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**A guide to 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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# **INVOLVE**

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

(formerly Consumers in NHS  
Research)

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# Contents

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<b>1. What is this guide about?</b>	Page 2
<b>2. What do we mean by ‘members of the public’?</b>	Page 2
<b>3. What are the benefits of paying people who use services</b>	Page 2
<b>4. What should be paid?</b>	Page 3
<b>5. Equity and Independence</b>	Page 3
<b>6. Expenses</b>	Page 3
<b>7. Payment for time, skills, and expertise</b>	Page 3
<b>8. Setting a rate for payments</b>	Page 4
<b>9. Choice for people who use services and the public about payments</b>	Page 4
<b>10. Acknowledgement and other forms of reward</b>	Page 5
<b>11. Agreements, contracts and ‘job descriptions’</b>	Page 5
<b>12. Things you need to be aware of when making payments</b>	Page 5
<b>13. Commissioning research</b>	Page 7
<b>APPENDIX 1 - Some useful sources of further information</b>	Page 9
<b>APPENDIX 2 - Useful publications</b>	Page 11
<b>APPENDIX 3 – Examples of payments</b>	Page 12

## **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’ of research, 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 deciding payments for expenses as well as for time and expertise. There are some examples of rates at the end of the guide. The document is not prescriptive about payment levels, but sets out principles of good practice. Almost every new situation where the public, and people who use services are involved in research is different in some respect to previous situations. We therefore welcome feedback that will help keep the guide as relevant, inclusive and as up to date as possible. The guide is available on our website and will be updated where appropriate.

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

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For the purpose of this guide, ‘members of the public’ are defined as people who use services, such as patients, informal (unpaid) carers, long-term users of services, organisations representing the interests of people who use services and people likely to be the target of public health and health promotion programmes.

## **3. What are the benefits of paying the public and people who use services?**

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- The additional expertise found in the perspectives of people who use services and the public is an important added value to research. Reimbursing the costs of public involvement and paying for time and expertise create an incentive for participation. 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 removes barriers that stop people participating. For example, being able to cover the cost of transport, use of phone, childcare, etc.
- It can indirectly lead to more effective and equitable participation of people who use services and the public by easing financial constraints. 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 supports equity of power in research partnerships which involve the public, people who use services, and professionals.

- It can be used to clarify the expectations and responsibilities relating to people's involvement.

## **4. What should be paid?**

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We recommend that in principle all expenses be reimbursed. Payments for time and expertise should also be considered as best practice. Rates 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.

## **5. Equity and Independence**

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- Paying people who use services and members of the public need not influence the independence of their views. A 'job description' can be drawn up with them to clarify and affirm their independent role.
- A 'job description' should be provided for all members of any formal group. This can help affirm the equitable status of all participants, including the members of public on the group.
- We suggest that payment is considered only for specific pieces of work, for example, peer review, report writing or attending a committee meeting. Thus independence is reinforced.

## **6. Expenses**

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We recommend that on principle, all expenses be reimbursed. They facilitate equal opportunities for participation, and people who use services should not end up out of pocket for work that is, in effect, a public service. Expenses should include:

- Travel (public transport, taxi fares, or an agreed private car mileage rate which includes wear and tear)
- Stopover (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/fax costs
- Stationery/equipment
- Carer costs
- Costs of a Personal Assistant of the individual's choice
- Conference fees
- Participation in training

## **7. Payment for time, skills and expertise**

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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 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, (although payment for expenses may be essential for some people to attend).

## **8. Setting a rate for payments**

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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. The Incomes Data Service (IDS) website may also be informative (See appendix 1)

## **9. Choices for people who use services about payment**

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

- 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 would prefer not to be paid. This may be because of altruism, financial circumstances, or because social security benefits are involved (see below).
- Some people may prefer that you make a donation to an organisation or charity they support or represent.
- It is important to make clear from the outset *when* payment and *what* payment can be expected. Payments, particularly expenses, need to be made promptly, or in some cases even in advance. This will be particularly important to people on low incomes.

## **10. Acknowledgements and other forms of reward**

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- If financial payment is possible, other ‘token’ forms of compensation are not recommended, although they may be the only alternative in some circumstances. However, specifically thanking and acknowledging individuals for their time and contributions should not be overlooked.

## **11. Agreements, contracts and ‘job descriptions’**

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- 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 manage 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.

## **12. Things you need to be aware of when making payments**

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### **▪ 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**

Expenses are generally not subject to tax unless they exceed the Inland Revenue ceiling (e.g. for mileage). Where members of the public are working in partnership with a research organisation, payments for time can sometimes be arranged through the organisation’s payroll system (e.g. via an ‘honorary contracts’ system) where tax and National Insurance are deducted. However, many organisations may not be able to do this.

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 Inland Revenue Office first to see if the specific situation qualifies for this kind of payment. 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 group to deduct Income Tax and National Insurance through its own payroll arrangements. However, please note the section below on Charities.

- **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' office<sup>1</sup> 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 if they so wish. 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 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 interest 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 of 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.

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<sup>1</sup> Formerly the 'Benefits Agency' office, these have now merged with local Job Centres as 'Jobcentre Plus'.

For more detailed information on Benefits rules in relation to service user involvement, we recommend the booklet '**A Fair Day's Pay**' published by the Mental Health Foundation.<sup>2</sup>

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.

- **Charities**

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). Many, but not all charities have a 'trading arm' which enables them to receive payment for services, and donate any 'profit' after costs, back to the core Charity.

Charities 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 Inland Revenue Office before proceeding.

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.

### **13. Commissioning Research**

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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 a little longer than usual (for example, extra time for recruitment and training).
- Research commissioners specifying the need for public involvement, should expect a project to budget for realistic costs for involving

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<sup>2</sup> 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](mailto:mhf@mhf.org.uk), or visit [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk) .

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, collaborate, with people who use services and the public or is it to be user led? (See the INVOLVE publication 'Public Involvement in NHS, public health and social care research: Briefing notes for researchers'.) The level of consumer 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 consumer 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 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 working up a research proposal.

## **APPENDIX 1**

### **Some useful sources of further information:**

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#### **The Benefits Agency/ Jobcentre Plus**

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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/cms.asp?Page=/Home/AboutUs/OurOffices>

#### **The Charity Commission:**

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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](http://www.charity-commission.gov.uk)

## **Employment Law and the National Minimum Wage**

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

ACAS Tailored Interactive Guidance on Employment Rights (TIGER) website:

<http://www.tiger.gov.uk/home.htm> ,

The Department of Trade and Industry website:

<http://www.dti.gov.uk/er/index.htm> ,

Income Data Service website:

<http://www.incomesdata.com/index.html>

## **Citizens Advice Bureaux (CAB)**

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Use <http://www.nacab.org.uk/index.ihtml> to find your local CAB and for other useful information.

## **Inland Revenue**

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For contact details for local tax offices use <http://www.inlandrevenue.gov.uk/>

Alternatively, for local Jobcentre Plus, Tax (Inland Revenue) and CAB offices, look them up in your local Thompson's or BT directories.

## **The National Association of Councils for Voluntary Services (NACVS)**

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NACVS have a directory of local Councils for Voluntary Services:

### **NACVS:**

3rd Floor

Arundel Court

177 Arundel Street

Sheffield

S1 2NU

**Tel:** 0114 278 6636, **Fax:** 0114 278 7004

**Email:** [nacvs@nacvs.org.uk](mailto:nacvs@nacvs.org.uk)

**Web:** [www.nacvs.org.uk](http://www.nacvs.org.uk)

## **The National Council for Voluntary Organisations (NCVO)**

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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](mailto:ncvo@ncvo-vol.org.uk)

[www.ncvo-vol.org.uk](http://www.ncvo-vol.org.uk)

## APPENDIX 2

### Useful publications

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

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

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](mailto:mhf@mhf.org.uk) , or visit [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk) .

For guidance on the different levels of consumer involvement and how the public can be involved in different stages of a research, refer to the INVOLVE publication '**Public Involvement in NHS, public health and social care research: Briefing notes for researchers**' Hanley et al, 2003. INVOLVE.

#### **INVOLVE**

Wessex House  
Upper Market Street  
Eastleigh  
Hampshire  
SO50 9FD

**Email:** [admin@invo.org.uk](mailto:admin@invo.org.uk)

Downloadable from the **INVOLVE website:** [www.invo.org.uk](http://www.invo.org.uk)

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## APPENDIX 3

### Examples of payments

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There is a range of different ways in which the public and people who use services have been paid:

- **The NHS Health Technology Assessment programme (HTA)** pay £111.18 or £138.71 (if there is preparation) a day for attending panel meetings including any induction/development days if the person is self-employed, not in paid employment or will lose a day's pay by virtue of attending a meeting. Travel, subsistence and carer costs are also paid. They also offer a fixed fee of £200 for peer reviews where the document is more than 200 pages long (2003).  
For each role HTA have a 'job description' and person specification.
- **The Department of Health** guidance on best practice for national R&D programmes says of payments for peer reviewers who are members of the public, or people who use services (as defined by INVOLVE), and who are being asked to provide a consumer perspective to a review (2003):
  - 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*                              £200  
For reviews of large reports or documents. For example reviewing long reports (over 200 pages)
- **The Joseph Rowntree Foundation** offer a fee of £75 per meeting to service users who are members of their advisory groups if they are unwaged, plus additional payments for preparation time. They will also pay for a support worker as necessary (2002).
- **The National Institute of Clinical Excellence (NICE)** pay £200 a day (2002) for some activities.
- **The National Nursing and Midwifery Council** pay £268 per day to all who attend, both professionals and service users (2002).
- **Devon Social Services** pay £50 for attending a meeting at full day rate and £25 for half day (2002).
- **Wiltshire and Swindon Users Network** is a user-controlled organisation committed to user involvement in all aspects of community care by long-term users of social care. They have formed a limited company by guarantee, in order that they may reimburse service users for all their involvement, including being directors of the organisation.

This principle is accepted by the local authority which provides their funds to resource user involvement.

As a basic principle, they pay users £5 per hour for running their own association and for being involved in different kinds of work planning, delivering and evaluating services that are requested by statutory services. In addition they have carried out two pieces of user-controlled research in which they have needed to negotiate different fee rates for different pieces of work according to the skills which are used by the users in research. So, for example, users involved in interviewing or in writing up some of the analysis have been paid different fee rates to those who are on the advisory group.

A fuller discussion about the principles and processes of involving users and how an organisation should note their fee levels to report annually to the Inland Revenue in relation to peoples benefits etc, can be found in 2 publications – 'I'm in control', available direct from the network, and forthcoming – 'Users Best Value, A Guide to Users Involvement in Best Value Reviews'. For further information contact Clare Evans, Wiltshire and Swindon Users Network, 7 Prince Maurice Court, Hambleton Avenue, London Road, Devizes, SN10 2RT. (2002)

- A paper published by **West Midlands MIND**, 'Partnerships in Mental Health' McHarron & Nettle, 1999 recommends the following:
  1. For attendance and participation at working groups/committees,/meetings/recruitment panels etc: minimum payment of £5.00 per hour or £15 flat rate sessional fee plus travel expenses and any necessary and reasonable subsistence costs.
  2. For training activities: A minimum fee of between £50 - £300. For example, £50 for a short plenary presentation, £75 for a workshop or seminar, £100 - £150 for a half day training event, and £200 - £300 for a whole day training event (2002).
- **The National Lottery Charities Board** pays user assessors of social and medical research proposals a fee of £125 plus expenses, the same in fact as other assessors (2002).
- **Gedling Primary Care Trust (PCT)** pay £95 per day to lay members participating in meetings (2002).
- **The Department of Health Strategic Review** of NHS R&D in Mental Health agreed to pay £350 a day to the employer organisation (a national charity) to recruit a service user to join the Advisory Group on a consultancy basis. The Mental Health Strategic Review also paid £150 to the members of a specially convened User Panel for their attendance at the meeting, plus expenses (2002).
- **MIND in Dacorum** recommend paying service users £10 per hour, £30 half-day, £65 full day for attendance at a meeting/panel/event for consultation, recruitment and selection, and auditing services (2003).



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Roger Steel  
INVOLVE  
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