

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.

	Expectations: Is there a clear and defined plan for the task or tasks that the patient will be involved with?
	Time commitment: How much time will patients be required to commit to the activities? Is there an anticipated end date or will the involvement be ongoing?
	Training and support: 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?
	Technology: 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).
	Evaluate: Evaluating how patients were involved and influenced research can provide insight into how to develop and improve involvement activities in future.

Costs

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.

	Venue: Is the venue accessible and are there disabled toilets and parking bays nearby?
	Travel times: 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.
	Give it time: Allow sufficient time to prepare for and conduct involvement activities.
	Support: 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.
	Feedback: 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).