomes are shared with Public Contributors.</p> <ul style="list-style-type: none"> Put in place mechanisms to provide feedback to PPIEP members following their participation in HRC activities. Encourage co-authorship of publications and dissemination materials. Develop recognition for research project/delivery teams that demonstrate outstanding PPIEP. 	HRC Operations Programme Manager, HRC Theme Project Managers

Aim 6: To plan, monitor and evaluate for impact

Aim 6: To plan, monitor and evaluate for impact		
Impact Expected	Public partnership activities are planned around the highest impact activities	
Alignment to HRC Research Inclusion Strategy	<p>Objective 1 - Build diverse leadership capacity to ensure diversity in our leadership and governance structures.</p> <p>Objective 2: Represent the patient community we serve in our research activities by ensuring our communications and range of activities are fair and free from bias.</p> <p>Objective 5: Embed research inclusion in the way we work, so that we can attract the best people and take forward the best ideas and the best research.</p>	
Involvement Standards	Impact and Evaluation	
Action Plan:		
Short Medium Long Term	Action	Responsible Person/Group
Short Term	<p>Review current evaluation process and identify improvements</p> <ul style="list-style-type: none"> Build upon the existing evaluation process to capture longer-term impact of PPIE on funding awards, research delivery, research outcomes and attitudes to research. 	HRC Directors, HRC Theme Leads
Medium Term	<p>Develop a framework and metrics for evaluation and monitoring of PPIEP activities</p> <ul style="list-style-type: none"> Use Public Involvement in Research Impact Toolkit (PIRIT) Tool to plan, assess and evidence impact of PPIEP approach for HRC projects. Encourage researchers to feedback to PPIEP quarterly in a formal setting. Use PROGRESS Plus tool to assess and report on research inclusion. 	NIHR@Leeds, HRC Strategic Programme Manager, HRC Theme Project Managers
Short Term	<p>Identify what we want to know and how we want to collect this e.g. do we want to understand impact broadly as an organisation or across research projects</p> <ul style="list-style-type: none"> Engage with PPIEP members and researchers to understand what impact means to them. 	HRC Directors, HRC Strategic Programme Manager, HRC Theme Project Managers
Long Term	Monitor relevance of (new) studies/products to patients needs.	HRC Strategic Programme

	<ul style="list-style-type: none"> Track and assess patient and societal impacts (i.e. whether or not studies are addressing an unmet patient need, usability and adoption). 	Manager, HRC Theme Leads
Long Term	<p>Monitor percentage cost of patient engagement initiative in overall grant/funding applications.</p> <ul style="list-style-type: none"> Track and monitor the proportion of financial costs directed to patient engagement activities in relation to the total amount of resources used in the planning and implementation of research activities. This would measure the efficiency of clinical trial design and implementation following the use of patient engagement activities. This can be used to determine financial return on engagement 	HRC Strategic Programme Manager

Resources

The HealthTech Research Centre in Accelerated Surgical Care is funded by the NIHR and has a budget for PPIEP activities, which include travel, subsistence expenses, pre-grant and participation activities. This budget will also cover costs for a HRC PPIEP Lead and community engagement and involvement activities. Added value will be leveraged through shared working with NIHR@Leeds.

The NIHR@Leeds partnership and Leeds Teaching Hospitals NHS Trust PPIEP team will provide access to training and capacity building resources for public contributors. This will standardise our offering and reduce the duplication of effort and resources for the communities we will be targeting. Additional capacity building opportunities for contributors from underserved communities will be provided through this joint working, as the Leeds Teaching Hospitals NHS Trust PPIEP Team has already established good relationships with underserved communities in the region, and they are already co-developing events and opportunities.

We will endeavour to make sure that all post-grant PPIEP activities are costed into researcher bids. No PPI member will be left out of pocket as a result of their involvement and costs incurred for involvement will be paid. The HealthTech Research Centre in Accelerated Surgical Care follows the NIHR Guidelines on payment for PPIEP work and has a policy on payment and recognition.

Reporting, Monitoring and Review of the PPIEP Strategy and Action Plan

We need to be sure that the activities we are involved in have added value. The governance and management structures mentioned on Pages 7 and 8 will have responsibility for reporting and monitoring.

The action plan and strategy are living documents and will be reviewed by the 30th April each year to reflect lessons learnt through self-assessment and changes in priorities/legislation.

Acknowledgements

This strategy has been developed in partnership between NIHR@Leeds in order to streamline and build upon our activities, efforts and resources. A series of meetings, surveys and focus groups have informed the content. We would also like to thank and acknowledge the people who have co-produced this strategy:

- Manoj Mistry
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- Carrol Lamouline
- EMRI Network
- NIHR@Leeds (NIHR Leeds Biomedical Research Centre, NIHR Leeds Clinical Research Facility)
- Kursh Siddique, BAME Voices
- HealthWatch Leeds

References

1. [PPI \(Patient and Public Involvement\) resources for applicants to NIHR research programmes](#)
2. [Patient and Public Involvement and Engagement Resource Pack](#)
3. [Involve patients](#)
4. [Payment guidance for researchers and professionals](#)

Glossary

Abstract

A brief summary of the study and its results. It should tell you what the study tried to show, how the researchers went about it, and what they found.

Advisory group

Many research projects have an advisory group (or steering group). The group helps to develop, support, advise and monitor the project. The group often includes people who use services, carers, researchers and other health and social care professionals, who can provide relevant advice.

Allied Health Professionals

Allied health professionals (AHPs) are people who work in health care professions distinct from dentistry, nursing, medicine, and pharmacy. They provide a range of diagnostic, technical, therapeutic, and support services in connection with health care, for example, occupational therapists, dietitians and podiatrists.

Biomedical Research Centres (BRCs)

NIHR's 20 Biomedical Research Centres (BRCs) are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics and medical technologies.

Carer

A carer is a relative, friend or partner who provides, intends to provide, or used to provide a substantial amount of care to another person on a regular basis, but not necessarily through living with them.

Chief investigator

The chief investigator (CI) is the person who takes overall responsibility for the design, conduct and reporting of a study.

Clinical research

Clinical research aims to find out the causes of human illness and how it can be treated or prevented. This type of research is based on examining and observing people with different conditions and sometimes comparing them with healthy people. It can also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical researchers will also sometimes analyse the information in patient records, or the data from health and lifestyle surveys.

Clinical trial

An experiment to compare the effects of two or more healthcare interventions. 'Clinical trial' is an umbrella term for a variety of healthcare trial designs.

Co-production

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. The assumption is that those affected by research are best placed to design and deliver it and have skills and knowledge of equal importance.

Co-sponsor

Where two or more organisations share a significant interest in a study, they may elect to act as co-sponsors.

Collaboration

Collaboration involves active, on-going partnership with members of the public in the research process. For example, members of the public might take part in an advisory group for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project.

Commissioned call

Calls for proposals based on pre-defined research questions developed to respond to the information needs of decision-makers (typically, but not exclusively, within the NHS).

Commissioned workstreams

Commissioned workstreams start with the information needs of decision makers typically, but not exclusively, within the NHS. These are refined and prioritised by experts in the field, and commissioning briefs are then advertised. Applications are assessed for compliance with the commissioning brief, scientific quality, feasibility and value for money.

Commissioner

A commissioner is the person (or organisation) who asks for a piece of research to be carried out.

Confidentiality

During a research project, the researchers must put data protection measures into place, to ensure that all of the information collected about the participants is kept confidential. This means that the researchers must get the participants' written permission to look at their medical or social care records. It also means that any information that might identify the participants cannot be used or passed on to others, without first getting the participants' consent. For example, when researchers publish the results of a project, they are not allowed to include people's names. This confidentiality will only be broken in extreme circumstances: where it is essential for the person's care, treatment or safety, where it is required by a court order, for example in a criminal investigation, or where it is necessary to protect the public.

Consultation

Consultation involves asking members of the public for their views about research, and then using those views to inform decision-making. This consultation can be about any aspect of the research process – from identifying topics for research, through to thinking about the implications of the research findings. Having a better understanding of people’s views should lead to better decisions.

Cost effectiveness

A measure addressing the cost implications of achieving health benefits. To facilitate comparisons, health benefits can be quantified in terms of ‘QALYs’ (Quality-Adjusted Life Years), which incorporate both extra life achieved and improvements in quality of life. Knowing the cost associated with each QALY gained can help decision-makers assess whether the introduction of a treatment or service should be recommended.

Cost effectiveness analysis

An economic analysis that views effects in terms of overall health specific to the problem, and describes the costs for some additional health gain (e.g. cost per additional stroke prevented).

CRFs

NIHR’s 23 Clinical Research Facilities (CRFs) are purpose built facilities in NHS hospitals where researchers can deliver early-phase and complex studies.

Data

Data is the information collected through research. It can include written information, numbers, sounds and pictures.

Data analysis

Data analysis involves examining and processing research data, in order to answer the questions that the project is trying to address. It involves identifying patterns and drawing out the main themes, and is often done with specialist computer software.

Data protection

All personal information is protected in the UK by the Data Protection Act 2018. This means that researchers have to put in all the necessary safeguards to protect the confidentiality of the information they collect about research participants. They should explain in the patient information sheet: how the participants’ data will be collected, how it will be stored securely, what it will be used for, who will have access to the data that identifies participants, how long it will be kept and how it will be disposed of securely.

DHSC

The Department of Health and Social Care (DHSC) is the government department supporting ministers in leading the nation's health and social care to help people live more independent, healthier lives for longer.

Diagnostic test

A diagnostic test is an indicator or predictor of an illness state. As such, the term needs to be interpreted broadly as it includes diagnostic tests, screening, tests to stage disease, treatment monitoring, and estimate prognosis estimation.

Dissemination

Dissemination involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through producing reports, publishing articles in journals or newsletters, issuing press releases or giving talks at conferences.

Diversity

Being reflective of the wider community. Having a diverse community, with people from a broad range of backgrounds represented in all areas and at all levels.

EDI

We are committed to equality, diversity, and inclusion in everything we do. Diverse people and communities shape our research, and we strive to make opportunities to participate in research an integral part of everyone's experience of health and social care services. We develop researchers from multiple disciplines, specialisms, geographies and backgrounds, and work to address barriers to career progression arising from characteristics such as sex, race or disability.

Empowerment

This is the process by which people who use services equip themselves with the knowledge, skills and resources they need to be able to take control over decisions and resources. It often involves people building confidence in their own strengths and abilities. It does not always mean people take control over all decisions or all resources.

Engagement

Ways in which research can be shared with the public in a two-way process. Engagement encourages researchers to listen and interact with the general public, for example, via science festivals, open days, media coverage.

Equality

Ensuring that everyone is given equal access to resources and opportunities to utilise their skills and talents.

Ethics

Ethics are a set of principles that guide researchers who are carrying out research with people. Ethical principles are designed to protect the safety, dignity, rights and well-being of

the people taking part. They include the requirement to ask each individual to give their informed consent to take part in a research project.

Ethics committees

The job of an ethics committee is to make sure that research carried out respects the dignity, rights, safety and well-being of the people who take part. Increasingly ethics committee approval is needed for health and social care research. Ethics committee members include researchers and health care professionals as well as members of the public.

Evaluation

This involves assessing whether an intervention (for example a treatment, service, project, or programme) is achieving its aims. A project can be evaluated as it goes along or right at the end. An evaluation can measure how well the project is being carried out as well as its impact. The results of evaluations can help with decision-making and planning.

Evaluative research

Evaluative research seeks to assess or judge in some way, providing useful information about something which cannot be gleaned by mere observation or investigation of relationships.

Evidence base

An evidence base is a collection of all the research currently available about a health or social care topic, such as how well a treatment or a service works. This evidence is used by health and social care professionals to make decisions about the services that they provide and what care or treatment to offer people who use services.

Evidence synthesis

Evidence synthesis involves the development of techniques to combine multiple sources of quantitative and qualitative data to derive best evidence for use in healthcare.

Feasibility studies

Feasibility Studies are pieces of research done before a main study in order to answer the question "Can this study be done?". They are used to estimate important parameters that are needed to design the main study.

Focus group

A focus group is a small group of people brought together to talk. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems.

Follow up

The observation over a period of time of study/trial participants to measure outcomes under investigation.

Full and appropriate funding

Full and appropriate funding is provided because no upper limit is placed on the amount of funding granted for a project. Subject to availability of funds, if the question is important enough and the science requires it, we will fund it. For University based projects, we will fund up to 80 per cent of the Full Economic Cost (FEC) of the research, and 100 per cent of the direct costs for NHS Trust based projects. Other organisations are welcome to apply to our programmes and should discuss costing with us.

Funder

An organisation providing funding for a study (through agreements, grants or donations to an authorised member of the employing and/ or care organisation). The main funder typically has a key role in scientific quality assurance. In any case, it remains responsible for securing value for money.

Health and care professionals (HCPs)

For the purposes of NIHR and other clinical academic funding, the definition of regulated healthcare professionals (HCPs) are those regulated and registered healthcare professionals, excluding doctors and dentists, who are currently registered with one of the national regulatory bodies, including the:

- Nursing and Midwifery Council
- Health and Care Professions Council
- General Dental Council
- General Medical Council
- General Optical Council
- General Osteopathic Council
- General Chiropractic Council
- General Pharmaceutical Council
- Pharmaceutical Society of Northern Ireland

This definition has been the result of a wide consultation process. It is to provide collective terminology for the largest workforce in the NHS, which includes nurses, midwives, allied health professionals, regulated clinical and practitioner psychologists, pharmacists, and healthcare scientists. Labels such as non-medics and professions allied to medicine, which categorise groups according to their relationship to medicine, has been controversial; and NMAHPs (nurses, midwives, and allied health professionals) is exclusionary for other regulated healthcare professionals, such as pharmacists and healthcare scientists.

While acknowledging that doctors and dentists also technically are healthcare professions, they are more publicly known as doctors and dentists.

This definition has been endorsed by the Clinical Academic Training Forum.

Health Research Authority

The Health Research Authority (HRA) is an NHS organisation established to protect and promote the interests of patients and the public in health research.

Health technology

Health Technology is an internationally recognised term that covers any method used by those working in health services to promote health, prevent and treat disease and improve rehabilitation and long-term care. "Technologies" in this context are not confined to new drugs or pieces of sophisticated equipment.

HealthTech Research Centres (HRC)

NIHR's 14 HealthTech Research Centres are centres of excellence located in leading NHS organisations across England. They accelerate the development of healthcare technologies to improve the effectiveness and quality of health and care services. They do this by helping medical device, digital technology and diagnostic companies (collectively known as healthtech) to develop, evaluate and validate new innovative health technologies to address pressing healthcare challenges. This includes help to generate evidence to demonstrate financial value (health economics) or improve operational efficiency in the NHS (real-world evidence generation).

Implementation

Implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice.

Inclusion

An approach where groups or individuals with different backgrounds are welcomed, culturally and socially accepted, and treated equally. Engaging with each person as an individual. A sense of belonging that is respectful of people for who they are.

Interview

In research, an interview is a conversation between two or more people, where a researcher asks questions to obtain information from the person (or people) being interviewed. Interviews can be carried out in person (face-to-face) or over the phone.

Investigator

A person who is conducting a (clinical) study. Those researchers leading the team are referred to as chief investigator or principal investigator.

Lay (lay person)

The term 'lay' means non-professional. In research, it refers to the people who are neither academic researchers nor health or social care professionals.

Lay summary

A lay summary is a brief summary of a research project or a research proposal that has been written for members of the public, rather than researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms that have to be included.

LTHT

Leeds Teaching Hospitals NHS Trust is one of the largest and busiest acute hospital trusts in the country, a regional and national centre for specialist treatment, a renowned biomedical research facility, and the local hospital for the Leeds community. They treat 1.5 million patients every year, including more than 200,000 emergency patients.

Medical device

Any instrument, apparatus, implement, machine, appliance, implant, software, material, or similar that can be used for: diagnosis, prevention, monitoring, treatment or alleviation of disease; investigation, replacement, modification, or support of the anatomy or of a physiological process; supporting or sustaining life; control of conception; disinfection of medical devices: that doesn't achieve its primary intended action in or on the human body by pharmacological, immunological or metabolic means.

Members of the public

When using the term 'public' we include 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 also include those members of the public who are potential recipients of health promotion programmes, public health programmes, and social service interventions. Other organisations may have different definitions of this term.

Mentor

A mentor is a person willing to share their experience, knowledge and wisdom to help, guide and support someone who is less experienced. Mentors act as friends, teachers and advisers. A person who is newly involved in research can ask for a mentor to help them adjust to their new role.

Methodology

The term methodology describes how research is done – so it will cover how information is collected and analysed as well as why a particular method has been chosen.

Monitoring

Maintaining contact with funded projects to ensure they progress satisfactorily and deliver meaningful results.

Morbidity

Illness or harm.

Mortality

Death.

NHS

National Health Service: government-funded medical and health care services that everyone living in the UK can use without being asked to pay the full cost of the service.

NHS research

NHS research is research carried out in the NHS or funded by the NHS. This includes research that takes place in local hospitals or GP surgeries, and larger studies commissioned by the NHS at a national level. For example a study based in a GP surgery looking at people's experience of long-term chronic pain or a randomised controlled trial to look at the best treatment for people with bowel cancer.

NICE

The National Institute for Health and Clinical Excellence recommends which treatments should be provided by the NHS. NICE makes extensive use of evidence generated by the NIHR programmes.

NIHR@Leeds

NIHR infrastructure hosted by the Leeds Teaching Hospitals NHS Trust. These include the NIHR Biomedical Research Centre, NIHR Clinical Research Facility, NIHR Leeds BioResource Centre.

NIHR Academy

The NIHR Academy is responsible for development and coordination of NIHR academic training, career development and research capacity development.

NIHR BioResource

The NIHR BioResource for Translational Research in Common and Rare Diseases (NIHR BioResource) is a national resource of patients and members of the general population who have volunteered to be called up for research based on their genotype and phenotype.

NIHR Health Informatics Collaborative

The NIHR Health Informatics Collaborative (HIC) has been set up to deliver high quality data in five key therapeutic areas across five of the largest university hospital trusts, each of which hosts a BRC.

NIHR National Biosample Centre

The NIHR National Biosample Centre provides high throughput and high quality biosample processing, storage and retrieval services to for NIHR-supported research, and research funded by partners of the Department of Health, such as the MRC, charities and industry.

Observational study

A study in which the investigators do not seek to intervene, but simply observe the course of events. There is a greater risk of selection bias than in experimental studies.

Outcome

A component of a participant's clinical and functional status after an intervention has been applied, that is used to assess the effectiveness of an intervention.

Outcome measures

Outcome measures are measurements of the effects of a treatment or service. They might include physical measurements – for example, measuring blood pressure – or psychological measurements – for example, measuring people's sense of well-being. So if someone takes part in research, they may be asked questions, or they may be asked to have extra tests to assess how well the treatment or service has worked.

Output

Published results from a research project. NIHR projects often generate papers that are published in the scientific literature. Full details of NIHR projects and their results are published in special reports or journals. Some projects generate briefing papers or other outputs for particular audiences.

Participant

An individual who is studied in a trial, often, but not necessarily, a patient.

Participation

The act of taking part in a research study, for example people being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.

Participatory research

This is a type of research where researchers and people who use services or carers are partners in a research project. The research addresses an issue of importance to service users or carers, who are involved in the design and conduct of the research, and the way the findings are made available. The aim of the research is to improve people's lives. This isn't a research method – it's an approach to research, a philosophy.

Patient and public involvement

Also known as PPI, involvement or public involvement. An active partnership between patients and the public and researchers in the research process, rather than the use of people as 'subjects' of research. Patient and public involvement in research is often defined as doing research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, and undertaking interviews with research participants. When using the term 'public' we include 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.

Patient Safety Translational Research Centres

Patient Safety Translational Research Centres (PSTRCs) conduct and support research to investigate ways to improve the safety, quality and effectiveness of the services that the NHS provides to its patients.

Peer review

A reviewing process for checking the quality and importance of reports of research. An article submitted for publication in a peer-reviewed journal is reviewed by other experts in the area.

Perspectives / user perspectives

A user perspective is often what people with experience of using health or social services are asked to bring when they get involved in research. They are asked to provide ideas, comments and suggestions based on the unique insight they have from their knowledge and experience of life with a health condition. They cannot be representative of everyone who uses a particular service, but they can offer their own perspective, and often that of other people.

Pilot studies

Pilot studies are a smaller version of the main study used to test whether the components of the main study can all work together. It is focused on the processes of the main study, for example to ensure that recruitment, randomisation, treatment, and follow-up assessments all run smoothly.

PIRIT

Public involvement in research impact toolkit - PIRIT is a set of pragmatic tools which aim to support researchers working with public contributors to:

- plan and integrate public involvement in research
- track public contributions and the difference they make to the research
- report impact against the UK Standards for Public Involvement

PPI

Patient and Public Involvement. In research, PPI takes various forms, from involvement of public contributors in priority setting, representation on committees, and as reviewers. NIHR appoint public board and panel members via open competition.

Primary outcome

The outcome of greatest importance.

Principal investigator

The principal investigator (PI) may be the chief investigator, or where the research is taking place across than one site, the principal investigator is the person at each site who is responsible for the day to day running of the research project.

Prioritisation

Rigorously examining potential topics for research to identify their importance and where the need for new evidence is greatest.

Probability

The chance or risk of something happening.

PROGRESS-Plus

PROGRESS-Plus is an acronym used to identify characteristics that stratify health opportunities and outcomes. **PROGRESS** refers to:

- Place of residence - where someone lives (e.g. the country, region, city, community and their characteristics, or urban vs. rural settings) comm
- Race/ethnicity/culture/language
- Occupation - e.g. unemployment, underemployment, informal employment, and unsafe working condition, as well as type of occupation
- Gender/sex
- Religion
- Education
- Socioeconomic status
- Social capital - e.g. social relationships and networks

Plus refers to:

- 1) personal characteristics associated with discrimination (e.g. age, disability)
- 2) features of relationships (e.g. smoking parents, excluded from school)
- 3) time-dependent relationships (e.g. leaving the hospital, respite care, other instances where a person may be temporarily at a disadvantage)

Public contributor

Public contributor is an umbrella term used to describe members of the public who take part in patient and public involvement activities. We use the definition of 'public' to include 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.

Public Partnerships

A term to collectively describe ways in which patients, service users, carers and members of the public work with researchers, and health and care professionals, in the creation and use of health and care research. Public partnerships encompasses participation, involvement and engagement; they are all important in the process of creating and making use of high quality research. Each can take place in isolation, or in parallel. Experience, as

well as research, has shown that they are mutually supportive in making research as relevant and impactful as possible. Use of the term Public Partnerships is not intended to replace, or make redundant, any existing terms or preferred ways of describing things.

Qualitative

Detailed subjective evaluation, used to capture views of individuals' and groups.

Qualitative analysis

The evaluation of data from qualitative research, for example, text data from interview transcripts.

Qualitative research

Qualitative research is used to explore and understand people's beliefs, experiences, attitudes or behaviours. It asks questions about how and why. Qualitative research might ask questions about why people want to stop smoking. It won't ask how many people have tried to stop smoking. Qualitative researchers use methods like focus groups and interviews (telephone and face-to-face interviews). This research does not collect data in the form of numbers but might collect data in the form of interview transcripts, or notes from focus groups.

Quantitative

Numerical evaluation of an intervention.

Quantitative analysis

Numerical evaluation of data.

Quantitative research

In quantitative research, researchers collect data in the form of numbers. So they measure things or count things. Quantitative research might ask a question like how many people visit their GP each year, or what proportion of children have had an MMR vaccine, or whether a new drug lowers blood pressure more than the drugs that are usually used. Quantitative researchers use methods like clinical trials.

Questionnaire

A questionnaire is a prepared set of written questions used to obtain information from research participants. Questionnaires can be completed on paper, using a computer or with an interviewer.

Remit

The area of authority or responsibility of an individual, group, or organisation.

Reporting bias

A bias caused by only a subset of all the relevant data being available.

Repository

An online archive of scholarly outputs (e.g., Europe PMC). The collection can include publications in peer-reviewed journals, books and book-sections, technical reports, working papers, monographs, conference presentations, research data, audio and visual materials or any other research content that has some scholarly value.

Representative

A representative is expected to speak on behalf of a larger group of people. If you've been asked to get involved in research as a representative of a particular group, you may want to think about how you can be confident that you are representing a wider range of people's views, rather than just offering your own perspective.

Research

The term research means different things to different people, but is essentially about finding out new knowledge that could lead to changes to treatments, policies or care. The definition used by the Department of Health is: "The attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods."

Research brief

A research brief is often written by a commissioner to describe why they want to commission a piece of research, what questions the research should address and sometimes how the research should be carried out. It might include information about when the research needs to be completed and how much money is available.

Research governance

Research governance is a process aimed at ensuring that research is high quality, safe and ethical. For more information, you can read the UK Policy Framework for Health and Social Care Research.

Research grant

Research grants are specific amounts of money given to researchers to carry out a particular piece of research. They might amount to millions of pounds for a major study about genetics for example, or a few hundred pounds for a local study about people's experience of using a particular service. Usually, in order to get research grants, researchers have to write a research proposal and receive a positive peer review.

Research Inclusion

Taking a whole systems approach to what we do and how we do it; identifying and removing long standing, structural barriers to success across our people, policies, processes and practices (the synergistic totality of our inclusion endeavours).

Research methods

Research methods are the ways researchers collect and analyse information. So research methods include interviews, questionnaires, diaries, clinical trials, experiments, analysing documents or statistics, and watching people's behaviour.

Research network

Research networks aim to bring together people who have an interest in research about a particular condition or group of people. Networks might be national or local, within the NHS or run by charities or other organisations.

Research partner

The term research partner is used to describe people who get actively involved in research, to the extent that they are seen by their 'professional' colleagues as a partner, rather than someone who might be consulted occasionally. Partnership suggests that researchers and service users/carers have a relationship that involves mutual respect and equality.

Research proposal

This is usually an application form or set of papers that researchers have to complete to say what research they want to do and how they want to do it. The proposal might be addressing a specific research brief and it will also cover the aim of the research, what the research questions are, who will be involved (both as participants and in carrying out the research), the time-scale and the cost.

Researcher

Researchers are the people who do the research. They may do research for a living, and be based in a university, hospital or other institution, and/or they may be a service user or carer.

Researcher-led

Open calls for researchers to apply for funding for their own topics and questions. These applications are prioritised in terms of NHS or other information need in a process similar to that of the commissioned workstreams. Applications are assessed for scientific quality, feasibility and value for money.

Retrospective study

A study in which the outcomes have occurred before the study commenced. Case-control studies and cohort studies can be retrospective, but randomised controlled trials never are.

Reviewer

An individual with specific knowledge, experience and skills in a field of practice who undertakes an independent review of a grant application, commissioning brief or document for publication. The comments made by this independent 'external reviewer' are used to inform the funding decision or the preparation of a written document.

R&I

Research and Innovation

Secondary outcome

An outcome used to evaluate additional effects of an intervention deemed as being less important than the primary outcomes.

Secondary research

A review of individual studies (each of which is called a primary study). A systematic review is a secondary study.

Service user

A service user is someone who uses or has used health and/or social care services because of illness or disability. Some people do not like this term because they feel it has negative connotations.

Setting

The research setting is the environment in which research is carried out. This could be a laboratory or a 'real' setting, such as the subject's working environment if you are conducting research into people's working lives.

Social care

Social care refers to a range of services provided across different settings, usually in the community. These include: home care, day care and residential care for older people; residential care and fostering for children; support for parents of disabled children; supporting mental health service users, physically disabled people and people with learning difficulties; and support for carers.

Social care research

Social care research involves finding out new knowledge (or testing out existing ideas) to do with social care. For example, social care research might address questions about people's experience of using different home care services or the best ways to train new foster parents.

Statistical analysis

Statistical analysis uses a set of mathematical rules to analyse quantitative data. It can help researchers decide what data means. For example, statistical analysis can assess whether any difference seen between two groups of people (for example between the groups of people in a clinical trial) is likely to be a reliable finding or simply due to chance.

Statistically significant

A result that is unlikely to have happened by chance.

Statistics

Statistics are a set of numbers (quantitative data) obtained through research. For example, the average age of a group of people, or the number of people using a service.

Sub-group analysis

An analysis in which the intervention effect is evaluated in a defined subset of the participants in a trial, or in complementary subsets, such as sex or age.

TRCs

Translational Research Collaborations (TRCs) bring together world-class health researchers within designated BRCs to effectively pull discoveries from the country's world-leading basic and translational research into real benefits for patients, share their considerable resources and world-leading expertise to improve treatment and care, and to maximise the impact of NIHR investment. The collaborations also play an important role in collaborating with the life sciences industry.

Treatment

The process of intervening with the aim of enhancing health or life expectancy. Sometimes, and particularly in statistical texts, the word is used to cover all comparison groups, including placebo and no treatment arms of a controlled trial and even interventions designed to prevent bad outcomes in healthy people, rather than cure ill people.

Under-served groups in research

The NIHR INCLUDE project identified the term 'under-served' by diverse stakeholders including patients and the public as the most appropriate term through a consensus workshop. The term has subsequently been adopted by the NIHR and more widely. The term reflects the perspective that the research community needs to provide a better service for people in these groups – the lack of inclusion is not due to any fault of the members of these groups. The term 'under-served' reminds us of this perspective in a way that alternative terms such as 'underrepresented' do not.

The work of the NIHR INCLUDE project shows that there is no single definition for an under-served group.

Some key characteristics that are common to several under-served groups are:

- lower inclusion in research than one would expect from population estimates
- high healthcare burden that is not matched by the volume of research designed for the group
- important differences in how a group responds to or engages with healthcare interventions compared to other groups, with research neglecting to address these factors

The key idea here is that the definition of 'under-served' is highly context-specific; it will depend on the population, the condition under study, the question being asked by research teams, and the intervention being tested. No single, simple definition can encompass all under-served groups.

User controlled research / user led research

User controlled research is research that is actively controlled, directed and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned and written up. The service users will run the research advisory or steering group and may also decide to carry out the research. Some service users make no distinction between the term user controlled and user led research, others feel that user led research has a different, vaguer meaning. They see user led research as research which is meant to be led and shaped by service users but is not necessarily controlled by them. Control in user led research in this case will rest with some other group of non-service users who also have an interest in the research, such as the commissioners of the research, the researchers or people who provide services.

User researcher

A user researcher is someone who uses or has used health and/or social care services because of illness or disability, who is also a researcher. Not all researchers who use health or social care services call themselves user researchers. Calling yourself a user researcher is making a statement about your identity as a service user as well as a researcher.