

How to make sense of payments for Public Contribution



Written by Peter Bates

Contents

Introduction	2
Q1: What financial relationships can people have with the research organisation?	2
Q2: Who can become a Public Contributor?	3
Q3: How many different types of payment can I receive?	3
Q4: How are expenses viewed by other organisations?.....	3
Q5: Is any other income I receive taken into account by DWP?	4
Q6: Do I have to take the money?	4
Q7: What is the maximum amount I can receive before my benefits are affected?	5
Q8: Does getting involved mean I will be considered fit to work?	6
Q9: How many hours a week can I spend on my Public Contribution?.....	6
Q10: How are these payments treated by other organisations?	6
Q11: What if I take time off from my normal job?	8
Q12: How does the research organisation set the rates if offers?	8
Q13: Are vouchers a good alternative?	8
Q14: What happens if the research organisation cancels?	9
Q15: Can you give an example of payment rates?	9
Q16: Where can I get specialist advice?	10
Q17: Can you summarise the headlines?	10

Introduction

Members of the public have many opportunities to participate in the activities of organisations that deliver health research¹. This paper focuses on payments² made to Public Contributors who advise health research projects³. It identifies some questions and a few answers regarding these payments, but reader, beware! The field is technical, complex, sometimes inconsistent and fast changing, so this document should not be treated as authoritative, and readers should take care to verify the accuracy of its statements.

Q1: What financial relationships can people have with the research organisation?

It is helpful to think about several different types of potential financial relationship with the research organisation, as set out below⁴. The research organisation will be keen to ensure that each of these activities is properly valued in its own right and the boundaries between them are clear, so that, for example, contractors do not displace paid staff and reduce the number of jobs available.

- (i) **Research participants** submit their data to answer the questions raised by researchers. They give formal consent to be weighed, measured or interviewed. In these situations, expenses will be reimbursed (such as travel costs to the interview) and sometimes a payment or gift voucher is offered to participants to say thankyou or to compensate the person for the inconvenience⁵. These payments to research participants are discussed elsewhere⁶.
- (ii) In contrast, patients and the public may form a Lived Experience Advisory Panel or shape the whole direction of the research project in other ways. Researchers sometimes call this '**Patient and Public Involvement (PPI)**', while the Department of Work and Pensions (DWP)

¹ Research is one of a family of activities where these arrangements apply. The other members of the family are education, charities and involvement that is required by law such as the NHS or local authorities. See https://www.scie.org.uk/co-production/supporting/paying-people-who-receive-benefits?utm_sfid=0030f00002qhrd8aai&utm_role=&dm_i=4o5,62hg5,4g50a0,nthfm.

² Sometimes these are called PPI payments, participation payments or recognition payments. We simply refer to payments, as the term participation refers to those people who agree to submit data which is analysed and reported by the research team. From this perspective, a 'participation payment' is received in acknowledgement of being a research participant, rather than anything provided in acknowledgement of contributing to the creation or governance of the research project. The term 'recognition payment' may help to show that it is not a payment made as part of a contract of employment, but more of a recognition of inconvenience and goodwill in assisting the research project and advancing the public good.

³ This paper covers activities where Public Contributors are involved in coproducing the whole research project, perhaps by sitting on a Lived Experience Advisory Panel and advising academics. It does not cover payments for serving as a research participant (we used to call this being a research subject) and providing data for analysis. In passing, we note that the term 'participation' has this precise meaning in research, so we try to avoid using this term for coproduction activities.

⁴ The Recollect 2 research study began with a launch meeting for the Lived Experience Advisory Panel and all the other advisors and members of the academic team who would be delivering the project. A section of that meeting covered payment arrangements for reimbursement of expenses and similar topics, so everyone got the same messages at the same time about eligible claims, timing of submissions, travel booking and so on. Doing it like this levelled up the power dynamics that are always in play in these discussions.

⁵ See Health Research Authority (2014) *Payments and incentives in research*. Downloaded from <https://www.hra.nhs.uk/documents/274/hra-guidance-payments-incentives-research.pdf> on 3 August 2020.

⁶ See [How to set payment levels for research participants](#).

calls it ‘service user and carer involvement or coproduction’ and in this paper the people who get involved in this way are termed ‘Public Contributors’. This is the subject of this paper, which draws on specialist advice available⁷. The status of Public Contributors is ambiguous.

- (iii) **Employees** of the research organisation are formally appointed through processes approved by the Human Resources Department and receive wages⁸⁹, while **Contractors** deliver a specific piece of work and receive a payment according to the contract. An example of the latter in a university context would be some occasional lecturers who are engaged on a casual basis via a contract. Both employees and contractors may have lived experience of the condition that is being researched¹⁰, but these workers are not the subject of this paper.
- (iv) Some organisations engage **Volunteers** to undertake a range of other tasks. For example, a charity might run a research project while also engaging volunteers in its fundraising department and employing staff to manage its drop-in centre. In general, volunteering is confined to non-profit organisations such as charities and those whose aim is community benefit. Volunteers should receive reimbursement of their expenses, but they do not normally receive any other payment.

Q2: Who can become a Public Contributor?

The definition provided by the DWP is wide, and can include patients, service users, carers and members of the public – anyone that the research team wish to consult on this basis.

Q3: How many different types of payment can I receive?

There are two different types of payment: (i) reimbursement of receipted expenses; and (ii) payments for service user and carer involvement.

Q4: How are expenses viewed by other organisations?

The general principle is that people who are employed on a full-time basis need to pay for some of their own expenses, such as home-to-office travel costs. This principle has been set aside for service user and carer involvement activities, which for these purposes is not considered to be

⁷ See Scott J (2020) *ESA and getting paid for service user involvement*. Available from https://www.amazon.co.uk/getting-paid-service-user-involvement/dp/B08B33M1FP/ref=sr_1_1?dchild=1&keywords=Judy+Scott+ESA&qid=1596179945&sr=8-1. The Department of Work and Pensions defines ‘service user involvement’ at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/881138/admv4.pdf paragraph V4120.

⁸ For example, NIHR (2021) *Payment guidance for members of the public considering involvement in research* explains that Public Contributors are not employed (page 3), but payments received will be treated as earnings (page 2). See also Question 10 below.

⁹ The HMRC website declares that ‘An employee is someone who works under an employment contract’ but does not explain that caselaw from Industrial Tribunals reveals that contracts do not have to be written down. See <https://www.gov.uk/employment-status/employee>. This is further discussed in question 10 below.

¹⁰ See Bates P (last amended 2020) [*How to take your lived experience to work*](#)

paid, full-time employment. The DWP and HMRC¹¹ ignore any expenses that you receive when they are calculating your entitlement to means-tested benefits and your tax obligations. This means that you can receive full reimbursement of all receipted expenses without any problems, as long as you receive exact reimbursement of actual receipted expenses.

Q5: Is any other income I receive taken into account by DWP?

Benefits are paid by DWP on the basis of (i) contribution, such as to people who have paid national insurance contributions in the relevant tax year; (ii) condition, such as a disability-related payment or child benefit; and (iii) need, where the person has no other means of support. Payments to meet need are sometimes called ‘means-tested’ benefits or ‘income-related benefits’. In order to target public funds where they are most needed, savings and other assets are sometimes taken into account and wealthy people are disqualified. Particular arrangements are built into the system to encourage people to become self-reliant, rather than to remain on benefits, and to maintain targeting, rather than continue to make payments to people who have gained income or wealth. One of these techniques is often called a ‘taper’ and is applied by gradually reducing the amount of benefit paid as income from other places rises. The DWP always retain the right to ask for proof of savings or other sources of income, and to investigate before making payments to an individual, to ensure that public funds are used properly.

These general principles shape the basic architecture of the benefits system and payments made for service user involvement are then dealt with in the ways explained in the following paragraphs.

Q6: Do I have to take the money?

The general principle used by the DWP in calculating entitlement to means-tested benefits is that they should be the place of last resort. In other words, you should take money from any other source first and only ask the DWP to top up what you have not been able to find from elsewhere. This means that in general they can treat in-kind benefits (such as a free lunch at work) and income you could have received but have refused as ‘notional income’, and assess your entitlement on the basis that you took the money or converted the in-kind benefit into its cash value. However, since 2018, ‘payments for service user and carer involvement’ are treated as exceptions to this general rule and are not considered to be notional earnings. So you can refuse the offer, take a lower amount or transfer your entitlement to a charity of your choice without negatively impacting your entitlement to means-tested benefits¹².

¹¹ For HMRC advice, see <https://www.gov.uk/hmrc-internal-manuals/employment-income-manual/eim71105>. The rules are different in other countries, so, for example, in the USA, annual payments in greater than \$600 must be reported by the payer to the Internal Revenue Service and can impact eligibility for welfare benefits – see Largent EA, Heffernan KG, Joffe S, Lynch HF (2019) Paying Clinical Trial Participants: Legal Risks and Mitigation Strategies *Journal of Clinical Oncology*. Download from <http://ascopubs.org/doi/full/10.1200/JCO.19.00250>.

¹² This point is reinforced in NIHR (2021) *Payment guidance for researchers and professionals* page 4.

Q7: What is the maximum amount I can receive before my benefits are affected?

Any payment can prompt the DWP to conduct a review of eligibility¹³. There are numerous kinds of benefit, and each benefit has its own rules about how much may be earned before entitlement is lost. This means that simply receiving the benefit listed in the table below is not sufficient to determine that this is the applicable maximum amount in any one case, as other conditions may be applied that would change the outcome. The table is given simply to illustrate that the figures vary widely across the benefits system, and should not be taken as a definitive statement of entitlement. Further details are available¹⁴. Keep in mind the following things:

- Some benefits are entirely withdrawn once the threshold is reached, while others taper.
- Some benefits are considered as a 'qualifying benefit' for others, such as where people receiving a certain benefit also receive free school meals or prescriptions.
- The same increase in income from one source can trigger several tapers or cancellations of other benefits, creating a poverty trap where the extra income from one source results in a net loss of household income.
- The research organisation is not obliged to make any payment at all. Nor is it obliged to pay at the maximum level.
- As has been seen, the principle guiding the benefits system is that people should be as self-reliant and independent of the state as possible, so should only seek public funds from the DWP if they have exhausted other sources of income. Ideally, people should not be rejecting opportunities to work or refusing service user involvement payments in order to remain financially dependent on the state.

Table 1: A few examples of the sums that may be earned weekly before benefits are affected.

Name of the benefit	Max ¹⁵
Personal Independence Payment	No limit
Income-related Employment and Support Allowance	£140
Universal Credit (if you have responsibility for a child or have 'limited capability for work' and do not receive housing support) ¹⁶	£118
Carer's Allowance when paid alongside Carer's Premium	£20
Jobseeker's Allowance (in certain circumstances)	£5
Support for Mortgage Interest ¹⁷	£0
Council Tax reduction	Varies

¹³ '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 due to limited capacity for work.' NIHR (2021) *Payment guidance for researchers and professionals* page 17.

¹⁴ See NIHR (2021) *Payment guidance for researchers and professionals* Page 20 onwards.

¹⁵ These figures were accurate in July 2020.

¹⁶ The rate is set at £515 per calendar month.

¹⁷ People in receipt of income-related Employment and Support Allowance will be subject to a 100% taper. Every penny they receive as a payment for service user involvement will be deducted from their Support for Mortgage Interest (SMI) in the following month. The situation is even harsher for people in receipt of Universal Credit. Any earnings of any amount, including payments for service user involvement, will entirely disqualify them from entitlement to SMI for the following nine months.

Q8: Does getting involved mean I will be considered fit to work?

The DWP pays a number of allowances to people who are unable to work due to disability, but obviously withdraws these payments if the person is assessed as fit to work. To help disabled people make the transition back into employment, there is a provision called 'permitted work'¹⁸ that enables the person to do a small amount of work and receive payment for it without losing their disability-related benefits. Service user and carer involvement is an acceptable form of 'permitted work'. Two conditions must be met – (i) the work must be part time (see below) and (ii) an application to DWP must be made and accepted before the work starts, using a Permitted Work form (PW1¹⁹). Advice is available²⁰ on how to complete form PW1 so that the DWP understand that service user involvement does not demonstrate that you are fit to work.

Q9: How many hours a week can I spend on my Public Contribution?

NIHR advises that '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 a week.'²¹ Since the DWP rules treat payments for service user involvement in the same way as part-time earnings, then the same rule applies. A job is considered part time if it is less than 16 hours a week.

Q10: How are these payments treated by other organisations?

Department of Work and Pensions (DWP). In the past, some staff at the DWP may have considered these payments as 'occasional voluntary payments' but there is now a clear declaration that they are to be treated as if they were earnings from a part-time job, so payments are covered by the Permitted Work rules²². You have an obligation to seek permission from the DWP or JobCentre Plus before you start your Public Contributor role and to report on any income received as part of your 'service user involvement activities'.

Local Council. The Council decides how much Council Tax each household has to pay. Some Councils recognise Permitted Work arrangements and so ignore income received under these conditions or apply a taper so that payments received for service user involvement do increase the amount payable, but by a percentage.

Her Majesty's Revenue and Customs. HMRC treat service user involvement payments as if they were casual earning from a part-time job. HMRC also administer the National Minimum Wage provisions. Employees under the age of 25 are entitled to the hourly pay rate defined as the

¹⁸ Some older people may remember a similar system in the past that was called 'therapeutic earnings' and a subdivision that applied before 2017 called 'supported permitted work' that has now been removed.

¹⁹ The PW1 form can be downloaded from

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/877639/permitt-ed-work-form-pw1.pdf

²⁰ See Scott J (2020) op cit, pages 7-9.

²¹ NIHR (2021) *Payment guidance for members of the public considering involvement in research* page 9.

²² Since April 2017, the higher Permitted Work weekly earnings limit is allowed at all times and there is no one year time limit – see NIHR (2021) *Payment guidance for members of the public considering involvement in research* page 13.

National Minimum Wage, while, for older employees, this is termed the National Living Wage. Enforcement action is undertaken by the HMRC, who treat service user involvement payments in the same way as earnings and can prosecute employers who break the rules. This means that the research organisation that offers service user involvement payments must set them at or above the hourly rate set by the National Minimum Wage or National Living Wage. You have an obligation²³ to tell HMRC about any income you receive as part of your service user involvement activities.

Industrial Tribunal. It is not clear whether an Industrial Tribunal would decide that a contract of employment was in place and so insist that all the other rights granted to employees should apply, such as payment of holiday pay and sick pay and other employee protections, such as the working hours directive and so on. If these rights were deemed to be in place, they would be drawn from those pertaining to other casual workers. If payments are proportionate to attendance, productivity or output targets, are made regularly and there are grounds for grievance if targets are not met or payments are not made, they are more likely to be viewed as wages and part of a contract of employment, even if there is nothing written down²⁴.

Research Organisation. Some research organisations assert that the offer of these service user involvement payments does not form part of a full contract of employment and so no one has an

²³ An online tool helps inquirers to check their employment status for tax purposes – see <https://www.gov.uk/guidance/check-employment-status-for-tax>. Advice from HMRC dated 3 January 2018 indicated they would not routinely ask for details of small payments and reimbursement of expenses in respect of participation in research. See <https://www.gov.uk/hmrc-internal-manuals/employment-income-manual/eim71105>, but ‘Previous regulations that may have meant one-off payments could be ignored for tax and benefit purposes are no longer applicable.’ – NIHR (2021) *Payment guidance for researchers and professionals* page 8.

²⁴ The UK Government offer a definition of a worker at <https://www.gov.uk/employment-status/worker>. It is possible to inadvertently create a verbal contract of employment with the Public Contributor. This would occur if there was (i) a ‘consideration’ where the employer and the individual exchange something of material value, and (ii) an ‘intention’ which would occur when the employer and the person intend to enter into a legally binding contract at some future date. The formation of a contract of employment could disrupt welfare benefits payments and tax liabilities for the employee and place obligations for National Minimum Wage, holiday pay and other employment benefits on the employer. If the Public Contributor is engaged via an NHS Volunteer Centre rather than the Human Resources Department and if there is a volunteer agreement in place, then these things may help to show that the role is not employment. It is more likely to be considered volunteering if it does not specify hours if it reinforces the fact that the volunteer can choose not to turn up, if it does not confer employment rights, and if it avoids any hint of obligation by using words such as job or supervisor. See the following examples from caselaw: (i) in *Armitage v Relate* 1994, Armitage had to provide a minimum number of ‘volunteer’ hours each week, and pay back the costs of her training if she did not provide a total of 600 hours ‘voluntary’ counselling. If she met these requirements, she could become a paid or sessional worker after 3 years. She was deemed to be an employee as there was both consideration and intention. (ii) In *Chaudri v Migrant Advice Service* 1997, Chaudri received £25 per week ‘expenses’ even though it was known she walked to the volunteering office and went home for lunch. She was paid the same weekly amount when she was on holiday. This was a clear consideration, so she was deemed to be an employee. (iii) *Murray v Newham Citizen’s Advice Bureau* 2000. A written agreement was in place setting out (i) a commitment to a minimum time period; (ii) a time period by which basic training must be completed; (iii) a grievance and disciplinary process; expense and other commitments including a process for claiming holiday. No one factor provided the proof, but the overall pattern indicated that there was a contract of employment in place.

entitlement to such a payment or a formal basis for grievance if such a payment is not made. It is important to keep in mind that the Industrial Tribunal, mentioned above, will set aside the view of the research organisation and make its own independent judgement about whether there is a contract of employment and ensuing employment rights due to the Public Contributor.

Q11: What if I take time off from my normal job?

If you choose to take time off from work in order to participate, the research organisation is under no obligation to compensate you for the loss of earnings. Public bodies, such as health services, the local authority or universities, are unlikely to offer payments to people who are already in receipt of a full-time salary from public funds²⁵. To support the health benefits of maintaining a work/life balance, research organisations should not encourage you to take up substantial responsibilities as a Public Contributor in addition to working full time.

Q12: How does the research organisation set the rates if offers?

There are a range of opportunities for involvement both within and beyond the engaging organisation. In a similar way to the market where different retailers offer different prices for the same product, participation activities may attract different payment levels. Organisations should endeavour to clearly label each item, so that potential participants know what they may receive before embarking on the activity.

Even within a single research organisation, payments may vary from one activity to another, depending on funding available and other factors. Where a member of the public is involved in more than one activity, the rate may vary for similar activities.

Wherever possible, the engaging organisation will take note of the examples provided by the National Institute for Health Research and other guidance from the Department of Health and elsewhere. A broad principle is to offer payment at a level that is comparable with that received by other members of the research team (such as salaried staff) to acknowledge the value placed on public involvement²⁶. Budget restrictions may reduce the availability of payments.

Q13: Are vouchers a good alternative?

While some organisations prefer to offer a voucher or payment in kind, this is rejected for the following reasons. First, it is less versatile than money for the person. Second, the means-tested welfare benefit system has power to treat a voucher or other 'in kind' item as if it were cash, so there are no benefits to the recipient. Third, for some people a voucher feels paternalistic and reinforces the social distance between staff and Public Contributors (unless the payroll department pays its employees in vouchers rather than money). Fourth, people who use illicit drugs have been given vouchers in the past to try and prevent them using the payment to buy drugs, despite the evidence showing that paying cash does not lead to the purchase of drugs or

²⁵ See National Institute of Health Research Central Commissioning Facility (Dec 2017) [Reward and recognition for public contributors: A guide to the payment of fees and expenses](#)

²⁶ See <http://www.invo.org.uk/good-practice-for-payment-and-recognition-things-to-consider/>

relapse. The UK Health Research Authority has declared that, unless there is clear evidence to the contrary about the specific recipient, research participants should be treated as autonomous persons and not treated differently to others²⁷, so there is no reason to apply a more restrictive rule to Public Contributors. Current finance and audit systems usually require payments to be made via bank transfer rather than in cash. However, vouchers have been offered to children and young people who coproduce research and NIHR advise that ‘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.’²⁸

Q14: What happens if the research organisation cancels?

If a planned activity is cancelled by the research organisation with less than 48-hour notice, Public Contributors will be able to claim a participation payment as if it had taken place. If longer warning is given, no payment will be made²⁹.

Q15: Can you give an example of payment rates?

The following table gives the scale of recognition payments announced by the Centre for Engagement and Dissemination at the National Institute of Health Research in June 2020³⁰. There is no obligation to match these rates, and further information on payment levels is available in [How to build an organising logic for structuring recognition payments for Public Contributors](#).

Activity	Payment	Example
Involvement in a task or activity such as reading and commenting on an abstract which equates to less than half an hour.	£12.50	Review papers for the development of NIHR Evidence Alerts.
Involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less.	£25	Participate in a focus group to provide feedback on a proposal.
Involvement in a task or activity likely to require some preparation and which equates to approximately two hours of activity.	£50	Teleconference with related papers to read or review a few short documents.

²⁷ HRA (2014) op cit, paras 6.1 and 6.2.

²⁸ NIHR (2021) *Payment guidance for researchers and professionals* page 23.

²⁹ This arrangement was established during the Recollect2 project and seems eminently sensible..

³⁰ See <https://www.nihr.ac.uk/documents/centre-for-engagement-and-dissemination-recognition-payments-for-public-contributors/24979>

Activity	Payment	Example
Involvement in a task or activity where preparation is required and which equates to approximately half a day's activity.	£75	Participate in a meeting to interview a small number of candidates who have applied to join a committee or panel, participate in a focus group, or deliver training.
Involvement in one-off, all-day meetings	£150	Attend a committee or panel meeting for the first time as an observer prior to becoming an active public member of a committee/panel.
Involvement in all-day meetings that require substantial preparation and / or responsibilities at the meeting.	£300	Participate as a CED public member at a stakeholder meeting.

Q16: Where can I get specialist advice?

Bedford Citizens Advice Bureau offers [specialist advice](#) on the relationship between payments and welfare benefits to anyone involved in research funded by the National Institute of Health Research³¹. To access this service, you need to provide a code for the NIHR-funded organisations that you are involved with and this is available from the NIHR Centre for Engagement and Dissemination. Some other organisations also subscribe to this service.

Q17: Can you summarise the headlines?

Responsibility for notifying agencies such as Jobcentre Plus, the Department of Work and Pensions or Her Majesty's Revenue and Customs lies with the recipient. Some welfare benefit payments are means-tested, and so reduce as the recipient's income from other sources rises. Such arrangements usually work on a principle of 'last resort', so people are expected to accept income from other sources before they ask for a 'top-up' from the benefits system. In other cases, receiving any funds from another source may trigger a review or disqualify the person from their entire benefits entitlement. We strongly advise individuals to seek advice on their personal circumstances before accepting payment.

³¹ See Scott J (11/6/2020) [ESA and getting paid for service user involvement](#). Also NIHR (2021) *Payment guidance for members of the public considering involvement in research* page 12.