

## Patient and Public Involvement

### Tips



### Starting point

It is helpful to start by writing a couple of paragraphs outlining your study in plain Language. That is using language that is clear and concise, with no unexplained technical terms or acronyms. It is not about being patronising or simplistic; it is about being clear and describing things in a way that can be understood easily by non-specialist readers.

### Next

Begin to think about your expectations of public and patient involvement in your study:

- What do you expect involvement to deliver?
- How many people you want to involve?
- What knowledge or experiences you would like the people you involve to contribute?
- What sort of activities will you want them to be involved in?
- Would you like to meet face to face? Talk over the telephone? Start an email or web based discussion group? Do you need to send them papers to review by post?
- Will they need to have IT skills and internet access?
- What other skills might they need?
- What sort of time commitment will you be asking them to make?

Then you will need to think about what resources you need to have in place to support the sort of patient and public involvement you want

- You may need funds for out of pocket expenses– especially travel– as well as “Thank You” payments
- Have you thought about training and support needs?
- Is there capacity to support people with different needs like motor, visual or cognitive impairment?

**INVOLVE** publish a useful guide to budgeting for PPI:

<http://www.invo.org.uk/wp-content/uploads/2013/07/INVOLVEMHRNBudgeting09Jul2013.pdf>

They also have an online tool to help calculate the costs:

<http://www.invo.org.uk/resource-centre/involvement-cost-calculator/>

## Things to consider when planning an involvement meeting

In no particular order:

- Booking an accessible room: Are there disabled toilets on the same floor? Lifts?
- Is it somewhere participants are likely to feel comfortable meeting?
- Is the venue accessible by public transport?
- Is there disabled parking and easy access to the building? Will you need to provide parking permits?
- Make sure those attending are aware of the address of the venue, the time of the meeting etc. If possible send out a map and clear directions for travel by car, bus, bicycle or train.
- What are the arrangements in your institution for booking taxis for those who need them – do you have an account that you can charge or do participants have to pay and claim the money back?
- Arrangements need to be made for when people arrive. Who will let them in? Hand out car parking permits? Show people to the room?
- Think about the time of day you intend to hold your meetings. Early mornings can be difficult, particularly for participants with care needs or responsibilities.
- Consider evening or weekend meetings, particularly if you need to attract working age and young adult participants. Is it possible for people to contribute remotely?
- Be clear what the meeting is about and have an agenda or plan for how it will run.
- Don't make the meetings too long, give people a chance to contribute as well as listen, and plan breaks.
- Create an atmosphere where people feel able to share ideas.
- Think about refreshments and dietary requirements: Do any of your participants have diabetes? Are they vegetarian? Gluten-intolerant?
- Provide up-to-date travel expense/payment forms and ensure they are filled out correctly. Is it possible for out of pocket expenses, like travel costs, to be reimbursed on the day? Is there any 'thank-you' payment? Have you made all this clear to participants?

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