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Payment guidance for researchers and professionals

This guidance has been compiled for a wide audience, but in particular it will be of value to:

- researchers who need to cost public involvement activities at any stage of the research process
- anyone in a professional role involved in costing public involvement, advising researchers on budgeting for involvement or who has an interest in the topic
- public contributors who want to know how their involvement in research is costed
- research advisors/ managers who provide guidance to the research community about involvement
- commissioners of research who invite funding applications from the research community reviewers and panel members who appraise research projects with costed involvement activities

NIHR has developed a <u>separate guidance document aimed at public contributors</u>, which you might also want to view.

Good practice for payment and recognition – things to consider

Before you start:

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- develop a clear policy on payment, expenses and recognition prior to involvement
- where possible you should involve the public contributors you'll be working with in the budgeting process
- at the outset, offer clear information for members of the public explaining what they are being offered, how they will be paid, how their involvement will be acknowledged, and what actions they need to take
- seek to ensure that members of the public are not financially worse off as a result of losing benefits through being involved in your research
- seek advice from your organisation's or institution's finance and human resources (HR) departments to ensure that your policy can be implemented
- do not underestimate your budget for involvement ensure that you have sufficient resources to coordinate and support involvement throughout your research, and that you can cover all necessary costs
- offer payment at a level that is commensurate with the nature and demands of the activity and is fair when compared to other members of the research team, to acknowledge the value placed on public involvement
- consult with members of the public about how they would like to receive payment or acknowledgement for their contributions

Throughout the involvement:

- where possible, be flexible when offering payment and recognition as individual's circumstances should be taken into account and may change
- where possible, pay for expenses in advance to avoid members of the public having to wait for reimbursement reimbursement of expenses should be processed promptly
- offer support to members of the public in the form of documentary evidence of any payment for involvement or expenses, so that they have information to provide to tax or benefits authorities

Other forms of recognition:

- thank members of the public for their contributions, whatever method of payment and recognition you decide upon keep those actively involved updated about the progress of your research, including feedback on how their contributions have made a difference
- offer appropriate learning and development opportunities to support and recognise the value of the contributions made by members of the public, with certificates to record what learning may have been achieved or sessions attended

- 1. Payments to individuals
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- 3. One-off payments
- 4. Fee,
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 or gift to
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- acknowledge the contribution of members of the public to your research in internal and external reports, publications, posters and presentations
- offer information about other <u>opportunities for involvement</u> and/or <u>participation in research</u> celebrate successes with those who have contributed to the research

When you are involving children and young people there are other things to consider. Look at our <u>specific guidance on involving</u> children and young people and specific payment guidance below.

Developing a payment policy

It is good practice to have a clear policy on payment and recognition in place prior to involvement, so that members of the public know in advance what is being offered and are able to make an informed decision about getting involved. However, policies do not need to be long or complex documents. They should explain, in plain English, what those involved should expect before, during and after their involvement, and the processes for claiming payment and expenses during that period.

A good payment and recognition policy:

Is based on guidance from all key persons

- is developed with the involvement and agreement of organisational finance and/or HR departments to ensure it can be fully implemented
- is developed with the involvement of members of the public
- is developed with the advice of an expert welfare benefits adviser on the multiple benefit conditions that must be followed by members of the public who are in receipt of state benefits
- includes measures to alleviate potential benefit barriers and to prevent misunderstandings with Jobcentre that may lead to benefits being stopped
- is written in clear language (<u>take a look at the Plain English</u> <u>summaries guidance</u>), and is available in a range of formats if required

Sets out payment rates to be offered and options for asking for a lower amount or declining payment

- provides a clear written information about the nature of the involvement, the amount offered, the duration and frequency of involvement and which expenses will be covered
- offers a clear explanation of what payment rates members of the public should expect to be offered for each activity – to do this it might be helpful to 'categorise' your involvement activities and allocate payment rates to these

- Trust facilities
- 6. Conferences fees
- 4. Involvement staffing
 - 1. Administrative support
 - 2. Public involvement coordinator and/or community engagement lead
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 - Risks to benefits of recommended payment rates
- 5. Payment systems
- 6. Welfare benefits
 - 1. Procedures for the recruitment of people for

- offers members of the public the option of asking for payment at a lower amount or declining a payment and offering to volunteer
- states if 'Pay As You Earn' PAYE is to be used and person asked to complete the HMRC form to obtain a tax code
- states where a person who is registered self-employed will be responsible for their own tax

Sets out which expenses may be reimbursed or covered

- clearly lists which expenses may be reimbursed and which not
- states the principles and any limitation on rates or refers to standard organisational policy
- states which expenses may be paid for in advance (covered) and which may be reimbursed

Explains the process of claiming payments and expenses

 clearly explains the procedures for claiming payment and/or expenses reimbursements, including any cut-off dates for organisational systems, and the likely timing of when payment will be received

Sets out procedures specifically for members of the public who receive benefits

- provides reliable information on the different benefit conditions and payment limits or disregards or provides access to Welfare Rights Advice
- <u>provides an example official letter</u> from the organisation to prevent misunderstandings with Jobcentre Plus staff that
- explains how involvement is different to employment and about support for mobility or care needs
- allows members of the public who receive state benefits sufficient time to obtain reliable advice on their benefit conditions and to consider what level of involvement and payment they can accept, and sufficient time to follow required Jobcentre Plus procedures

Policy implementation and review

- ensure that staff who administrate the Policy have prior training and ongoing support
- the Policy is reviewed and updated regularly to ensure that it remains appropriate
- the Policy offers a named person who should be contacted if there is a problem with payment or expense

Budgeting for involvement

- involvement who are in receipt of state benefits
- 2. Updates on welfare benefits regulations
- 3. In brief information for
 staff who are
 administering
 payments and key
 issues for payments
 to people who
 receive benefits
 - 1. People who receive Employment and Support Allowance: Permitted work and completion of PW1 forms
 - 2. People who receive 'New style Employment and Support Allowance' together with Universal Credit for housing costs
 - 3. People who are about to transfer to Universal Credit from Employment and Support Allowance
 - 4. Universal Credit
 - 5. People who receive Carer's Allowance
 - People who receive Jobseeker's Allowance
 - 7. Reimbursed expenses
 - 8. Notional earnings rule
 - 9. One-off payments
 - 10. Use of high street or gift

The aim of this section is to provide advice on how to cost for patient and public involvement at every stage of the research planning cycle, whether that's a planned focus group in a study underway or putting together the budget for a grant application.

Involving people in research usually requires resources in the form of time and money. It is really important to account for the costs of involvement in a research study at the earliest stage possible. Without having these resources available you will struggle to effectively involve people.

If you are applying for funding, check if the funder has an involvement policy or guidance notes on budgeting or finance. It's likely they will be looking for value for money in any application. These will help to provide a framework for involvement costs and activities as the research project is being planned and will help minimise the risk of under budgeting for planned involvement activities.

Getting started with budgeting

Planning the budget for involving patients, members of the public, service users and carers in your research involves estimating the costs so you can allocate a budget. These costs may need to be reviewed and amended throughout the course of a study.

Many research funders, such as the National Institute for Health Research (NIHR), will actively encourage and expect public involvement to be adequately budgeted for in research grant applications. However, it will be very important to demonstrate value for money when requesting financial support for involvement. It is very difficult to obtain funding for public involvement later if it has not been built into your research grant application at the outset.

If you are new to budgeting for involvement in research, it can help to have a step-by-step process to take you through the entire project cycle/timeline. This will ensure that you do not miss out any activities or costs. The steps below can be used at any stage in the research process.

Step-by-step process to get started with budgeting for involvement

This step-by-step process is a recommended approach to budgeting. We do understand that often in involvement things change and evolve, for example when co-producing a research project. Therefore, you might consider some flexibility to account for changes in costs as the research project progresses. You might also want to consider involving the public contributors you'll be working with in this process of setting out your budget for involvement.

Step 1: Framework selection Select a framework for mapping involvement costs. This might be vouchers

- 11. Averaging Rule
- 4. Resources on welfare benefits
 - 1. Benefits Advice Service
 - 1. Who is the Benefits Advice Service for?
 - 2. Information for NIHR organisations
 - 3. How to access the Benefits Advice Service
 - 2. Citizens Advice Bureau (CAB)
 - 3. Disability Rights UK
- 7. Tax and employment status
 - 1. Is involvement employment?
 - 2. Income tax
 - 3. HMRC EIM71105
 - 4. Tax and employment status resources
- 8. Reward and recognition for children and young people involved in research
 - 1. Things to consider
 - 1. Consult
 - 2. Clarify
 - 3. Discuss
 - 2. Expenses
 - 3. Payment
 - 1. High street vouchers
 - 2. Monetary payment
 - 4. Other forms of recognition
 - 1. More
 - information
- 9. Further information

the research project cycle or a project timeline.

Step 2: Planning your involvement Make a plan of the involvement activities you intend to incorporate into your research.

Step 3: What are the costs?

For each activity, identify the specific costs that you will need to budget for.

Step 4: How much will it cost?

Estimate the cost or range of costs against each involvement activity.

Step 5: Mapping

Map the involvement activities onto your selected project framework so that you know exactly when in the project timeline costs are allocated.

More information about how to implement this step-by-step process can be found below where we talk about working out the involvement costs for your study.

Try to ensure that all members of the public involved in research studies are well supported. Within small projects this will usually be the responsibility of the chief investigator, which will have implications for the researcher's time and may need to be costed at the outset of the project.

Remember the importance of paying expenses for members of the public in advance or ensure that they are paid promptly after their involvement in an event or activity – they should not be out of pocket for contributing to your research.

Involvement is not participation

Taking part in a research study as a participant does not constitute public involvement. In the <u>NIHR Briefing Notes for Researchers</u> you will find NIHR's definitions of involvement, engagement and participation. It is important not to mix up the costs for activities that are part of a study protocol, such as a focus group attended by study participants, with the costs of actively involving the public in a research study. This resource does not deal with how to budget for participation costs and this would need to be done separately.

Do not under budget

Do not under budget for involvement when applying for research funding. Reviewers will check whether the costs reflect the reality of effective public involvement or the support/training you are planning. They will also look for value for money. While some people may end up choosing not to accept payment for involvement

- 1. Examples of payment policies
- 2. Other guidance and resources
- 10. Acknowledgements

activities, budgeting should be done on the basis that they will. There may be other ways of recognising someone's contribution, for example by paying for them to attend a conference or a training course.

Involvement costs before a study is funded

If you want to cover involvement costs in advance of obtaining research funding, you will need to find specific pre-funding sources of support. Most of the NIHR Research Design Services (RDS) offer a bursary scheme which allows researchers to apply for a small amount of money from their local RDS to pay for public involvement in a study before an application for funding is made. Alternatively you might want to check whether your institution or organisation provides such funding.

What do you need to budget for?

In this section we provide a list of the common costs associated with active involvement in research. You should cost for the involvement relevant to your study, ensuring the costs are matched to what you plan to do and show value for money. For each item, we explain why this cost might be incurred and, where possible, give some examples. Depending on your plans for involvement, there may be other costs not listed here that you need to account for.

For any costs you should check if your institution/organisation has standard rates, for example for mileage, or has an existing supplier you can use to help you to calculate the estimated costs.

Payment and reward

You will need to decide how you will reward members of the public getting involved in your research. You might want to offer an honorarium payment, to each person every time they make a contribution, for example for taking part in a project advisory group meeting. Or you may want to give a non-monetary reward, such as a training course or conference that is not part of the costed involvement activity.

Payments to individuals

These are payments to members of the public in recognition of time, skills and expertise. The rate you offer will depend on a number of factors as each situation is different. For example, one-off consultations are likely to have lower rates than ongoing involvement through project groups and undertaking the research. It may be helpful to ask yourself the following questions when deciding what rate best suits the situation:

 what level of skills, expertise and experience are you seeking/expecting from members of the public for this involvement?

- what are the time commitments involved in the role they are playing in the project (including preparation, reading, travel, communication, meetings and so on)?
- what level of responsibility do you expect the person to hold in the project?

For a guide to NIHR payment rates, which can be used as a guide to set your payment rates, see section below 'Payment rates'.

Get to know your organisation's process for paying fees and expenses to members of the public as part of planning your project and aim to have a system in place to pay people and reimburse their expenses before involvement starts. Include a copy of or make reference to your organisation's payments and expenses policy within the research grant application. It is good practice to offer payment whenever possible to members of the public you involve in your research. However, receiving payment can have implications for people receiving any form of benefit. It is very important that people receiving state benefits get expert advice prior to accepting payment. Find out more about how payment might impact welfare benefits in the section below 'Welfare benefits'.

Vouchers or tokens for individuals

Proxy payment such as vouchers can be offered as a reward and recognition for involvement, especially for one-off events or consultations. Such rewards are usually offered to children and young people under 16 years who are not in receipt of benefits instead of cash payments. Where people are in receipt of benefits, 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; for more information on how vouchers may impact individuals on welfare benefits, please see the appropriate paragraph on the section below 'Welfare benefits'.

One-off payments

Payments for one-off involvement are now treated the same as any other payment. For those on welfare benefits, these payments are subject to the same restrictions as payments for longer term involvement. Previous regulations that may have meant one-off payments could be ignored for tax and benefit purposes are no longer applicable.

Fee, donation or gift to a group or network

If you are working with a patient or service user group, you may want to pay a fee, make a donation or purchase a gift for the group. A fee or donation gives the group control over how they use the money for their own interests. It's important to pay the fee directly

to the group as payment through an individual may affect their eligibility for welfare benefits or have different tax implications.

Funding for additional training and learning

Another reward for members of the public is to pay for the costs of training and other learning opportunities. These courses may be offered through your university or NHS Trust.

Honorary appointment

Giving people an honorary status, such as lay fellow or research partner, at the university or NHS Trust is often used as a way to reward and recognise their contributions. They can then have access to facilities such as the library, seminar series and other research opportunities. There may not be any costs attached to this but it may involve a Disclosure and Barring Service check.

Expenses for members of the public

In addition to offering payment for involvement, out of pocket expenses should also be offered to ensure that individuals do not end up financially worse off for providing what is, in effect, a gift of their own lived experience. Ideally, expenses should be covered in advance; for example, by booking accommodation or providing train tickets. For some people receiving welfare benefits it may be essential to pay upfront for expenses in advance. Where expenses are reimbursed after the event, this needs to be done promptly. This is very important to people on low incomes. The exact nature and rates of reimbursement will be in accordance with the rules and procedures of the commissioning organisation.

Travel

It is important to cover the cost of travel for any involvement. The costs usually covered include standard class rail fare, reimbursed bus fares or mileage. However, it is important to remember that some people may need alternative travel, for example a taxi, due to their support requirements. Booking rail tickets in advance and travelling at off-peak times can reduce costs.

Most organisations will have their own rates for reimbursing mileage when people use their own car. Alternatively, <u>Her Majesty's Revenue and Customs (HMRC) provide guidance on mileage costs.</u>

It is important to consider how many journeys will be needed for each person over the course of the project. Recruiting public contributors from a wide geographical area may be necessary for a national study or a study of a rare condition. This can greatly increase travel costs and add substantially to the overall involvement budget. You might want to consider a hybrid model whereby you combine face-to-face meetings with remote working.

Remote/ home working costs

Some public contributors will make use of home office supplies as part of their involvement. This might include use of a telephone or internet connection to join meetings remotely, and / or it might include printing out papers at home that have been sent via email. Where public contributors participate in meetings remotely from their home, NIHR provides for a standing allowance of £5 per meeting to cover the cost of telephone calls, paper, printing ink and paper, internet connection and other home sundries.

Subsistence

Subsistence costs are for time spent away from home and the costs that need to be met because of this, for example paying for meals, snacks and refreshments. Check if your organisation/institution has a maximum amount that can be covered. HMRC advises benchmark rates of £5 for one meal/five hours away from home and £10 for two meals/10 hours away from home.

When people are in receipt of benefits you must reimburse the exact amount, not a rounded up figure, as rounded up amounts are treated as earnings.

Childcare

Some people may need support for childcare to get involved. People may have their own arrangements in place and charges will vary. There is guidance you can review for average childcare costs.

Carer costs

People who have a caring role may need a replacement carer to enable them to get involved with research. They may have their own arrangements in place and costs will vary. There is guidance you can review for carer costs.

Personal assistants

Some disabled people have a personal assistant to support them to get actively involved in research. Some people use the term support worker. The cost of personal assistants is highly variable and depends on local circumstances. People who have personal assistants will often have their own arrangements regarding the activities undertaken and the cost of these. Organising a personal assistant through an agency might cost you around National Living Wage which £8.72 per hour for adults over 25 years of age. If the personal assistant is staying overnight, there may be a reduced hourly rate for that time.

Overnight accommodation

If members of the public are travelling some distance or taking part in an involvement activity such as training over several days, they may need overnight accommodation. Affordable accommodation can be sourced from city and regional tourist information centres and directly from hotels.

Involvement activity

Finding people

Recruiting members of the public to get involved with research studies can be a key involvement activity cost. At the outset of the study it is important to think about who will be responsible for this activity and how much time the recruitment process will take. It is also important to think about where people will be recruited from and the cost of working with partners in the recruitment process such as charities, patient groups or local service commissioning organisations.

In order to recruit members of the public to get involved with a research study you may want to advertise the opportunity in local or national newspapers, on local or national radio, at conferences and in relevant newsletters. Advertising costs will vary depending on the medium but a small advertisement in a local newspaper may start at around £200. These costs can be reduced by using free advertising channels such as e-communities and networks.

<u>People in Research</u> is managed by NIHR and offers a free place to advertise involvement in research opportunities.

Training and learning costs

Training and induction for members of the public may be required for many involvement activities. They will need to have adequate preparation for their role and also be supported to carry it out well. This support may range from an induction process through to indepth training, for example in interview techniques. It's also important to think about the training and learning needs of the research team – are they ready for involvement? It may help to find out about existing training and learning resources.

Venues and catering

The cost of venue hire for meetings and events will vary depending on location. Venues in major cities such as London can be very expensive. Some commercial organisations offer free venues for activities involving the public as part of their Corporate Social Responsibility (CRS) agenda. Other voluntary and third sector organisations offer venues at reduced rates. You might want to think about using university venues to host events at a reduced cost or for free, or you might find that community centres have reasonable prices.

Venues need to be accessible, so it is important to consider issues such as wheelchair access, proximity to a railway station, ground floor facilities and so on, since this will impact on choice of venue and cost. It is better to have an accessible venue that accommodates all public needs at a higher cost, than a cheaper one that proves to be inaccessible.

You will usually want to provide refreshments at meetings and events. Depending on the duration of the meetings, this can range from just tea/coffee and biscuits to a full lunch menu. Venues where meetings are held will often provide refreshments on a cost per head basis. Rates for refreshments vary but an average cost for coffee and buffet lunch is £10-20 per head.

Equipment and books

It may be necessary to provide equipment or books for members of the public getting involved. This will be important when they have a particular role such as peer interviewing and will need audio recording equipment. It might also be cost effective to provide technology such as a tablet computer for teleconferencing instead of holding face-to-face meetings, especially if long distances are involved. Check if your organisation/institution has a purchasing agreement with a particular supplier to help you budget for this.

Access to university/NHS Trust facilities

Members of the public may require access to university/NHS Trust libraries, IT services, access to research relevant to the topic they're engaged with and so on. There may not be a cost for such access but you may need to account for staff time in setting up the arrangement.

Conferences fees

Involved members of the public may need to attend conferences and events. This might be as a networking activity to recruit further members of the public into a study, to listen to the presentation of research related to the study or to present research findings once the study has ended and results are known. Involvement costs for these activities may include travel and hotel costs, conference fees and presentation skills training. Conference fees are usually upwards of around £200. It is always a good idea to check if bursaries are available from the conference organisers for members of the public to attend.

Involvement staffing

You may decide that dedicated staff time to facilitate and/or support involvement is required for your study. <u>If you are involving members of the public as peer interviewers or co-researchers</u>, it is good

practice for them to be employed on the same terms and conditions as other research assistants. However, the situation is different if a person is receiving welfare benefits; it is likely they will not be able to accept similar terms and conditions or be employed. These individuals must seek advice before taking up similar positions. You can find out more about how involvement payments can affect individuals in receipt of welfare benefits in the relevant section below.

Other staff support that may be required can range from some extra administrative support through to a dedicated involvement coordinator or community engagement lead as part of the team. To help you decide what staffing is required to support the involvement consider the following questions:

- does your team have the capacity and expertise to facilitate public involvement?
- will you be working with an experienced involvement group or will you need to reach out to different groups and communities and/or people new to research?
- how much support and training are members of the public likely to need?

You'll need to take the same approach in working out the costs of staffing for involvement as you do when working out other staffing costs and follow your own organisational recruitment procedures.

Administrative support

It is likely that you will need some dedicated administrative support to process payments/ rewards and expense claims for members of the public. The administrator may also help with organising involvement events if required.

Public involvement coordinator and/or community engagement lead

Depending on the duration and scope of the research study and experience of the research team, you may decide to employ a public involvement coordinator. Their role could include liaising with and supporting members of the public during the study, organising meetings and focus groups, engaging with specific communities or being a bridge between researchers and members of the public.

Independent facilitator

An independent facilitator or other person with expertise in engaging with patients and the public might be useful if they have very specific skills which are not available within the research team, for example running a focus group or a meeting with very young children or with participants with specific disabilities or impairments such as hearing loss or communication problems. Rates for

facilitators will vary depending on the specific skills required and can be upwards of around £400 per day.

Peer researchers/interviewers

There are different models of involving peer interviewers or coapplicants in studies. Sometimes this is done on a sessional basis with peer interviewers being paid for each interview carried out. In other cases, peer interviewers are employed on full- or part-time contracts with the host organisation. If you decide to employ peer interviewers, it is important that such posts are graded appropriately by the employing institution's HR department. The model which best suits you will probably depend upon the duration of involvement and the tasks involved. Please see sections below on payment rates and information for individuals who are in receipt of welfare benefits.

Other costs

You might need to consider specific support for individuals with hearing, mobility or visual impairments. Communication support for people with hearing impairments includes using microphones, hearing/induction loops, talk-to-type conversion (sometimes called palantype), speech-to-text reporters and sign language interpreters. Hearing/ induction loops are often integrated into venues but you will need to use a personal address system and microphones. Making sure venues used for involvement events are accessible is vital when involving people with mobility impairments. You may also need to consider the hire of equipment such as walking aids, wheelchairs or mobility scooters.

Disclosure and Barring Service

Depending upon the role members of the public have in your research, they may require a <u>Disclosure and Barring Service (DBS)</u> check, for example involvement activities requiring members of the public to take part in peer interviews in a healthcare setting or having direct contact with young people and children. <u>A basic DBS check costs £23</u> (as of 1 April 2021).

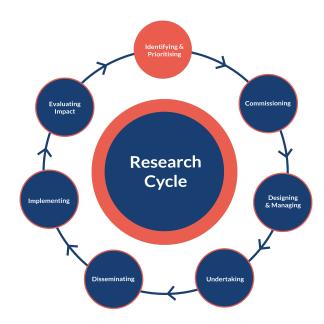
Language translation and interpretation

It might be necessary to translate some of the study materials, such as focus group topic guides, research protocols and research findings, in order to involve members of the public whose first language is not English. Taking part in focus groups might also involve the services of an interpreter. Many universities and NHS trusts have their own translation and interpretation policy and access to translation and interpretation providers. For example, you can find out more about The Big Word translation service.

Working out the costs for your study

Step 1: Framework selection

Using diagrams and timelines to help you think about and plan for involvement activities is a helpful method for deciding where in the research project involvement activities are likely to occur. A diagram of the research cycle and a table illustrating a project timeline are reproduced here to help you get started.



Example project timeline

Step 2: Planning your involvement

Before you can budget for involvement, you need to know how you will be involving the public in your research. We are not going to be prescriptive about that here, as the involvement and how you plan to carry it out will depend upon the research and why you are involving the public. However, for ideas of involvement activities to plan for see the NIHR Briefing Notes for Researchers.

Involving members of the public in your research will take additional time and this needs to be allowed for. Extra time should be built in for regular review of progress and to identify and alleviate pressure points during the project.

Step 3: What are the costs?

Refer to the section titled 'What do you need to budget for?' of this guidance to identify which costs you will need to account for. In that section we provide a list of the common costs associated with active

involvement in research. For each item, we explain why this cost might be incurred and, where possible, give some examples. You may not need to budget for every item in the list as you will only need those items relevant to your involvement plans. Depending on your plans for involvement, there may be other costs not listed here that you need to account for.

Step 4: How much will it cost?

The actual costs of involvement need to be worked out for each individual study and using the estimated costs relevant to the locality or organisation. It is important to show value for money when applying for research funding.

Step 5: Mapping the involvement onto the project framework

Once you have estimated all the costs, it's a good idea to map the involvement activities onto your selected project framework so that you know exactly when the costs will be incurred.

Payment rates

It is important that members of the public who are asked to become involved in this work are offered payment for their involvement, and are informed of the rates being offered before they agree to undertake the work. The rate of payment that you make is at your discretion, but there may be rates suggested by your organisation or institution. There are no nationally recommended rates of payment and the amounts that public contributors are paid for involvement varies widely, dependent on activity and organisational finances/budget constraints.

In 2009, the NIHR agreed payment and reimbursement rates for involvement with the Department of Health, setting out parameters within which payment should be offered for involvement in committees or as a peer reviewer.

The <u>NIHR Centre for Engagement and Dissemination's payment</u> <u>policy</u> sets out the following rates for honorarium payments, which can be used as a guide/ benchmark:

£12.50

For involvement in a task or activity such as reading and commenting on an abstract which equates to less than half an hour. For example, reviewing papers for the development of Alerts.

£25

For involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less. For example, participating in a focus group to provide

feedback on a proposal.

£50

For involvement in a task or activity likely to require some preparation and which equates to approximately two hours of activity. For example, a teleconference with related papers to read or review a few short documents.

£75

For involvement in a task or activity where preparation is required and which equates to approximately half a day's activity. For example, participating in a meeting to interview a small number of candidates who have applied to join a committee or panel, participating in a focus group, or delivering training.

£150

For involvement in all-day meetings. For example, attending a committee or panel meeting as an observer prior to becoming an active public member of a committee/panel.

£300

For involvement in all-day meetings that require substantial preparation. For example, when chairing or co-chairing a meeting or when carrying out other discretionary work, which requires additional responsibilities.

Attending training courses and conferences

Payments may also be offered by Programmes for attending training courses and conferences. For attending a full day of training or event organised by NIHR programmes a payment rate of £150.00 may be offered. For attending other relevant training courses / conferences, agreed in advance between the NIHR programme and the individual, the following should be covered:

- paying the fee for the course / event
- · paying out of pocket expenses

In addition, a nominal payment for attending the event may be offered.

Risks to benefits of recommended payment rates

Any payments provided that are above the weekly limits for certain benefits will lead to their benefits being stopped. These limits are £143 a week for ESA, £128 a week for Carer's Allowance, or £80 a month if paid monthly for other benefits. Although Universal Credit has in theory a taper system, it is likely that a payment of £150 for example for one day will trigger a review of entitlement if Universal Credit is received because of limited capacity for work.

If the research project is funded by the NIHR, you can advise individuals to seek independent advice and access the Benefits

Advice Service. More information on this can be found in the section below. Furthermore, individuals can be paid less, or turn down the payment altogether, to suit their circumstances.

If a member of the public prepares for a meeting but is unable to attend (for example due to illness) a nominal amount can be offered depending on the level of preparation already undertaken prior to the meeting.

Payment systems

Payment systems for public involvement in research studies are not always straightforward and can vary. In practice, the way that you make payments for involvement will depend on local organisational/institutional circumstances. Some organisations will use petty cash for making payments, while others require invoices or pay through payroll. Payment method will also depend on the employment status of public contributors (See section below 'Tax and employment status).

However, administration issues and complex systems can sometimes result in individuals waiting for payment. Begin talking with your finance department as early as possible to find out about the payment systems in place in your organisation. Your organisation might also have a public involvement and engagement team; you might wish to contact them for advice. It is worth considering that other parts of your organisation might not know what public involvement is, or how it differs from research participation. In the NIHR Briefing Notes for Researchers you will find NIHR's definitions of involvement, engagement and participation, and other useful content which might help you through these conversations.

Regardless of the payment method, you should explain to public contributors the procedures for claiming payment, including any cut-off dates for organisational systems, and the likely timing of when payment will be received. You can ask your finance department for timelines of payment.

Welfare benefits

It is important to be aware that benefits can be affected if payment for involvement is made. There are strict limits on the amount of money that people receiving welfare benefits can earn. Where people are receiving state benefits they are required to notify Jobcentre Plus of any paid or voluntary activity. They may also need permission to undertake any paid activity. Benefit conditions are complex and limits on payments that can be received without benefits being affected vary widely and can differ for each person, sometimes from year to year. It is advisable in all cases to seek advice from an appropriate source. You can find more information on the Benefits Advice Service below.

This section was last updated in March 2021. 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 below information.

Procedures for the recruitment of people for involvement who are in receipt of state benefits

Where people who are in receipt of state benefits are amongst members of the public who are being recruited for involvement you will need to ensure that staff provide appropriate information and support as follows:

- 1. as appropriate, ensure the person has identified the benefits they receive - they are likely to be in receipt of more than one benefit type
- 2. ensure person is given reliable guidance which is up-to-date on the relevant benefit conditions that apply to them and on their earning limits and disregards, and on guidance on liaising with Jobcentre Plus – this can be in the form of leaflets commissioned from a Welfare Rights Advisor or by the use of the Benefits Advice Line service provided by Bedford Citizens Advice through a subscription from NIHR
- 3. the Payment guide for members of the public contains a brief summary of the different benefit conditions that may apply
- 4. provide an offer of involvement, describe involvement activity, pay rates, duration of events, frequency of involvement events
- 5. explain that the person can ask to be paid less where their benefit limits are below the amount offered, or choose to volunteer instead
- 6. allow time for the person to consider their decision
- 7. agree next steps. Provide the official letter from your organisation that explains why involvement is different to employment and about support for mobility or care needs
- 8. allow time for a person to obtain permission for paid involvement or notify paid involvement and take or post the official letter from your organisation to the relevant Department for Work and Pensions or Jobcentre Plus office
- 9. as and when all liaison with Jobcentre Plus is completed, to fill in the HMRC form 'Starter Checklist' so that a tax code can be obtained

Updates on welfare benefits regulations

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.

In brief - information for staff who are administering payments and key issues for payments to people who receive benefits

People who receive Employment and Support Allowance: Permitted work and completion of PW1 forms

There are strict weekly earning limits. A person paid £1 more than the weekly limit of £143 will have their benefits stopped. 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. NIHR strongly advises individuals to contact the Benefits Advice Service before starting to complete the PW1 form.

The organisation asking for a person's involvement should provide an official letter addressed to the Jobcentre that explains:

- 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.

The letter is for the person to give to the Jobcentre when they notify their plans.

The <u>official letter for Jobcentre Plus</u> may be adapted for these purposes.

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

People who qualify for 'New Style ESA must claim Universal Credit for their housing costs. All of the benefit rules and earning limits apply as described above for Employment and Support Allowance. However there is now a catch. Earnings up to full amount allowed for ESA of £143 week, will reduce the Universal Credit monthly payment for the costs of the rent. The Universal Credit monthly work allowance of £293 is the amount that can be received before Universal Credit is reduced by 63pence for every £1 over the work allowance.

ALERT FOR STAFF IF A PERSON RECEIVES A MORTGAGE INTEREST LOAN - Payments for mortgage interest loan will be stopped for 9 months if the person is paid any money at all.

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 in order to prevent loss of additional rates in Universal Credit.

Universal Credit

Universal Credit has been introduced to eventually replace a number of benefits, including Income Support, income-related Employment and Support Allowance, Income-based Jobseeker's Allowance, Housing Benefit, Child and Working Tax Credits. People who receive Universal Credit will have signed a contract with the Jobcentre to commit to requirements such as job search, training, work experience and to take a job if this is offered. They must prioritise this contract.

Prior permission for earning is not required. People are required to report net earnings before the end of the benefit month in an online journal provided by the Jobcentre.

Where they receive Universal Credit because of limited capacity for work they should:

- state in the journal that they are doing 'service user involvement' and
- about support for mobility or care needs
- provide or post the official letter addressed to the Jobcentre provided by the organisation that explains:
 - 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 to work
 - support measures for mobility and care needs will be provided as required

The purpose of these precautions is to prevent misunderstandings with the Jobcentre staff. There is a risk that they presume a person may have recovered from their health condition and that they are now ready for work.

People who receive Universal Credit and who have limited capacity for work or are responsible for a child have a 'work allowance'. This is the amount of money they can earn before Universal Credit is reduced the following month by 63pence for every £1 over. The work allowance for this group if they also receive the costs of their rent is £293 a calendar month. If they have no housing costs the work allowance is £515 a month.

Other people who receive Universal Credit do not have a work allowance. Any net earnings lead to a reduction of Universal Credit the following month of 63pence for every £1 earned.

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. However, if Disability Living Allowance or Personal Independence Payment are not also received, earnings of only £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 before service user involvement starts. Where people have continued health problems it is advisable to take an official letter from the organisation 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 <u>information in the letter for Jobcentre Plus</u> 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. It was fully withdrawn three years ago. 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 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.

Resources on welfare benefits

NIHR Letter for Jobcentre Plus

Benefits Advice Service

This free, confidential and personalised service (launched in January 2015) is coordinated by the Bedford Citizens Advice Bureau to support members of the public whose welfare benefits may be affected by payment for involvement.

Who is the Benefits Advice Service for?

- members of the public involved with NIHR organisations or NIHR funded research projects
- researchers and staff within NIHR organisations or NIHR funded research projects who are supporting members of the public to get involved

Some other health and social care research organisations also subscribe to this service. Other partners who are also part of the service are:

- HRA
- Social Care Institute for Excellence
- NHS England
- Health and Care Research Wales (was Involving People)

Information for NIHR organisations

Specially trained staff with knowledge of how payment for involvement might affect those in receipt of state benefits will be available to offer free personalised advice.

For staff, the service can provide:

- advice on the implications of offering payments and reimbursing expenses to members of the public
- advice on offering and processing payments and expenses for involvement.

It is important to allow members of the public with enquiries to contact the benefits advice service directly, rather than raising any enquiries on their behalf. This will avoid misinterpretation or confusion in any advice offered.

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.

- 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 lease 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 <u>Citizen's Advice Bureau</u> <u>website</u> 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 <u>Disability Rights UK</u> on 0330 995 0400 (this is not an advice line).

Tax and employment status

NIHR is aware that there might be confusion around the tax implications of payment for involvement. Below we provide some guidance on how to navigate tax for involvement payments, however we advise organisations to seek independent expert advice on the matter if in doubt.

Organisations have the responsibility to understand the tax rules and apply them to their own systems and processes. Each organisation has to make their own decision if public involvement payments are employment income for tax purposes. Another important point to note is that for HMRC, a consistent approach to assessment, action and record keeping relating to payment is key.

Is involvement employment?

The finance and/or HR departments of universities and NHS trusts sometimes query the employment status (employed, self-employed, worker or volunteer) of people carrying out involvement. This is important because if someone is seen as 'employed' then they are entitled to a number of benefits including sick pay and so on.

Here are the HMRC definitions of the terms used above:

- employee
- self-employed
- worker (including casual worker)
- volunteer

The first step to understand the potential tax implications of public involvement payments is to understand whether the public contributor is an 'employee' or not. HMRC have a useful <u>online tool</u> 'Check employment status for tax', which you can use to check whether someone might be considered as employed or self-employed in law for tax purposes.

Where it is determined that the person is not an employee, then the organisation should work out if the person is a casual worker or self-employed by reviewing the government's definition of worker, or self-employed.

Where public involvement activities are deemed to be 'casual work':

- any form of contract will be akin to a zero hours contract
- contractual or Statutory Sick Pay, and maternity or paternity pay are not payable
- the organisation can offer the option of joining the business's pension scheme but the stakeholder pension will not apply
- holiday pay pro-rata will apply

Once you have determined someone's likely employment status this information should help you decide tax implications, and whether they need to be registered as an employee or casual worker. It will be useful to discuss and agree this with your organisation's Finance and/ or HR departments/ key contacts.

Income tax

Tax will only be due on a person's income once it rises over the given personal tax allowance. There are two ways to manage tax implications that may arise from making payments for involvement work:

- obtain a tax code for the person from HMRC and as advised deduct tax at source from the payment being made
- 2. if the person is self-employed, ask them to supply their HMRC self-assessment registration number HMRC will accept that as they are registered for self-assessment it is the payee's responsibility for paying any tax that may be due

It is important to note that people who are in receipt of state benefits because they are unemployed and possibly have limited capacity for work, should not be asked to register as self-employed. This is because HMRC and Jobcentre Plus now share such information. The Jobcentre will be likely to treat a registration for self-employment as a declaration that the person has found employment and can have their benefit payments stopped.

It may also be possible for your organisation to obtain a 'dispensation' from the HMRC. This is a formal agreement that payments need not be taxed at source. This often resolves a number of concerns that are raised by university or NHS finance departments when paying people for involvement work.

HMRC EIM71105

The 'HMRC 2004 Employment Income Manual (EIM71105) on Research volunteers, lay participants and participants in clinical trials guidance' states that attending meetings to inform the research process and direction "are unlikely to fall within the definition of "earnings" for PAYE or NI purposes" and that as such "there will be no tax or NIC liability arising on the individual if the sums received do no more than reimburse the individual's reasonable costs of participating in the trial or research".

However, interpretation of this guidance and subsequent reliance on this to determine tax implications for public involvement payments can be tricky. Public involvement in research spans a variety of activities, and is not limited to participation in meetings (as explicitly referenced in the guidance). Furthermore, the EIM71105 guidance does not provide a definition of what 'reasonable costs' are. To address these issues, an organisation-wide approach is key. Some universities have decided to approach this by agreeing which involvement activities fall in line with the EIM71105, and deciding their own definition of reasonable, based on their interpretation of

the guidance, organisational appetite to risk, and independent external advice. For this, it is key to engage with finance and HR departments, and public contributors where reasonable.

Where public involvement activities are in line with the EIM71105, these payments would not be classed as employment income by HMRC and consequently there would be no obligation to deduct tax. Where involvement activities do not fall within the EIM71105 guidance, then the organisation will need to further understand whether the public contributor is employed or not (see above).

IR35

Off-payroll working (IR35) is the short name for the "intermediaries" legislation, which is a set of tax rules that apply to those who work for a client through an intermediary, which can be a limited company or a "personal service company". This applies to many contractors. IR35 helps to stop contractors taking roles that would otherwise be paid employment, and to apply correct use of taxation in employment. As public contributors are (mostly) not contractors or personal service companies this would indicate this tax is not applicable to public involvement. As most public involvement that includes an offer of payment for involvement is performed without a contract, there is no mutual obligation, no control and it doesn't fit the definition of employment, it is highly unlikely that IR35 is applicable. It is nonetheless advisable to ensure that you review the individual circumstances alongside your finance department, and seek expert advice where needed.

Tax and employment status resources

HMRC 'Employment status checklist'

HMRC 'Check employment status for tax'

HMRC Income Tax: general enquiries

<u>HMRC 2004 Employment Income Manual (EIM71105)</u> on Research volunteers, lay participants and participants in clinical trials, pertaining to tax and involvement

More can be found about IR35 regulations on the GOV.UK website, including an IR35 helpline

<u>ACAS Helpline</u> provides clear, confidential, independent and impartial advice on employment rights and rules

Reward and recognition for children and young people involved in research

Children and young people involved in research should receive appropriate reward and recognition for their contributions. This demonstrates the value that you place on their time, commitment and expertise when involved in your research activities. Many of the things to consider when involving adults also apply when involving children and young people; however there are other specific issues that you should think about when planning involvement that includes young people.

You can find more information about involving children and young people in our guidance <u>Involving children and young people as advisors in research.</u>

Things to consider

Consult

Ask children and young people how they want to be rewarded and recognised. As with adults, appropriate forms of recognition may vary. For children and young people, these factors may include the age of those involved, and the level and type of involvement undertaken.

Where possible:

- consult young people about how they want to be rewarded and acknowledged
- provide options and build in flexibility to allow for individuals' preferences or personal circumstances
- include information about reward and recognition in any material provided about the involvement activity (and for the parents or carers of young children too)

Clarify

A clear and consistent policy that explains how children and young people will receive reward or recognition, and for which activities, will help to clarify the process for everyone.

Where possible:

- develop a policy that reflects with wishes of the children and young people involved
- ensure the policy meets local organisational or institutional requirements (such as with local finance and HR departments)

Discuss

If working with, or recruiting through, a young person's organisation or an existing young people's groups, find out what local processes are in place.

Where possible:

 discuss reward and recognition issues with the group's coordinator (or organisation) at the earliest opportunity be prepared to discuss the options, as some children and young people's organisations involve young people as volunteers, or may offer other forms of reward to acknowledge their contributions

Expenses

As with adults, children and young people (and their parents) should not be out of pocket for being actively involved in research. For many, ensuring that expenses are covered can be the determining factor in a young person's decision to be involved, as some may find it difficult to meet these costs otherwise, even temporarily. Where possible:

- cover expenses in advance direct to a service provider (such as to a travel company for rail tickets) to avoid young people having to claim reimbursement
- include the costs incurred by an accompanying adult or family member, or those of a support worker, when appropriate
- ensure that any reimbursed expenses are processed quickly and easily

Payment

Bearing in mind the issues raised in this NIHR guidance on payment for public involvement, and the things to consider above, you may want to offer the options below to children and young people when discussing payment and reward for involvement. Find out what they would prefer and discuss what may be possible within your budget, and within your organisational or funder guidance.

You may also want to review these options regularly to ensure your chosen option remains the right one for the children and young people with whom you are working.

You should ensure that any methods to be used, and any levels of reward that you decide upon, are appropriate for the ages of those involved.

High street vouchers

High street vouchers are often the preferred option for rewarding young people where they are under the age of 16 years old and will not be in receipt of benefits. Gift vouchers that are redeemable in a range of high street shops are usually the most popular, but vouchers can be obtained for cinemas, restaurants and other activities (for example, see high street vouchers).

- if this is the preferred option, ask the children and young people you are involving which vouchers they would like.
- be aware that some organisations and institutions prohibit the use of gift vouchers, so check with your host organisation before making any offer

Monetary payment

Although not all children and young people under the age of 16 years will want to be paid, or be able to do so because of organisational policy, the offer of monetary payment can be a factor in enabling some children and young people to become involved in research. Offering payment may also increase the diversity of those you involve and broaden the range of perspectives included, for example young people who are living independently or may have to take time off from work to be involved. Payment may be especially appropriate for involvement activities that require more time or responsibility, or where gift vouchers are not the preferred option. The methods of payment should be appropriate, as some children and young people may not have bank accounts into which money can be paid. The methods may need to be flexible so that individual's circumstances can be accommodated. Be mindful of the legal restrictions that limit the times and amount of hours that children and young people aged under 16 can undertake as paid activity (see the 'Participation Works' document 'How to remunerate and reward children and young people's involvement' for an explanation of the legal restrictions). Be aware that young people of working age over the age of 16 years may be in paid employment, or in receipt of welfare benefits. In these circumstances, the same considerations apply as for adults with regards to tax and benefits. The Benefits Advice Service is available to offer free, confidential advice for those involved with organisations or studies supported by NIHR.

Other forms of recognition

Children and young people's contribution to research should always be acknowledged and reported back to individuals and groups. Other examples of other ways that children and young people might be recognised for their contributions include:

- organising group meals out, or other social events (or sports activities)
- providing opportunities to learn new skills (such as designing and writing information, video production or website design)
- providing certificates that acknowledge the young person's contribution for educational portfolios. It is helpful to personalise these and
- provide details of the specific training or activity that the child or young person has been involved in
- offering references for employers, colleges and universities
- providing opportunities to share and celebrate success (for example, when reporting within an organisation or project, when publishing the research, or when presenting at conferences or other dissemination events)
- exploring formal accreditation for extended involvement in longer-term projects, for example through <u>ASDAN (Award</u>

Scheme Development and Accreditation Network) or the Open College Network in your area. This can be a very effective and appropriate way of acknowledging the work of individual young people. Time and cost implications, however, need to be explored before these opportunities are offered (NCB Guidelines, 2011)

More information

ASDAN (Award Scheme Development and Accreditation Network)

Children's Rights Alliance for England

National Children's Bureau's guidelines for research

Participation Works document 'How to remunerate and reward children and young people's involvement'

Further information

Examples of payment policies

NIHR Centre for Engagement and Dissemination recognition payments for public contributors

NIHR Central Commissioning Facility Reward and recognition for public contributors

Other guidance and resources

NIHR payment guidance for public contributors

NIHR Letter for Jobcentre Plus

NIHR Briefing Notes for Researchers

Learning for Involvement

NHS Research & Development Forum

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. NIHR staff cannot offer you advice on tax, National Insurance or welfare benefits issues; if in doubt you should seek appropriate expert advice. NIHR accepts no liability for decisions or actions taken as a result of its guidance. You are always recommended to take your own tax, finance or legal advice.

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 review in March 2022. If you have any suggestions for additional resources or amendments to this guide, please contact us ced@nihr.ac.uk

This version incorporates and updates content from several INVOLVE website pages, and the following previous guidance documents:

Mental Health Research Network and INVOLVE (2013) <u>Budgeting</u> <u>for involvement: Practical advice on budgeting for actively involving the public in research studies</u>, Mental Health Research Network, London and INVOLVE, Eastleigh. The authors of this resource were Julia Cartwright, Thomas Kabir and Lucy Simons. The project advisory group were: Suzy Bourke, Karen Burnell, Pam Carter, Jean Cooper Moran, Alison Ford, Ferhana Hashem, David Hindle, Jenny Newman, Chloe Sheppard, Natalie Simon, Christine Vial, Amander Wellings.

National Institute for Health Research Programmes Payment and Reimbursement Rates for Public Involvement (2009) This guidance was developed by INVOLVE in agreement with the Department of Health.

Reward and recognition for children and young people involved in research - things to consider NIHR would like to acknowledge the contribution of the London Generation R Young Persons Advisory Group (YPAG) at Great Ormond Street Hospital, who helped to shape the content of this guidance and Louca-Mai Brady for sharing her expertise during its development.

INVOLVE IR35 regulations: Statement - October 2017

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