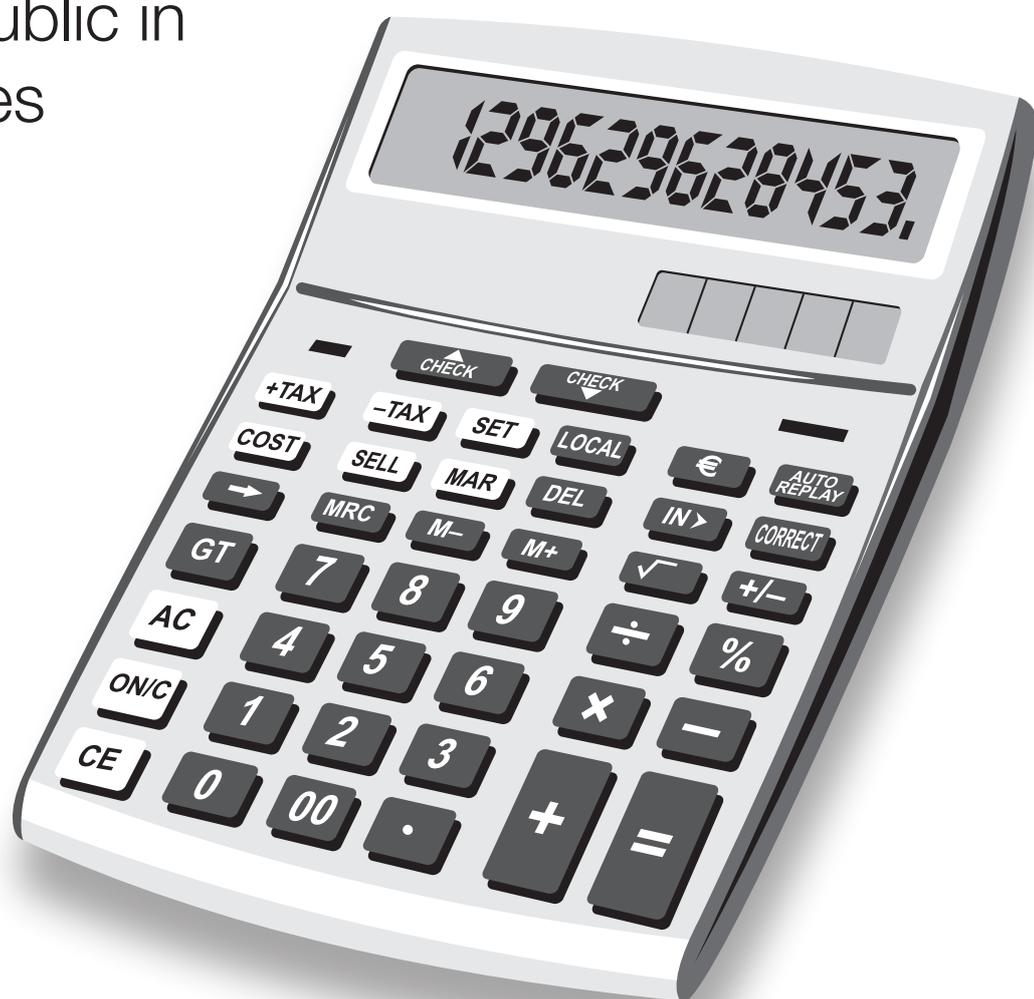


Budgeting for involvement:

Practical advice on
budgeting for actively
involving the public in
research studies

June 2013



About this resource

This guide 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.

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The information for this resource was gathered using feedback, expertise and support from a project advisory group. The group comprised people who have direct experience of budgeting for involvement in research – advising on involvement in research, reviewing applications for research with involvement activities and conducting involvement research.

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‘It is important to give researchers a tool to think about the real cost of involvement, otherwise it will not happen.’

Service user from the Mental Health Research Network

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Key tips are offered throughout the tool to help point you to some of the main things to think about. They were compiled by the project advisory group which supported this resource.



1. Introduction

1.1. Who is Budgeting for involvement for?

This resource has been compiled for a wide audience, but in particular it will be of value to:

- researchers who need to cost involvement activities at any stage of the research process
- public contributors who want to know how their involvement in research is costed
- research advisors who provide guidance to the research community about involvement
- reviewers who appraise research projects with costed involvement activities
- commissioners of research who invite funding applications from the research community.

1.2. Aim of the Budgeting for involvement resource

The purpose of this resource is to provide advice on how to cost for patient and public involvement at **every stage of the research planning cycle**, whether that's a planned focus group in a study underway or putting together the budget for a grant application.

This resource:

- provides practical guidance on **what costs** are associated with involvement in research including payments to patients, members of the public, service users and carers for their time, skills and expertise
- includes a step-by-step process for **planning** involvement, identifying the **associated costs** and considering **where** in the research cycle and project timeline involvement costs might occur
- gives **examples** of the budgets for involvement in research projects
- contains useful web and text-based **resources**

- links to a simple online **cost calculator** to help work out the actual costs of involvement for individual studies – see www.invo.org.uk/resource-centre/involvement-cost-calculator

Key tips



Involving people in research usually requires resources in the form of time and money. It is really important to account for the costs of involvement in a research study **at the earliest stage possible**. Without having these resources available you will struggle to effectively involve people.

If you are applying for funding, check if the funder has an involvement policy or guidance notes on budgeting or finance. It's likely they will be looking for value for money in any application. These will help to provide a framework for involvement costs and activities as the research project is being planned and will help minimise the risk of under budgeting for planned involvement activities.

When allocating costs for involvement activities ask the questions: 'Am I doing my patient and public involvement properly?' and 'Am I really accounting for all the costs that might be incurred?' This will ensure that the true cost of involvement activities is accounted for at the project outset. Remember that it is important not to under-estimate costs when budgeting for involvement activities.

'Money equals respect. By allocating proper involvement costs to research projects will allow the public to be engaged in research and expand the realisation that involvement is something to be respected and valued.'

INVOLVE advisory group member and
NIHR lay reviewer

1.3. 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. These costs may need to be reviewed and amended throughout the course of a study.

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.

If you are new to budgeting for involvement in research, it can help to have a step-by-step process to take you through the entire project cycle/timeline. This will ensure that you do not miss out any activities or costs. The steps can be used at any stage in the research process. Table 1 summarises the step-by-step process. Go to [Section 3](#) for more information and a worked example using a dummy research study.

Table 1: Step-by-step process to get started with budgeting for involvement

| Step | Activity |
|--|---|
| Step 1: Framework selection | Select a framework for mapping involvement costs. This might be the research project cycle (diagram 1, page 17) or a project timeline (table 2, page 17). |
| Step 2: Planning your involvement | Make a plan of the involvement activities you intend to incorporate into your research. |
| Step 3: What are the costs? | For each activity, identify the specific costs that you will need to budget for. |
| Step 4: How much will it cost? | Estimate the cost or range of costs against each involvement activity. See the dummy example used throughout Section 3 and the involvement case studies in Section 6 for examples of how other people have budgeted for involvement. Go to the online cost calculator www.invo.org.uk/resource-centre/involvement-cost-calculator to work out the budget for your study. |
| Step 5: Mapping | Map the involvement activities onto your selected project framework so that you know exactly when in the project timeline costs are allocated. |

Key tips



Try to ensure that all members of the public involved in research studies are well supported. Within small projects this will usually be the responsibility of the chief investigator, which will have implications for the researcher's time and may need to be costed at the outset of the project.

Having opportunities to be involved with more than one aspect of research is likely to make members of the public feel more connected and involved with all aspects of the research. Therefore, promoting a variety of ways for involvement in a piece of research is important. This requires appropriate budgeting from the outset.

Remember the importance of paying expenses for members of the public in advance or ensure that they are paid promptly after their involvement in an event or activity – you don't want them to be out of pocket for contributing to your research.

'It can be tricky to feel fully connected to a study when you are just employed one day a week. I avoid this on CORE by being involved in wider aspects of the research.'

(CORE – Optimising team functioning, preventing relapse and enhancing recovery in crisis resolution teams)

Public Involvement Coordinator
– CORE study

1.4. What do we mean by public involvement in research?

INVOLVE and the Mental Health Research Network (MHRN) define 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, members of the public working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants (see INVOLVE 2012 Briefing notes for researchers www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/).

Throughout this document when we talk about the **public**, we mean:

- patients and potential patients
- people who use health and social care services (service users)
- people who provide care/support on an informal (that is unpaid) basis (carers)
- parents or guardians
- disabled people
- members of the public and local communities who may be targeted by public health or health promotion initiatives
- organisations representing people who use health and social care services.

We are aware that terms other than **public** are used to describe people who get involved with research. The MHRN uses the terms service user and carer. Other people use terms such as patient, research advocate, consumer or lay member. All these terms are valid and useful. For simplicity, we stick with **public** and **member of the public** throughout this resource.

When we talk about **active involvement** in research, we mean a partnership between members of the public and researchers in the research process, rather than the participation of people as subjects of research.

Active involvement in research may take many forms, for example:

- reviewing a research proposal
- attending a meeting
- preparing for a meeting or other activity by reading relevant documents
- participating in a training event
- interviewing others or facilitating focus groups
- analysing or interpreting results.

Taking part in a research study as a participant does not constitute ‘active involvement’. It is important not to mix up the costs for activities that are part of a study protocol, such as a focus group attended by study participants, with the costs of actively involving the public in a research study. This resource does not deal with how to budget for participation costs and this would need to be done separately. Payments for participation in research studies are sometimes referred to as incentives or inconvenience payments. Discussion about these types of payments is provided by the National Research Ethics Service in their guidance on participant information sheets and consent forms.

Useful website:

National Research Ethics Service directory of guidance for researchers
www.nres.nhs.uk/applications/guidance/

See the INVOLVE Briefing notes for researchers for further explanation of active involvement and the terms engagement, involvement and participation www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/



Key tips

Do not **under** budget for involvement when applying for research funding. Reviewers will check whether the costs reflect the reality of effective public involvement or the support/training you are planning. They will also look for value for money.

While some people may end up choosing not to accept payment for involvement activities, budgeting should be done on the basis that they will. There may be other ways of recognising someone's contribution, for example by paying for them to attend a conference or a training course.

1.5. Dealing with involvement costs before a study is funded

Sometimes it will be necessary to cover involvement costs in advance of obtaining research funding. In such a situation a few sources of support are available. Most of the NIHR Research Design Services (RDS) offer a bursary scheme which allows researchers to apply for a small amount of money from their local RDS to pay for public involvement in a study before an application for funding is made. (For details of the ten RDS and their contact details see: www.invo.org.uk/find-out-more/information-for-researchers/research-design-services-information/).

Aside from this, some university departments may be able to allocate some funds for this. Some local or national patient groups are free to consult, for example Very Important Kids (www.youngminds.org.uk/for_children_young_people/youngminds_manifesto_about_v_i_k), and some groups supported by the NIHR Clinical Research Network (www.crnc.nihr.ac.uk/homepage).

2. What do you need to budget for?

In this section we provide a list of the common costs associated with active involvement in research. You should cost for the involvement relevant to your study, ensuring the costs are matched to what you plan to do and show value for money. For each item, we explain why this cost might be incurred and, where possible, give some examples. Depending on your plans for involvement, there may be other costs not listed here that you need to account for.

For any costs you should check if your institution/organisation has standard rates, for example for mileage, or has an existing supplier you can use to help you to calculate the estimated costs.

We have organised these cost elements into five categories. These categories are mirrored in the online cost calculator www.invo.org.uk/resource-centre/involvement-cost-calculator/ which you can use for working out the costs for your own study.

The actual costs quoted in this section were correct in April 2013.

2.1 Payment and reward

- Fees to individuals
- Vouchers or tokens for individuals
- Other rewards for individuals
- Fee, donation or gift to a group or network
- Funding for additional training and learning
- Honorary appointment

2.2 Expenses for members of the public

- Travel
- Subsistence
- Childcare
- Carer costs
- Personal assistants
- Overnight accommodation
- Home office costs

2.3 Involvement activity

- Finding people
- Training and learning costs
- Venues and catering
- Equipment and books
- Access to university/NHS Trust facilities
- Conferences fees

2.4 Involvement staffing

- Administrative support
- Public involvement coordinator
- Independent facilitator
- Peer researchers/interviewers

2.5 Other costs

- Disclosure and Barring Service (previously called Criminal Records Bureau (CRB) checks)
- Language translation and interpretation
- Support for people with impairments

2.1. Payment and reward

You will need to decide how you will reward members of the public getting involved in your research. You might want to offer a fee, like an honorarium, to each person every time they make a contribution, for example for taking part in a project advisory group meeting. Or you may want to give a non-monetary reward, such as a training course or conference that is not part of the costed involvement activity.

Key tip



Whatever reward you decide upon, remember to thank people for their contributions.

Fees to individuals

These are payments to members of the public in recognition of time, skills and expertise. The rate you offer will depend on a number of factors as each situation is different. For example, one-off consultations are likely to have lower fees than ongoing involvement through project groups and undertaking the research. It may be helpful to ask yourself the following questions when deciding what rate best suits the situation:

- What level of skills, expertise and experience are you seeking/expecting from members of the public for this involvement?
- What are the time commitments involved in the role they are playing in the project (including preparation, reading, travel, communication, meetings and so on)?
- What level of responsibility do you expect the person to hold in the project?

Here are some examples of payment rates:

- The INVOLVE daily committee fee of £150 includes payment for preparation and attendance at a meeting.
- Members of the public who become involved with research in the Faculty of Health and Life Sciences, University of West of England are offered £19.40 per hour for attending meetings and £120 per day for research work.

Further examples can be found in appendix 3 of the INVOLVE Payment for involvement document www.invo.org.uk/wp-content/uploads/2012/11/INVOLVEPayment-Guiderev2012.pdf

Payment systems for public involvement in research are not always straightforward. It is important that you find out how to manage these payments through your organisational systems. [Section 4](#) provides more information about this, some frequently asked questions and a number of other helpful information sources.



Key tips

Get to know your organisation's process for paying fees and expenses to members of the public as part of planning your project and aim to have a system in place to pay people and reimburse their expenses before involvement starts.

Include a copy of or make reference to your organisation's payments and expenses policy within the research grant application.

It is good practice to offer payment whenever possible to members of the public you involve in your research. However, receiving payment or a fee can have implications for people receiving any form of benefit. It is very important that people receiving state benefits get expert advice prior to accepting payment.

Vouchers or tokens for individuals

Proxy payment such as vouchers can be offered as a reward and recognition for involvement, especially for one-off events or consultations. Such rewards are usually offered to children and young people instead of cash payments. Vouchers used to pay people on welfare benefits are subject to the same restrictions as cash payments.

Other rewards for individuals

An incentive such as a prize draw may be used to encourage members of the public to get involved, especially for one-off involvement events or consultations. This might be a cash prize or an item such as a book or tablet computer. One-off gifts do not usually affect a person's entitlement to welfare benefits (see [Payment for involvement](#) for more advice on one-off payments as gifts

www.invo.org.uk/posttypepublication/payment-for-involvement/).

Fee, donation or gift to a group or network

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. A fee or donation gives the group control over how they use the money for their own interests. It's important to pay the fee directly to the group as payment through an individual may affect their eligibility for welfare benefits.

Funding for additional training and learning

Another reward for members of the public is to pay for the costs of training and other learning opportunities. These courses may be offered through your university or NHS Trust and would be in addition to any training or learning that is required for the involvement role (see [Involvement activity section below](#)).

Honorary appointment

Giving people an honorary status, such as lay fellow or research partner, at the university or NHS Trust is often used as a way to reward and recognise their contributions. They can then have access to facilities such as the library, seminar series and other research opportunities. There may not be any costs attached to this but it may involve a Disclosure and Barring Service check (see [Other costs section below](#)).

2.2. Expenses for members of the public

Key tip



Always ensure that the public are never out of pocket as a result of becoming involved in research. Try to cover travel costs directly or in advance to allow people to get to involvement activities, for example by booking tickets via a travel agency or website.

Travel

It is important to cover the travel for any involvement. The costs usually covered include standard class rail fare, reimbursed bus fares or mileage. However, it is important to remember that some people may need alternative travel, for example a taxi, due to their support requirements.

Booking rail tickets in advance and travelling at off-peak times can reduce costs, for example the cost of a standard class return rail fare from Oxford to London travelling at peak times is £56.40 compared to an off-peak fare of £25.00 and £19.00 for advance booking.

Most organisations will have their own rates for reimbursing mileage when people use their own car. Alternatively, Her Majesty's Revenue and Customs (HMRC) provide guidance on mileage costs and suggest 45p per mile for the first 10,000 miles in a tax year.

Key tips



It is important to consider how many journeys will be needed for each person over the course of the project.

Recruiting public contributors from a wide geographical area may be necessary for a national study or a study of a rare condition. This can greatly increase travel costs and add substantially to the overall involvement budget.

Useful websites:

National Rail Enquiries

www.nationalrail.co.uk

HM Revenue and Customs

www.hmrc.gov.uk/rates/travel.htm

'Involvement costs need to be pragmatic and feasible. Sometimes the cost of a taxi to transport a service user to a venue is more pragmatic and feasible than paying for their bus pass.'

Patient and public involvement lead

Subsistence

Subsistence costs are for time spent away from home and the costs that need to be met because of this, for example paying for meals, snacks and refreshments. Check if your institution has a maximum amount that can be covered. HMRC advises benchmark rates of £5 for one meal/five hours away from home and £10 for two meals/10 hours away from home.

Useful website:

HM Revenue and Customs

www.hmrc.gov.uk/manuals/eimanual/EIM05231.htm

Childcare

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.

Useful website:

Money Advice – Cost of Childcare Calculator

www.moneyadviceservice.org.uk/en/tools/cost-of-childcare-calculator

Carer costs

People who have a caring role may need a replacement carer to enable them to get involved with research. They may have their own arrangements in place and costs will vary. If care needs to be organised through an agency they will usually charge £7.50-40.00 per hour. The NIHR Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) suggests budgeting £200 per day for a replacement carer.

Useful website:

NIHR Dementias and Neurodegenerative Diseases Research Network

www.dendron.org.uk

Personal assistants

Some disabled people have a personal assistant to support them to get actively involved in research. Some people use the term support worker. The cost of personal assistants is highly variable and depends on local circumstances. People who have personal assistants will often have their own arrangements regarding the activities undertaken and the cost of these. Organising a personal assistant through an agency will usually cost £7.50-40.00 per hour. If the personal assistant is staying overnight, there may be a reduced hourly rate for that time.

Overnight accommodation

If members of the public are travelling some distance or taking part in an involvement activity such as training over several days, they may need overnight accommodation. Affordable accommodation can be sourced from city and regional tourist information centres and directly from hotels. Reasonable rates can vary from £68 to £75 per room per night depending on location and advance booking.

Useful website:

Hotel booking website

www.booking.com

Home office costs

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.

2.3. Involvement activity

Finding people

Recruiting members of the public to get involved with research studies can be a key involvement activity cost. At the outset of the study it is important to think about who will be responsible for this activity and how much time the recruitment process will take. It is also important to think about where people will be recruited from and the cost of working with partners in the recruitment process such as charities, patient groups or local service commissioning organisations (see example below).

In order to recruit members of the public to get involved with a research study you may want to advertise the opportunity in local or national newspapers, on local or national radio, at conferences and in relevant newsletters. Advertising costs will vary depending on the medium but a small advertisement in a local newspaper may start at around £200. These costs can be reduced by using free advertising channels such as e-communities and networks.

Useful website:

Shaping our Lives has an e-newsletter about getting involved in research.
www.shapingourlives.org.uk

Useful website:

People in Research is managed by INVOLVE and offers a free place to advertise involvement in research opportunities.
www.peopleinresearch.org

Example: Norfolk and Suffolk Public and Patient Involvement in Research group (PPIRes)

PPIRes has a panel of approximately 70 lay members from Norfolk and Suffolk and works closely with researchers to develop proposals. PPIRes provides lay panel members to participate as members of project steering groups. Here are some examples of costs included in grant proposals:

| Activity | Cost to be included in a grant application, inclusive of overhead for PPIRes |
|---|---|
| Steering/Management Group | £110 per person per meeting |
| Advisory Group | £30 per person per meeting |
| Research Activity | £12.50 hourly rate |
| Dissemination: Local event (1 day) | £100 per person per day |
| Dissemination: Presenting at a National Conference (2-3 days) | £175 per person per day |

Currently PPIRes aims to pay lay members:

- up to £25 per steering group meeting and £25 per specialist lay pre-meeting
- £12.50 per hour for identified research activities
- up to £75 per day for presenting at local conference
- up to £100 per day for presenting at national conference.

Please note: This is a work in progress.

These are indicative figures only developed in response to changing needs and landscapes.

Training and learning costs

Training and induction for members of the public will be required for many involvement activities. They will need to have adequate preparation for their role and also be supported to carry it out well. This support may range from an induction process through to in-depth training, for example in interview techniques.

It's also important to think about the training and learning needs of the research team – are they ready for involvement? It may help to find out about existing training and learning resources.

Useful website:

INVOLVE Developing training and support
www.invo.org.uk/resource-centre/training-resource/

'Where service users and carers have been the interviewers (or focus group facilitators), being involved in some way with the analysis makes the process feel more complete'

Public Involvement Coordinator
– CORE study

Venues and catering

The cost of venue hire for meetings and events will vary depending on location. Venues in major cities such as London can be very expensive. Some commercial organisations offer free venues for activities involving the public as part of their Corporate Social Responsibility (CRS) agenda. Other voluntary and third sector organisations offer venues at reduced rates. The Dementias and Neurodegenerative Disease Research Network (DeNDRoN) Public and Patient Involvement guidance suggests allocating £60 for venue hire per meeting.

Additionally as part of the requirement for UK universities to have a more open public engagement agenda in research, it may be possible to use university venues to host events at a reduced cost or for free.



Key tips

Venues need to be **accessible**, so it is important to consider issues such as wheelchair access, proximity to a railway station, ground floor facilities and so on, since this will impact on choice of venue and cost. It is better to have an accessible venue that accommodates all public needs at a higher cost, than a cheaper one that proves to be inaccessible. For more advice on accessibility see INVOLVE (2012) Strategies for diversity and inclusion in public involvement: supplement to the briefing notes for researchers www.invo.org.uk/posttypepublication/strategies-for-diversity-and-inclusion-in-public-involvement/

When you think about venues for involvement activities, consider using community and corporate facilities which offer accommodation for free as part of their business in the community and corporate social responsibility agenda. This can keep costs down and also build new networks for the dissemination of research findings.

You will usually want to provide refreshments at meetings and events. Depending on the duration of the meetings, this can range from just tea/coffee and biscuits to a full lunch menu. 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.

Equipment and books

It may be necessary to provide equipment or books for members of the public getting involved. This will be important when they have a particular role such as peer interviewing and will need audio recording equipment. It might also be cost effective to provide technology

such as a tablet computer for teleconferencing instead of holding face-to-face meetings, especially if long distances are involved. Check if your institution has a purchasing agreement with a particular supplier to help you budget for this.

Access to university/NHS Trust facilities

Members of the public may require access to university/NHS Trust libraries, IT services and so on. There may not be a cost for such access but you may need to account for staff time in setting up the arrangement (see Section 2.4).

Conferences fees

Involved members of the public may need to attend conferences and events. This might be as a networking activity to recruit further members of the public into a study, to listen to the presentation of research related to the study or to present research findings once the study has ended and results are known. Involvement costs for these activities may include travel and hotel costs, conference fees and presentation skills training. Conference fees can vary from £200 to £400.

Key tip



It is always a good idea to check if bursaries are available from the conference organisers for members of the public to attend.

2.4. Involvement staffing

You may decide that dedicated staff time for involvement is required for your study. If you are involving members of the public as peer interviewers or co-researchers, it is good practice for them to be employed on the same terms and conditions as other research assistants. Other staff support that may be required can range from some extra administrative support through to a dedicated involvement coordinator as part of the team.

To help you decide what staffing is required to support the involvement consider the following questions:

- Does your team have the capacity and expertise to facilitate public involvement?
- Will you be working with an experienced involvement group or recruiting people from scratch?
- How much training and support are members of the public likely to need?

Working out the costs of involvement staffing will be the same as other staffing costs for the research project and you will need to seek advice about pay scales and other costs at your organisation.

Administrative support

It is likely that you will need some dedicated administrative support to process payments/rewards and expense claims for members of the public. The administrator may also help with organising involvement events if required.

Public involvement coordinator

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.

A public involvement coordinator can cost between £20,000 and £30,000 per annum depending on skills and responsibilities.

See [Examples 5 and 6](#) in Section 6.

‘Where somebody like myself is specifically employed to be a Public Involvement Coordinator having additional supervision/support from an experienced service user researcher is important.’

*Public and Patient Involvement Coordinator
– CORE Study*

Independent facilitator

An independent facilitator or other person with expertise in engaging with patients and the public might be useful if they have very specific skills which are not available within the

research team, for example running a focus group or a meeting with very young children or with participants with specific disabilities or impairments such as hearing loss or communication problems.

Rates for facilitators will vary depending on the specific skills required and can range from £400 to £1,000 per day.

Peer researchers/interviewers

There are different models of involving peer interviewers or co-researchers in studies. Sometimes this is done on a sessional basis with peer interviewers being paid for each interview carried out. Rates for interviews will vary, but are typically £60-75 per interview.

In other cases, peer interviewers are employed on full- or part-time contracts with the host organisation. If you decide to employ peer interviewers, it is important that such posts are graded appropriately by the employing institution's human resources department.

The model which best suits you will probably depend upon the duration of involvement and the tasks involved.

See Example 1 for an example of a study involving peer interviewers.

2.5. Other costs

Disclosure and Barring Service (previously called Criminal Records Bureau (CRB) checks)

Depending upon the role members of the public have in your research, they may require a [Disclosure and Barring Service \(DBS\)](#) check, for example involvement activities requiring members of the public to take part in peer interviews in a healthcare setting or having direct contact with young people and children. A DBS check currently costs between £26 and £44 depending on the level.

Useful website:

The Disclosure and Barring Service
www.gov.uk/disclosure-barring-service-check/overview

Language translation and interpretation

It might be necessary to translate some of the study materials, such as focus group topic guides, research protocols and research findings, in order to involve members of the public whose first language is not English. Taking part in focus groups might also involve the services of an interpreter.

Many universities and NHS trusts have their own translation and interpretation policy and access to translation and interpretation providers.

Useful website:

The Big Word translation service
www.thebigword.com

Support for people with impairments

Hearing impairments

Communication support for people with hearing impairments includes using microphones, hearing/induction loops, talk-to-type conversion (sometimes called palantype) and sign language interpreters. Hearing/induction loops are often integrated into venues but you will need to use a personal address system and microphones.

Hire of a personal address system and two microphones typically costs around £160 per day. Speech-to-text reporters typically cost £250 for half a day.

Useful Website:

Action on Hearing Loss
www.actiononhearingloss.org.uk

Mobility impairments

Making sure venues used for involvement events are accessible is vital when involving people with mobility impairments. You may also need to consider the hire of equipment such as walking aids, wheelchairs or mobility scooters.

Hire of a mobility scooter typically costs around £80 per day.

3. Working out the costs for your study

This section takes you through a step-by-step process to plan and budget for involvement. The steps can be used at any stage in the research process. You can begin at any point of the process and use whichever steps are most useful to you.

Whilst this section helps you budget for involvement, following this process when

applying for a research grant will not guarantee funding as research funders take a range of things into account when making their decisions.

To help demonstrate the process of costing involvement we are going to use a dummy project which includes four common ways of involving the public.

Our dummy project

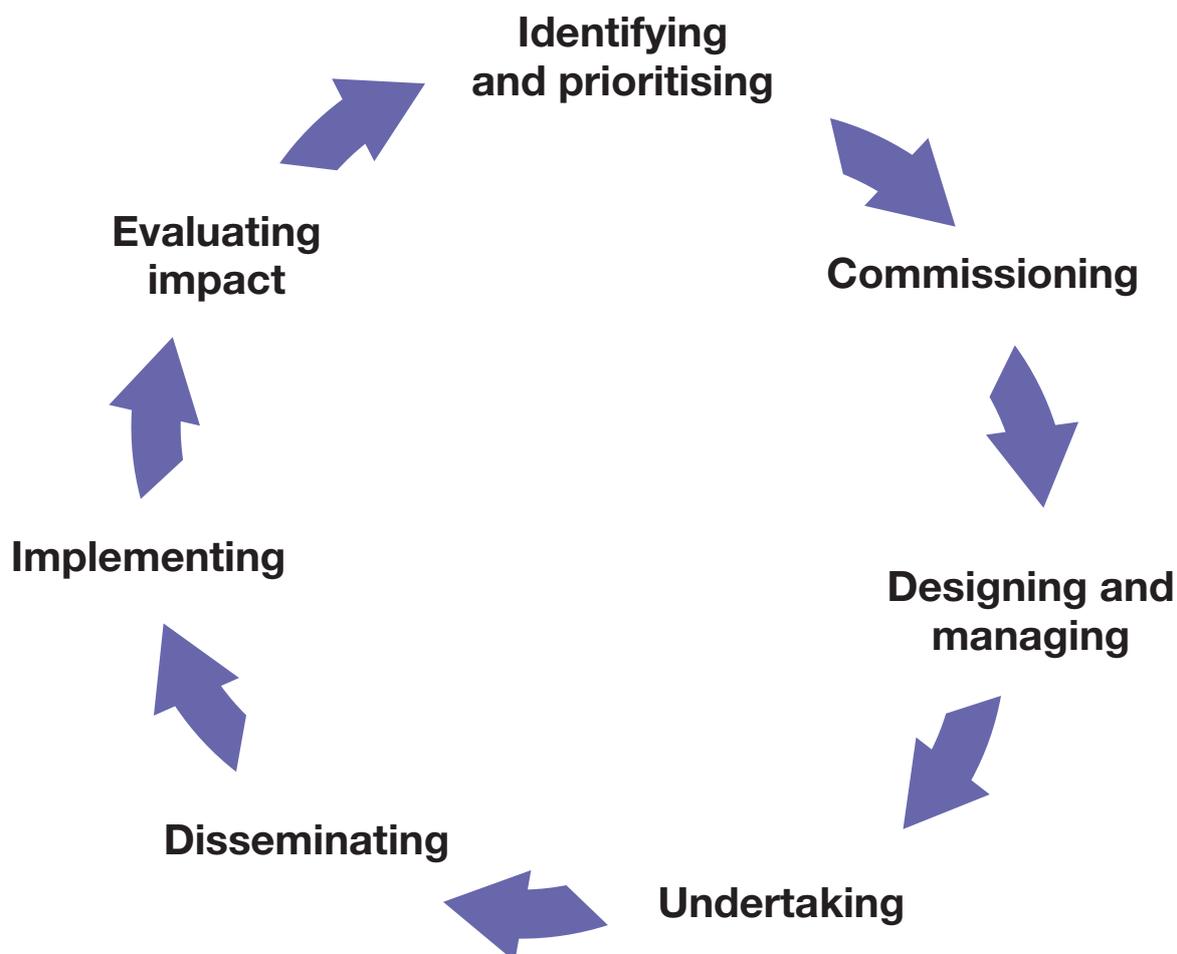
| | |
|---------------------------------|---|
| Title | Peer to peer – what do service users who use mental health services think? |
| Study aims | To explore the views of service users who use mental health services about a new peer support service |
| Ways of involving people | <ol style="list-style-type: none">1. A focus group* with people who use mental health services to consult on the important topics for service user interviews in the main study itself.2. Two people who use mental health services are part of the study steering group.3. Two peer interviewers undertake interviews with other service users who use mental health services to find out their views on the new service.4. The peer interviewers participate in a one-day national conference to support the dissemination of the research findings. |

*This focus group is to consult with service users about their priorities for topics to explore in the subsequent interviews with other service users about their experiences of peer support. In this context it is not a method of data collection.

Step 1: Framework selection

Using diagrams and timelines to help you think about and plan for involvement activities is a helpful method for deciding where in the research project involvement activities are likely to occur. A diagram of the research cycle and a table illustrating a project timeline are reproduced here to help you get started.

Diagram 1: The research cycle



This diagram is reproduced from the INVOLVE Briefing notes for researchers (2012) www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/

Table 2: Example project timeline

| Involvement activity | Jan | Feb | Mar | Apr | May | Jun |
|----------------------|-----|-----|-----|-----|-----|-----|
| Activity 1 | | | | | | |
| Activity 2 | | | | | | |
| Activity 3 | | | | | | |
| Activity 4 | | | | | | |

Step 2: Planning your involvement

Before you can budget for involvement, you need to know how you will be involving the public in your research. We are not going to be prescriptive about that here, as the involvement and how you plan to carry it out will depend upon the research and why you are involving the public. However, for ideas of involvement activities to plan for see the INVOLVE Briefing notes for researchers www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/

The examples in [Section 6](#) also provide examples of how the public has been actively involved in a wide range of research projects.

Key tip



Involving members of the public in your research will take additional time and this needs to be allowed for. Extra time should be built in for regular review of progress and to identify and alleviate pressure points during the project.

Step 3: What are the costs?

Refer back to [Section 2](#) of this publication to identify which costs you will need to account for. In that section we provide a list of the common costs associated with active involvement in research. For each item, we explain why this cost might be incurred and, where possible, give some examples. You may not need to budget for every item in the list as you will only need those items relevant to your involvement plans. Depending on your plans for involvement, there may be other costs not listed here that you need to account for.

Step 4: How much will it cost?

The actual costs of involvement need to be worked out for each individual study and using the estimated costs relevant to the locality or organisation. To show how you can do this in practice, we set out what these costs might look like for our dummy project below.

Key tip



Use the **Involvement cost calculator** www.invo.org.uk/resource-centre/involvement-cost-calculator/ to work out the costs specific to your project. Explanatory text is provided to help you get the most out this tool.

It is important to show value for money when applying for research funding

Our dummy project – estimated involvement costs

All costs for this were calculated using real costs for train tickets, hotels and so on as at April 2013.

Involvement activity 1 – focus group

A focus group with people who use mental health services to consult on the important topics for service user interviews in the main study itself.

| | Cost description | Quantity | Cost each (estimated) | Item total |
|-------------------------------|---|----------|-----------------------|------------------|
| Payment and reward | Fees to 20 members of the public for attending the focus group | 20 | £50 | £1000 |
| | Fees to 2 members of the public for review of focus group transcript analysis | 2 | £100 | £200 |
| Expenses | Travel for 20 members of the public – local travel in Oxford | 20 | £10 | £200 |
| Involvement activities | Finding people – advert in local newspaper | 1 | £200 | £200 |
| | Venue hire | 1 | £60 | £60 |
| | Catering for 20 members of the public – coffee on arrival and buffet lunch | 20 | £10 | £200 |
| Involvement staffing | Independent facilitator to moderate the focus group | 1 | £650 | £650 |
| Total estimated costs | | | | £2,510.00 |

Involvement activity 2 – study steering group

Two people who use mental health services are part of the study steering group.

| | Cost description | Quantity | Cost each (estimated) | Item total |
|------------------------------|--|----------|-----------------------|------------------|
| Payment and reward | Fees to 2 members of the public – steering group meetings | 6* | £150 | £900 |
| Expenses | Travel for 2 public members – day return off-peak standard rail fare from Oxford to London | 6* | £25 | £150 |
| Involvement activity | Venue and catering costs will be accounted for elsewhere in the project budget | 0 | | |
| Total estimated costs | | | | £1,050.00 |

*3 meetings x 2 people

Involvement activity 3 – peer interviews

Two peer interviewers undertake interviews with other service users who use mental health services to find out their views on the new service.

| | Cost description | Quantity | Cost each (estimated) | Item total |
|------------------------------|--|----------|-----------------------|------------------|
| Payment and reward | Fee to peer interviews for training days | 4* | £50 | £200 |
| | Fee to individuals for each interview | 20 | £75 | £1,500 |
| Expenses | Travel for interview training – 2 members of the public day return off-peak standard rail fare from Oxford to London | 2 | £25 | £50 |
| | Travel for interviews – local journeys in the Oxford area by car (45 pence per mile x 10 miles) | 200** | £0.45 | £90 |
| Involvement activity | Venue hire for 2 day interview training | 2 | £60 | £120 |
| | Peer interview training by independent consultant | 2 | £500 | £1000 |
| Other costs | Disclosure and Barring Service check – enhanced | 2 | £44 | £88 |
| Total estimated costs | | | | £3,048.00 |

*2 people x 2 days. **20 journeys of 10 miles each

Involvement activity 4 – attending a national conference

The peer interviewers participate in a one-day national conference to support the dissemination of the research findings.

| | Cost description | Quantity | Cost each (estimated) | Item total |
|------------------------------|--|----------|-----------------------|----------------|
| Payment and reward | Fees to members of the public for preparing and giving conference presentation | 2 | £150 | £300 |
| | Fees to members of the public for writing a lay summary of research findings | 2 | £100 | £200 |
| Expenses | Travel return off-peak standard rail fare from Oxford to Birmingham | 2 | £34.30 | £68.60 |
| | Hotel accommodation – single room for one night booked in advance | 2 | £75 | £150 |
| Total estimated costs | | | | £718.60 |

Step 5: Mapping the 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.

Using our dummy project, we have mapped the activities and costs on to a project timeline.

Our dummy project – involvement time plan

| Activity | Jan | Feb | Mar | Apr-Jul | Aug | Sep |
|--|--|---|---|---|---|--|
| Involvement activity 1: focus group | Advertise focus group in local newspaper to recruit participants £200 | Run focus group £2,310 | | | | |
| Involvement activity 2: steering group meetings | Meeting 1 To discuss focus group recruitment and peer interview training £350 | | Meeting 2 Using the focus group information develop the interview questions £350 | | | Meeting 3 To discuss feedback from national conference event £350 |
| Involvement activity 3: peer interviewing (including training) | | Training in qualitative interviewing £1,458 | | Peer interviewers carry out interviews with other members of the public who use mental health services £1,590 | | |
| Involvement activity 4: national conference | | | | | Attend and present at national conference £718.60 | |
| Costs for each period | £550 | £3,768 | £350 | £1,590 | £718.60 | £350 |

4. Advice on payment systems, welfare benefits and taxation

4.1. Payment systems and policy guidance

Payment systems for public involvement in research studies are not always straightforward. If payment is organised via the NHS, a simple system of paying people directly into their bank accounts without tax deductions might be arranged. However, administration issues can sometimes result in individuals waiting for payment. Universities can sometimes have complex payment systems, where some activity can be claimed through expenses and some through payroll with tax deducted. As early as possible begin talking with your finance department to find out about the systems in place in your organisation.

4.2. Welfare benefits and earned income

There are strict limits on the amount of money that people receiving welfare benefits can earn. The rules are complicated and a full consideration of involvement and benefits is not possible within this text. However the following sources will cover the issues that commonly arise:

1. Mental Health Research Network (MHRN) Service users and carers payment policy

The National Institute for Health Research (NIHR) MHRN has produced a comprehensive two-part guide to making payments to service users and carers for involvement work, which can be downloaded from www.mhrn.info. The titles of these two documents are:

- MHRN Service users and carers payments policy: Benefits systems and conditions around paid and voluntary involvement (January 2012).

- MHRN Service users and carers payments policy: Service user and carer participation: helpful benefit rules and benefit pitfalls to avoid (January 2012).

2. INVOLVE Payment for involvement: a guide to making payments to members of the public actively involved in NHS, public health and social care research (INVOLVE, 2010 www.invo.org.uk/posttypepublication/payment-for-involvement/).

3. NIHR MHRN Payments logbook for involvement work (MHRN, 2013) is a document that allows involved people to record all income that they receive in a logbook format so that any enquiries from the Department for Work and Pensions or Her Majesty's Revenue and Customs (HMRC) can be quickly responded to. www.mhrn.info/data/files/MHRN_PUBLICATIONS/MHRN_Payments_LogbookPartA.pdf

4.3. Making payments for involvement: Frequently asked questions

How do I make payments to members of the public?

In practice the way that you make payments for involvement will depend on local circumstances. Some organisations will use petty cash for making payments, while others require invoices. You should establish what means of payment may be available to you to pay people for involvement as soon as possible.

What rate should I offer?

The rate of payment that you make is at your discretion, but there may be rates suggested by your organisation or institution. There are no nationally recommended rates of payment and the amounts that service users are paid for involvement varies widely. Examples of rates other people have offered are in Appendix 3 of the INVOLVE guide Payment for involvement www.invo.org.uk/posttypepublication/payment-for-involvement/

Will involved people be employees?

The finance and/or human resources departments of universities and NHS trusts sometimes query the employment status (employed, self-employed or volunteer) of people carrying out involvement. This is important because if someone is seen as 'employed' then they are entitled to a number of benefits including sick pay and so on. There is no single definition in law of what it means for someone to be employed or self-employed. HMRC have a useful online tool, which you can use to check whether someone might be considered as employed or self-employed in law. The Advisory, Conciliation, and Arbitration Service (ACAS) operates a useful telephone helpline that can be freely consulted on any employment matter. Once you have determined someone's likely employment status this information should help you decide whether they need to be registered as a casual employee or if they can be paid for each session.

Do involved people have to pay tax when they receive fees?

Payments for involvement are subject to tax in the same way as any other income. Tax will only be due on a person's income once it rises over the given personal tax allowance. There are two ways to manage tax implications that may arise from making payments for involvement work:

1. deduct tax at source from the payment being made
2. make a payment to someone on the basis that they are self-employed and state that it is the payee's responsibility for paying any tax that may be due.

It may also be possible for your organisation to obtain a 'dispensation' from the HMRC. This is a formal agreement that payments need not be taxed at source. This often resolves a number of concerns that are raised by university or NHS finance departments when paying people for involvement work.

Useful websites:

HMRC Employment Status Indicator

www.hmrc.gov.uk/calcs/esi.htm

Advisory, Conciliation and Arbitration Service (ACAS)

www.acas.org.uk

5. Further information

Mental Health Research Network (MHRN) publications

MHRN (2013) NIHR MHRN Payments logbook for involvement work

www.mhrn.info/pages/publications.html

MHRN (2012) MHRN model payment policies for service users and carers

www.mhrn.info/pages/mhrn-model-payment-policies-for-service-users-and-carers-.html

MHRN (2010) Mental health researchers' toolkit for involving service users in the research process

www.mhrn.info/pages/mental-health-researchers-toolkit-for-involving-service-users-in-the-research-process.html

INVOLVE publications

INVOLVE (2012) What you need to know about payment: an introductory guide for members of the public who are considering active involvement in NHS, public health or social care research INVOLVE, Eastleigh

www.invo.org.uk/posttypepublication/what-you-need-to-know-about-payment/

INVOLVE (2012) Briefing notes for researchers: public involvement in NHS, public health and social care research INVOLVE, Eastleigh

www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/

INVOLVE (2012) Strategies for diversity and inclusion in public involvement: supplement to the briefing notes for researchers INVOLVE, Eastleigh

www.invo.org.uk/posttypepublication/strategies-for-diversity-and-inclusion-in-public-involvement/

INVOLVE (2010) Payment for involvement: a guide to making payment to members of the public actively involved in NHS, public health and social care research INVOLVE, Eastleigh

www.invo.org.uk/posttypepublication/payment-for-involvement/

Other useful publications

Department of Health (2006) Reward and recognition: the principles and practice of service user payment and reimbursement in health and social care. A guide for service providers, service users and carers www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138523 (copy and paste this link into an internet browser to access the publication from the Department of Health document archive)

Participation Works (2009) How to remunerate and reward children and young people's involvement www.participationworks.org.uk

Patient and public involvement bursaries for involvement in research design

For more information about bursaries for covering the costs of involvement in research design, contact your local Research Design Service. A list is available through the INVOLVE website www.invo.org.uk/find-out-more/information-for-researchers/research-design-services-information/

West Midlands Research Design Service has a short report of their bursary scheme on their website

www.rds-wm.nihr.ac.uk/web/guest/ppi-main

Advertising involvement opportunities

INVOLVE manages a website for advertising involvement opportunities called People in Research

www.peopleinresearch.org

Public engagement

For more information about public engagement with research contact the National Coordinating Centre for Public Engagement

www.publicengagement.ac.uk

6. Examples of budgeting for involvement

The following examples show how others have budgeted for involvement in research. We have chosen them to demonstrate a range of different ways of involvement, types of study and costs. We have provided links to further information where available.

Example 1: A study involving mental health service users and carers as peer interviewers and advisors via service user and carer working groups

| | |
|-------------------------------|--|
| Title | Investigation of the impact of introducing individual placement and support in a mental health catchment area (the WISE study) |
| Date | 2010 |
| Study aims | To find out how much difference individual placement and support makes when it is introduced to a mental health catchment area (the London Borough of Camden) and how to maximise its uptake and success. |
| Involvement activities | Steering committee Service users research forum consultation Service user interviews Training service users as interviewers and offering supervision to peer interviewers. |
| Involvement costs | Service user involvement: £25,000 (10% of the total budget) was set aside for service user researcher involvement as peer interviewers. This covered costs of training service users in interviewing skills, service users carrying out 80 interviews for the study and attending regular group supervision and helping with data analysis. Service user researchers were paid at £15 per hour on a sessional basis. Service users research forum: A fee of £300 per consultation was paid to this group for two consultations during the study. |
| Weblink | www.mhrn.info/data/files/MHRN_PUBLICATIONS/INVOLVEMENT_CASE_STUDIES/WISE_study.pdf |
| Acknowledgement | Dr Bryn Lloyd-Evans |

Example 2: A study involving a lay representative on the project steering group

| | |
|-------------------------------|---|
| Title | The development and feasibility of an intervention to reassure patients about test results in rapid access pain clinic (RACPC) |
| Date | 2012 |
| Study aims | <ol style="list-style-type: none"> 1. To adapt the New Zealand intervention for use with all patients in RACPC rather than just those with negative results. 2. To adapt the intervention for use by nurses rather than health psychologists. 3. To develop a distance learning training programme for nurses to facilitate the intervention, so aiding adoption by RACPCs across the NHS if found effective. 4. To evaluate the intervention from the perspective of participants and clinic staff, to discover its acceptability within NHS RACPCs. 5. To undertake a pilot trial of the intervention compared with usual care in order to give indications of its effectiveness in promoting reassurance with test results, and to inform recruitment strategies and sample size calculations for a future multi-centre randomised controlled trial of efficacy and cost-effectiveness. |
| Involvement activities | <p>Design and management of research study Feedback by lay members on project steering group on all aspects of running and managing the study, especially the acceptability of trial documentation and the intervention.</p> <p>Design and management of grant application Lay representatives on the steering group reviewed and advised on the protocol development and grant application for a future multi-centre RCT of the intervention.</p> <p>Undertaking the research Patients were involved in determining the feasibility and practicality of the intervention through taking part in interviews and focus groups. The information gained from these helped to inform the decision-making process and, along with the expert reference group, determined the final content of the intervention.</p> <p>Dissemination of research findings Lay members were part of a writing group for dissemination of results.</p> |
| Involvement costs | <p>Steering group expenses: £2,000 (travel costs, room hire, refreshments)</p> <p>Patient representative expenses: £1,500 (attending focus groups/interviews/steering group meetings)</p> |
| Acknowledgement | Dr Gill Furze |

Example 3: A study involving older people using the co-research methodology

| | |
|-------------------------------|---|
| Title | Understanding and improving transitions of older people: a user and carer centred approach |
| Date | 2008-11 |
| Study aims | <ol style="list-style-type: none"> 1. Explore older people's experiences of moving across service boundaries. 2. Identify different needs of older people – service users and carers. 3. Draw out policy and practice implications for the way in which services prepare and support older people and their carers in transition. 4. Support and share the learning from implementation of project findings in four health and social care communities. |
| Involvement activities | <p>Design and management of research study 22 older co-researchers participated in the design, conduct, analysis and presentation of the research, including carrying out qualitative interviews in their local area.</p> <p>Several co-researchers attended local steering group meetings, and 'All Sites Day' events which were held every six months and brought together people from the four case study sites to share emerging findings and shape the ongoing development of the study.</p> <p>Training in peer interviewing All co-researchers attended training sessions to support them in the role and give them opportunities to shape the research process.</p> <p>Involvement of voluntary sector partners The co-research model was supported by a local voluntary sector partner organisation in each of the case study areas. Partners worked with the research team to recruit, train and provide ongoing support to co-researchers, as well as providing venues for training sessions and meetings.</p> <p>Disseminating the study findings Some co-researchers accompanied members of the research team to conferences, where they were involved in presenting the findings of the research.</p> |
| Involvement costs | <p>Co-researcher budget = £12,000 to cover:</p> <ul style="list-style-type: none"> ■ recruitment costs ■ training materials ■ Criminal Record Bureau checks ■ fees to individuals ■ reimbursement of travel costs. <p>Co-researchers were paid £10 per hour for all data collection and analysis activities (including preparation and travelling time) and there was a sessional rate of £25 (half-day) or £50 (full day) for attending meetings and presenting at events.</p> <p>£2000 honoraria payment made to voluntary sector partners covered the cost of using their rooms and support from the organisation's staff in the recruitment and training of co-researchers.</p> |
| Acknowledgement | Jo Ellins |

Example 4: A study involving a consultation

| | |
|-------------------------------|---|
| Title | Consultation on the patient and public involvement (PPI) functions within the National Institute for Social Care and Health Research Clinical Research Centre (NISCHR CRC) |
| Date | 2011 |
| Study aims | To identify how NISCHR CRC can ensure effective PPI in high quality and people focused research within the research infrastructure of Wales. |
| Involvement activities | <p>Focus group Six service users were involved in the focus group.</p> <p>Task and finish group face-to-face meetings The task and finish group developed a consultation document which set out the current and future PPI functions for NISCHR CRC. One member of the Involving People Network was recruited to provide a lay perspective.</p> |
| Involvement costs | <p>Cost for each focus group: Travel – £180.80 Accommodation – £80 Subsistence – £30 Honorarium – £260 Catering – £20</p> <p>Costs for each task and finish group meeting: Travel – £156.80 Accommodation – £80 Subsistence – £30 Honorarium – £130 Catering – £10</p> |
| Acknowledgement | Natalie Simon |

Example 5: A trial of peer facilitated self-management with an involvement coordinator

| | |
|-------------------------------|--|
| Title | Optimising team functioning, preventing relapse and enhancing recovery in crisis resolution teams – the CORE study |
| Date | Start date – 2011 |
| Study aims | The CORE study is a five-year, NHS-funded research programme run by Camden and Islington NHS Foundation Trust and University College London. It is looking at how to improve the way in which Crisis Resolution Teams (CRTs) function. It will involve developing and evaluating a resource kit to help CRTs achieve good practice as well as a peer-led recovery group for people leaving CRT care. |
| Involvement activities | <p>Peer researcher working groups There are two peer researcher working groups (service users and carers) with a total of 20 members. Members will attend four consultation meetings per year and undertake additional consultancy in between when required. They will also carry out 60 interviews for the study between them and undertake relevant training and supervision.</p> <p>Public involvement co-ordinator Employed through the NHS for the whole five years of the study to promote public involvement and to coordinate the working groups.</p> <p>Consultancy of senior service user An experienced service user research is part of the study team and a co-applicant on the grant application.</p> <p>Excess treatment costs These are paid to five NHS Trusts to pay and cover supervision costs of four peer support workers per Trust to deliver the peer-facilitated self-management programme to study participants in a randomised trial.</p> |
| Involvement costs | <p>Peer researcher working groups £49,500 budgeted for costs of two peer-researcher working groups (service users and carers) during the course of the five-year study. All budgeted at £15 per hour on a sessional basis plus travel costs.</p> <p>Public involvement coordinator £34,000 for a Public involvement coordinator 0.2 full time equivalent at NHS Band 5 post.</p> <p>Consultancy of senior service user £20,000 consultancy fee for a senior service user as a study applicant (10 days per year, £400 per day)</p> <p>Excess treatment costs £180,000 excess treatment costs (in total)</p> |
| Weblink | www.nsun.org.uk/news/ucl-core-programme/ |
| Acknowledgement | Dr Bryn Lloyd-Evans |

Example 6: A large cohort study with an integrated involvement programme

| | |
|-------------------------------|--|
| Title | ALSPAC (Avon longitudinal study of parents and children) cohort study |
| Date | Since 1991 and ongoing |
| Study aims | To assist scientists worldwide with research into a wide range of health problems by studying parents and children in the long term |
| Involvement activities | <p>Participation manager role:</p> <ul style="list-style-type: none"> ■ Liaising with study participants ■ Implementing initiatives to re-engage non-attending study participants ■ Training and managing participation team ■ Overseeing ALSPAC participants' panel <p>Research associate cohort retention role:</p> <ul style="list-style-type: none"> ■ Reviewing literature on cohort retention strategies ■ Reviewing development of communication methods for cohort engagement ■ Devising and managing randomised trials on cohort engagement methods ■ Analysing data to identify response to different communication methods ■ Carrying out qualitative study of ALSPAC cohort to ascertain non-engagement ■ Developing guidelines for maximising cohort participation and retention <p>Public relations officer role:</p> <ul style="list-style-type: none"> ■ Developing marketing strategies to engage families ■ Writing press releases for local and national media ■ Fielding enquiries from local and national media ■ Arranging social events for participants ■ Designing e-newsletters and promotional material for families ■ Liaising closely with specialist web developer over web design and content <p>Participation worker role:</p> <ul style="list-style-type: none"> ■ Enrolling and consenting 3rd generation cases with others ■ Enrolling and consenting non-study parent of 3rd generation case with others ■ Fielding linkage queries from cohort members ■ Contacting parents by phone to encourage clinic attendance ■ Assisting with development of recruitment strategies to meet targets ■ Following up the young people to encourage the completion of questionnaires <p>Participant advisory panel and public relations:</p> <ul style="list-style-type: none"> ■ Travel and hospitality for the participant advisory panels which meet four times per year ■ Attending local events |
| Involvement costs | <p>Participation manager: £28,161 per year</p> <p>Research associate cohort retention: £18,019 per year</p> <p>Public relations officer: £25,124 per year</p> <p>Participation worker: £10,142 per year</p> <p>Participant advisory panel and public relations: £9,934 per year</p> |
| Weblink | www.bristol.ac.uk/alspac/ |
| Acknowledgement | Dr Lindsay Brown |

Example 7: A study involving service users and carers as researchers at multiple stages of the project

| | |
|-------------------------------|---|
| Title | Is there a pathway to recovery through care coordination? Emancipatory action research with mental health service users, carers, and professionals within Northumberland, Tyne and Wear |
| Date | 2010-13 |
| Study aims | <ol style="list-style-type: none"> 1. Explore the experiences of mental health service users, carers and professionals with regards to the delivery of care coordination and the concept of recovery. 2. Examine and map the involvement and level of control of both service users and carers conducting a mental health research project. 3. Develop a series of quality measure tools with mental health service users and carers to be used in the examination of both care coordination and recovery. 4. Develop a best practice care coordination tool kit with training and other material for those interested in both emancipatory action research and mental health care coordination and recovery. 5. Provide a collaborative platform for the future cascade of work both locally and nationally around recovery, quality care coordination and mental health service user and carer led research. |
| Involvement activities | <p>Service users and carers have led the following activities:</p> <ul style="list-style-type: none"> ■ Designing the original research question ■ Developing the methodology ■ Being co-applicants on the funding bid ■ Attending a local research ethics committee meeting ■ Undertaking the research ■ Designing the delphi questionnaire, semi structured interview schedule and narrative interviews ■ Conducting the interviews ■ Analysing the delphi and interview data ■ Presenting at research conferences ■ Designing the dissemination tool kit |
| Involvement costs | <p>A laptop computer was given to each third sector organisation to carry out the research. Cost £1500.</p> <p>Service user researcher costs: Involvement costs: £3750 Travel costs (data collection): £2500 Travel and subsistence (research and steering group activities): £5000</p> <p>An extra £4000 was obtained from the North East Mental Health Research Hub to cover the development of a mental health service user and carer training course; this included university accreditation.</p> |
| Acknowledgement | Helen Atkins |

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