

A woman with long brown hair and black-rimmed glasses is looking towards the camera. She is wearing a dark purple turtleneck sweater and a white name tag that reads 'ARTHRITIS RESEARCH UK'. In the background, a man with glasses is partially visible, looking down. The setting appears to be a professional or research event.

Patient & Public Involvement

A researcher's guide

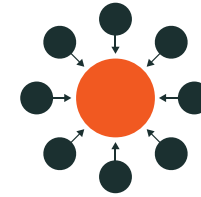


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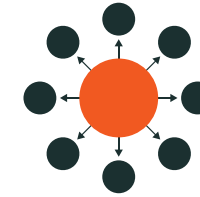
What is Patient and Public Involvement?

Patient and Public Involvement (PPI) in research, is defined as **research carried out 'with' or 'by' patients and those who have experience of a condition**, rather than 'for', 'to' or 'about' them. Whilst engagement and participation are important ways of interacting with people with arthritis in research, we believe that involvement provides very influential and meaningful insight that is essential to anyone aspiring to improve the quality of life of people with arthritis.



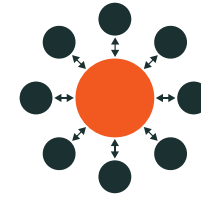
Participation

People take part in a research study.



Engagement

Information and knowledge about research is provided, and disseminated.



Involvement

Where members of the public are actively involved in research projects and in research organisations.

Why we Involve People with Arthritis

By adopting meaningful patient involvement approaches to our research activities, we will increase the relevance of our work, enhance research excellence and help to ensure studies with patient participation are as safe, sensitive and ethical as possible.

How we Involve People with Arthritis

We integrate patient insight into the charity via our patient insight partners (PIPs). We involve our PIPs in a number of different activities ranging from priority setting partnerships that steer strategy, to reviewing grant applications. When reviewing grant applications, PIPs contribute in parity to research experts, taking part in lay peer review and acting as integral members of our subcommittees. With this approach we gain relevance, but not at the expense of scientific excellence.



Having my experience count in a useful, positive way to bring about change is really rewarding and empowering.

Jane Taylor, Chair of Arthritis Research UK Patient Insight Partner group



Guidance for Basic Researchers

This section is a guide to patient involvement at different points in the basic research cycle and how to initiate involvement.

Why Involve Patients in Basic Research?

Both involvement and engagement activities are very beneficial to those conducting laboratory-based basic research. We recognise that involvement may be challenging to implement in this type of research. As such, engagement activities, including presenting to patient groups, participating in charity engagement events and institute open days, may be the most appropriate way to gain patient insight for some forms of basic research. However, if these activities are entered into with an open mind and a willingness to listen and be guided by new perspectives, they can form the foundation for meaningful involvement activities in future.

How can Patient Involvement enhance Basic Research?

Greater relevance

Involving patients ensures that researchers demonstrate accountability to people with arthritis and that the work being undertaken has the greatest relevance.

Stronger funding applications

Applications reviewed or written by patients clearly illustrate aims, patient benefits and study importance to all reviewing committee members.

Improved communication

Engaging with a new audience and more people will improve verbal and written communication skills – practice makes perfect!

Motivation and focus

Hearing from people living with arthritis and what the difference research makes to their lives will provide an extra level of motivation.

Novel perspectives

Involving patients in research brings new insight and perspective to the table that basic researchers don't routinely hear.

Increased recruitment

Patients can increase sample donation and the retention of crucial donors by helping to write accessible, engaging patient information and devising patient sensitive study designs.

New ideas

Talking to wider groups of patients, particularly at early stages of research, broadens the field of influence thus generating novel challenge, discussion and ideas.

Public interest and engagement

Patients involved and invested in studies are excellent research advocates and can generate more interest from the general public.

Greater impact

Studies have shown that carefully considered involvement activities make for more impactful research.

Patient Involvement within the Basic Research cycle

Not all stages of the basic research cycle can involve people with arthritis meaningfully. The below stages and methods of involvement demonstrate that there are still many opportunities to gather patient insight to the benefit of basic research. Ideally involvement activities should be carried out as early as possible in setting research priorities and questions with subsequent involvement in the proceeding stages. However, any of the below activities at any stage can be meaningful in isolation.

Priority Setting

Help to identify and prioritise the unmet needs of people with arthritis

- Identify patient need
- Ensure relevance to the arthritis community
- Highlight new research directions

Identify patient need

Hold focus groups to bring together people living with arthritis for a one-off directed discussion on specific questions in a research topic can uncover fresh insight.

Ensure relevance to the arthritis community

Involving a long-term advisory group provides consistent patient insight ensuring that relevance and initial priorities are retained throughout.

Highlight new research directions

Broad topic, informal workshops encourage discussion and debate between all relevant stakeholders including researchers, people with arthritis, industry and healthcare professionals.

Application and Design

Ensuring grant and ethics applications & study information are accessible to a non-research audience

- Review lay material in application
- Design material for participants

Review and write lay material in application

Utilise a focus group to write grant applications and study information so they are accessible to a non-research audience.

Design material for participants

A one-off group of prospective sample donors can help to prepare patient engagement information, consent forms and to design sampling schedules and methodology that are sensitive to the needs of people with arthritis.

Dissemination

Ensuring research is communicated widely, is accessible and is engaging to the public

- Identify key message
- Tailor key message to target audience
- Plan and participate in outreach

Identify key message

Sharing findings with patients not previously involved in the study will highlight the research outcomes that are most important to patients and the public.

Tailor key message to audience

Focus group testing of key study messages will lead to better communication and engagement with the research.

Plan and participate in outreach

A study advisory group, involved throughout, can develop and deliver engagement activities to disseminate research findings.

Basic Research Q&A

The below are some of the most common questions and statements made by basic researchers about PPI. Consider the responses and factor this in to the planning of engagement and involvement activities.

I work in the lab – how can patient involvement be beneficial?

There are a number benefits to the basic researcher and these are detailed in the previous section. We believe that involvement challenges you to ask the question “how is this relevant to patients?” Understanding this creates an impact mindset, focusing your research where needed and sets your work on a trajectory toward future patient benefit.

I just don't know where to start

We recognise that it is difficult for a basic researcher to know how to start a mutually valuable involvement activity. Why not simply start by giving presentations to patient or public groups with a Q&A or networking session afterwards. Having an open discussion can help focus your research on patient

need, reveal future involvement activities and be incredibly motivating.

Patient involvement isn't relevant to me

If you are funded by us, no matter how basic the research, you share a duty to improve the quality of life of people with arthritis. Engaging and involving people with arthritis demonstrates to your funder and reviewing panels that you have considered and prioritised patient needs.

Where can I find people to engage with and involve?

Most universities have a public engagement and/or involvement team who would be very pleased to hear from you. Public and patient/charity groups meet regularly all over the UK and are open to discussions about research relevant to them.



Having patient insight partners in committee discussions has been a really positive move. They cut through jargon and ask the simple but important questions that we scientists rarely do

Professor Luke O'Neill, Chair of Arthritis Research UK Disease Subcommittee

Case Study \ Charis Pericleous

Charis is an Arthritis Research UK Career Development Fellow working at Imperial College London on the molecular mechanisms of autoimmune dysfunction in people with lupus and antiphospholipid syndrome.

How did you get into patient involvement?

My research aims to improve management of patients with autoimmune rheumatic disease by creating better tests and more targeted treatments. Since my work is for the patients' benefit, I began engaging with patients in order to find out firsthand what is important to them, and thus directly involve them in identifying what my research priorities should be.

How did you involve people with arthritis in your research?

I routinely attend dedicated rheumatology clinics, and have discussions with patients about my research. In contrast to appointment slots, which are usually time limited, my time is not restricted and this gives patients and I the opportunity to have a meaningful discussion, about my work, their condition, and any other research-based questions they may have.

What impact did this have on your research?

Meeting patients highlighted a real desire for alternative treatments. They were supportive of my more basic work which aims to understand how disease arises and progresses, and excited by its potential to lead to the eventual design of new, targeted therapies. I consider patients' opinions to be paramount for the success of any research project that aims to provide patient benefit, and so,

the constructive feedback I received ensured that what I was doing was relevant to them.

Was it what you expected?

Involving patients in my work has been much more rewarding than I anticipated. I now have a better understanding of how patients manage their condition and the profound impact that rheumatic disease can have on quality of life, which, for a basic scientist like myself provides a real focus and drive.

Is there any advice you'd like to give someone considering implementing PPI in their research?

Try something you're comfortable with, or maybe slightly out of your comfort zone, and see where it leads you. My experience shows that patients, and the public, want to learn more about their own/a loved one's disease and are very interested in research and want to help in any way they can; whether that is providing their unique perspective, challenging research assumptions and even becoming regular sample donors.

Want to read more like this? Visit arthritisresearchuk.org/patientinsight to access the full interview and others like this.



Patients and the public, want to learn more about their condition, and are very interested in research and want to help in any way they can

Charis Pericleous



Guidance for Clinical Researchers

This section will look at how patient involvement can enhance clinical and applied health research at all stages of research.

Why Involve Patients in Clinical Research?

Clinical and applied health research, by its very nature, has clear and tangible primary aims to improve the quality of life of people with arthritis. It has been shown that this type of research clearly benefits a great deal from the involvement of people with arthritis. This insight becomes crucial to ensure the quality of any research that has people with arthritis as participants in the study.

How can Patient Involvement enhance Clinical and Applied Health Research?

Recruit quicker and to target

Clinical studies and trials are more likely to recruit the number of participants required if patients are involved in the design of the study and patient information.

Improved patient retention

Participants are more likely to continue in a clinical study if the methodology is sensitive to the patient – patient involvement in design ensures this.

Appropriate study outcomes

People with arthritis can help identify the most important and relevant patient reported outcome measures, so therapies/interventions are evaluated on the patient benefit.

Enhanced research design

The way studies are conducted, data captured and information assessed can be improved through PPI.

Stronger funding applications

Applications reviewed or written by patients clearly illustrate aims, patient benefits and study importance to all reviewing committee members.

Quicker ethics approval

Patients can help identify and address ethical issues and write applications leading to faster approvals. PPI is an essential component of Health Research Authority approval.

Safer

Patients with the condition being studied can act as prospective study participants, identifying safety issues that need addressing before the study begins.

Meaningful study conclusions

Conclusions drawn from research findings by people with arthritis are more relevant and transferable to genuine patient benefit.

Wider dissemination and engagement

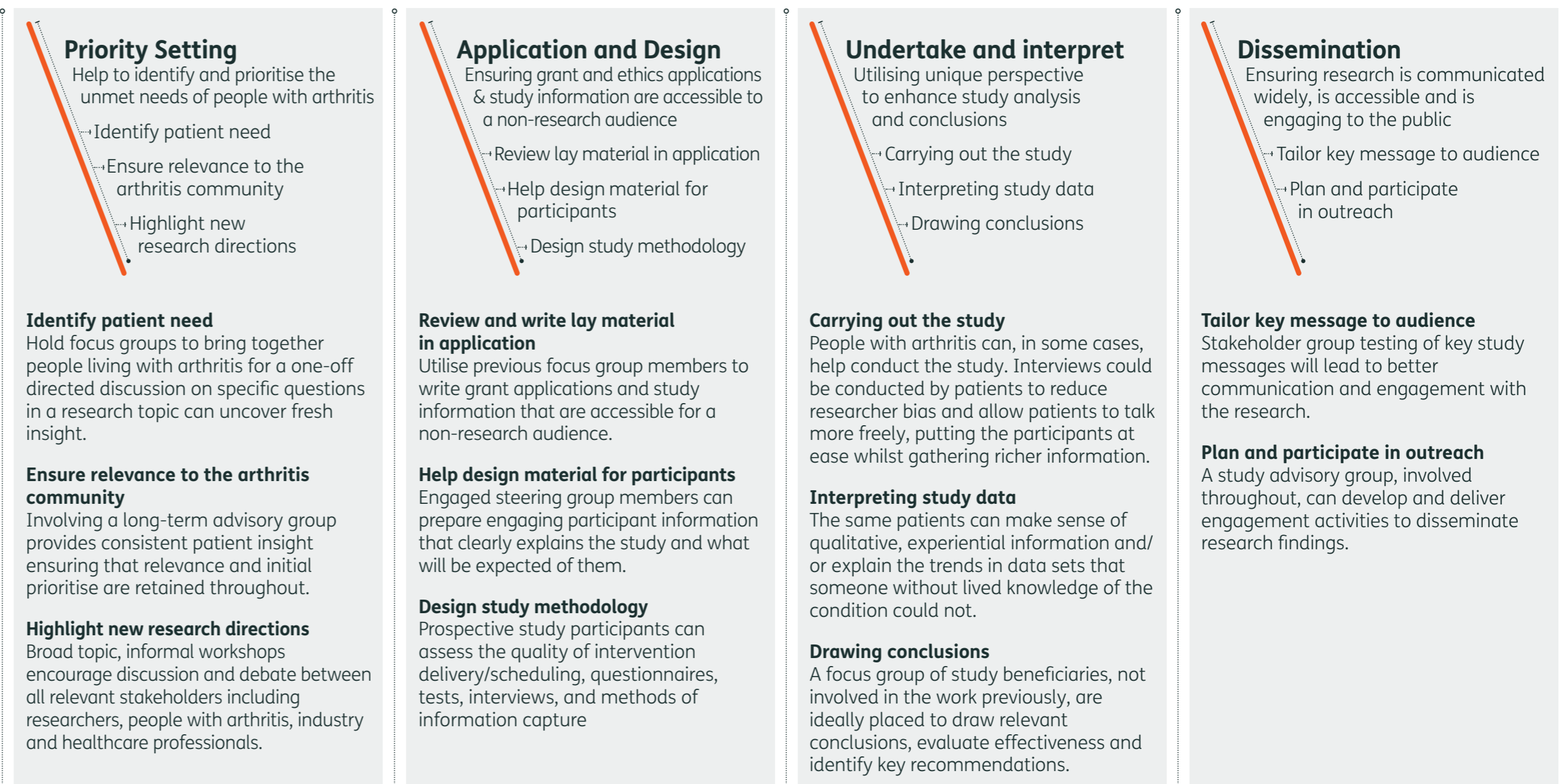
Involved patients are well-placed to advise on methods of public engagement in order to disseminate research findings widely.

Greater impact and influence

Patient involvement can lead to your findings having greater impact and stronger influence on institutions and organisations up-taking and implementing study outcomes.

Patient Involvement within the Clinical Research cycle

We believe that at most stages of the clinical research cycle, people with arthritis can be involved meaningfully and to the mutual value of the participants and researchers. The below stages and methods of involvement are just a few examples of how to gather patient insight to the benefit of clinical and applied health research. Ideally involvement activities should be carried out as early as possible in setting research priorities and questions, with subsequent involvement in the proceeding stages. However, any of the below activities, at any stage, can be meaningful in isolation.



Clinical Research Q&A

The below are some of the most common questions and statements made by clinical and applied health researchers about PPI. Consider the responses and factor this in to the planning of involvement activities.

When's the best time to do an involvement activity?

Earlier the better! Doing so ensures patient relevance throughout the research cycle, and identifies areas that could benefit from involvement from the very outset.

Patient involvement isn't relevant to me

If you identify as a clinical or applied health researcher, then involving people with arthritis in your work will always be beneficial. You have a duty of care to those participating in your study and involvement can not only ensure that participants are safe, feel comfortable and are engaged but also improve the quality of your findings.

I can't afford to do PPI

Ideally, you should always outline and fully cost your involvement activity in

applications for funding. Arthritis Research UK uses this information to assess the relevance and potential patient impact of your proposal when evaluating your application. However, if you need additional funding for PPI activity, please get in touch with the involvement team.

I have published! - my job is done

It certainly isn't. Getting published in peer review journals is a great measure of impact but don't forget to feedback your findings to your patient involvement group and show them how they made a meaningful impact to your work. This will challenge you to think about how study outcomes could be implemented in practice to the benefit of people with arthritis. Never forget to acknowledge the contributions of your involvement group who have generously donated their time.



The value of patient insight in clinical research is undeniably huge. A bit of initial effort on PPI can greatly improve study quality and outcomes.

Chris Macdonald, Research Involvement Manager, Arthritis Research UK

Case study \ Caroline Flurey

Caroline is a Senior Lecturer in Public Health at the University of West England exploring the experiences, coping styles and support needs of men with rheumatoid arthritis (RA).

What were you doing and why did you feel you needed it?

PPI was important to enable me to include the perspective of a man with RA (of which I am neither!) in the design of the study to make sure I was asking appropriate questions in a way men would relate to and be willing to respond to.

How have you involved people with arthritis in your research?

I have involved people with arthritis in my work throughout the design process (advising on interview questions, patient information sheets and questionnaires), as a co-facilitator in focus groups, in the analysis process, and as co-authors.

How has involving people with arthritis affected your research?

Involving people with RA has enabled me to design my studies in the way most acceptable and attractive to patients, to encourage engagement and participation. People with RA also provide a different perspective when interpreting results, which has led to a more patient centered conclusions from my studies.

Is there any advice you'd like to give someone considering implementing PPI in their research?

Practical tips would be to avoid using jargon in your team meetings, work with your patient research partner (PRP) to break down any barriers (e.g. doctor patient relationship within a research

team), give PRPs time to speak, consider including two PRPs on a research project to reduce the burden on each of them, and offer reimbursement for expenses (they may be too polite to ask).

Ultimately though, listen to your PRPs, it's the patient's role to provide their experience, but it's your job to apply the meaning of that to shaping your own research design. There is so much to learn from listening to and involving patients in every stage of the research process.

Personally, what have you gained from the involvement?

I was invited into the home of a patient research partner when they were having a RA flare, to demonstrate the impact this had on their day-to-day life. This gave me an insight into what it is like for people to live with RA by observing the changes in someone I knew well. This was more powerful than any explanation of RA I could have read in an academic text.

Want to read more like this? Visit arthritisresearchuk.org/patientinsight to access the full interview and others like this.



It's the patient's role to provide their experience, but it's your job to apply the meaning of that to shaping your own research design.

Caroline Flurey

How to Ensure Patient Involvement is Meaningful

It is important to implement considered patient involvement to get the most value out of researchers' and patients' time. There are a number of steps and principles that can be adopted to maximise the benefits of carrying out public and patient involvement.

Good planning

Research has shown that carefully considered involvement activities have the most impact on research.

Strive towards diversity

No one person can represent all stakeholders, a diverse range of people with experience of arthritis provide a well-rounded input.

Give it time

Allow sufficient time to prepare and conduct involvement. As volunteers, patients should not be given impractical timelines or rushed.

Feedback

Tangible proof of how the study benefitted from their input is hugely rewarding for people that were involved in research.

Consider managerial roles

Patients taking on responsive and managerial roles (e.g., study management group) can have a greater impact on research than those in oversight roles (e.g., advisory panel).

Evaluate

Evaluating how patients were involved and influenced research can provide insight into how to develop and improve involvement strategies in future.

Involve early

People involved in planning stages are more engaged, and can become committed collaborators throughout the study, providing greater value.

Be considerate

Dependent on their condition, the people involved may have medical issues (e.g. pain, fatigue, accessibility requirements), as well as economic, social and work considerations to be sensitive of when planning activities.

Budget

Involving patients has associated costs to consider (travel, recruitment, materials, training, expenses etc.), and should ideally be accounted for in applications.

Recognition

Patients invest a lot of time into research, it is important to acknowledge their contribution and to not accidentally appropriate their contribution.

Manage expectations

Be up front about what you expect from patients and what they can expect from the study. Unmet expectations lead to frustration and disengagement.

Advice

Where can I find people to involve with my research?

There are many patient advocacy groups and charity networks that can be contacted. If you have a project you would like to involve or engage our patient network with, contact us.

People in Research: The National Institute for Health Research (NIHR) run a service to advertise research involvement opportunities to the public and patients peopleinresearch.org

Research Design Service (RDS): If you are applying to the NIHR, the RDS can provide information on relevant groups and networks who may be interested in collaborating rds.nihr.ac.uk/public-involvement/for-researchers/

How can I cover the cost of Patient involvement?

It is important to budget for patient involvement activities in grant applications in order to cover costs associated with recruitment, training, travel, facilities hire, refreshments and expenses. It is also important to factor in the cost of staff time.

To budget appropriately use INVOLVE's (national advisory group for involvement in research) involvement cost calculator invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/

Arthritis Research UK Patient Involvement and Engagement fund

We recognise that involvement may not have been budgeted into existing grants making it difficult to start involving patients in research. Funding is therefore available to research award holders who want to integrate involvement activities in to their research. Contact us through patientinsight@arthritisresearchuk.org to find out more.

Is there any additional support and advice?

Arthritis Research UK: For advice about how to start involving people with arthritis in research you can visit arthritisresearchuk.org/patientinsight or contact us through patientinsight@arthritisresearchuk.org

INVOLVE: There are a number of other very useful resources from guidance on how to write effectively for lay audiences, to examples of involvement activities, and putting things in to practice at <http://www.invo.org.uk/>

The James Lind Alliance: brings patients, carers and clinicians together in Priority Setting Partnerships to identify and prioritise the Top 10 uncertainties, or unanswered questions, about the effects of treatments <http://www.jla.nihr.ac.uk/>

Generation R: NIHR funded national young persons' advisory group that support the design and delivery of paediatric research. <http://generationr.org.uk/>

Resources

The information presented in this booklet was evidenced from a variety of systematic reviews, case studies and our experience of PPI within the organisation. A handful of the available reviews were referenced and are listed below. An extensive source of evidence for further reading is INVOLVE's publications library invo.org.uk/resource-centre/libraries/publications-by-involve

Evidence

Exploring Impact: Public involvement in NHS, Public health and social care research.

Staley, 2009 // Extensive report identifying how research is influenced by PPI
invo.org.uk/wp-content/uploads/2012/01/INVOLVEexploringimpactSummary2009.pdf

ReseArch with Patient and Public invOLvement: a RealisT evaluation – the RAPPORT study.

Wilson et al., 2015 // Health services and delivery research Explores the outcomes, barriers and enablers of effective PPI

Models and impact of patient and public involvement in studies carried out by the Medical Research Council Clinical Trials Unit at University College London: findings from ten case studies.

South et al., 2016 // Trials Impacts of PPI across many clinical trials

Exploring the impact of public involvement on the quality of research: examples, Eastleigh

INVOLVE, 2013 // Case studies of PPI use in healthcare research

Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study. Health Expectations.

Crocker et al., 2016 // Explores the roles patients may play in the research team

Patient engagement in research: a systematic review.

Domeneq et al., 2014 // BMC Health Services Research Investigating the impact of PPI on recruitment and dissemination

Lay involvement in the analysis of qualitative data in health services research: a descriptive study

Garfield S et al., 2016 // Research Involvement and Engagement. The impact of PPI on data collection and analysis in applied health research

Shared Learning Group on Involvement in Research Involving people in laboratory based research

Shared Learning Group, 2016 // A discussion paper Exploring the impact of PPI in laboratory based research across different charities

Benefits of engagement: What's in it for me?

Research Councils UK, 2010 // The benefits of public engagement for researchers

Investigating pathways to impactful PPI

From tokenism to meaningful engagement: best practices in patient involvement in an EU project.

Supple et al., 2015 // Research Involvement and Engagement Principles for successful PPI based on the experience of an EU project

What Difference Does Patient and Public Involvement Make and What Are Its Pathways to Impact?

Dudley et al., 2015 // Qualitative Study of Patients and Researchers from a Cohort of Randomised Clinical Trials. PloS One Recommendations for meaningful PPI in clinical trials

An evidence base to optimise methods for involving patient and public contributors in clinical trials: a mixed-methods study

Gamble et al., 2015 // Health Services and Delivery Research Recommendations for impactful PPI in clinical trials

Debate on the challenges of quantifying PPI

Research 'Is it worth doing?'

Staley, 2015 // Measuring the impact of patient and public involvement in research Involvement and engagement

Evaluation of public involvement in research: time for a major re-think?

Edelman and Barron, 2015 // Journal of health services research & policy

Opinions on the value of PPI in research

Meet patients to get your motivation back

Nuriel, 2012 // Nature

Patient and public involvement in basic science research—are we doing enough?

Dobbs and Whitaker 2016 // BMJ Blog

NIHR Senior Investigators: Leaders for patient and public involvement in research

INVOLVE 2014 // INVOLVE:Eastleigh The attitudes of senior researchers towards PPI

Close to the bench as well as at the bedside

Callard, Rose and Wykes. 2012 // Involving service users in all phases of translational research Health Expectations Importance of patients in all stages of translational research

Communication and engagement

Engagement support

<http://www.rcuk.ac.uk/pe/Guides/>

Help with lay communication

www.plainenglish.co.uk/free-guides.html

Writing in plain English

<http://www.invo.org.uk/resource-centre/plain-english-summaries/>

About us

At Arthritis Research UK, we invest in breakthrough treatments, the best information and vital support for everyone affected by arthritis. We believe that by harnessing the power of exceptional science we can overcome the pain, isolation and fatigue arthritis causes, making everyday life better for all 10 million people with arthritis in the UK.

Our long term commitment is to prevent and cure arthritis, and to transform the lives of people with arthritis. To achieve this, the research we fund must be addressing genuine unmet patient needs. The only way to ensure this is relevant is to actively involve people with arthritis in our research activities.

Our principles

Our patient involvement activities, and those of our funded researchers, should be purpose-driven and conducted in a meaningful and non-tokenistic way. This will ensure that these initiatives are valuable to researchers, the charity, and above all, to people with arthritis.

Contact Us

arthritisresearchuk.org/patientinsight
patientinsight@arthritisresearchuk.org



When we integrated people with arthritis in our research activities, the value of their insight -in conjunction with scientific expertise- was immediately obvious

Stephen Simpson, Director of Research and Programmes, Arthritis Research UK



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