

Good practice for Involving people with Arthritis

In creating standards for involvement at Arthritis UK, we aim to support our colleagues, health professionals, researchers and people with arthritis to understand our expectations of involvement. While we may have described our standards, we hope all would consider how they can exceed the standards and achieve best practice.

Involving people with lived experience will do more than fulfil our standards, it will increase the quality of your work, for example its relevance and impact, which could attract greater recognition and funding. Not to mention it can be fun and motivating for you, as well as extremely empowering for people with arthritis who get involved - some have even described it as part of their self-management journey. Involvement can build awareness of the challenges and experiences people with arthritis face, and mean that confidence in organisations, research and healthcare is increased.

Involvement from the beginning

Before you start a project, working together to define the priorities, and areas of unmet need is key to making sure your project is going to have impact where it's needed most.

What this looks like in practice:

- A group which includes people with arthritis alongside other stakeholders to consider and refine the priorities, scope, question, aim or design of a project.
- Input from people with lived experience into the plan for continued involvement across the lifecycle of the project to ensure this is realistic and appropriate.

Share the decision-making power

Decisions are made in partnership, in at least one point but ideally throughout your work.

What this looks like in practice:

- Building relationships and trust with people as part of the team, with them actively involved in contributing to the different stages of the process.
- Valuing all contributions and recognising people as a whole beyond their arthritis.
- Listening to experiences, and ideas with respect and openness – not just consulting.
- Releasing a degree of control and being open to changing your approach.
- Being transparent in involving people with lived experience in project groups and meetings, e.g., steering committee, project management meetings, setting agendas.
- Remaining accountable and approachable, enabling two way feedback.

Planning is required

Thought given to the resource required to involve people, and the approach you are taking. Consider what this will look like and how you can get the most meaningful input.

What this looks like in practice:

- Develop a clear visible plan which explores why and when you want to involve people with arthritis, as well as how you will achieve this – and review it regularly.
- A ringfenced budget for involvement. Reasonable out of pocket expenses should be paid, and reimbursement for people's time should be given wherever possible.
- Account for the time it takes to do involvement well.

Ensure flexibility and understanding

When working with people with lived experience, it is important to remember that they have often other commitments, but also their health and ability to engage may fluctuate.

What this looks like in practice:

- Offering different ways for people to get involved e.g., in writing or anonymously.
- Giving plenty of notice of meeting dates and deadlines can help.
- Always consider accessibility - might you need to provide information in a different format, level access meeting rooms or alternative when people have painful days.

Always consider diversity and inclusion

Ensure you involve a group of people who are representative of the community for whom your project hopes to impact. Explore barriers and work together to remove them.

What this looks like in practice:

- Consider your project through various lenses, equality impact assessments can help.
- Use other organisations or connections to advise on your plans, language and to help you reach a range of people – some communities may prefer to be involved as groups not individuals.
- Engage in training around EDI for yourself and your team.
- Use your network's contacts to reach further.

Be clear with communication

To involve people in a meaningful way, you need to share information about the project and progress, the more understandable it is the better input you will get from your interactions.

What this looks like in practice:

- Use of plain language, no jargon, or acronyms.
- Well timed, relevant information provided for effective contributions e.g., time commitments, aims, regular updates on the project and the impact of people's input.
- Consider non-academic communication channels.
- People with lived experience shaping or writing content and giving presentations.

Support, learning and recognition is provided

See people with lived experience as assets, considering in advance what guidance, information, and support you could provide, and ensuring this is proportionate to the involvement activity you are conducting. They have many skills which could help your project in a variety of ways, beyond where you anticipate, so take time to get to know them.

What this looks like in practice:

- Opportunities to find out more about the project and meet with the team and peers.
- Routes for people with lived experience to raise concerns or challenge.
- Opportunity for confidence and skills development
- A fun and supportive environment
- Capture the impact of involvement on your project and people - collecting peoples feedback and stories is a great way to do this.
- Saying thank you, inviting people to events, sharing the difference they have made with others – this shows respect and value of their input.