

INVOLVE

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

NHS

*National Institute for
Health Research*

A guide to 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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Please note: This guidance is currently under review. A revised version will be published later in 2009.

1. 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, not as ‘subjects’ or participants, but as partners in the various stages of research, from identifying and prioritising topics, and commissioning, to evaluation and dissemination.

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

- **Reimbursement of expenses.** By ‘reimbursement’ we mean reimbursing expenses incurred by a member of public whilst being involved in research related activity. This is distinct from payments for time and expertise. All expenses should be reimbursed, and this booklet gives guidance on how. Reimbursement is distinct from payment for time and expertise.
- **Payments for time, skill and expertise.** By payment we mean payment made to members of the public for their input of time, experience and expertise into the research process. Payments for time and expertise should also be considered as 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, the guide does not attempt to be prescriptive about rates of payment.

2. What do we mean by ‘members of the public’?

For the purpose of this guide, ‘members of the public’ are defined as:

- Patients
- Informal (unpaid) carers
- Parents/guardians
- Users of health and social care services
- Disabled people
- Members of the public who are the potential recipients of health promotion programmes, public health programmes and social services interventions
- Groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services
- Organisations that represent people who use services.

3. What are the benefits of reimbursing expenses and paying the public and people who use services?

- The additional expertise found in the perspectives of people who use services and the public is an important added value to research. Reimbursing costs and paying for time and expertise creates an incentive for active involvement. This allows a broader range of people to be involved.
- Payment is a tangible way to acknowledge the value of public contributions. People have a right to be valued as citizens, 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, people who use services, and professionals.
- It supports inclusion. Offering payments can enable people who are often excluded in 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 alleviating incentives.
- 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 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 organisation.
- It helps reduce barriers that stop people participating. For example, being able to cover the cost of transport, use of phone, childcare, etc.
- It can be used to clarify the expectations and responsibilities relating to people's involvement.

In 2006, the Department of Health published 'Reward and Recognition', an important landmark document concerning reimbursement and payment for members of the public who contribute to health and social care services and research.¹

¹ 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**' DH.

4. Equity and independence

- Paying people who use services and members of the public does not influence the independence of their views.
 - A 'job description' can be drawn up with them to clarify and acknowledge the independent role of the individual involved.
 - A 'job description' can also be agreed for all members of any formal group to confirm their equitable status.
-

5. Reimbursement of expenses

All out of pocket expenses should be reimbursed. Reimbursement of expenses facilitates equal opportunities for participation, and people who use services should not end up financially worse off for providing what is, in effect, 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)
- Overnight accommodation, etc.
- Subsistence (food etc. whilst on 'business' or bought due to having to be at a certain place at a certain time)
- Childcare
- Telephone/internet access/fax costs
- Stationery/equipment
- Carer costs
- Costs of a Personal Assistant of the individual's choice
- Conference fees
- Participation in training

Reimbursement for expenses, needs to be made promptly, or in some cases even in advance. This will be very important to people on low incomes.

6. Payment for time, skills and expertise

People who use services 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's 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.

7. Setting a rate for payments

Rates paid will depend on a number of variables, as each situation is different. It may be helpful to ask yourself the following questions:

- How does the principle of equity apply in this situation?
- What level of skills, expertise, and experience am I seeking/expecting from the people who use services on the 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 am I expecting 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 have tackled these issues in Appendix 3.

8. Choice for people who use services about payment

When offering payment for the involvement of people who use services, the importance of choice cannot be over-estimated:

- 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.
 - There may be reasons why some people might choose not to be paid. This may be because of altruism, financial circumstances, or because of the potential impact on social security benefits, or tax (see Section 11). These 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 can be expected, as this informs people's choices about whether or not to get involved.
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9. Acknowledgements and other forms of reward

- 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 enhancing the experiential benefits for individuals who get involved. These might include training and learning, attending conferences, confidence building, help with ongoing learning, CV development, and future employment, for example.
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10. Agreements, contracts and 'job descriptions'

- 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 a group in ways which optimise their capacity to contribute.
- 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).

- Terms and conditions must be provided to people if they are being paid for a service (but not if it is just expenses) as Employment Law applies.
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11. Things you need to be aware of when making payments

- **Employment Law**

Employment Law applies wherever a person is being paid for a service. If you work in an organisation, the Human Resources department staff should be able to advise you about Employment Law. Otherwise use the links in appendix 1 to check what your responsibilities are where Employment Law applies.

- **National Insurance and Tax**

Reimbursement of expenses is generally not subject to tax as it is not counted as income.

Where members of the public are working in partnership with a research organisation, payments for time can often be arranged through the organisation's payroll system where tax and National Insurance are deducted at source.

Lump sum payments can be made to members of the public as 'contractors' or 'consultants' who are responsible for their own tax and National Insurance contributions, but it is important to check with the Status Officer at your local HM Revenue and Customs office first to see if the specific situation qualifies for this kind of payment. Where tax and National Insurance is not deducted by the paying organisation, then the individual is responsible for informing HM Revenue and Customs. If the income is taxable then this is usually declared through annual self assessment tax return forms.

If the member of public is part of an organisation or group which is being paid for consultancy work by a research organisation, then it may be possible for the organisation to deduct Income Tax and National Insurance through its own payroll arrangements. However, please note the section below on Voluntary Organisations.

Some organisations run finance systems that are flexible, and able to offer a choice about whether tax is deducted at source or not. However, many do not offer this flexibility.

- **People on State Benefits and Allowances**

Members of the public, and perhaps more often, people who use services, may be in receipt of social security benefits payments. It is very important to be aware that these benefits can be affected if payment is made. There are a number of different kinds of benefits and more than one kind may apply to a single individual. Each benefit has different conditions attached to it, including different ceilings on what additional income can be earned, if any, before benefit payment is affected. It is the responsibility of an individual of normal working age receiving benefit to first notify their local 'Jobcentre Plus' office² of their intention to accept additional income.

People in receipt of state benefits and allowances have an obligation to declare changes in their circumstances to their local Jobcentre Plus office. Individuals should be made aware of this, and advised to talk to their local Jobcentre Plus or Citizen's Advice Bureau first. Ultimately this must be in the individual's control, but failure to make appropriate enquiries or to notify the Jobcentre Plus beforehand could result in state benefits being withdrawn, which could be a serious matter for the individual concerned.

The fear of losing benefits can sometimes discourage people who use services from becoming involved where they would otherwise have made an important contribution to a project. If you or your organisation check with the local Jobcentre Plus about a particular situation in advance this can sometimes provide the assurance needed. However, different Jobcentre Plus offices tend to have different ways of interpreting the rules, and attitudes to a particular situation may differ. In some cases special arrangements have been successfully negotiated. However, in any event, all payments should only be made with the agreement of the individual concerned.

One of the biggest difficulties for people on sickness or disability benefits becoming actively involved with research or other health and social care services, is that Jobcentre Plus offices can interpret their involvement as readiness for work whether or not payment is being offered. If this is the case, then the Jobcentre Plus office can withdraw any sickness or disability benefits as a result. That you want to involve, and pay people for their expertise and experience as long term users of health and social care services, may be of no relevance to the person interpreting the benefits rules. This potential contradiction is one very good reason for checking in advance with the local Jobcentre Plus office as to where you and the people you want to involve actually stand.

In some cases organisations have been able to set up ongoing working agreements with their local Jobcentre Plus office. Whether or not this is achievable in your area may depend on the nature of the work involved and the way the local agency interprets its responsibilities.

² Formerly the 'Benefits Agency' office, these have now merged with local Job Centres as 'Jobcentre Plus'.

For more detailed information on state benefits rules in relation to service user involvement, we recommend the booklet '**A Fair Day's Pay**' published by the Mental Health Foundation.³

The Department of Health publication 'Reward and Recognition' also provides useful additional information.⁴

There is a Department of Work and Training website (see Appendix 1) which contains detailed information on different social security benefits, and also has information about local Benefits Offices. We also list in appendix 2 publications that address the benefits rules in relation to involvement in health and social care services in detail.

The problems of the service user involvement and benefits issue are further explored in '**Contributing on equal terms: Service user involvement and the benefits system**' published by the Social Care Institute for Excellence.⁵

- **Paying Voluntary Organisations**

When research organisations are paying groups or organisations representing the interests of people who use services that have charitable status, it is important to ensure they know if they are entitled to receive payments for their services under charity law. Payment for *services* is not the same as making a charitable *donation*. If in doubt advice should be available from their local Council for Voluntary Services (CVS), the National Council for Voluntary Organisations (NCVO), or the Charities Commission (see appendix 1). Many, but not all voluntary organisations have a 'trading arm' which enables them to receive payment for services, and donate any 'profit' after costs, back to the core organisation.

Voluntary organisations may not always be in a position to pay the public and people who use services for their time. However, charities wishing to pay their members for involvement in research are advised to check with the Charities Commission and their local HM Revenue and Customs office before proceeding.

³ Scott, J. 2003 '**A Fair Day's Pay**' Mental Health Foundation (£8, or free for people who are unwaged). Call 020 7802 0304, email: mhf@mhf.org.uk, or visit www.mentalhealth.org.uk

⁴ 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**' DH.

⁵ Turner, M. Beresford, P. (2005) '**Contributing on equal terms: Service user involvement and the benefits system**' Social Care Institute for Excellence. Call 020 7089 6840, or email publications@scie.org.uk to request copies or visit <http://www.scie.org.uk/publications/> to download.

Charity Trustees may not as a rule, be paid for any work carried out on behalf of the Charity. Dispensations must be sought from the Charity Commission for a Trustee to be paid.

- **Practicalities, principles and choices**

Most, if not all of the potential complications of making payments to the public and people who use services are generated by institutions. Individuals making a contribution of their time and effort should be supported, treated equitably and with respect, and appropriately rewarded. They should certainly not end up being marginalised by these institutional systems.

Paying someone might be complex, but it should not detract from the principle that offering payment may be entirely appropriate. Payment where appropriate should be offered, and the individual allowed to make an informed choice as to whether to accept it.

12. 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:

- 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).
- Research commissioners specifying 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.
- It is helpful, when promoting effective public involvement for commissioning bodies, to inform those applying for funds for research projects that the additional costs of this involvement can be considered in an application.
- When reviewing research proposals, consideration needs to be given to different levels of public involvement. For example, is the project to simply 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.

- Tokenism should be avoided. It is not cost effective, undermines the principle of public involvement, and has a negative effect on the individuals involved as well as their constituencies.
- Care needs to be taken when reviewing public involvement aspects of research proposals, that the researchers have given due consideration to the practicalities and benefits of public involvement. Have they specified intentions for proper support and training of people who use services and made provision for any special arrangements? Exactly how will they involve them and how will they check that this remains effective?
- Bear in mind that 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.

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

APPENDIX 1

Some useful sources of further information:

The Benefits Agency / Jobcentre Plus

For general information on benefits use

<http://www.dwp.gov.uk/lifeevent/benefits/index.asp>

Jobcentre Plus

<http://www.jobcentreplus.gov.uk/cms.asp>

To find your local Jobcentre Plus

<http://www.jobcentreplus.gov.uk/JCP/Aboutus/Ouroffices/LocalOfficeSearch.aspx>

The Charity Commission:

There are three regional offices covering England and Wales:

London:

Harmsworth House
13-15 Bouverie Street
London EC4Y 8DP

Telephone: 0870 333 0123

Fax: 020 7674 2300

Taunton:

Woodfield House
Tangier
Taunton
Somerset
TA1 4BL

Telephone: 0870 333 0123

Fax: 01823 345003

Liverpool:
20 Kings Parade
Queens Dock
Liverpool
L3 4DQ

Telephone: 0870 333 0123
Fax: 0151 703 1555

Website: www.charity-commission.gov.uk

Citizens Advice Bureau (CAB)

Website: www.citizensadvice.org.uk

To find your local CAB and for other useful information use:

www.citizensadvice.org.uk/winnn6/contact_us/contactus/cita_offices.htm

If you do not have internet access, details of your local CAB can be found in local telephone directory, from your local public library, or local council office.

Employment Law and the National Minimum Wage

The following websites provide a broad range of information on Employment Law and related areas:

Direct Gov: www.direct.gov.uk

The Department of Trade and Industry website:

<http://www.dti.gov.uk/employment/pay/national-minimum-wage/index.html>

HM Revenue and Customs

To find out more about Tax and National Insurance:

- **Website:** www.hmrc.gov.uk
 - National Insurance Registration Helpline - 0845 9157006.
 - Self Assessment (Income Tax) order line 0845 9000 404
 - Self Assessment (Income Tax) Helpline - 0845 9000444
 - Tax & Benefits Confidential - an advice line that offers people operating in the hidden economy confidential help and information to help them put their affairs in order - 0845 608 6000
 - Helpline for newly Self-Employed - 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 - 0845 9154515
 - To search for your local Enquiry Centre for a face to face service, see www.hmrc.gov.uk/enq/index.htm
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National Association for Voluntary and Community Action

NAVCA has a directory of local Councils for Voluntary Services:

NAVCA:

3rd Floor
Arundel Court
177 Arundel Street
Sheffield
S1 2NU

Tel: 0114 278 6636

Fax: 0114 278 7004

Email: navca@navca.org.uk

Website: <http://webdb.navca.org.uk/liodir/home.aspx>

The National Council for Voluntary Organisations (NCVO)

Regent's Wharf
8 All Saints Street
London
N1 9RL

Telephone: (0207) 713 6161

Fax: (0207) 713 6300

Minicom: 0800 01 88 111

Helpdesk: 0800 2 798 798

Email: ncvo@ncvo-vol.org.uk

Website: www.ncvo-vol.org.uk

APPENDIX 2

Useful publications

Attree, J. 2003 '**Payment protocol and benefit information for service user involvement in Hertfordshire**' Mind in Dacorum

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 CSIP/NIMHE 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.

This document is no longer available from CSIP/NIMHE but can be downloaded from the Social Perspectives Network website at http://www.spn.org.uk/fileadmin/SPN_uploads/Documents/valuing_involvement.pdf (accessed 07 April 2009)

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**' DH.

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 Department of Health website www.dh.gov.uk.

Scott, J (2008) '**Payment for involvement in research: helpful benefit rules and systems for avoiding benefit problems**' INVOLVE. Obtainable from INVOLVE, Wessex House, Upper Market Street, Eastleigh, Hampshire, SO50 9FD. Email: admin@invo.org.uk Also available to download from the INVOLVE website www.invo.org.uk

Scott, J. 2003 '**A Fair Day's Pay**' Mental Health Foundation (£8, or free for people who are unwaged). Call 020 7802 0304, email: mhf@mhf.org.uk or visit www.mentalhealth.org.uk.

Scott, J. Seebolm, P (ed) 2002. '**Payments and the benefits system: A guide for managers making payments to survivors and service users involved in improving mental health services**' King's College London

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

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 and people who use services have been paid. The following examples show the year to which they were relevant in brackets. 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.

Guidance has been agreed with the Department of Health in 2006 for the **National Institute of Health Research programmes** on payment rates to members of the public for attendance at committee meetings and carrying out peer review. It says that people who are asked to be members of a committee, or review proposals or reports, should be paid a fee if they are not in receipt of a full time salary from public funds and they meet **both** of the following criteria:

- they are members of the public or people who use services (as defined by INVOLVE)
- they are being asked to provide a public perspective at the meeting or to the review.

Payment rates are:

Committee fee

- for attendance at and preparation for a committee meeting a daily rate of **£150.00**.

Peer review fee

- **Lower level £50** - for reviews of short documents such as research briefs and vignettes or lay summaries of reports.
- **Middle level £100** - for reviews of larger amounts of information. For example reviewing several grant applications, or medium length reports (50 - 200 pages).

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

- **The NIMHE West Midlands Mental Health Development Centre** pays service users for training on the following scale (2005):

Short presentation (up to 30 minutes)	£40.00
Presentation / workshop/ seminar (up to 60 minutes)	£75.00
Half day workshop/ training event	£125.00
Whole day training event	£250.00
Consultancy/ other substantive work	To be negotiated locally

- **The National Institute for Health and Clinical Excellence (NICE)** pay patient and carer members of NICE guideline development groups and public health programme development groups £200 per day long meeting. This fee covers attendance as well as a considerable amount of background reading needed between meetings

Members of the public who sit on the NICE Citizens Council receive £150 per day for their attendance

A member of a NICE independent advisory committee (technology appraisal committee, guideline review panels, interventional procedures advisory committee, public health interventions advisory committee, research and development committee) will receive expenses only.
(2005).

- **The Big Lottery Fund** pays user assessors of social and medical research proposals a fee of £130 plus expenses, the same in fact as other assessors.
(2005).
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INVOLVE

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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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