

# Payment guidance for members of the public

December 2021

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This guide is for patients, carers and members of the public 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 offered expenses or payment 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.

The National Institute for Health Research (NIHR) has developed a separate [guidance document aimed at researchers and professionals](#), which you might also want to view to learn more about how your involvement in research is costed.

## 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 - you should not be left out of pocket as a result of becoming actively involved in research
- the organisation offering involvement should provide you with clear written information about the nature of the involvement, the duration and frequency of involvement, the amount they are offering you and what expenses they will cover.
- if you are receiving state benefits, receiving any form of payment may affect your benefit claim, and therefore it is vital that you also get expert advice from a benefits advisor regarding your personal circumstances
- it is your choice whether or not you accept payment for involvement in research
- receiving payment of a fee for involvement is likely to have implications for you if you are currently employed, unemployed, receiving state benefits or retired - this is because the payment you receive might be treated as earnings

## Section 1 - What do we mean by public involvement in research?

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; for example, participation in a clinical trial. Active involvement may take the form of consultation, collaboration, co-production or user control. We 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.

We use the definition of 'public' to include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.

You can find more information on involvement in research, guidance and resources on the [NIHR website](#). You can also browse the [NIHR Glossary](#) for useful information.

## Section 2 - Payment for involvement

It is good practice for organisations to offer 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 payment for your time, skills and expertise. 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.

### 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. Indeed, involvement can be a stepping stone towards employment. If you have a question about involvement and employment, you must first obtain reliable benefits advice.

## Section 3 - Having a policy

It is good practice for organisations involving people in research to have a written policy (document) giving details about their approach to paying people for involvement. A policy helps to clarify the situation for everyone and avoids people being treated differently on different occasions.

The policy should:

- set out what expenses will be covered by the organisation
- set out how much they will be offering to pay for different involvement tasks or activities
- acknowledge your right to choose whether or not you are paid for your involvement and to ask to be paid a lower amount if benefit conditions set a limit
- acknowledge benefit conditions that may apply to you and that you must follow
- provide you with an [official letter](#) providing a written explanation of service user involvement to show the Jobcentre
- explain the procedure for claiming both payment and expenses
- where you are not in receipt of state benefits (except a State Pension), explain any responsibilities you may have in declaring payment for tax, National Insurance and state benefits purposes
- include contact details for the individual or team who is responsible for administering the payments and resolving any difficulties that may arise

## Section 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. If you are not sure whether an expense will be covered check with the organisation in advance.

Organisations often have an upper limit for some expenses. 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 (for example telephone, postage, stationery and other equipment)
- learning and personal development opportunities

## 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.

Where reimbursements to a bank account are used, it is good practice for an organisation to:

- make payments for time and for reimbursed expenses separately, to avoid confusion
- reference reimbursed expenses on an electronic bank transfer called BAC to ensure the Jobcentre ignore the amount and do not treat it as payment for time

## Section 5 - Payment for time, skills 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.

Please remember that 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. If you choose not to accept payment this will not affect your state benefits. You can accept a lower amount of payment to ensure this does not go over the maximum you can accept, and it will not affect your benefits providing you tell the Jobcentre that this is service user involvement.

### 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
- 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.

## 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:

### 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 and you have followed mandatory Jobcentre Plus benefit conditions.

If the payments you receive exceed the earnings limit that applies to you or you have not obtained prior permission or 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 follow your benefit conditions if you are getting involved in research. (See section 8 for sources of help and advice). There is a list of the different benefits that you could be claiming and a brief summary of the benefit conditions in section 9 below.

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, in 2007, it states: "Recruitment for involvement should not be confused with recruitment for employment."

However you cannot expect Jobcentre Plus staff to be aware of this, and it is important for the organisation that has recruited you for involvement to [provide you with a letter](#) that you can show the Jobcentre. The letter should explain that service user involvement is about consultation with a person who has personal experience of using health and social care services because of their health condition or other circumstances, and as such cannot be confused with work or capacity for work. The letter should state that the organisation will provide assistance where a person has mobility problems or care needs and so the involvement cannot be interpreted as indicating a reduction in mobility or care needs.

### 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 Support. Staff at the Pension

Service can tell you how earnings may affect your Pension Credit. The Pension Service may agree to treat payments for intermittent involvement as spread across several months. Your local authority can tell you how earnings may affect Housing Benefit and Council Tax Support. They are likely to treat payments as spread across 5 weeks.

## If you are liable for income tax and National Insurance

Payments made to you for involvement are usually subject to tax and National Insurance deductions if your taxable income exceeds your annual Tax Personal Allowance. This is £12,570 from April 2021-22. Some organisations deduct tax automatically but many do not. You can ask if the organisation involving you deducts tax and National Insurance at source. If so, you must have fulfilled your benefit conditions to either obtain permission for involvement or to notify the Jobcentre before the organisation sends your details to HMRC. This is because HMRC notify the Jobcentre when a person's details are sent to HMRC to set a tax code.

People who are registered self-employed, or have some taxable income from another source which deducts tax, should declare payments for involvement as required by HMRC.

People who are in receipt of a state benefit because they are unemployed or have limited capacity for work cannot register with HMRC as self-employed so as to complete a self-assessment and pay tax if it is due. HMRC will advise Jobcentre Plus and benefits may be stopped.

People whose taxable income is below the annual Personal Allowance set by HMRC should not have deductions and should not pay tax.

## Section 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.

If you receive welfare benefits - You should tell the Jobcentre that any expenses are for service user involvement.

Although Jobcentre Plus says that you can do as much volunteering as you wish, in practice you would be wise to keep your voluntary hours to under 16 hours a week.

If you are in receipt of Universal Credit for unemployment you must continue to fulfil your claimant commitment contract with the Jobcentre. Your contract may include being available to take up paid work immediately. Your contract may include looking for work for 35 hours a week.

If you are in receipt of Employment Support Allowance, or Universal Credit for limited capacity for work, the Jobcentre may decide to review your entitlement to an incapacity benefit if your volunteering shows you can be active for 16 hours or more a week.

## Notional earnings rule - changes from April 2015

The notional earnings rule no longer applies for payment for public involvement in research. (In the past benefits might have been affected if you refused payment or if you asked for less than the amount offered as this might have been regarded as 'notional earnings').

## Section 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.

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

## Section 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.

### Benefits Advice Service

This free, confidential and personalised service is coordinated by the Bedford Citizens Advice Bureau to support members of the public whose welfare benefits may be affected by payment for involvement.

If you are a member of the public involved in an NIHR organisation, or in a research project funded by the NIHR, you can use the service. There are different ways you might be involved, such as in reviewing research funding applications, as a member of an NIHR board or panel, or working with an NIHR funded research team or study.

The benefits advice service is free and confidential to use. When telephoning the service you will be able to speak to a specialist Welfare Benefits adviser at Citizens Advice Bedford. You will be required to provide information regarding your circumstances and then the benefits adviser will usually call you back. All information given is confidential and will not be shared

with any third parties without your express written permission, including sharing any information with NIHR.

The service:

- provides advice based on the benefits you are receiving, to help you decide if and how you want to get involved in research or receive payment for your involvement
- supports you should you need to make contact with the Department for Work and Pensions, or other benefits agencies about payments for involvement

The service is not able to give advice on tax or National Insurance queries or for benefits enquiries relating to payment for participating in research (for example, for taking part as a subject of a clinical trial or research study).

## How to access the Benefits Advice Service

For more information on how to access this service, please contact the NIHR Centre for Engagement and Dissemination [ced@nihr.ac.uk](mailto:ced@nihr.ac.uk) or call 020 88437117.

- tell us the name of the NIHR organisation you are involved with, or the name of the NIHR programme funding the research project you are involved with
- we do not need to know anything about your benefit situation.
- we will give you an email address (or telephone number) so that you can contact the Benefits Advice Service directly. We will also give you a code - please give this code to the service when you contact them.
- the service prefers that the first contact is by email if possible - the service will then arrange a time to call you.
- if you do not know if the organisation you are involved with is part of the NIHR, please contact the person who asked you to get involved

## Citizens Advice Bureau (CAB)

You can find your local CAB either on [the website](#) or by telephoning 0800 144 8848 (for England) or 0800 702 2020 (for Wales).

## Disability Rights UK

Helpful online source of information and advice on benefits. You can also obtain copies of their factsheets and publications by contacting [Disability Rights UK](#) on 0330 995 0400 (this is not an advice line).

## HM Revenue and Customs

[HMRC website](#)

## NIHR guidance and resources

[Payment Guidance for researchers and professionals](#)

[An example of an official letter from the organisation that is involving you, for you to show Jobcentre Plus](#)

Additional NIHR guidance and resources can be found on the [NIHR website](#).

## Section 9 - More information on welfare benefits regulations

Last updated for the year April 2021-2022. With thanks to Judy Scott, independent consultant, for her continued expert guidance on the effects of welfare benefits regulations on payment for involvement. To the best of our knowledge, the information contained herein is accurate and reliable at the date of publication; however, we do not assume any liability for the accuracy and completeness of the above information.

Welfare benefits regulations can be complicated. These updates offer guidance on some recent changes to the regulations that may affect people who are offered payment for public involvement in research while receiving welfare benefits.

The NIHR Centre for Engagement and Dissemination strongly advises anyone who receives welfare benefits to seek expert, personalised advice before accepting payment for involvement. The Benefits Advice Service, provided by Bedford Citizens Advice Bureau, offers free and confidential advice that is specific to individuals' circumstances and uses the latest regulations.

A note on terminology: The Department for Work and Pensions regulations refer to public involvement as 'service user involvement', and it is advisable to use this term when corresponding or discussing payment for public involvement with welfare benefits authorities.

### People who receive Employment and Support Allowance income-related: Permitted work and completion of PW1 forms

Permitted work rules affect people who are in receipt of Employment and Support Allowance. There are weekly earning limits. People who receive Employment and Support Allowance are required to notify their intention to start paid involvement before it commences. Paid work or paid involvement is called 'Permitted Work'. A form (PW1) is now provided online and must be downloaded, completed and sent back before involvement starts. However, the Department of Work and Pensions has confirmed that they will accept notification of paid involvement under the 'Permitted Work' rules over the telephone, providing it is followed immediately by a

completed permitted work form (PW1). People starting 'service user involvement' should state this on the PW1 form. People should send the PW1 form by recorded delivery and keep a copy for their records. Since April 2017 and a change in the legislation, the higher Permitted Work weekly earnings limit is allowed at all times; there is no one year time limit.

In April 2021, the higher Permitted Work limit was increased to £143 a week (this is usually reviewed in April of each year, when the National Living Wage rate is increased).

Permitted work rules can be complicated. NIHR strongly advises individuals to contact the Benefits Advice Service before starting to complete the PW1 form. The Permitted Work form PW1 is available online from the [government website page on Employment and Support Allowance](#).

It is advisable to enclose an official letter addressed to the Jobcentre from the organisation asking for your involvement when submitting the Permitted Work form. The letter should explain that:

- people are recruited because of their experience of using health or social care services
- involvement is about consultation and cannot be used to assess capacity for work
- support measures for mobility and care needs will be provided, as required

Some of the information in the [example letter for Jobcentre Plus](#) may be adapted for these purposes.

## People who receive 'New style Employment and Support Allowance contribution based' together with Universal Credit for housing costs

People who have fallen ill and cannot continue to work, after a period of employment of about two years or more, may have sufficient NI credits to qualify for contributory Employment and Support Allowance for 12 months. (instead of claiming Universal Credit). This is described as 'New Style ESA'. However, a person with housing costs of either rent or mortgage interest cannot get these paid as before (by the local authority or through Income Support) but must claim Universal Credit instead. All of the benefit rules and earning limits apply as described above for Employment and Support Allowance. You can follow the same procedures as described above.

However there is now a catch. This is because although you can earn up to £143 a week and your Employment and Support Allowance is not affected, the part of your benefit that is paid by Universal Credit has completely different earning rules. If your earnings are up to the full amount allowed of £143 a week, the Universal Credit monthly payment for the costs of your rent will be reduced.

Your Universal Credit monthly work allowance of £ 335 is the amount you can receive before your Universal Credit is reduced. So for instance if you earn £100 a week for a calendar month, you will have received £433. (Calendar month = £100 week x 52 divided by 12 months)

Your ESA will not be affected. But your Universal Credit for your rent will be reduced by 55 pence for every £1 over your work allowance of £335 a month.

$£433 - £335 = £98$  over the work allowance.

$£98 \times 55\% = £53.9$  reduction of Universal Credit.

OR

If you receive payments for a mortgage interest loan, Universal Credit has a benefit rule that is completely different to all other benefits that applies to payments for your mortgage interest loan. If you earn so much as £1 in a week, your mortgage interest payments will be stopped for 9 months.

This benefit rule means that unless you can pay your mortgage interest through regular earnings (Universal Credit has a £557 monthly work allowance if you do not claim housing costs for a mortgage or rent) you cannot earn any money at all if you need your mortgage interest to be paid.

## People who are about to transfer to Universal Credit from Employment and Support Allowance

People who receive Employment and Support Allowance who have permission for Permitted Work earnings of £143 a week should reduce their earnings to £140 a week BEFORE they are transferred to Universal Credit. They should notify the Jobcentre of the reduction. A regulation in Universal Credit may lead to the additional benefit payments for Limited Capacity for Work, or Limited Capacity for Work Related Activity, being either withdrawn or reviewed if their earnings exceed the National Living Wage x 16 hours a week ( $£8.91 \times 16 = £142.56$ ). The small discrepancy between these amounts indicates that this may be an unintentional oversight but as yet this rule remains.

## Universal Credit

Universal Credit has been introduced to eventually replace a number of benefits, including Income Support, Income-related Employment and Support Allowance, Income-related Jobseeker's Allowance, Housing Benefit, Child and Working Tax Credits.

The process of transferring people who receive other benefits to Universal Credit is taking longer than anticipated.

Anyone currently receiving Employment and Support Allowance and who is undertaking Permitted Work should read the guidance in the box above.

Universal Credit allows some people to earn up to a certain monthly 'work allowance' before reductions of the benefit. People can start earning without asking for prior permission. This system should mean that involvement arrangements are easier to manage.

Earnings received should be notified to the Jobcentre before the next Universal Credit payment is due. People notifying earnings from 'service user involvement' should state this on Universal Credit online form.

See the guidance below on reimbursed expenses and notional earnings.

Where people are receiving Universal Credit for health reasons is advisable to take or post an official letter from the organisation that is asking for your involvement to the Jobcentre or Work Programme Provider. The letter should explain that involvement is about consultation and cannot be used to assess capacity for work, and that support measures for mobility and care needs will be provided as required (some of the information in the [example letter for Jobcentre Plus](#) may be adapted for these purposes).

Earnings in a calendar month that are in excess of the work allowance will lead to Universal Credit being reduced by 55 pence for every £1 over the work allowance.

You will be eligible for a work allowance if you (and/or your partner) either:

- have responsibility for a child, and/or
- have limited capability for work

The Universal Credit monthly work allowances are set at:

- £335 if your Universal Credit includes your rent. This is shared with a partner if any.
- £557 if you do not receive Universal Credit for your rent. This is shared with a partner if any.

Please note: Single people and couples without children do not have a work allowance. All earnings will lead to Universal Credit being reduced by 55 pence for every £1 of earnings (for example, earn £100 a month and Universal Credit is reduced by £55).

There is one exception, which applies to people who are in receipt of Universal Credit with a component for a mortgage interest loan. In these instances receipt of any earnings (even £1) will lead to the mortgage interest element of Universal Credit being stopped – this stoppage will be for 39 weeks.

The regulations for Universal Credit can be complicated. We strongly advise individuals to contact the Benefits Advice Service at the earliest opportunity if they are unsure how payment for involvement might affect them.

## People who receive Carer's Allowance

Earnings of up to a limit of £128 a week do not affect Carer's Allowance. Earnings must be reported to the Carers Allowance Unit as soon as possible. Prior permission is not required. However, people who also receive a carer's premium will have this reduced for every £1 earned over £20 a week. Where people receive Housing Benefit this will be reduced (after the carers premium) by 65 pence for every £1 earned over £20 a week.

## People who receive Jobseeker's Allowance

Earnings of up to £20 a week do not affect Jobseeker's Allowance if it is received together with Disability Living Allowance or Personal Independence Payment or the recipient is a lone parent. Otherwise, earnings of only £10 a week shared with a partner or £5 a week are disregarded. Earnings over the disregarded amount will result in Jobseeker's Allowance being reduced £1 for every additional £1 earned.

Prior permission must be obtained from the Work Coach at the Jobcentre before service user involvement starts. Where people have continued health problems it is advisable to take an official letter from the organisation that is asking for your involvement to the Jobcentre or Work Programme Provider. The letter should explain that:

- involvement is about consultation and cannot be used to assess capacity for work
- support measures for mobility and care needs will be provided as required

Some of the information in the [example letter](#) for Jobcentre Plus may be adapted for these purposes.

## Reimbursed expenses

The benefits rules on ignoring reimbursed expenses for public involvement are consistent across all benefits. People who are in receipt of any benefit will have reimbursed expenses for public involvement ignored – that is, reimbursed expenses will not be seen as earnings and will not affect their benefits, regardless of whether the involvement is in research, service provision or education, or with a charity, the NHS or a local authority. People who are paid for involvement should be provided with a payment slip that shows the amount of reimbursed expenses separately to the payment amount. If expenses are included in a single 'thank you' payment, the expenses portion of the payment will not be ignored and the whole payment will be classed as 'earnings'. For example, a 'thank you' payment of £25 that also covers any travel costs will be seen as £25 of earnings and this may affect the person's welfare benefits entitlements. Reimbursed expenses must exactly match the expenditure.

## Notional earnings rule

The notional earnings rule does not apply to public involvement. The notional earnings rule previously stated that any payment offered for involvement would be treated as earnings, whether or not the payment has been accepted. Members of the public now have the option of refusing a payment for involvement, or asking for payment of a lower amount, without it affecting welfare benefits.

## One-off payments

The ruling which once ignored payments made for a single activity during a one-year period has now been withdrawn. Previously, Jobcentre Plus agreed to ignore payments for one-off activities, but this no longer applies. One-off payments are now treated like any other payment.

## Use of high street or gift vouchers

High street or gift vouchers may be treated as earnings, and viewed by the benefits authorities in the same way as other forms of payment. These payments need to be declared in the same way as cash, cheques or bank transfers. However in some circumstances HMRC will treat vouchers as a gift and not subject to NI or tax deductions. In this case the Department for Work and Pensions follows suit and treats the vouchers as a gift that does not affect benefits. The vouchers can be used to obtain goods in supermarkets. An organisation that wishes to be able to provide vouchers for service user involvement that will be treated as gifts should contact their tax office to request a ruling. Low amounts such as a £30 voucher will be more likely to be agreed.

## Averaging Rule

An averaging rule may be applied to payments that are above an individual's weekly earnings limit (if the welfare benefit they receive has this condition), so that it is 'averaged' over a longer period of time. Jobcentre Plus may apply this rule where there is a cycle of work or public involvement (e.g. every two weeks) or where the employer pays monthly or quarterly in arrears. For example, where the employer pays monthly in arrears someone receiving a benefit with a weekly earnings limit of £20 may be offered £80 for two involvement activities, and may be able to accept it if they request that it be averaged over four-week period, which would mean they have weekly earnings of £20, within their earnings limit. This only applies to payments for at least two activities within the averaged period. One of these activities could include preparation in advance of a meeting. The averaging rule should be requested in advance of the involvement and before any agreement to claim payment. The Benefits Advice Service offers advice on how to apply for this ruling and what to do if the application is not successful.

## Section 10 - Questions to ask 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, for example 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 payment related issues (for example, the Benefits Advice Service)

coordinated by the Bedford Citizens Advice Bureau; a local Citizens Advice Bureau or welfare rights advice organisation)?

Specific considerations and questions if you receive state benefits:

- does the organisation demonstrate that they are familiar with benefit conditions?
- does the Policy include measures to ensure you can obtain reliable information on your benefit conditions and keep to these conditions?
- will the organisation provide you with a written explanation about service user involvement and why it cannot be treated to assess capacity for work, or mobility or care needs, for you to show the Jobcentre?

## Acknowledgements

This resource was reviewed by the NIHR Centre for Engagement and Dissemination in March 2021 for accuracy and currency. The NIHR endorses this resource.

We would like to thank Judy Scott, independent consultant, for her advice and feedback on this guidance. Judy has been an integral part of the review process for this guidance document, providing expert advice on the effects of welfare benefits regulations on payment for involvement, and on the topic of payment for involvement overall.

This guidance is due for a review in March 2022. If you have any suggestions for additional resources or amendments to this guide, please contact us [ced@nihr.ac.uk](mailto:ced@nihr.ac.uk)

The previous version was referenced as: INVOLVE (2011) [What you need to know about payment: an introductory guide for members of the public who are considering active involvement in NHS, public health or social care research](#). INVOLVE, Eastleigh.

The first version of this guidance (2011) was written by Alison Faulkner, Lucy Simons and Sarah Buckland at INVOLVE. Additional contributors included: Judy Scott, Kati Turner, Maya Albert, Members of the Service User Advisory Group Institute of Psychiatry, King's College London, Pam Carter, Patsy Staddon, Sarah Hamilton.