

**Costing Patient, Carer & Public Involvement
within studies with The Newcastle upon Tyne
Hospitals NHS Foundation Trust**

Introduction

At The Newcastle upon Tyne Hospitals NHS Foundation Trust not only do we have worldwide reputation for the quality of our healthcare, but also as a leading provider of clinical research.

Our research work helps us to stay at the forefront of healthcare and offer the very best services for our patients.

As a tertiary referral centre for a wide range of clinical conditions we have around 1.4million patient contacts per year, and recruit in the region of 15000 patients to clinical trials. We recognise the huge importance and contribution of patient and public involvement in research.

The Trust has developed this guidance to support the costing of patient and public involvement in research and we hope you find this of use.

If you have any suggestions about how this guidance could be improved then we are keen to hear from you, please contact Trust.R&D@nuth.nhs.uk

We look forward to working with you in the near future

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Purpose of guidance

The intention of this document is to provide a guide which provides practical advice on how to budget for involving patients, carers and the public in research. It will be helpful for working out the costs of involvement at any stage of the research process – whether that’s a planned focus group in a study underway or putting together an entire budget for a study. It may be particularly helpful when designing research studies and applying for funding. However, following this advice will not guarantee funding will be awarded. Research funders take a number of factors into account, including value for money, when making decisions about which research to fund. As with any aspect of budgeting for research, it is important to justify the costs involved.

Paying people for involvement in research might be complex but it should not detract from the principle of offering payment. Payment, where appropriate, should be offered and the individual allowed to make an informed choice about accepting it.

Definition of patient, carer and public involvement in research

INVOLVE defines “public involvement in research” as research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them. This includes, for example, working with research funders to prioritize research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.

Examples of patient, carer and public involvement in research are:

- As joint grant holders or co-applicants on a research study
- Involvement in identifying research priorities
- Commenting and developing patient information leaflets or other research materials
- Undertaking interviews with research participants
- User/carers research carrying out the research

When using the term ‘public’ we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

Getting started with budgeting

Planning the budget for involving patients, members of the public, service users and carers in your research involves estimating the costs so you can allocate a budget.

Many research funders, such as the National Institute for Health Research (NIHR), will actively encourage and expect public involvement to be adequately budgeted for in research grant applications. However, it will be very important to demonstrate value for money when requesting financial support for involvement. It is very difficult to obtain funding for public involvement later if it has not been built into your research grant application at the outset

What do you need to budget for?

We recommend that all individuals who are actively involved in research should receive payment or a voucher for their time.

There are currently no nationally agreed rates of payment and the amounts that members of the public are paid can vary widely. INVOLVE offers guidance which informs the platform of this costing tool.

We have listed common costs associated to Patient Carer and Public involvement in research. A more comprehensive list is available in INVOLVE Payment Policy:

<http://www.invo.org.uk/wp-content/uploads/2014/11/INVOLVE-internal-payment-policy-FINAL-August2014.pdf>

Associated costs	Description of cost	Suggested Cost
Involvement in a brief task or activity	For involvement in a brief task or activity requiring little or no preparation. For example: <ul style="list-style-type: none"> Participating in a short meeting with no preparation Reviewing a brief document such as a leaflet 	£25.00
Involvement in a task which equates to half a day's activity	For involvement in a task or activity which equates to approx. half a day's activity. For example: <ul style="list-style-type: none"> A 2-3 hour meeting with papers to read in advance Leading on submission of an article to a newsletter. 	£75.00
Involvement in a task which equates to a full day's activity	This is a standard daily fee offered for preparation, attendance at and follow up from; <ul style="list-style-type: none"> Project Advisory Group/Steering Committee Meeting Project Advisory Board/Steering Board Meeting 	£150.00
Group donations	If you are working with a patient or service user group, you may want to pay a fee, make a donation or purchase a gift for the group.	£100.00
Catering /subsistence costs	Venues where meetings are held will often provide refreshments on a cost per head basis. Rates for refreshments vary but an average cost for coffee and buffet lunch is £10-20 per head. Her Majesty's Revenue and Customs (HMRC) advises benchmark rates of £5 for one meal/five hours away from home and £10 for two meals/10 hours away from home.	£5.00
Travel costs (per mile)	Most organisations will have their own rates for reimbursing mileage when people use their own car. Alternatively, HMRC provide guidance on mileage costs and suggest 45p per mile for the first 10,000 miles in a tax year.	£0.45
Other costs <ul style="list-style-type: none"> Venue hire 	The cost of venue hire for meetings and events will vary depending on location.	

<ul style="list-style-type: none"> • Carers • Childcare costs expenses • Stationary costs • Hotel/accommodation costs • Staffing 	<p>Organising a personal assistant through an agency will usually cost £7.50-40.00 per hour.</p> <p>Some people may need support for childcare to get involved. People may have their own arrangements in place and charges will vary. If childcare needs to be organised through an agency they will usually charge £50-60 per day.</p> <p>Members of the public getting involved may sometimes carry out tasks from their own home, which incur costs such as telephone calls, postage or printing. If this is likely, it is important to decide how to reimburse these costs and include them in your budget.</p> <p>Reasonable rates can vary from £68 to £75 per room per night depending on location and advance booking.</p> <p>Depending on the duration and scope of the research study and experience of the research team, you may decide to employ a public involvement coordinator. Their role could include liaising with and supporting members of the public during the study, organising meetings and focus groups and being a bridge between researchers and members of the public.</p> <p>A public involvement coordinator can cost between £20,000 and £30,000 per annum depending on skills and responsibilities.</p>	
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Involving patients and members of the public in your research will take time and will also need to be allowed for.

Mapping involvement onto the project framework

Once you have estimated all the costs, it's a good idea to map the involvement activities onto your selected project framework so that you know exactly when the costs will be incurred.

Here is a template you may wish to complete.

	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Total Costs
Year 1													
Year 2													
Year 3													
Year 4													

If you require any further information or support in designing or costing your patient and public involvement in research please do not hesitate to contact:

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Contact Telephone no: 0191 2820774

Useful Information

INVOLVE - <http://www.invo.org.uk/>

NIHR Research Design Service - <http://rds-ne.nihr.ac.uk/about/contact-us/>