



Payment for involvement

A guide for making payments to members of the public actively involved in NHS, public health and social care research

INVOLVE

Promoting public involvement
in NHS, public health and
social care research

About this guide

This guide was first published in February 2002 and revised in August 2006 under the title: A guide for reimbursing and paying members of the public who are actively involved in research: For researchers and research commissioners (who may also be people who use services).

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What is this guide about?

This guide is about the payment of **members of the public** who are **actively involved** in health and social care research (see section 1.1 for definitions of these terms). It applies when people are partners in the various stages of research, from identifying and prioritising topics, and commissioning, to evaluation and dissemination. It does not apply to people taking part in research as ‘subjects’ or participants.

This guide has been organised into three parts:

- **Part 1** provides the context for the guide. It provides definitions for the terms we will use throughout the guide and describes the general principles in relation to making payments for active involvement in research.
- **Part 2** gives more detailed information about the practical considerations when making payments.
- The **appendices** contain information about other sources of advice, support and information.

The guide is intended primarily for use by researchers and research managers and may also be helpful to research commissioners. It includes guidance on:

Covering expenses

By ‘covering expenses’ we mean either paying for the costs directly or reimbursing the costs that are incurred by a member of the public whilst being involved in research related activity. All out of pocket expenses should be covered. Covering expenses is not the same as payment for time, skills and expertise.

Payments for time, skill and expertise

By ‘payments’ we mean payment made to members of the public for their input of time, skills and expertise into the research process. Payments for time and expertise should be considered best practice. Rates of payment will depend on a number of variables which are covered in this guide, and some examples are given. However, because each situation is different, we do not attempt to be prescriptive about rates of payment.

Issues you need to be aware of when making payments

Making payment to members of the public for their involvement in research can be complex. Issues that need to be thought about include:

- whether tax and National Insurance should be deducted from payments
- ensuring people stay within benefit conditions if they receive state benefits
- whether employment law applies.

Part 1: General principles

1.1

What do we mean by public involvement in research?

At INVOLVE, when we talk about members of the **public** we mean:

- patients and potential patients
- people who provide care or support on an informal (i.e. unpaid) basis
- parents/guardians
- people who use health and social care services
- disabled people
- members of the public and communities who might be targeted by health promotion, public health and social care
- groups asking for research because they believe they have been exposed to potentially harmful substances or products
- organisations that represent people who use health and social care services.

The term **public** also embraces the rich diversity of people in our multi-cultural society whether defined by age, colour, race, ethnicity or nationality, disability, gender or sexuality who may have different needs and concerns.

By **involvement** we mean an active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research.

Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.

1.2

The benefits of covering expenses and payments for involvement

The additional expertise brought by the perspectives of members of the public is important to add value to and improve the quality of research (see Staley (2009), details in Appendix 2). Covering costs and paying for time, skill and expertise creates an incentive for active involvement. This may allow a broader range of people to be involved.

- Payment is a tangible way to acknowledge the value of public contributions and contributing to health and social care research is effectively a public service.

- It supports equity of power in research partnerships which involve the public and professionals.
- Making payments to the public involved in research is intended to support inclusion. Covering expenses and offering payments can enable people who are often overlooked or ignored by mainstream society to get involved and make a contribution to research affecting them. It may be that they have relevant experience of great value to a project, but their circumstances, which may involve day to day difficulties, could mean that getting involved is not a priority for them unless there are ways to help with such difficulties.
- It can indirectly lead to a more effective and equitable involvement of people who use services and the public by easing financial constraints on them. For example, there are likely to be financial and institutional implications to accessing information, and acquiring knowledge and skills (through training, advice, books, conferences, internet, etc.) for someone not employed by or linked to a University or health or social care organisation.
- Covering expenses and making payments can help reduce barriers that stop people getting involved, for example, being able to cover the cost of transport, use of phone and office facilities, childcare or other care costs, etc.
- Having an expenses and payment policy can be useful to clarify the expectations and responsibilities relating to people's involvement.

1.3

Choice, equity and complexity

Where possible, it can be mutually beneficial to negotiate rates of payment, conditions, and 'job descriptions' with local or national service user groups as appropriate.

Choice

When offering payment for the involvement of the public, the importance of choice cannot be over-estimated. There may be reasons why some people might choose not to be paid and prefer to get involved as a volunteer. In other instances people may ask to be paid a lower amount than offered. This may be because of altruism or financial circumstances. These things are a matter of individual choice, and not reasons for avoiding the offer of payment in the first place.

It is important to make clear from the outset **when** and **what** payment is being offered. It informs people's choices about how and if to get involved. It also enables people who are in receipt of benefits to get advice about how payment may affect their entitlement to benefits (see section 2.4).

Equity and independence

The public should be paid for their time and expertise to a level consistent with other members of the research team. This will depend on a variety of factors and circumstances. For example, it is unfair to expect people who are unpaid to sit alongside paid non-executive members of research

advisory groups or committees, or to ask them to give their time for free when others are paid for their time as part of their day job, or through locum fees. On the other hand, where a committee/group is entirely voluntary, payment for time cannot reasonably be expected.

One of the arguments often put forward against paying members of the public when involved in research is that receiving a financial reward will compromise the independence of their views. However, this argument is not made in relation to professional researchers and should not apply to members of the public.

An agreement about the role of a member of the public, like a 'job description', can be jointly drawn up to clarify and acknowledge the independent role of the individual involved. This could also apply to other members of any formal group to confirm their equivalent status.

Complexity

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.

Most, if not all of the potential complications of making payments to the public and people who use services are generated by institutional financial systems. Individuals making a contribution of their time and effort should be supported, treated equitably and with respect, and appropriately rewarded. These institutional systems should not end up being barriers or disincentives to people getting involved in research.

1.4

Acknowledgements and other forms of reward

Payment is not the only form of reward for involvement that can be considered. Many people choose to become involved with research for the opportunity to learn new skills, make a contribution, and meet new people and groups. Working conditions within a group can be as important to members of the public and people who use services as payments. It is important to support people in ways which optimise their capacity to contribute.

- Specifically thanking and acknowledging individuals for their time and contributions should not be overlooked whether they are paid or not.
- Consideration should be given to other forms of reward to enhance the experience for individuals who get involved. This might include, for example, training and learning, attending conferences, confidence building, help with ongoing learning, access to facilities such as a library, CV development and future employment.
- At some parts of the research cycle, for example, designing a study, preparing a grant application (see section 1.6 below), and disseminating the research findings, access to adequate funding to

pay for people's time, skill and expertise may be harder to achieve. Possible approaches to tackle this might be applying for specialist funding for the design and grant application stage, for example through some of the regional National Institute for Health Research (NIHR) Research Design Services (see Appendix 1 for more information). However, these may not be universally available or appropriate for all settings. Therefore, thinking about and making available alternative forms of reward and recognition may be particularly useful to encourage involvement in these stages of research.

1.5

Policies, procedures and agreements

It is good practice for any organisation intending to involve the public in their work to ensure that policies are set out in advance to explain when payments will be made and what expenses will be covered.

- Policies should be written in clear language and available in a range of formats.
- Consultation with the organisation's finance and human resource departments, as well as with people who may get involved may be required to set out the policies and procedures.
- The policy should be given to all involved people **prior to their commitment** and should explain the detailed procedures for having expenses covered or claiming payments for time, skills and expertise.
- The policy should also be regularly reviewed to ensure it is effective and appropriate.

Information to include in a payment and expenses policy

- When expenses will be covered and payments made for time, skills and expertise.
- Who can claim payments and in which circumstances (e.g. only people who are not already employed full time in the public sector).
- The responsibilities of the person receiving payment and of the organisation (e.g. for tax, National Insurance and state benefit purposes).
- The procedures for claiming payments, including cut-off dates for organisational systems and dates payment will be received.
- Who to contact if there is a problem.

For an example of an expenses and payment policy, please see the INVOLVE policy on expenses and payments. This can be downloaded from our website at www.invo.org.uk/Documents.asp

Informal agreements or 'job descriptions' may help to clarify roles and responsibilities. Sample job descriptions are available in the INVOLVE publication 'Involving the public in NHS, public health and social care research: Briefing notes for researchers' (See Appendix 2).

1.6

Commissioning research

Paying members of the public for their active involvement in research means there are implications for research project budgets and therefore for Research Commissioners in allocating funds. The following points may be helpful.

- It is important when commissioning bodies are promoting public involvement to inform those applying for funds for research projects that the additional costs of the involvement should be included in an application.
- Research commissioners who specify the need for public involvement should expect a project to budget for realistic costs for involving members of the public and design application forms and guidance notes accordingly.
- Public involvement can mean that research can take longer than it might otherwise (for example, extra time for recruitment, training and involvement in research tasks).
- When reviewing research proposals, consideration needs to be given to different levels of public involvement. For example, is the project to consult, or collaborate, with people who use services and the public or is it to be user-controlled? (See the INVOLVE publication 'Public Involvement in NHS, public health and social care research: Briefing notes for researchers'). The level of public involvement is important as not only can it influence the cost of a project, but it also influences the degree of 'added value' to a project.
- Whereas the costs of actively involving people who use services and members of the public can be built in to applications for research funding, researchers may have already incurred expenditure for involvement before funding is given. For example, the costs of involving people who use services in writing a research proposal.

University of West of England 'Credit Union'

As part of the Service User and Carer Involvement in Research approach in the Faculty of Health and Life Sciences at the University of the West of England, a 'credit union' has been set up.

The credit union aims to enable researchers to fund the early involvement and payment of service users in the development of research grant applications and the design of research



studies. Faculty researchers can apply to the credit union for a small amount of money to fund this initial involvement. The grant application will include core support for the scheme in the budget which, if awarded, will be paid back to the credit union.

The aim is for successful grant applications to put back more than was 'borrowed' initially. In this way successful bids will replenish the credit union funds to a slightly greater extent than their initial 'loan' thus offsetting the unsuccessful bids which are supported by the scheme.

Further information about the scheme is available in an INVOLVE newsletter article, Winter 2008/09 edition, available from the INVOLVE website at www.invo.org.uk/Newsletters.asp

Further information on public involvement on commissioning boards, in grant applications, and in peer reviewing research proposals, can be found in a series of guidelines about commissioning research on the INVOLVE website www.invo.org.uk

Part 2: Putting it into practice

This second section of the guidance considers in more detail some of the practical considerations for making payments and covering expenses. These relate to tax and National Insurance, state benefits and employment law.

The actual procedures for making payments and covering expenses will depend upon the financial systems within individual organisations. Therefore, it is not appropriate to provide information about these in this guide. As described in section 1.5, it is good practice for all organisations who involve the public in their research to develop a policy which sets out the approach and procedures for covering expenses and payments within that organisation. For an example of an expenses and payment policy, please see the INVOLVE policy on expenses and payments. This can be downloaded from our website at www.invo.org.uk/Documents.asp

Many of the issues identified here are also discussed in the Department of Health publication 'Reward and Recognition', an important landmark document covering expenses and payment for members of the public who contribute to health and social care services (see Appendix 2).

2.1

Covering expenses

All out of pocket expenses should be covered. Equal opportunities for involvement are facilitated if expenses are covered. Members of the public should not end up financially worse off for providing a public service. The following expenses should be carefully considered:

- travel (public transport, taxi fares, or an agreed private car mileage rate which includes wear and tear – see Appendix 1 for information about HMRC approved rates)
- overnight accommodation
- subsistence (food and refreshment whilst on 'business' or bought due to having to be at a certain place at a certain time)
- childcare or replacement carer/person providing support
- costs of a Personal Assistant or Support Worker of the individual's choice
- telephone, internet access, fax costs, stationery and other equipment – covering these costs is particularly important for members of the public who work from their own home and therefore may incur considerable costs which may be 'invisible' in organisational settings
- conference fees
- training courses or sessions

Ideally, expenses should be paid by the research organisation on behalf of involved members of the public to prevent the involved person being 'out-of-pocket'. This involves, for example, purchasing travel tickets in advance, paying directly for childcare or a replacement carer. You may need to make arrangements with other organisations, for example, a travel service or taxi company to be able to cover these costs directly. This will be very important to people on low incomes who may be unable to meet these extra costs and would therefore be excluded from involvement. For people who are receiving state benefits, paying expenses directly is often essential to prevent reimbursed expenses being counted as income (see section 2.4 for more detail).

When expenses are reimbursed after the event this should be done promptly. In some cases, it may be necessary to ensure reimbursement is in cash because some groups and people do not always have access to a bank account for paying in cheques or receiving payments through electronic transfer.

If expenses are to be reimbursed after the involvement activity, clear guidance should be provided to the involved people as to which items can be covered and any upper limits on expenditure, for example, daily subsistence rates, restrictions of modes of travel if not agreed in advance. This is important to prevent anyone finding themselves out of pocket through being unaware of any limits or restrictions and also prevent any misunderstanding about what costs can be covered.

2.2

Setting rates for payments

Specific rates for time, skills and expertise will depend on a number of factors as each situation is different. It may be helpful to ask yourself the following questions when deciding what rate best suits the situation.

- How does the principle of equity apply in this situation?
- What level of skills, expertise, and experience you are seeking/expecting from members of the public for this project?
- What are the time commitments involved in the role they are playing in the project (including preparation, reading, travel, communication, meetings etc.)?
- What are the comparative levels of pay and responsibility of participating professionals?
- What level of responsibility you expect the person to shoulder in respect of the project?
- What are the local and national pay conditions for the equivalent role?
- What is the current national minimum wage? (See Appendix 1 for web links to sources that will keep you up to date)

There are examples of how some organisations and researchers have set payment rates in Appendix 3.

2.3

One-off payments as a gift

When making a payment for a one-off involvement activity which takes place on one day only, the payment is viewed as a thank you gift. The payment should be a reasonable amount for the activity and there should be no prior involvement within the same financial year (from 6th April).

Although the Jobcentre Plus¹ should be informed of the payment, it should not affect a person's entitlement to state welfare benefits (provided the amount does not take their savings above the capital limit for benefits). Tax and National Insurance do not usually apply to one-off payments and should not be deducted. Notifying HM Revenue and Customs about one-off payments is not required.

A letter of thanks should be provided for the involved person when making one-off payments (see Appendix 4, letter 1, for an example letter). This letter can be used to explain the type of payments should the Jobcentre Plus or HM Revenue and Customs inquire.

If there is further involvement by that person in the same financial year, any payments will be subject to the usual benefit rules and may be subject to Tax and National Insurance deductions (see sections 2.4 and 2.5 below).

2.4

People receiving state benefits

Members of the public getting involved in research may be receiving state benefit payments. It is very important to be aware that these benefits can be affected if people receive payments.

- People in receipt of benefits must keep to the conditions of those benefits on what they can do and the amount they can be paid.
- If a person, even inadvertently, breaches their benefits conditions in some way while offering their help through involvement, their benefits income could be stopped pending an enquiry.
- In some instances, through misunderstandings and errors they could lose their benefits income permanently.
- Paying people with cash alternatives, for example, gift vouchers, does not avoid the issues of paying people for involvement – the same conditions apply.

¹ Formerly the Benefits Agency office. The Jobcentre and Benefits Agency merged to become JobCentre Plus from the 1st April 2002.

Benefit conditions

The benefit conditions are complex and limits on payments that can be received without benefits being affected vary widely and differ for each person, sometimes from year to year. Because of this we do not intend to provide detailed information on the different conditions for individual benefits in this guide. However, we do list some principles which should be followed when involving people who are in receipt of benefits.

- Let people know that they must inform the Jobcentre Plus or Pension Service (when receiving Pension Credit) of any paid or voluntary activity.
- Notifying the Jobcentre Plus about involvement activity should take place before HM Revenue and Customs are given the person's details for tax purposes (if required). This is essential as HM Revenue and Customs liaise with Jobcentre Plus who may assume a person has commenced full-time employment and stop their benefits immediately.
- There is an upper limit to the number of hours people can spend on involvement activities in a week, usually 16 hours or less.
- Some benefits have a set amount of earnings that is disregarded but earnings must still be declared.
- Some benefits have 'Permitted Work' rules which require a person to keep to conditions which set exact limits on the earnings a person can receive on a weekly basis. These limits vary from year to year. Some people can use 'Supported Permitted Work' rules and they can receive the same amount year on year.
- If a person is paid via another organisation or donates their earnings to charity they will be treated by the Jobcentre Plus as if they had received the full amount.
- One of the biggest difficulties for people on benefits because of ill health or disability is that Jobcentre Plus offices can interpret involvement as readiness for work whether or not payment is being offered. Organisations can provide a standard letter which explains why involvement is different from work and should not be used as a measure of capacity for work. Please see Appendix 4, letter 2, for a copy of this letter.

Benefits pitfalls to avoid

In October 2009, new legislation came into force which intended to ease some of the benefit barriers to involvement. However, the legislation applies only where there is a statutory duty to involve people, for example, as required by NHS Trusts under section 242 of the National Health Service Act 2006. At the time of writing it is not clear whether involvement in research will come under these new regulations. At INVOLVE we are working with the Department of Health and the Department of Work and Pensions to clarify this issue.

Until we get confirmation that involvement in research can take advantage of the new

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regulations, two important issues must be borne in mind when involving people receiving benefits in research.

1. Notional Earnings Rule

If people ask to be paid a lower amount or turn down an offer of payment to be involved on a voluntary basis the '**notional earnings**' rule may be applied. This is where the Jobcentre Plus offices treat them as if they had accepted the higher offer. This situation is called 'notional earnings' because it may be judged that a person has refused income so that they keep their entitlement to state benefits.

2. Expenses treated as earnings

When a person is paid for their involvement, **reimbursements of expenses may be treated as earnings** by the Jobcentre Plus. This can result in a person having the reimbursed expenses deducted from their benefit income. However, if these costs are paid directly by the organisation this can be avoided. Therefore it is good practice to pay for travel and other expenses directly, for example, by providing travel tickets.

Also see Scott, J. (2008) **Payment for involvement in research: Helpful benefit rules and systems for avoiding benefit problems**. INVOLVE, Eastleigh (further details in Appendix 2).

As part of their policy on service user and carer payments, the National Institute for Health Research (NIHR) Mental Health Research Network has produced a useful and detailed guide about benefit conditions and systems around paid and voluntary involvement. This can be downloaded from their website (see Appendix 2 for further details).

Making use of the benefit 'averaging' rule

As indicated above, the benefit system sets disregards and limits to the amount a person receiving benefits can be paid. These usually apply on a weekly basis. Often the amount disregarded or limited is too low to enable the person to agree to several hours of paid involvement during one week. However, one approach to managing this can be the use of the **benefit 'averaging' rule**.

This can be applied if there are to be two or more involvement events over time, for example, a cycle of involvement over a four or five week period or a pay period. This rule allows more than the weekly disregard or limit to be paid for involvement in one week if no paid involvement takes place in other weeks. Therefore, if the average payment per week over the period designated is not above the disregard or limit for each week then benefits are not affected. The involved person must ask Jobcentre Plus in advance if they will treat payments as averaged.

Getting access to information for organisations

The fear of losing benefit income can sometimes discourage people who use services from becoming involved where they would have otherwise made an important contribution to a project. Many people are unaware of the benefit conditions.

It is the individual person's responsibility to find out about their benefits conditions and notify the Jobcentre Plus of their intentions to take up an offer of involvement. However, it is good practice for those who wish to involve people in their research to support people to get appropriate advice.

- If you are not experienced in this area, you should consider seeking advice from an appropriate source prior to involving people. This could be, for example, the Jobcentre Plus, welfare rights organisations, other organisations which involve people, or local supported employment projects.
- Advice from such organisations will be of a general nature rather than specific to an individual's circumstances.
- Some organisations offer benefits advice via websites and premium rate telephone lines. However, these services are not regulated and the quality of the advice is unchecked.
- Even if you have experience of dealing with benefits issues, you should avoid offering benefits advice yourself as there may be a risk of wrongly informing someone as changes to the regulations are often introduced.
- If you, or your organisation, check with the local Jobcentre Plus about a particular situation in advance, this can sometimes provide the assurance needed for individual people.
- However, different Jobcentre Plus offices tend to have different ways of interpreting the rules, sometimes on different occasions, and attitudes to certain situations may differ.

Individual welfare rights advice

In many cases, people will need to get reliable welfare rights advice before committing to involvement and before agreeing a payment rate that their benefit conditions allow. However, because the benefit conditions are often specific to each individual and the particular combination of benefits they receive, good advice can be hard to find. Local welfare rights advice centres including the Citizen's Advice Bureaux may not be familiar with the complex benefit rules associated with involvement and may need to set up training for their advisors before they could offer advice.

It would be worth exploring what welfare rights advice services are available locally and whether your organisation can access them, for example, the NHS trusts in your area may have a welfare rights service. Contact with the local voluntary service organisations may be helpful (see Appendix 1 for the national contact details).

Milton Keynes Citizen's Advice Bureau Involvement Helpline

A specialist telephone advice service, the Involvement Helpline, has been set up by Milton Keynes Citizen's Advice Bureau to provide confidential, personalised and professional advice to people who are considering paid or voluntary involvement with health or social care organisations. Access to the service is ONLY via organisational subscription at present (see Appendix 1 for contact details of this service). →

It may be worth finding out whether your organisation, or one with which you link, has or would be willing to set-up a subscription to this service. The advisors at the Involvement Helpline are experienced in a range of situations including those where individuals receive a number of different benefits and how getting involved would impact on these in different ways. With the permission of the individual, the advisors will contact the Jobcentre Plus, the Pensions Service or other relevant agency on their behalf if required.

2.5

Tax and National Insurance

Reimbursement for expenses is generally not subject to tax as it is not counted as income, but they may need to be declared if the person is self-employed or receiving taxable benefits. Payments for time, skill and expertise, except for one-off events (see section 2.3), are usually subject to tax and National Insurance.

- Most organisations, other than certain university research activities (see below), that pay people for involvement, will be required by HM Revenue and Customs to check if tax and National Insurance should be deducted at source (usually through the Pay As You Earn (PAYE) system).
- The advice given will be specific to the type of involvement activity undertaken in each organisation or context, therefore the advice may not be applicable in other organisations or contexts.
- When tax or National Insurance are expected to be deducted at source, the person receiving payments must be asked to provide a P45, or if this is not available they should be asked to complete a P46 form. HM Revenue and Customs will advise on their tax code and if deductions should be made from payments.
- People who are registered self-employed with HM Revenue and Customs, for example, independent consultants, are responsible for declaring their income via self-assessments, therefore no tax and National Insurance should be deducted from payments to people who are self-employed.

Exemption from deducting tax and National Insurance

The former Inland Revenue, now HM Revenue and Customs, agreed certain principles and procedures with the British Universities Finance Directors Group. HM Revenue and Customs issued a circular about universities and lay people's tax liabilities when involved in research. See Appendix 5 for a copy of this circular.

If you are based in a university, you may be able to use this guidance in order to be exempted from treating payments under PAYE. Your Finance Department may want to apply to the local HM Revenue and Customs tax office to confirm agreement to this arrangement. A description of the involvement in the research activities should be set out and a copy of the circular from HM Revenue and Customs can be enclosed.

Where tax and National Insurance is not deducted by an organisation, the person who is paid for involvement may become responsible for notifying HM Revenue and Customs of payments received at the end of the tax year. This is only if their total taxable income is above their tax threshold.

2.6

Employment law

Advice from the Advisory, Conciliation and Arbitration Service (ACAS) indicates that where payment for involvement is one-off or casual, and there is no expectation that further involvement will be offered or accepted, employment law is unlikely to apply.

When paid involvement is expected to be ongoing or planned into the future, whether this can be deemed paid employment rests on a number of factors. These include:

- **mutuality of obligation** – the extent to which an organisation is required to offer ongoing involvement and whether the involved person is obliged to accept it
- **control** – the extent to which an organisation or the involved person decides what tasks are to be carried out, whether by specific people, and how and when the tasks are carried out.

Deciding if or when an employment relationship exists can be complex and is usually approached on a case by case basis. ACAS can provide general advice on their national helpline (see Appendix 1). If you have a Human Resources department, staff should be able to advise you. If there is any doubt it is advisable to seek independent legal advice.

Where there is ongoing paid involvement, with mutual obligation and control resting with the organisation, an individual may be classed as a 'worker' and as such they may gain rights to some core employment rights and protections. One approach to managing this is by using flexible arrangements, such as a bank registration agreement. This approach is explained more fully and an example provided in the Department of Health's Reward and Recognition document (see Appendix 2). More information about employment status can be found on the Direct.gov website (see Appendix 1 for details).

There may be times when a formal employment relationship will be the most suitable arrangement, for example, if you want regular weekly involvement over a number of months or you are employing someone as a user researcher. Most organisations can provide part-time contracts and these can even be for as little as 2-5 hours per week.

If children or young people are involved in paid activity, there are legal restrictions on the times and amount of hours they can undertake activities. These are explained in the Participation Works document '**How to remunerate and reward children and young people's involvement**' (see Appendix 2).

Involving people via another organisation

If you want to involve people in your research via another organisation, for example, support projects or patient associations, there are a number of considerations to bear in mind.

- Before making payments to groups or organisations that have charitable status and represent the interests of members of the public who use services, it is important to ask them if they know whether they are entitled to receive payments for their services under charity law.
- Payment for **services** is not the same as making a charitable **donation**. Charities have a constitution that will set out what they are allowed to do. They should check if they are allowed to pay the service users of the charity for involvement.
- If in doubt they can get advice from their local Council for Voluntary Services (CVS), or the Charities Commission (see Appendix 1). Many, but not all voluntary organisations have a 'trading arm'. This enables them to receive payment for services, and donate any 'profit' after costs, back to the core organisation.

Payments may be made to charities or other organisations for two main reasons.

- Payments in recognition of the administrative costs of arranging and supporting service users of the charity to be involved in your work which may be paid or voluntary involvement.
- Payments to cover the costs for service users for their involvement i.e. the charity will make the payments to the service users for their time, skill and expertise on your behalf and you will reimburse the charity.

In both of these cases if the service users of the charity or organisation are receiving state benefits they should advise Jobcentre Plus of their involvement (whether voluntary or paid) and the same issues apply if you were paying the individuals directly (please see section 2.4 above).

Appendix 1: Useful sources of further information

■ **Advisory, Conciliation and Arbitration Service (ACAS)**

www.acas.org.uk

National helpline for advice about employment law

Telephone: 08457 47 47 47

(Minicom users) – 08456 06 16 00

National Office

Acas National

Brandon House

180 Borough High Street

London

SE1 1LW

■ **Charities Commission**

www.charity-commission.gov.uk

Central telephone number: 0845 3000 218

There are four regional offices covering England and Wales:

London:

Harmsworth House

13-15 Bouverie Street

London

EC4Y 8DP

Taunton:

Woodfield House

Tangier

Taunton

Somerset

TA1 4BL

Liverpool:

20 Kings Parade

Queens Dock

Liverpool

L3 4DQ

Newport:

8th floor

Clarence House

Newport

NP19 7AA

■ **Citizens Advice Bureau (CAB)**

www.citizensadvice.org.uk

This website has a search facility to find the nearest CAB. If you do not have internet access, details of your local CAB can be provided by the central administrative offices Tel: 0208 833 2181. Alternatively, details can be found in your local telephone directory, from your local public library, or local council office.

■ Milton Keynes Citizens Advice Bureau

www.mkweb.co.uk/CITIZENS_ADVICE/

Provides the Involvement Helpline telephone advice service for subscribing organisations

Wendy Lehmann

Acorn House

361 Midsummer Boulevard

Milton Keynes

MK9 3HP

Email: Wendy.lehmann@mkcab.org.uk

Telephone: 01908 609 072

■ Department of Work and Pensions

Leaflet on benefit rules for part-time paid work for people who are in receipt of Incapacity Benefit, Severe Disablement Allowance, Income Support for incapacity

www.dwp.gov.uk/publications/dwp/2002/disability/guide_nov02.pdf

Leaflet on benefit rules for part-time paid work for people who are in receipt of the **Employment and Support Allowance**

www.dwp.gov.uk/esa/pdfs/t03-esa-factsheet-current-work.pdf

■ Direct Gov

www.direct.gov.uk/en/index.htm

UK Government Official Information

Includes advice on employment law, minimum wage and benefits

■ Jobcentre Plus

For **general information** on benefits use:

www.dwp.gov.uk/lifeevent/benefits/index.asp

Jobcentre Plus:

www.jobcentreplus.gov.uk/cms.asp

To find your **local Jobcentre Plus**:

www.jobcentreplus.gov.uk/JCP/Aboutus/Ouroffices/Search/LocalOfficeSearch.aspx

■ HM Revenue and Customs (HMRC)

www.hmrc.gov.uk

- National Insurance Registration Helpline: 0845 9157006
- Self Assessment (Income Tax) order line for forms and leaflets: 0845 9000 404
- Self Assessment (Income Tax) Helpline: 0845 9000444
- Approved mileage rates: www.hmrc.gov.uk/rates/travel.htm

- Tax & Benefits Confidential: 0845 608 6000 – an advice line that offers confidential help for people operating in the informal economy – that is, not registered for tax and therefore unknown to HMRC. See also www.hmrc.gov.uk/taxbenconf/
- Helpline for newly Self-Employed: 0845 9154515 – enables the self-employed to register for National Insurance, tax and VAT. Arranges advice/support via seminars/visits from Business Support Teams and offers callbacks for follow up/additional help. See also www.hmrc.gov.uk/startingup
- To search for your local Enquiry Centre for a face to face service – www.hmrc.gov.uk/enq/index.htm
- HMRC Circular EIM71105 that exempts University Research Programmes from deducting tax. In search box put: 'Research volunteers, lay participants and participants in clinical trials'

■ National Association for Voluntary and Community Action

www.navca.org.uk

NAVCA has a directory of local Councils for Voluntary Services

NAVCA

The Tower

2 Furnival Square

Sheffield

S1 4QL

Telephone: 0114 278 6636

Fax: 0114 278 7004

Textphone: 0114 278 7025

Email: navca@navca.org.uk

■ National Council for Voluntary Organisations (NCVO)

www.ncvo-vol.org.uk

Regent's Wharf

8 All Saints Street

London

N1 9RL

Telephone: 020 7713 6161

Fax: 020 7713 6300

Minicom: 0800 01 88 111

Helpdesk: 0800 2 798 798 / helpdesk@askncvo.org.uk

Email: ncvo@ncvo-vol.org.uk

■ Office of Public Sector Information

Employment Rights Act 1996: www.opsi.gov.uk/acts/acts1996/ukpga_19960018_en_1

Employment Act 2008: www.opsi.gov.uk/acts/acts2008/ukpga_20080024_en_1#pb2-l1g8

■ Research Design Services

The purpose of the Research Design Services (RDS) is to help NHS researchers and those working with NHS partners to prepare proposals for submission to national funding competitions for applied health or social care research. There is one RDS in each Strategic Health Authority area in England.

Most of the RDS have provision for funding public involvement in the development of grant applications (i.e. before project-specific funds are available to research teams). This is often referred to as pre-protocol work.

More information on how to find the RDS in a region and their contact details can be found on the INVOLVE website www.invo.org.uk/RDS1.asp

Appendix 2: Useful publications

■ Bacon, J. and Olsen, K. (2003) **DOING THE RIGHT THING: Outlining the Department for Work and Pensions' approach to ethical and legal issues in social research Department of Work and Pensions**

This Guidance has been designed for staff in the Department of Work and Pensions who commission research. It covers the legal background to conducting research, and also sets out standards of practice. It includes guidance on one-off payments for taking part in research activities. It is available to download from the Department of Work and Pensions website www.dwp.gov.uk type 'Doing the Right Thing' into the search facility (accessed 28th April 2010).

■ Care Services Improvement Partnership/National Institute for Mental Health in England (2007) **Valuing Involvement: Making a real difference, strengthening service user and carer involvement in NIMHE and CSIP, payment and reimbursement policy guide**

This policy guidance was produced to support NIMHE/CSIP national and regional centres in the practice of reimbursing and paying service users and carers for their involvement. It aims to promote consistency of approach and fairness across centres. It provides detailed guidance in relation to benefit conditions and systems. The benefit rates and limits on earnings are now out of date but the benefit rules will remain correct to October 2009.

This document is no longer available from CSIP/NIMHE but can be downloaded from the Social Perspectives Network website at www.spn.org.uk/fileadmin/SPN_uploads/Documents/valuing_involvement.pdf (accessed 28th April 2010).

■ Commission for Social Care Inspection (2007) **Benefit barriers to involvement, finding solutions. A report from the seminar held by the Joint Participation Steering Group**

This publication reports on a joint seminar held to bring together relevant stakeholders to share information on the benefit barriers to involvement, provide clear examples of how these barriers impact upon involvement, and to propose solutions to the current problems.

This document is available from the Social Care Institute for Excellence, Goldings House, 2 Hay's Lane, London, SE1 2HB, Telephone: +44 (0)20 7089 6840, Textphone: +44 (0)20 7089 6893, email: info@scie.org.uk It can also be downloaded from www.scie.org.uk/publications/misc/bbi/index.asp (accessed 28th April 2010).

■ 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**

A substantial guide explaining good practice in paying and reimbursing people involved in health

and social care service improvement. Contact the DH Publications Orderline, PO Box 777, London SE1 6XH. Telephone: 0870 155 54 55. Fax: 0162 372 45 24. Or download from the publication library on the Department of Health website www.dh.gov.uk/en/Publicationsandstatistics/Publications/index.htm (accessed 28th April 2010).

■ **Mental Health Research Network (2010) Benefits conditions and systems around paid and voluntary involvement**

The guide provides a flow chart and detailed information for a wide range of different state benefits and how these may be affected by paid or voluntary involvement. It is available from Service Users in Research, Institute of Psychiatry, King's College London, PO Box 77, De Crespigny Park, London, SE5 8AF. Telephone 020 7848 0644. Email: mhrnppi@kcl.ac.uk. Or download from www.mhrn.info/index/ppi/SUR/Payment-information.html (accessed 30th March 2010).

■ **Participation Works (2009) How to remunerate and reward children and young people's involvement.**

This guide introduces some practical examples of how to remunerate and reward children and young people and looks at issues surrounding the development of a remuneration and reward policy. It is available from Participation Works, 8 Wakley Street, London, EC1V 7QE. Enquiry line: 0845 603 6725. It can be downloaded from www.participationworks.org.uk/resources (accessed 28th April 2010).

■ **Scott, J. (2003) A Fair Day's Pay: A guide to benefits, service user involvement and payments**
Mental Health Foundation

This booklet provides guidance for health and social care services when involving people who are receiving benefits. The benefit rates and limits on earnings are now out of date but the benefit rules will remain correct to October 2009. It is available from the Mental Health Foundation at the cost of £5 from the Mental Health Foundation, London Office, 9th Floor, Sea Containers House, 20 Upper Ground, London, SE1 9QB. Or from the publications orderline 020 7803 1101 or mhf@mhf.org.uk

■ **Scott, J. (2008) Payment for involvement in research: Helpful benefit rules and systems for avoiding benefit problems** INVOLVE

This leaflet was written by Judy Scott for a workshop held at the INVOLVE National Conference November 2008. The benefit rules and systems described had been confirmed, tested or occurred in actual situations in 2007/08. Obtainable from INVOLVE, Wessex House, Upper Market Street, Eastleigh, Hampshire, SO50 9FD. Email: admin@invo.org.uk. Downloadable from the INVOLVE website: www.invo.org.uk.

■ **Staley, K. (2009) Exploring impact: Public involvement in NHS, public health and social care research** INVOLVE

This report explores the impact of public involvement through an in-depth review of published literature. It draws together a wealth of examples of how public involvement is conducted, and what

difference it is making. Obtainable from INVOLVE, Wessex House, Upper Market Street, Eastleigh, Hampshire, SO50 9FD. Email: admin@invo.org.uk. Downloadable from the INVOLVE website: www.invo.org.uk.

■ Turner, M. Beresford, P. (2005) **Contributing on equal terms: Service user involvement and the benefits system** Social Care Institute for Excellence

This publication is available to download or order through the post from the Social Care Institute for Excellence. Contact the SCIE publication order line on publications@scie.org.uk or download from the website at www.scie.org.uk/publications/reports/report08.asp (accessed 28th April 2010).

For guidance on the different levels of consumer involvement and how the public can be involved in different stages of research, refer to the INVOLVE publication **Involving the public in NHS, public health and social care research: Briefing notes for researchers**, Hanley et al, 2004. INVOLVE. Obtainable from INVOLVE, Wessex House, Upper Market Street, Eastleigh, Hampshire, SO50 9FD. Email: admin@invo.org.uk. Also downloadable from the INVOLVE website: www.invo.org.uk

Appendix 3: Examples of payments

There is a range of different ways in which the public have been paid. The following examples were current in 2010. Some organisations may have changed their rates and processes. Please note that the National Minimum Wage changes over time and this can be checked at www.direct.gov.uk.

■ Examples 1: NIHR Research Programmes (Commissioning)

Guidance has been agreed with the Department of Health for the National Institute for Health Research (NIHR) programmes on payment rates to members of the public for involvement with the work of the programmes. Payment rates are:

Committee fee

£150.00 – The daily committee fee includes payment for both preparation and attendance at a meeting.

Higher rates are payable for some committee meetings which require higher levels of preparation or additional responsibilities.

Peer review fee

Lower level £50.00 – for reviews of short documents such as research briefs, commissioning briefs, vignettes, outline proposals, or lay summaries of reports (less than 50 pages).

Middle level £125.00 – for reviews of larger amounts of information. For example reviewing several grant applications, or medium length reports (50 - 200 pages).

Higher level £200.00 – for reviews of large reports or documents. For example reviewing long reports (over 200 pages).

(The full guidance is set out in INVOLVE (2009) National Institute for Health Research: Payment rates for public involvement. The document is available from INVOLVE, Wessex House, Upper Market Street, Eastleigh, Hampshire, SO50 9FD. Email: admin@invo.org.uk. Also downloadable from the INVOLVE website: www.invo.org.uk)

■ Examples 2: NIHR Research Networks

Mental Health Research Network

Mental health service users and carers are involved in various ways with the Mental Health Research Network:

£150.00 is offered to service users participating in various meetings.

- Service Users in Research committee meetings where the meetings are around three hours long. Members of the committee are expected to provide a written update on service user involvement

activities in their locality before the meeting and provide feedback to the locality afterwards.

- Service Users in Research advisory board meetings where the meetings last around three hours and require extensive reading of a number of papers before each meeting.

£100.00-£150.00 has been offered for various writing, peer reviewing and proof-reading activities.

£150.00 has been offered for service users presenting at the Service Users in Research launch conference.

National Cancer Research Network

Consumers recruited by the National Cancer Research Network Coordinating Centre as members of the National Cancer Research Institute (NCRI) Clinical Studies Groups and as Core members of the NCRI Consumer Liaison Group are offered an attendance allowance plus reasonable travel and subsistence expenses for attendance at:

- agreed induction training
- meetings of the Consumer Liaison Group
- meetings of their designated Clinical Studies Groups and associated subgroups.

The rates offered are:

Consumer Liaison Group Meetings	£150.00
Clinical Studies Group Meetings	£150.00
Clinical Studies Sub-Group Meetings/Working Group	£50.00*
Conferences/Training Days (per day)	£30.00

*unless a loss of a day's work is incurred through attendance at this meeting, in which case the allowance increases to £150.00

■ Examples 3: University public involvement groups

Faculty of Health and Life Sciences, University of West of England

Service users and carers who become involved with research in the Faculty of Health and Life Sciences, University of West of England are offered the following rates of pay:

Meetings	£19.40 per hour
Research work	£120.00 per day

Keele University, Arthritis Research Campaign National Primary Care Centre

The Arthritis Research Campaign National Primary Care Centre at Keele University has a Research User Group (RUG). Members of the group are offered the following rate of pay:

Half day meeting	£75.00
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■ Examples 4: Research studies/projects

Study title: Extension of mammographic breast screening to the over 70s: Assessment of efficacy, practicality and patient preferences 2007-2010 (Funded by NIHR Research for Patient Benefit Programme)

Two members of the North Trent Cancer Research Network Consumer Research Panel provided a patient perspective throughout the duration of the project. This included:

- involvement in the original proposal submission
- membership of the steering group throughout the three years
- advice and comment on the development of the research instruments (patient information sheets, consent forms, ethics submissions, interview topic guides and questionnaire development)
- reading and commenting on the patient interview transcripts (anonymised)
- contributing to the preparation of abstracts and papers for publication, and in doing so have become named authors on the papers.

They were offered **£10.00** per hour (plus travel expenses) for attending study steering group meetings. This rate was also offered for any associated work undertaken outside of the study meetings. For example reading or commenting on study documentation.

Study title: A study to develop devices to correct deformities for use with people who have foot drop following stroke (funded by the NIHR Health Technology Devices Programme)

Within this study 10 service users were sought for an advisory role to inform the project team's design discussions and decision making processes. They took part in a series of eight meetings during the course of the study.

Payment rate of **£50.00** was offered for each half day meeting. Arrangements were made with the host organisation's Finance Department to pay this fee in cash on the day of meetings for user's convenience and so that they are not out of pocket nor have lengthy claim forms to complete.

Appendix 4: Standard letters

Sections in **bold** and **[square brackets]** are to be completed by the organisations sending the letter.

■ Letter 1: Explanation of one-off involvement and payment as a thank you gift

Purpose: For members of the public if taking part in one-off involvement in the tax year

To: Members of the public

Dear

Thank you for your interest in participating in this one-off event with **[name of organisation]** and contributing to **[describe activity]**. As a lay person with direct personal experience of **[insert description of experiential knowledge]**, your contribution to our work is very important.

In appreciation we would like to provide you with a gift of £ **[insert amount]** as a thank you. As this is a one-off gift, and you have not been involved with **[name of organisation]** before this year, it is not taxable. If you are in receipt of state benefits the gift will not affect your benefits. If you are in receipt of benefits you can show this letter to Jobcentre Plus to explain your involvement with **[name of organisation]**. In addition, our policy is to cover expenses that are incurred necessarily, wholly and exclusively in the course of involvement.

[insert details of how the person will receive the payment]

Yours sincerely...

■ Letter 2: Explanation of the difference between involvement and work

Purpose: For people who are receiving state benefits because of ill-health or disability to provide to Jobcentre Plus to clarify they are getting involved (and not employed). The text of this letter has been agreed by the Jobcentre Plus policy team.

To: Jobcentre Plus

Dear Sir or Madam,

I am writing to you to advise you about the involvement of **[insert name of service user/carer/member of the public]** with **[name of organisation]** to clarify the nature of the activity.

[insert an explanation of the work of the organisation]

[name of organisation] wishes to advise you that we involve people because of their experience of using health and/or social care services. Recruitment for involvement should not be confused with recruitment for employment. Involvement is usually part-time, intermittent, and events may be monthly, quarterly or annual. Each involvement event is usually for less than a few hours in any one week, and may be voluntary or paid. Due to the nature of involvement we expect that the person who is involved will prepare for a meeting or event in advance, and will need to follow up after the meeting with notes and discussion. Any payments offered to a person are intended for all three stages of the involvement meeting or event.

We provide support measures so that people who have ill-health, physical or sensory impairments, a learning disability and older people are able to reach our meetings or events, in order to participate. The support measures may include the provision of transport, the provision of a personal assistant, a support worker, facilitator or communicator. We will provide an interpreter for people whose first language is not English if required.

The support where this is provided is also for the preparation before the meeting or event and follow up notes and discussion afterwards. The support will include as is required, (through a personal assistant, a support worker, facilitator or communicator) support to travel to and from the place of the involvement.

These measures and support are provided so that people who are unable to work and who have significant care or mobility needs can participate and talk about their experiences of using health and/or social care services. We are particularly concerned that involvement is not mistaken to represent capacity for work or for any reduction in care or mobility needs.

Yours sincerely...

Appendix 4:

HM Revenue and Customs circular

HM Revenue and Customs have issued the following circular as guidance to universities in respect of involving people in their research programmes:

EIM71105 - Research volunteers, lay participants and participants in clinical trials

See **EIM71100** for general guidance on the treatment of volunteers and unpaid office holders.

The former Inland Revenue agreed the following principles and procedures with the British Universities Finance Directors Group on 13 October 2004. As well as covering specific issues in the situations specified it illustrates the approach that should be taken with volunteer workers.

Research volunteers, lay participants and participants in clinical trials

In the course of undertaking research, particularly social science or medical research, volunteers are required to take part in tests, submit to measurements or be interviewed. They are usually paid a small sum to cover out of pocket expenses and as compensation for the time spent. Some of the volunteers may be members of staff of the university, but their participation in the research is not part of their duties of employment and they do it in their own time and are under no obligation to take part.

Closely related to the above is the use of “lay” people or “users” in research. Here the people in question are invited to attend meetings to give their views on various matters to inform the research process and direction. Often they will be former or current patients, representatives of particular groups such as retired people, or representatives from charities. Payment is made to them for their participation in the meetings.

Tax consequences for the university

In the circumstances above, HMRC agrees that the amounts paid to those concerned are unlikely to fall within the definition of “earnings” for PAYE or NI purposes. No employment relationship exists and as such PAYE and NIC would be inappropriate.

Under Section 16, Taxes Management Act 1970, HMRC is entitled to ask for details of payments to non-employees at their discretion; but they would not routinely ask for details for small payments such as these.

Tax consequences for the individuals receiving the payments

There will be no tax or NIC liability arising on the individual if the sums received do no more than reimburse the individual’s reasonable costs of participating in the trial or research, including costs of travel and subsistence.

However should the sums paid exceed those reasonable expenses then the excess may fall to be chargeable to tax as Miscellaneous Income, potentially giving rise to personal tax liabilities of the individuals which should be notified to the Inland Revenue under Self Assessment.

END (See Appendix 2 for details of where you can download this circular).

INVOLVE is a national advisory body that is funded by the National Institute for Health Research to promote and support public involvement in NHS, public health and social care research and development.

If you would like to know more about what we do, please contact us:



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in NHS, public health and
social care research