Developed over three years by a UK-wide partnership, the standards are a description of what good public involvement looks like and encourage approaches and behaviours that are the hallmark of good public involvement such as flexibility, sharing and learning and respect for each other.

Planning your public engagement activities:
A step by step guide

Principles of engagement developed by the community organisations represented on Egality’s Advisory Board. At the heart of these is the core principle that community organisation leaders and teams offer an expertise and skill set of high value, and they should be respected and treated as such.

This toolkit provides guidance, tips and templates to help you plan, deliver and evaluate your patient involvement. Once you’ve planned how you want to involve patients, we can also help you find them.
A practical guide to patient and public involvement in lab-based research

The guide, created by The King’s Fund and Picker has been developed with input from ICSs, patient leaders, and engagement and experience experts. They have put together a set of principles for systems to adopt to ensure that the voices of people and communities are at the heart of partnership working.

This guide includes theory, rationale, and examples of best practice, in the involvement of patients, service users, carers, and members of the public in quality improvement. Patient and public involvement includes timely opportunity for these groups to provide input as advocates for other patients.

The Evidence library has been developed for people with an interest in research into public involvement in research. It includes articles that cover the impact of public involvement on research the nature and extent of public involvement in research and contains references up to 2015. * INVOLVE was replaced by NIHR Centre for Engagement and Dissemination in April 2020, this website is no longer actively updated or supported.
The NIHR-INCLUDE Guidelines provide: a strategic overview of potential points for intervention to improve inclusion of under-served groups across the life course of research; key objectives to improve inclusivity; guiding principles for stakeholders to apply the guidance.
Payments Guidance

Guidance document aimed at organisations that pay public contributors as part of their involvement of members of the public in research. It is also intended for use by researchers and research staff with a responsibility for public involvement in research.

This briefing for local authorities, charities and organisations that support people who use services and their carers, looks at how people and carers who receive state benefits can get involved in paid co-production, involvement, participation in health and social care, highlighting what they need to be aware of to avoid any loss of benefits.

This guide is for patients, carers and members of the public thinking about getting actively involved in research, and you are being offered expenses and/or payment for your involvement. It offers answers to some frequently asked questions and suggests where you might get advice about your particular circumstances.
Inclusive opportunities
Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

The Centre for Ethnic Health Research has one clear vision: “To reduce ethnic health inequalities”. We do this by working with patients, the public, community and voluntary sectors, researchers, health and social care organisations.

How to engage underserved groups. This paper pools what we know about how to engage with groups in society that are sometimes called ‘seldom heard’ in order to improve health and add value to health services or research organisations.

Trial Forge Guidance 3: randomised trials and how to recruit and retain individuals from ethnic minority groups—practical guidance to support better practice.

This briefing from the Social Care Institute for Excellence looks at how people and carers who receive state benefits can get involved in paid co-production, involvement, participation in health and social care, highlighting what they need to be aware of to avoid any loss of benefits.
We recognise the power asymmetries that exist in ethical and legal debates around the development of data-driven technologies, and will represent people in those conversations. We focus not on the types of technologies we want to build, but on the types of societies we want to build.
Support & Learning: Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

UK Standards for Public Involvement one-hour training package. The course is aimed at public involvement leads, the research community, researchers, health and allied health and social care professionals and members of the public involvement community.

This course is to provide you with information on the work of INCLUDE and help you to understand who under-served groups are. It also highlights what the barriers are for under-served groups getting involved in research, why it is important to include under-served groups in research and the course provides examples of INCLUDE in practice.
Governance

Governance for Participation; This ‘Bite-size guide’ sets out the principles for embedding patient and public voice (PPV) in governance frameworks for commissioning and service development, and suggests some practical steps you can take to ensure accountability to the public and those affected by plans and decisions.

Our vision is of ‘nothing about us without us’. Meaningful involvement for us means involvement that makes a difference: it should improve services and improve the mental health, wellbeing and recovery of everyone experiencing mental distress.
This is a practical guide for researchers on involving the public in working out how to communicate findings – from the earliest stages of projects, and on the most challenging of subjects. It draws on our experience of working with researchers on socially or scientifically difficult issues of public interest.
The Public Involvement Impact Assessment Framework (PiiAF) and related guidance is primarily aimed at researchers who wish to design an assessment of the impact of public involvement in their research.

GRIPP2 (short form and long form) is an international guidance for reporting of patient and public involvement in health and social care research.

The STARDIT system features standardised data reporting about initiatives, including who has been involved, what tasks they did, and any impacts observed. STARDIT is designed to support a culture of partnership across disciplines and is, wherever possible, aligned and interoperable with existing reporting models and frameworks.

Patient focussed medicines development patient engagement quality guidance. A tool that contains seven quality measures to assess projects to involve patients, and capture the quality of the public engagement project and the benefit it brings to the stakeholders involved.
The Patient Experience Library puts a wealth of patient experience evidence in one place with free search and unlimited downloads. Our team brings together expertise in communications, software development and information management, combined with a passion for getting patient voices heard.

The Cube Evaluation Tool framework, a four-dimensional framework that will allow you to map the quality of public involvement experience.
Localised Resources

Vocal creates opportunities for people to find out about, and have a voice in, health research in Greater Manchester.
From defining research priorities to designing trials, people affected by Parkinson's are playing a vital role in shaping research.

We are the UK's national autism research charity. We focus on giving autistic people the opportunity to live long, happy, healthy lives. We do this by funding research, shaping policy and working with autistic people to understand their needs.

Providing patients with accessible and reliable information and training on medicines research and development and other therapeutic innovations. A patient-led partnership working across stakeholders to enhance patient engagement.

The Patient Experience Library started with this thought: if clinical research databases are feasible, why not a patient experience research database? A patient-centred NHS learns from patient experience. We don't need to do "doctor knows best" any more. We're in this together.
The involvement network is a group of people affected by cancer who want to make a difference to the lives of others facing cancer. They share their views to help us to beat cancer while ensuring that we’re meeting the needs of future patients and their families.

At Versus Arthritis we work to enable and support local NHS services to provide the best possible care for people with arthritis and other musculoskeletal conditions. We firmly support the involvement of people with lived experience in the designing of local services.

The Patients Association is an independent patient charity campaigning for improvements in health and social care for patients. Uniquely for a charity with a remit covering all health and care issues, we work with patients directly: they are our members and supporters, and also the people who benefit from our help and advice services.

With more than 180 members, National Voices is the coalition of health and social care charities in England. Together our members work for a strong patient and citizen voice in health and care, and services that are built around people.
We are an independent membership organisation and the UK’s only mental health charity to center the survivor and lived experience voice. We bring individuals and groups together to communicate and support each other, and we amplify and advocate for the voice of lived experience to challenge policy and practice.

The James Lind Alliance (JLA) believes that addressing uncertainties about the effects of a treatment should become accepted as a routine part of clinical practice, and patients, carers and clinicians should work together to agree which, among those uncertainties, matter most and deserve priority attention.

The McPin Foundation is a mental health research charity. We believe research is done best when it involves people with relevant personal experience that relates to the research being carried out. We call this expertise from experience.
The ABPI exists to make the UK the best place in the world to research, develop and use new medicines and vaccines. We represent companies of all sizes who invest in discovering the medicines of the future. Our members supply cutting edge treatments that improve and save the lives of millions of people.

The Association of Medical Research Charities (AMRC) is a membership organisation dedicated to supporting medical research charities in saving and improving lives through research and innovation. We ensure our member charities fund the best research by developing guides, providing training, and carrying out an audit of their funding processes.

We are the independent, expert voice of biomedical and health research in the UK. The Academy’s vision is good health for all supported by the best research and evidence. Our mission is to help create an open and progressive research sector to improve the health of people everyware.

Find out what it means to get involved with Cancer Research UK through patient involvement. You can work with us, to shape, influence or guide projects as they develop. The insight of people affected by cancer and cancer patients is helping us to beat cancer while ensuring that we’re meeting the needs of patients and their families.
Cochrane is an international network with headquarters in the UK, a registered not-for-profit organization, and a member of the UK NCVO. Cochrane is for anyone interested in using high-quality information to make health decisions. Cochrane evidence provides a powerful tool to enhance your healthcare knowledge and decision-making.

Health and Care Research Wales is a networked organisation, supported by Welsh Government, which brings together a wide range of partners across the NHS in Wales. We work together to promote research into diseases, treatments, services and outcomes that can lead to discoveries and innovations which can improve and even save people’s lives.

The Health and Social Care Research and Development (HSC R&D) Division is part of the Public Health Agency. Its work is based on the principle that the best health and social care must be underpinned by knowledge, based on well conducted research, which can then be applied in the delivery of care.

Our mission is to unite the UK’s health and care data to enable discoveries that improve people’s lives. We do this by uniting, improving and using health and care data as one national institute. Our 20-year vision is for large scale data and advanced analytics to benefit every patient interaction, clinical trial, biomedical discovery and enhance public health.
Our vision is for high-quality health and social care research that improves people’s health and wellbeing, and our core purpose is to protect and promote the interests of patients and the public in health and social care research.

The Medicines and Healthcare products Regulatory Agency regulates medicines, medical devices and blood components for transfusion in the UK. The agency plays a leading role in protecting and improving public health and supports innovation through scientific research and development.

The National Co-ordinating Centre for Public Engagement (NCCPE) has an international reputation for inspiring and supporting universities to engage with the public.

The NIHR has launched a new Centre for Engagement and Dissemination (CED) that brings together its activities in patient and public involvement, engagement and participation with its strengths in research dissemination. The NIHR CED will further enhance the strong collaborative culture in engaging with patients, service users, carers and the public across the NIHR, providing coordination and thought leadership across the health and care system.
Our area faces some major health and social care challenges. Our work aims to tackle those challenges. The North East and North Cumbria covers a large geographical area but has a relatively small population of around three million people. Across our area, we have the highest rates of poverty, unemployment, poor health and early death, in England.

Patient and public involvement is important to the work of the Accelerated Access Collaborative. We work with people and communities to ensure that the research priorities and innovations we support are developed in collaboration with people with lived experience of a particular service or health condition.

NHS Research Scotland promotes and supports excellence in clinical and translational research in Scotland so that patients can benefit from new and better treatments. We work to ensure that NHS Scotland provides the best environment to support clinical research.

PPFMD’s goal is to improve global health by co-designing the future of healthcare for patients WITH patients. Its mission is to bring together initiatives and best practices that integrate the voice of the patient thereby speeding up the creation and implementation of an effective, globally standardized framework – that involves patients as partners.
Together with our members, we aim to shape policy that allows universities to deliver the greatest impact possible for students, staff, the economy, and the communities they serve. By demonstrating these benefits, we’re helping UK universities build trust with policymakers and the public.

Launched in April 2018, UKRI is a non-departmental public body sponsored by the Department for Business, Energy and Industrial Strategy. We bring together the seven disciplinary research councils, Research England, which is responsible for supporting research and knowledge exchange at HE institutions in England, and the UK’s innovation agency, Innovate UK.