

# How to use this booklet

This booklet is intended as a guide to help you start involving people with arthritis in your research, it can also be a handy reference for those more experienced in Patient and Public Involvement (PPI) activities.

Throughout this booklet, we will use the term "arthritis" in the broadest sense, to cover all forms of arthritis and musculoskeletal disease. Much of our guidance will be applicable to involving people of all ages, however we recognise that there are specific considerations to keep in mind when involving children and young people. These will not be covered in depth within this booklet, and so in the resources section we include links to further information to help you involve children and young people in your research.

# **Acknowledgements**

The production of this booklet would not have been possible without the hard work of Patrick Lawson-Statham, research placement student, and the valuable input of patient insight partners Debra Dulake and Jane Taylor, as well as researchers and patient partners Andrew Hunt, Bethan Jones, Gareth Jones, Suzanne Verstappen and Valerie Sparkes.

"For me, working with patients has been the best thing I've done for my PhD. Not only for the work that I've done, but how I'm going to implement it and what it means beyond."

Bethan Jones, PhD student, University of West England

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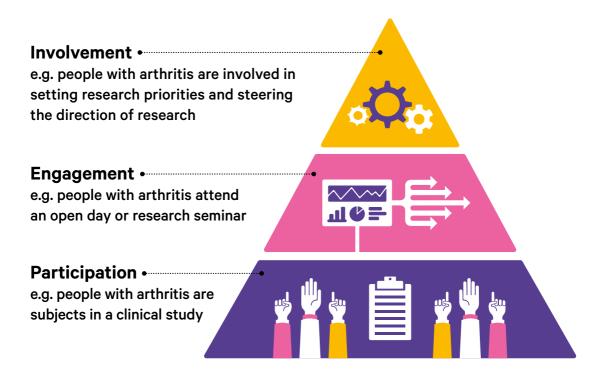
# **SECTION 1:**

# 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. Adopting meaningful patient involvement approaches into your research activities can increase the relevance of your work, enhance research excellence and help to ensure studies with patient participation are as safe, sensitive, ethical and successful as possible.

Whilst engagement and participation can also be valuable ways of interacting with patients and the public, we consider involvement to be the gold standard that you should strive to implement throughout the course of your research project, from inception to conclusion. Ideally, all three elements should be incorporated.

# Involvement, engagement and participation



# How does Versus Arthritis involve people with arthritis?

At Versus Arthritis, we're doing everything we can to push back against arthritis. Our ambition is to ensure that one day, no one will have to live with the pain, fatigue and isolation that arthritis causes. To achieve this, the research we fund must address genuine unmet patient need. The only way to ensure this is to actively involve people with arthritis in our research activities, from setting research priorities through to evaluating the outcomes of research projects.

For example, our current strategic focus on pain was driven by insight that showed for people with arthritis, pain colours everything, and that over 70% of people with arthritis are in daily pain due to their condition. Our pain strategy was co-developed by people with arthritis alongside other stakeholders, and they also reviewed applications to subsequent funding calls. While this is an example of patient involvement shaping research priorities and strategy at the level of a funding organisation, PPI can similarly help researchers develop important questions or new areas of research in a research institute or individual lab group.

"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."

#### Luke O'Neill, Chair of the Versus Arthritis disease subcommittee

We integrate patient insight into the charity via our patient insight partners (PIPs), who are involved in a wide range of activities from contributing to priority setting partnerships that steer strategy, reviewing grant applications, attending parliamentary events as advocates for their condition, interviewing fellowship applicants – and even working with us on the production of this booklet.

When reviewing grant applications, PIPs contribute alongside research experts, taking part in lay peer review and acting as equal members of our subcommittees. With this approach we gain relevance from the input of people with lived experience of arthritis, alongside the critical review from scientific peer reviewers.

We believe that patient involvement activities should be purpose-driven and conducted in a meaningful way to ensure that they are valuable to researchers, the charity, and above all, to people with arthritis.

# **SECTION 2:**

# Getting started with your involvement activities

The research cycle describes all stages of a study from conception and setting of research priorities, through to dissemination of results. This is a continuous process and involving people with arthritis at each stage of the research cycle ensures a focus on the patient throughout the research project, as well as a consistent input of influential and meaningful insight.

There are opportunities to involve people with arthritis at each stage of the research cycle, but if you are just starting out, you may want to initially focus on one stage and use this as a starting point from which to expand your involvement activities in the future.



#### Some examples of involvement activities are:

- Bringing together a focus group to discuss research priorities
- Setting up a patient group (sometimes called a lay faculty) to review grant applications
- Co-designing participant recruitment materials and patient information leaflets
- Including people with arthritis in management and advisory groups
- · Asking people with arthritis to feedback on publications, presentations and posters
- Asking patients to help design an engagement event for the public.

"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 at Versus Arthritis

# Things you can do today to get started Find out if your department, institution or local health provider already has a patient group that you could make connections with Arrange a meeting with a patient or a group of patients to discuss your research Invite a patient or several patients to your next lab meeting Contact a patient group to ask if they would be happy to give feedback on a grant or conference abstract

# **SECTION 3:**

# Engaging in PPI for basic science researchers

Involving people with arthritis in basic or fundamental discovery research may seem more challenging to implement as you are less likely to meet patients on a regular basis. However, we believe that it is possible to involve people with arthritis meaningfully at all stages of the basic science research cycle.

Involving patients from the very beginning of your research, at the priority setting stage, ensures that the research maintains a patient focus throughout. This involvement can then continue through to, and beyond, project completion. Although the ideal is involvement at all stages of the research cycle, any of the below activities can also be meaningful in isolation.

# How can involvement enhance basic research?

**Greater relevance and impact:** Involving patients ensures that researchers demonstrate the relevance and accountability of their work to people with arthritis.

**Stronger funding applications:** Applications reviewed or written by patients can show more clearly the aims, patient benefits and study importance.

**Improved communication skills:** Widening your engagement will improve your communication skills and help you explain your work simply and compellingly – practice makes perfect!

**Motivation and focus:** Researchers report that hearing from people living with arthritis the difference research makes to their lives can provide extra motivation and focus.

**Novel perspectives and new ideas:** Involving patients in research brings new insight, ideas and perspectives to the table which can generate novel challenges, discussions and ideas.

**Improved translation:** Involving people with arthritis in measuring the outcomes in animal studies which would later be relevant to humans can help with translation to clinical studies.

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

# **CASE STUDY: GARETH JONES**

Gareth is a career development fellow at the University of Bristol, funded by Versus Arthritis. His research is focused on the study of early inflammatory arthritis, and the mechanisms that control disease progression.

## Have you had any previous experience of patient involvement?

Before attending a PPI workshop (run by Versus Arthritis), very limited – my previous experience was more engagement. We would invite patients to the lab so that they would get to see what we did and the equipment we use. Although this type of engagement can potentially feed into involvement because it improves patient understanding of what scientists actually do, enabling them to be more informed when giving feedback on research.

#### How did the patients respond to the lab visits?

Great actually! Naively I was a little worried that patients would be less supportive of basic research. Maybe because they saw basic research as something that was further away from patient benefit, perhaps 7 - 10+ years down the line. However, it has been very positive, and my experience is that patients do value basic research.

#### How do you intend to involve people with arthritis in your research?

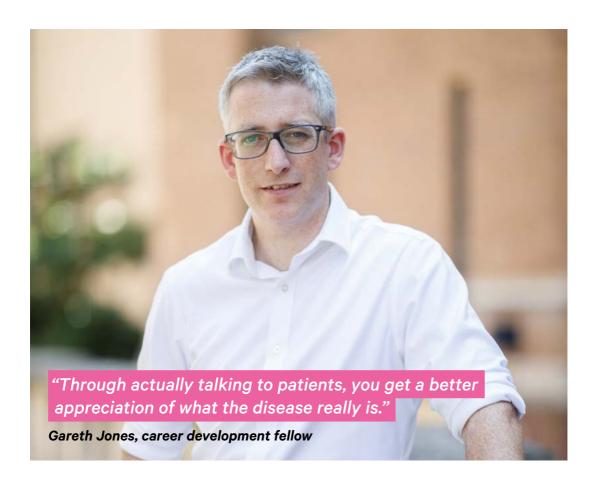
I met with a patient last week and the plan is for that patient to be continuously involved in the research. This means to be involved in lab meetings every now and again, to feedback into the research that is ongoing, into the new questions we are developing – helping make sure that they are important to patients. Also in terms of dissemination of our research, whether that's feeding back to students preparing posters, presentations for conferences or publications but also potentially for public engagement.

#### What have you gained personally from the involvement?

So, I guess it is that more personal link - it is very easy for us basic scientists to be obsessed with our interests, where we are locked away doing experiments and reading papers about arthritis. Through actually talking to patients you get a better appreciation of what the disease really is. Alongside that you get the motivation to do the research and an added sense of responsibility. These days, I guess my research has become a little more translational rather than only pure basic research. For that I have developed collaborations that allow me to investigate early clinical observations.

#### What difficulties have you experienced and how have you overcome them?

I think establishing PPI can be challenging for basic scientists, who don't have that regular link with patients. I have just moved Universities and developing PPI from scratch was a big concern. But, if you have a look around there should be somebody that can help you meet patients, or there may already be an established patient involvement group.



#### Have you got any advice for researchers just beginning to do PPI?

What I've done is start off small, by getting feedback on grant applications, and now I hope that I am moving onto the next stage where patients are involved at all stages of the research and being integrated more within the research group. That's the ambition really, we are just starting off there. There should be small steps you can take to gradually improve your patient involvement. You'll see the benefits of it, even at that early stage where you're getting feedback on grant applications. That early communication will help form those relationships and you can build on those to develop PPI.

# In your opinion, is it valuable to involve patients beyond the research conception phase?

I don't think you have to limit patient involvement to new projects you are starting or grant applications that you are preparing. Patients can become part of your research pipeline whatever stage your project is at, whether those particular individuals have been involved in the project in the past or not. Whether you are preparing a conference presentation or putting a poster together outlining research you have already done – patient feedback can help improve those and help you communicate that message.

If you would like to hear more from Gareth, you can view a video interview with him on our website www.versusarthritis.org/research/involving-people-with-arthritis/

"Being able to be part of something that is so positive, means I can look at my condition in a much more positive way."

Andrew Hunt, patient PhD co-supervisor



# **SECTION 4:**

# **Engaging in PPI for clinical researchers**

Clinical and applied health research, by its very nature, has a clear and tangible aim to improve the quality of life for people with arthritis. Research has shown that patient insight is crucial to ensure the quality of clinical studies. We believe that people with arthritis can be meaningfully involved at all stages of clinical research projects, to the mutual value of the participants and researchers. Ideally involvement activities should be carried out as early as possible when setting research priorities and questions, with subsequent involvement in the proceeding stages. However, any of the below activities can also be meaningful in isolation.

#### How can patient involvement enhance clinical and applied health research?

**Greater relevance and impact:** Involving patients ensures that researchers demonstrate the relevance and accountability of their work to people with arthritis.

**Enhanced research design and stronger funding applications:** The way studies are conducted, data captured and information assessed can all be improved with PPI. Applications reviewed or written by patients clearly illustrate aims, patient benefits and study importance. People with arthritis can also help identify the most important and relevant outcome measures.

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

Improved recruitment and retention of participants: Clinical studies are more likely to meet recruitment targets if patients are involved in the design of the study and development of patient information sheets. Participants are also more likely to continue in a clinical study if the methodology is sensitive and acceptable to patients e.g. number of hospital visits.

**Safer studies:** Patients can act as prospective study participants and identify safety issues that need addressing before the study begins.

**Wider dissemination of outcomes and greater influence:** Involved patients are well-placed to advise on methods of public engagement in order to disseminate research findings widely. Patient involvement can lead to your findings having greater impact and stronger influence on institutions and organisations up-taking and implementing your study outcomes.



# CASE STUDY: BETHAN JONES AND ANDREW HUNT

Bethan is a PhD student at the University of West England, funded by Versus Arthritis, investigating what information, skills and support people with inflammatory arthritis need in order to take an active role in their healthcare. Andrew has systemic lupus erythematosus (SLE) and osteoarthritis and is a patient co-supervisor of Bethan's PhD.

#### What inspired you both to get involved in PPI?

Andrew: I left the teaching profession very suddenly and went from a 70-hour week to nothing. My occupational therapist thought, this guy needs to do something. It started from there, but it quickly became a way of building on my previous profession. I am still part of the learning process, so when Beth came along it worked perfectly.

**Bethan:** I was lucky enough to be working with patient partners in my clinical job before I came into my PhD, I always found it really rewarding and enjoyable. It feels wrong to be doing research about people without involving them.

#### What involvement activities do you currently undertake together?

Bethan: It's evolved as time has gone on. At the start it was very much me getting a sense of the literature and the field, often that involved going to Andrew and saying, can I talk to you about this? Does this happen to you, does this happen at your appointments, or how do you cope between appointments? How do you prepare for that? As the project developed, I would send him very short literature summaries, often intended to be in lay language, but as things have progressed it became very evident that Andrew's literature skills are much better than mine! Since then, Andrew's involvement has included helping me consider the design and application of interview schedules, as well as talking through results, and questionnaire and study design.

Andrew: I come to everything and I am expected to contribute, it's not a tick box, you are part of the team. We meet semi-socially, where we're not restricted by time, and we'll often spend quite a lot of time discussing even a tiny part of the research.

#### How has PPI benefitted you on a personal level?

**Andrew:** Massively, absolutely massively. To be part of something that is so positive, means that I can look at my condition in a much more positive way. There's strangely a value in my condition now because I can use it to give back to something that is going forward and will help patients like me.

**Bethan:** My research would have gone a very different way if not for Andrew. It would have taken me about 18 months more to get the important points, and I don't think there's enough cake in the world to reflect my gratitude for that!

# Do you have any tips or key considerations to suggest to researchers embarking on/considering undertaking PPI?

**Andrew:** From that first meeting I remember very little about the PhD, it was more about establishing mutual trust and the fact that I'm not coming with an agenda. For this sort of work, that mutual trust, and respect for Bethan's PhD, that's what I want to see.

Bethan: I'm really glad you mentioned the expectations because this was something that I remember trying to set early. I didn't want Andrew's involvement to seem like an after-thought. Having a vague plan from the beginning was important, even if it was just to agree that we meet up for coffee every couple of months in person. Those sorts of practicalities were really helpful. I am very open about how much extra thought I hadn't realised I was doing, in terms of making sure Andrew got documents through to review and if he had the time, because this isn't his full-time job, he's not paid for this, he does this out of a sense of goodwill and a taste for a cup of coffee.

"For me, working with patients has been the best thing I've done for my PhD."

Bethan Jones, PhD student, University of West England

# Would you like to give any parting advice to researchers who may be hesitant to involve patients in their research?

**Bethan:** For me, working with patients has been the best thing I've done for my PhD. Not only for the work that I've done, but how I'm going to implement it and what it means beyond. It's so much fun. It makes the PhD process a lot more bearable at the later stages, take it from me.

**Andrew:** Those who are reluctant need to speak to a researcher that's involved patients very productively. I think researchers need buddies as well who can say, you might be a bit worried however, the value could be immense.

If you would like to hear more from Bethan and Andrew, you can view a video interview with them on our website www.versusarthritis.org/research/involving-people-with-arthritis/

# EXAMPLE PATIENT INVOLVEMENT PATHWAYS IN CLINICAL AND BASIC SCIENCE RESEARCH

#### **Priority setting:**

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

# Application & design:

- Review lay material in grant application
- Design material for participants

# Undertake & interperet:

- Carry out the study
- Interpereting study data
- Drawing conclusions

#### Dissemination:

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



# **BASIC RESEARCH**

Professor Smith is a researcher at the Austin Institute studying biomarkers for the early diagnosis of osteoarthritis.

Professor Smith invites a patient group to a meeting to discuss his research group's library of biomarkers and they help choose several which have the possibility to confer patient benefit.

Professor Smith writes a grant to Versus Arthritis based upon the patient feedback. Prior to submission, the application is distributed to the patient group for feedback.

The grant application is accepted and the research undertaken. The patients reviewed the data and advise on conclusions.

A PhD student in the Smith group is presenting the data at an international conference. They practice their presentation in front of the patient panel and ask for feedback.



# **CLINICAL RESEARCH**

Dr Brown is a clinician at the Chesterfield Royal Hospital and wants to study the effect of different orthotics on the gait of patients with total ankle replacements (TARs).

Dr Brown contacts
TAR patients via
hospital clinics to ask
if they are interested
in forming a research
user group, to discuss
the advantages and
limitations of current
ankle orthotics.

Prior to undertaking the study, Dr Brown needs ethical approval. The patients review the ethics application and advise on changes. The patient panel design and review the experimental protocol and patient information leaflets for the study.

Members of the patient panel copresent the results at orthopaedic conference.

...>

# **SECTION 5:**

# Checklist for planning your involvement

Developing an involvement plan before you begin will maximise the benefit of your activities and ensure that they are suitable and accessible for people with arthritis. This may seem daunting, so to help you we have produced the following checklist of key things to take into consideration.

## **Needs and expectations**

Ensure, prior to beginning any involvement activities, that you have a clear idea of the aims and objectives of your planned activities.

| <b>Expectations:</b> Is there a clear and defined plan for the task or tasks that the patient will be involved with?   |
|--|
| <b>Time commitment:</b> How much time will patients be required to commit to the activities? Is there an anticipated end date or will the involvement be ongoing?                                    |
| <b>Training and support:</b> Will training be necessary in order for patients to fully take part? Will there be a support structure for those involved with the research?                            |
| Grants: Will the patient be a co-applicant on grant applications?  |
| <b>Technology:</b> Patient access to software/technology may not be the same as your own, will this be provided? Will software training be necessary?  |
| Consider managerial roles: Patients taking on responsive and managerial roles (e.g. study management group) can have greater impact on research than those in oversight roles (e.g. advisory panel). |
| <b>Evaluate:</b> Evaluating how patients were involved and influenced research can provide insight into how to develop and improve involvement activities in future.                                 |

#### Coete

People with arthritis should not be left out of pocket as a result of taking part in involvement activities. Involvement costs should be factored into your grant application from the beginning.

| Account for patient expenses: Travel, sustenance, childcare, carer costs, accommodation and home office costs. Ensure these are paid promptly. |
|--|
| Training, support and access to software: All of this may come with a cost.  |
| Activities: Advertisements, venues, catering, conference fees.   |
| Awareness: Ensure the people you involve are aware of what they are entitled to.   |

#### **Practical considerations**

It is important to ensure your involvement activities are accessible for people with arthritis.

| <b>Venue:</b> Is the venue accessible and are there disabled toilets and parking bays nearby?  |
|--|
| <b>Travel times:</b> Consider implications of early starts and plan around times of heavy traffic.   |
| Meeting time: Suited to patients condition, travel and age.  |
| Breaks: Factor in time for regular and reasonable breaks.  |
| <b>Give it time:</b> Allow sufficient time to prepare for and conduct involvement activities.  |
| <b>Support:</b> First meetings can be daunting, consider having a brief introductory telephone call prior to the involvement activity, or pairing those new to involvement with a buddy who is more experienced and can provide support. |
| Strive for diversity: No one person can represent all stakeholders, however a diverse range of people with experience of arthritis can provide well-rounded input.   |
| <b>Feedback:</b> Tangible proof of how studies benefited from involvement is hugely rewarding for people who were involved.  |

As well as the many potential benefits, it is also important to be aware of and plan for the challenges that you may face, for example sustaining involvement and resistance (this could be from fellow academics or the patients themselves).

# Top tips for meaningful involvement

"Keeping in regular contact is a must to make the patients feel valued and like they made a difference."

Debra Dulake, patient insight partner

"Ask 'Is this relevant to a patient'. Constantly asking that question helps you identify those opportunities."

Gareth Jones, career development fellow

"I found it useful to ask the patients about how we organise our activities and get them to help shape those activities."

Helen Wright, career development fellow

# **SECTION 6:**

# First steps in PPI - Getting started

We hope that the many benefits of involvement activities to both the patients and your research are clear, and that you now have an idea of the different types of involvement activities that are possible. Before you start, the first step is making contact with the appropriate people to get involved in your research. Some researchers, especially in a clinical setting, may already have established patients or existing patient groups which would be a good place to start. For those without pre-existing patient links, we have produced a list of suggested ways in which you may be able to get in contact with patients and the public, to help you get started on your involvement journey:

- In clinic: Do you interact regularly with patients in the clinic who may want to get involved in your research?
- At your university: Are there pre-existing patient groups at your University or Institute? If not in your institute, look elsewhere within your University or even other local Universities - be creative!
- Patient involvement channels: Several online channels allow you to advertise PPI opportunities such as People in Research.
- **Social media:** Advertising opportunities on social media can be a good way to reach patients.
- Look locally: You can advertise in local community groups, local charities, GP surgeries, local newspapers, patient support groups and NHS trusts. See INVOLVE advice on advertising PPI opportunities.
- **INVOLVE directory:** This resource has a list of networks and organisations that support PPI in research.
- Charities: Charities often have patient involvement integrated within their
  organisations and may be able to help put you in contact with suitable patient groups.
   Versus Arthritis has over 250 local patient groups across the UK who may be interested
  in supporting you with your research. Please contact us to discuss this further.

A common question is, how many people with arthritis should I involve? The answer will vary depending on the nature of the involvement activity you are planning. In some cases, there may be a benefit to having a small number of patients involved throughout the course of the research project, for example one or two patients attending regular research meetings, or a single patient acting as a patient co-supervisor on a PhD studentship. However, in other cases, for example reviewing grant proposals or taking part in discussions around future research priorities, it is useful to collect a more diverse range of opinions and feedback. It is important to note that quantity is not a substitute for quality, and that the number of individuals involved should be proportionate and appropriate to the nature of the activity.



# **SECTION 7:**

# Lay communication

Lay communication is an important skill for scientists. Examples of lay communication activities include writing lay summaries in grant applications, reporting to your funders, public engagement events, PPI activities – and of course speaking to your friends and family about what you do. Successful lay communication can be an extremely effective tool in research dissemination if done correctly.

#### Where to start?

- Who are your audience? What do they already know?
- Why are you speaking to them?
- What do you want to tell them?

# Building an easily understandable research story

- Beginning What is the background? Why is your research question important?
- Middle What are you doing?
- End How will your research make a difference?
- **Consider** What are your take home messages? What can you omit without changing the message?

# Top tips for communicating in plain English

- Consider your audience carefully
- Speak to colleagues for guidance or examples, and ask for help and/or feedback if you are unsure
- Practice with a non-scientist could be a friend/partner/child/grandparent
- Do not reuse work intended for other audiences (unless appropriate)
- Do not use acronyms or complicate matters with too much scientific detail
- Avoid incomprehensible diagrams and graphs
- Do not make assumptions about what the reader will know
- Do not oversimplify

# **SECTION 8:**

# Communicating involvement activities in your grant applications

As well as being an invaluable activity to improve the quality of your research, patient and public involvement is a requirement of Versus Arthritis funding. Therefore, it is important to be able to effectively communicate this involvement in your grant applications.

#### In your Versus Arthritis grant application, you will be asked:

- How have you involved patients in developing this application?
- How will patients or patient groups be involved in steering and implementing the research?
- How do people with arthritis stand to benefit from your research?

"Think about how you would explain this. What is the story of your research - start from the outside and move in. So why this area? Why this particular protein or pathway? Why now? Where will this take you (and us) in the future?"

### Jane Taylor, patient insight partner

Here you would describe your meaningful involvement activities at the various stages of the research cycle. Our patient insight partners will review the quality of the patient involvement, the relevance to the charity and potential for patient benefit. They will want to see a realistic and well-thought out plan for your involvement activities.

Some areas of the application will require technical language however the lay abstract, questions in the application details section and strategic focus sections should be written in non-technical language. These are important parts of the application and require careful consideration. We would caution against leaving these until the last minute!

"It's all about clarity, if you understand where we're going, what we're trying to do, it doesn't have to be written in words of fourteen syllables or more!"

Andrew Hunt, patient PhD co-supervisor

# **SECTION 9:**

# **Further information and resources**

The information in this booklet has been collated from a variety of reviews, case studies and our experience of PPI within the organisation. We hope that this booklet has provided you with enough information to begin the public and patient involvement process. If you would like to find out more, a selection of PPI resources, evidence and opinions are listed below for your information.

**Versus Arthritis:** Further information can be found on our website *versusarthritis*. *org/research/involving-people-with-arthritis/* or by contacting patientinsight@ versusarthritis.org.

**INVOLVE:** The INVOLVE website contains numerous resources about beginning in PPI, a PPI cost calculator as well advice on involving young adults and children invo.org.uk/find-out-more/invo.org.uk/posttypepublication/a-guide-to-actively-involving-young-people-in-research/

**Generation R:** GenerationR is a national network of Young People's Advisory Groups (YPAGs) based across the UK and is funded by the NIHR. It exists to support the design and delivery of paediatric research in the UK. *generationr.org.uk*/

**BANNAR:** For guidance on the involvement of young people in rheumatology research. bannar.org.uk/default%20documents/BANNAR\_interim\_guidance.pdf

**Sharebank:** A regional network whose members share knowledge and experience of PPI https://www.invo.org.uk/current-work/sharebank/

# **Evidence**

Exploring the impact of public involvement on the quality of research examples INVOLVE, 2013. Describes case studies of PPI use in healthcare research

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

Garfield S et al., 2016; Research Involvement and Engagement.

Patient involvement in clinical research: why, when, and how Sacristán et al., 2016; Patient Preference and Adherence.

# **Guidance**

Guidance on co-producing a research project INVOLVE, 2018.

What do young people with rheumatic conditions in the UK think about research involvement? A qualitative study

Parsons et al., 2018; Pediatric Rheumatology

# Opinions on the value of PPI

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

Close to the bench as well as at the bedside Callard, Rose and Wykes, 2012; Health Expectations

# **Communicating in plain English**

Plain English campaign
plainenglish.co.uk/free-guides.html

NIHR: INVOLVE - Plain English summaries

https://www.invo.org.uk/resource-centre/plain-english-summaries/



# **About us**

We're Versus Arthritis. We've come together, taking the best of both organisations and our rich histories of working with and for people with arthritis to do even more.

We're 10 million people living with arthritis. We're fundraisers, supporters, bakers, health professionals, volunteers, campaigners and researchers. Together, we're demanding that the pain and isolation of arthritis is no longer tolerated. We're pushing to defy arthritis. We are Versus Arthritis.

# **Our principles**

We're proud to be one of the leading medical research charities when it comes to incorporating routine patient and public involvement into our research funding decision-making process.

Our patient insight partners are a group of people from across the UK who have a wide range of experiences of living with a musculoskeletal condition. The patient voice is now integrated fully into all our research activities through close collaboration with our patient insight partners. They are instrumental in bringing a patient perspective to the research decision-making process.

We're constantly looking for new ways to expand our patient involvement activities. By listening to our patient insight partners and working collaborative with other organisations, we're putting people with arthritis at the centre of research.

# Contact us

patientinsight@versusarthritis.org. versusarthritis.org/research/involving-people-with-arthritis/



For more information please visit our website versusarthritis.org

0300 790 0400

- f /VersusArthritis
- **y** @VersusArthritis
- @ WersusArthritis

Versus Arthritis Copeman House St Mary's Gate Chesterfield S41 7TD