



*National Institute for
Health Research*

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

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

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About this guide

This guide is for you if you are thinking about getting actively involved in research (see section 1 for definitions of these terms) and you are being offered expenses and/or payment for your involvement. It offers answers to some frequently asked questions and suggests where you might get advice about your particular circumstances.

This guide does not attempt to answer all of the questions you might have about being paid for involvement; it is a complex area and it would be difficult to cover everyone's individual circumstances. We strongly advise you to get expert advice about your own personal financial circumstances before accepting payment for involvement in research.

This is the second of two guides about payment for involvement published by INVOLVE. The other guide, which is aimed at researchers and research commissioners responsible for paying people for their involvement, contains more detail about some of the issues touched on here. See **Payment for Involvement:** a guide for making payments to members of the public actively involved in NHS, public health and social care research (INVOLVE, 2010).

This guide supplements the information in our main publication for members of the public – **Public Information Pack** (INVOLVE, 2007). This pack is a series of four booklets which aims to explain some of the basic ideas about public involvement in research, helps you think through what you might like to do and how to get started.

This guide was written by Alison Faulkner in consultation with Lucy Simons and Sarah Buckland at INVOLVE.

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Thanks

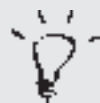
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Key tips

'Key tips' are offered throughout the guide to help point you to some of the key things to think about.



Key points

- It is good practice for an organisation to cover any expenses you incur as a result of your involvement and to offer you a payment for taking part. You should not be left out of pocket as a result of becoming actively involved in research.
- Receiving payment of a fee for involvement is likely to have implications for you whether you are currently employed, unemployed, receiving state benefits or retired. This is because the payment you receive will be treated as earnings.
- The organisation offering involvement should provide you with clear written information about the nature of the involvement, the amount they are offering you and what expenses they will cover (see section 3).
- **If you are receiving state benefits, receiving any form of payment may affect your benefit claim. It is vital that you get expert advice from a benefits advisor or from Jobcentre Plus regarding your personal circumstances.**
- Reimbursed expenses may in some cases be regarded as earnings – and can therefore affect your benefits. There are ways of avoiding this (see section 4).
- Receiving payments may also have implications for you if you are liable for income tax and National Insurance, receiving a pension or pension credits or tax credits.
- It is your choice whether or not you accept payment for involvement in research. There may be other rewards and benefits offered by the organisation involving you, for example, training, trips or visits, and meeting people. However, if you choose not to accept payment or to be paid a lower amount and you are on state benefits, you need to be aware of the ‘notional earnings’ rule (see section 6).

Questions to ask of the organisation involving you:

- Does the organisation have a payments policy?
 - If so, can you have a copy?
- How much is the organisation offering to pay you – and for what involvement activities?
- How much time do they expect this involvement to take up?
- Will the organisation pay your expenses?
 - If so, which expenses will they cover?
- What expenses can they pay directly or in advance, e.g. travel tickets, accommodation?
- How do you claim back any expenses you have paid for yourself?
- If a fee is being offered, how do you claim this?
- Who in the organisation is responsible for dealing with payments and expenses on your behalf?
 - Who can you contact if a problem arises?
- Does the organisation have access to any local or specialist sources of advice and information on payments related issues (for example, a local Citizen's Advice Bureau/welfare rights advice organisation; the Milton Keynes Citizen's Advice Bureau Involvement Helpline)?

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

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

- patients and potential patients
- people who use health and social care services
- people who provide care/support on an informal (i.e. unpaid) basis
- 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.

When we talk about **involvement in research**, we mean an active partnership between members of the public and researchers in the research process, rather than the participation 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. Active involvement would include, for example, advising on a research project, assisting in the design of a project, or carrying out the research.

The benefits of public involvement in research

Research that includes the perspectives of members of the public is more likely to produce results that can be used to improve services. As a member of the public, you bring different perspectives, skills and knowledge to the research process from those offered by researchers and health and social care professionals. Your involvement helps to ensure that the entire research process is focused on what is important to people and is therefore more relevant and acceptable to patients and the users of services. These are some of the ways in which you might benefit from being involved in research:

- **having a say** in research that might affect you, your family or friends
- getting research done that is **important** to you
- **learning** about research and the subject being researched
- **meeting** new people and developing your abilities
- a chance to make a **contribution**.

“

Medical knowledge isn't the only important knowledge. It's important to know what it's like to actually have a condition or to use services and how that impacts on someone's life; medical knowledge doesn't tell you that.

Service user – quote taken from INVOLVE leaflet (2010)

”



2. Payment for involvement

It is good practice for organisations to pay you for your involvement in research. This is one way in which you can be rewarded for the time, skills and expertise that you contribute to the research process. Paying people for their involvement in research helps to support more equal partnerships between researchers and members of the public. It helps to support the inclusion of people who might not otherwise be able to get involved, whether for financial or other reasons relating to access. Consequently, it widens the potential pool of people who might influence the course of research.

When we talk about **payment for involvement** we mean covering any out of pocket expenses that you incur (you should not be out of pocket for any involvement) and it may also include a payment for your time, skill and expertise.

We deal with these two types of payment separately in this guide:

■ **Covering expenses – see section 4**

By ‘covering expenses’ we mean either paying for your expenses directly or reimbursing any costs incurred by you whilst you are involved in research. All out of pocket expenses should be covered.

■ **Payment for time, skills and expertise – see section 5**

This refers to payment for the contribution you make to the research process of your time, skills and expertise.

Involvement and employment

For the most part, we are talking about involvement as distinct from employment in this guide. However there are circumstances in which people are involved in research through being employed – sometimes full or part time and sometimes within the state benefit rules on earnings. Indeed, involvement can be a stepping stone towards employment. For more discussion about these issues, see Payment for Involvement (INVOLVE, 2010).

3. Having a policy

It is good practice for organisations involving people in research to have a written policy giving details about their approach to paying people for involvement. A policy helps to clarify the situation for everyone involved and avoids people being treated differently on different occasions. Some organisations may have two separate documents: an expenses policy, setting out their policy and procedures for paying expenses, and a payments policy, setting out rates of pay for different involvement/research activities and how to claim for them. The policies should:

- set out what expenses will be covered by the organisation
- set out how much they will pay for different involvement tasks or activities
- acknowledge your right to choose whether or not you are paid for your involvement
- explain the procedure for claiming both payment and expenses and how you will be paid
- include contact details for the individual who is responsible for administering payments and resolving any difficulties that arise.

For an example of a payment and expenses policy see the INVOLVE Policy on payments and expenses for members of the public including INVOLVE Group members, February 2010 (available from INVOLVE).

Key tip



Ask for a copy of the organisation's payments and expenses policies



4. Payment of expenses

Any reasonable expenses you incur through being involved in research should be covered by the organisation involving you. This is to ensure that involvement in research is equally accessible to people on low incomes and those with health and social care needs or disabilities. The organisation should be able to give you clear written information about their expenses policy on request. The following expenses may be covered:

- all travel costs
- overnight accommodation and subsistence (i.e. food and drink) where appropriate
- childcare or replacement carer costs
- costs of a Personal Assistant or Support Worker
- conference fees
- administration costs
 - e.g. telephone, postage, stationery and other equipment
- training.

Payment of expenses in advance or direct to source

It is good practice for an organisation to pay your expenses directly or in advance, where possible, rather than reimbursing you at a later date. Examples of this include: booking travel tickets or accommodation in advance, and paying costs directly to a personal assistant or replacement carer.

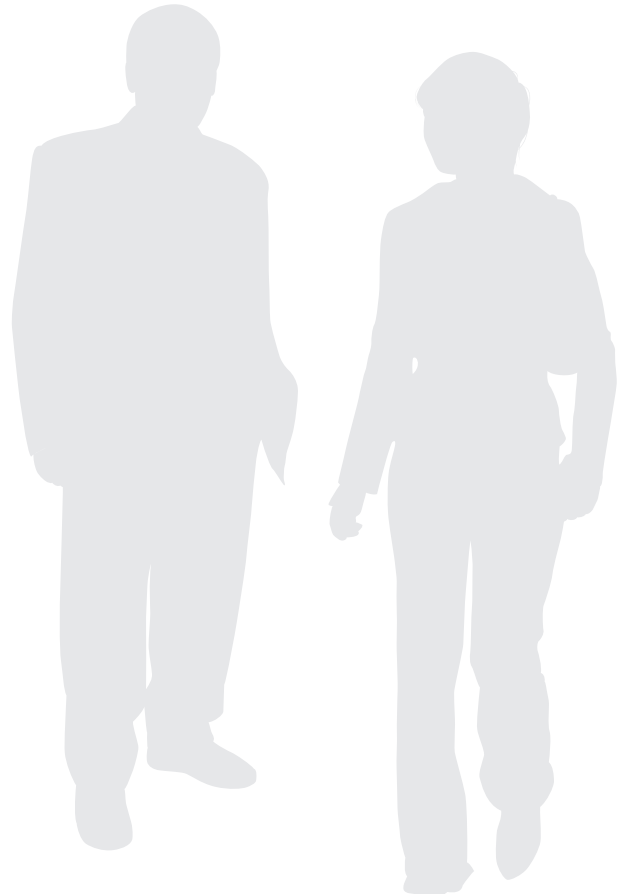
Paying expenses in this way avoids you being out of pocket before you are reimbursed for the costs incurred. Some organisations can take several weeks to reimburse expenses. Having your expenses paid in this way also avoids another potential problem. If you are receiving state benefits and being paid a fee for involvement, any expenses reimbursed to you can be treated as earnings and affect your benefits (see note 1 on page 19). Payment in advance or direct to source avoids this from happening. If you volunteer your time, expenses can be reimbursed without affecting your benefits.

Key tips



Ask the organisation for written information about what expenses they can cover to support your involvement.

Ask to have your expenses paid directly or in advance where possible (e.g. travel tickets, accommodation, caring costs)



5. Payment for time, skill and expertise

How much and for what?

Different organisations will offer you different rates for involvement in research. This is because there is no set guidance on this and some organisations can afford to pay more than others. However, any organisation should be able to tell you how much they can pay you and for what activities.

Examples of activities you may be paid for

- reviewing a research proposal
- attending a meeting
- preparation time: some organisations will pay you to prepare for a meeting or other activity by reading relevant documents
- participation in a training event: may or may not involve the payment of a fee but should entail reimbursement of expenses required to attend
- interviewing others or facilitating focus groups: you may be paid for each interview or focus group
- involvement in analysis or interpretation of results.

Each of these may be paid on a one-off basis, or on an hourly or daily rate. Find out exactly how much time you are expected to contribute and whether you will be paid for travel time as well.



The implications of being paid for involvement

Receiving payment of a fee for your involvement in research is likely to have implications for you whether you are currently employed, unemployed, receiving state benefits or retired. This is because the payment you receive will be treated as earnings. There are a number of ways in which receiving payment for involvement may affect your current financial situation:

(i) If you are receiving state benefits:

Benefit rules on part-time earnings are complicated. The rules set limits on the amount you can be paid and the number of hours you can do. Different benefits have different earnings limits and these limits change from year to year. Nevertheless, it is important to remember that you can receive payment for involvement as long as it falls within the disregarded amount or earnings limit that applies to your benefits.

If the payments you receive exceed the earnings limit that applies to you or you have not informed Jobcentre Plus of your intention to become involved in research, you may be in danger of having your benefits reduced or withdrawn. **It is your responsibility to get expert advice about this (for example, from your local Citizen's Advice Bureau or Jobcentre Plus) and to inform Jobcentre Plus if you are getting involved in research. (See section 8 for sources of help and advice).**

If you are receiving benefits because your health status or disabilities affect your ability to work, you will need to ensure that Jobcentre Plus understands that 'involvement' is different to employment. Jobcentre Plus has issued guidance to their staff explaining that involvement is not the same as work. In the text of a letter agreed with Jobcentre Plus policy team, it states: "Recruitment for involvement should not be confused with recruitment for employment" (INVOLVE Payment for Involvement, p.27)

(ii) If you are receiving retirement pension

Any earnings you receive in retirement counts as ‘taxable income’ along with income from your State Pension, personal or company (occupational) pensions and from certain taxable benefits.

Bear in mind that any money you earn after State Pension age may affect income-related benefits such as Pension Credit, Housing Benefit and Council Tax Benefit (see note 2 on page 19).

Staff at your pension centre can tell you how earnings may affect your Pension Credit. Your local authority can tell you how earnings may affect Housing Benefit and Council Tax Benefit (see note 2 on page 19).



(iii) If you are liable for income tax and National Insurance

Payments made to you for involvement are usually subject to tax and National Insurance. Some organisations deduct these automatically but many do not. When tax and National Insurance are not deducted at source, you will need to notify HM Revenue and Customs of the payment if your annual income exceeds your personal income tax allowance at the end of the financial year. For further information and advice about this, you can contact your local HM Revenue and Customs office.

One-off payments

If you take part in a single one-off involvement activity within a tax year (April – March) with an organisation (for example, a consultation event or focus group), any payment received is viewed as a ‘thank you gift’ and should not affect your benefits. Ideally the organisation will give you a letter of thanks that you can show to Jobcentre Plus, as you will still need to notify them of the payment. Tax and National Insurance do not usually apply to one-off payments and should not be deducted. You do not need to notify HM Revenue and Customs about one-off payments.



Key tips

If you are receiving state benefits, we recommend you seek expert advice tailored to your particular situation and the benefits you receive to ensure you do not breach the conditions of your benefits.

Inform Jobcentre Plus/Pension Centre of your intention to become involved in research.

An example letter explaining the difference between involvement and employment is given in the INVOLVE Payment for Involvement guide (page 27). Some people have found this a useful way of communicating with Jobcentre Plus.

Find out how much money you are being offered and for what activities, and how many hours you are expected to contribute. There is likely to be some flexibility about this; try to get it right for yourself.

Find out if the organisation involving you deducts tax and National Insurance at source. If not and you believe that you are liable to pay income tax and National Insurance, you must declare any payment you receive for involvement to HM Revenue and Customs at the end of the tax year.

Remember: you have the right to choose not to be paid.

6. What if I choose not to be paid?

Some people prefer not to be paid for their involvement, but to do it on a voluntary basis. Some people ask to be paid a lower amount than first offered because of benefit rules on earnings. People are aiming to avoid the potential difficulties that arise if they are receiving state benefits. However, there is one potential pitfall to choosing not to be paid or paid less that you need to be aware of (see notional earnings rule below).

According to Jobcentre Plus (leaflet: Volunteering while getting benefits – see section 8 for how to access this leaflet) you can volunteer as many hours as you like while you are getting benefits as long as you keep to the basic rules. These are:

- If you get Jobseeker's Allowance, you will still need to be looking for paid work:
 - you must be free to go to an interview if given 48 hours' notice, and
 - you must be able to start work within one week of receiving notice from Jobcentre Plus.

- You can still be a volunteer and get Employment Support Allowance, Incapacity Benefit or Income Support:
 - as long as you comply with the basic rules (above), and you let Jobcentre Plus know before you start, and tell them about any expenses you may get.

See note 2 about these benefits on page 19.

Notional earnings rule

The problem with choosing not to accept a payment that is offered or to be paid less than the going rate than others who are being paid for their involvement in research, is that Jobcentre Plus may regard the money that you could have been paid as 'notional earnings'. If this is the case, they may deduct money from your benefits as if you were being paid this amount. The assumption being made is that you are denying yourself an income.

See note 1 on page 19.

7. How will I be paid?

Most organisations will prefer to pay your fees and expenses by electronic transfer directly into your bank account (called BACS). However, they may pay some expenses in cash or by cheque. Some may pay fees and expenses using different methods. They should detail the method for claiming and the way they will pay you in their payments policy (as outlined in section 3).

It is common for payments to be delayed by several weeks, due to the administrative processes involved in most organisations.

Key tip



Find out how you will be paid and the likely delay between claiming and receiving payment



8. Sources of information and advice:

We hope this guide has answered some of your questions. In this section we present a list of resources that may be able to provide you with more detailed information.

Citizen's Advice Bureau (CAB):

You can find your local CAB either on the website www.citizensadvice.org.uk or by telephoning 0208 833 2181.

Involvement Helpline:

Some organisations subscribe to a specialist Involvement Helpline hosted by Milton Keynes CAB; if the organisation involving you subscribes to it, you can get free confidential telephone advice from specially trained advisors.

Commission for Social Care Inspection:

Benefit barriers to involvement: finding solutions October 2007. Available from the Shaping Our Lives website www.shapingourlives.org.uk/ourpubs.html

Department for Work and Pensions:

www.dwp.gov.uk

They publish several helpful leaflets, for example:

- Benefit rules for part-time paid work for people who are in receipt of the Employment and Support Allowance.
- Benefit rules for part-time paid work for people who are in receipt of Incapacity Benefit, Severe Disablement Allowance, Income Support for incapacity
- Volunteering while on benefits

Disability Alliance:

Helpful online source of information and advice on benefits. You can also obtain copies of their factsheets and publications by contacting Disability Alliance on 020 7247 8776 (this is not an advice line).

All Factsheets are available at www.disabilityalliance.org/fact.htm

All publications are available at www.disabilityalliance.org/shop.htm

HM Revenue and Customs:

www.hmrc.gov.uk

Jobcentre Plus:

www.Jobcentreplus.gov.uk

INVOLVE:

The following are available to download from www.invo.org.uk

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).

Payment for involvement in research: helpful benefit rules and systems for avoiding problems. Written by Judy Scott for INVOLVE conference workshop (INVOLVE, 2008).

If you have any suggestions for additional resources or amendments to this guide, please contact us.

Notes:

1. The benefits rules have been changed for service users who are involved or consulted by public bodies where there is a legal requirement to involve people; for example, in the design or delivery of services. In this situation, expenses can be paid in full without it affecting your benefits and the notional earnings rule does not apply. There is currently no legal requirement for people to be involved in research.
2. The information about state benefits in this guide is accurate as of March 2011. The Welfare Reform Bill published in January 2011 proposes to replace some of these benefits with Universal Credit. It is anticipated that changes will not be made until 2013 at the earliest.

INVOLVE

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in NHS, public health and
social care research

INVOLVE is a national advisory body that is funded by the National Institute for Health Research to 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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