

Going cheap on expenses



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Introduction

The National Institute for Health and Care Research insists that the research it funds is coproduced with people who have lived experience, although practice falls short¹. Opportunities to participate are advertised to the public on the [People in Research website](#).

Some Public Contributors need support from others to enable them to participate or to free them from their caring responsibilities so that they can give time to the research study. However, many adverts on the *People in Research* website assume that if the task is online, no expenses will be incurred. This excludes participants and deprives the research teams of their input². *People in Research* has advised³ that they encourage research teams to follow the [NIHR guidance](#) on reimbursement of expenses, which clearly states that 'It is expected that (receipted) out-of-pocket expenses are always reimbursed'⁴. Such expenses may include the cost of remote/home working, carers and personal assistants, but it appears that *People in Research* has no role in monitoring compliance or challenging alternative practices.

In the text below, I have analysed a sample of these adverts. Fewer than half of involvement opportunities offered any reimbursement of expenses and fewer than one in ten explicitly offered to reimburse the costs of carers or personal assistants. The offer of expenses reimbursement is so patchy and inconsistent that the ethics underpinning best practice⁵ are obscured, guidance is routinely ignored by research teams, unintended and potentially harmful consequences arise in the market, and movement towards compliance is indiscernible. In these ways, the offer of expenses reimbursement matches arrangements for recognition payments to Public Contributors⁶ and payments to research participants⁷.

Dataset

Adverts on the *People in Research* website carry a closing date and expired items are removed from public view, so data must be collected when it is live⁸. On 23 December 2024, 33 adverts were open, and subsequent entries made up to the date shown in this page's footnote have been tracked to enlarge the dataset to a total of 42 adverts. All adverts were reviewed whether the involvement opportunity was online or in person. At the point when an advert was added to this dataset, the contact person for the study was emailed to inform them of the online link to this report and invite their comment.

As this is a survey of the adverts found on the *People in Research* website, it does not necessarily represent the actual offer made by teams. Some text boxes in the advert proforma are constrained by a character limit (but this does not apply to the payment and expenses fields) and only one document may be uploaded to accompany the advert, so in at least one case reported here, details of the payment regime was sacrificed in favour of a role profile. A future study might ask study teams

to provide full details prior to analysis, but this brief investigation explores the message communicated by the *People in Research* website since this will act as an early filter in the recruitment process.

Findings are set out below.

Reimbursement of Expenses

The following table summarises the findings of the present survey. It shows that 38% of adverts offered reimbursement of expenses, which is fewer than the 51% found in a sample of 37 adverts reviewed in 2022⁹, suggesting a deterioration in practice.

Offered reimbursement of...	Number	Percent
Expenses	16	38%
A contribution towards the cost of internet access	5	12%
Travel costs	5	12%
Subsistence costs	3	7%
Carer's costs	2	5%

At least one research institution invited interested Public Contributors to contact them for additional information regarding expenses.

It can be difficult to decode the advert, since some use ambiguous terms like 'workshop' (which might be online or in person) and some permit the involvement activity to be completed at home but do not indicate whether there is an in-person offer too. Meetings can take a hybrid form with some members choosing to connect onscreen while others consider meeting in person is the best way to participate. Reimbursing travel costs empowers people to choose. Best practice in relation to travel costs includes booking tickets in advance wherever possible and sending them to the Public Contributor, so that the financial outlay is made by the research institution rather than the individual traveller. Some disabled persons are unable to use public transport so need a taxi. Some of the adverts offered 'reasonable travel expenses', perhaps with the qualifier 'if agreed in advance'.

Carer's costs may be incurred by disabled persons, so the principle of 'anticipatory reasonable adjustments' comes into force, obliging the research team to set up these arrangements in advance so that the offer is normalised, timely and easily accessible¹⁰. It is unreasonable to expect disabled persons to plead for a special favour each time they require an adjustment to be made.

Reimbursement of expenses usually involves a bank transfer, so research institutions will obtain the bank details of Public Contributors and pay the exact sum matching the reimbursement value.

Recognition payments

Whilst the main purpose of this exercise is to examine the offer of expenses reimbursement, it is worthwhile to also capture evidence on recognition payments from the adverts.

Recognition payments are not wages, but sometimes declare an hourly rate, which increases the chance that this will be perceived by an Industrial Tribunal as pay for work done under a verbal or

written contract of employment. Yet, unlike wages payments, some research institutions decline to publish payment levels in the advert. The following explanations may be offered in justification of this practice:

- Perhaps the research team is only interested in hearing from people who are comfortably off.
- Perhaps they imagine that anyone who needs to check the details of remuneration is greedy rather than altruistic and is therefore an unreliable witness who should be excluded.
- Declaring the level of payment may increase the number of people who lie about their health condition as part of a fraudulent claim. Official guidance¹¹ has acknowledged that some research teams may respond by leaving details of the involvement incentive out of social media communications. However, there is limited evidence¹² to indicate that this is an effective mitigation and so it is not actively recommended. People lie in other circumstances too¹³, including academics¹⁴, but leaving information about pay grades off job adverts would not be an acceptable safeguard against ineligible applicants.
- Innocent explanations are possible too – such as where the team want to respond creatively to a wide range of possible circumstances rather than provide a single, superficial answer.

A few adverts offered payments ‘in line with NIHR rates’ but did not specify what that meant. This assumes that readers will be familiar with them or know where to find the information already, which is an odd assumption to make on a website intended to serve the public. The preamble on the website could include a link to the NIHR rates.

The ethics, benefits and potential harms of giving the Public Contributor a shopping voucher rather than the money are discussed elsewhere¹⁵. In summary, there is limited evidence in support of this practice, although we might guess that the different format reinforces the distinction between the reimbursement of expenses made via bank transfer and the recognition payment made via a voucher¹⁶. Secondly, while it offers an opportunity to people who have not got a bank account, such as some homeless people and some asylum seekers, it also provides an opportunity for ineligible persons who wish to avoid providing their bank details and other identifiable information about themselves¹⁷. Here, we simply record the number of adverts which state that recognition payments will be offered via a voucher. It is notable that many adverts gave no information about the mode of payment, so the number of number of studies that use vouchers may be much higher than shown here.

Lotteries or prize draws are another means of awarding recognition and distinguishing the payment from routine wages for designated work. Evidence on the impact of financial incentives in general and lotteries in particular on behaviour change is complex, with one study¹⁸ finding that the offer of a large lottery payment discouraged participation. It is likely that both vouchers and lotteries are adopted for the benefit of the organisation rather than the Public Contributor.

Of those who specified a sum, the median was £30. Several adverts did not indicate the time required for the task or the total number of payments that were to be made. It is even more challenging when the advert does not make clear what Public Contributors are being asked to do. In one example from this dataset it was uncertain whether the people were being recruited as study participants or members of the study delivery team, whether meetings would be in person or online or whether the agenda comprised editing patient-facing information, advising on how to recruit minoritized participants or something else. It would appear that staff at *People in Research* neither coach contributors nor vet or edit contributions.

For these reasons, it was impossible to discern which role was most financially advantageous. The payment level is sometimes set by the research funder and rates vary from one funder to another¹⁹, so these inequalities between studies are baked in and cannot be revised by the individual study team.

The proportion of studies in the sample that offered no recognition payment at all (33%) was below the 59% found in my sample from 2022²⁰, suggesting improvement has taken place over time.

Studies that	Number	Percent
Offered a recognition payment but did not give its value	5	12%
Paid with a voucher	5	12%
Specified an hourly rate	14	33%
Prize draw or lottery instead of a payment	0	0%
Did not offer a recognition payment.	14	33%

A dozen justifications for denying payments to research participants are discussed elsewhere²¹ and all of them may also play out in the context of research coproduction. For example, one study in this sample claimed that payment was not being offered and expenses could not be reimbursed since it was a student (PhD) project. It is well-nigh impossible for an individual PhD student to acquire the funding they need to offer payments and reimbursement of expenses after the doctoral research is already set up. Instead, the responsibility lies with those who create the opportunity - who should factor in these costs at the same time as they set all other operating costs for the student – pay, travel expenses, computer equipment and costs of coproduction with Public Contributors.

Conclusion

The UK National Institute of Health and Care Research has tried to adopt a practical and ethical approach to the coproduction of research with Public Contributors. Meanwhile, its *People in Research* website advertises all participation opportunities, irrespective of the arrangements for individual studies. Adverts commonly exclude Public Contributors who face financial hardship by failing to offer a contribution towards internet costs and also neglect those who draw on carers by failing to offer reimbursement of carer costs. Overlooking these citizens will exacerbate broader inequalities in access to healthcare, research and coproduction.

How this paper is being written

The investigation that generated this paper is driven by simple curiosity. The work is unfunded and is conducted as a piece of citizen science rather than under the control of any organisation. Accountability is achieved by following the *How to write in public* framework²². I am grateful to the people²³ who have contributed to this evolving resource. Please send me your suggestions for further improvements.

¹ [The 37 Test – Peter Bates.](#)

² An especially poignant example from this sample relates to stroke research. One study is intended to ‘increase the diversity of patient and public involvement and engagement in shaping stroke research across the East of England for those less likely to be consulted about shaping stroke research priorities and implementation.’ This study is seeking Public Contributors but offers no recognition payment or reimbursement of expenses. See [The Anglian Stroke Partnership for Increasing Research Engagement \(ASPIRE\) Programme - People in Research.](#)

³ Personal communication, 23/12/2024: “People in Research, as a platform, is not involved in those decisions that researchers make and NIHR’s input comes in the form of [Payment guidance for researchers and professionals](#), in which we do recommend that individual’s circumstances are taken into consideration when payment decisions are made. Sometimes researchers, at the point where they advertise their involvement opportunity, have not figured out all of the parameters of what they can offer for payment, and side on caution, opting to avoid putting in writing something they are not yet certain they can honour.”

⁴ Annex 2 of [Payment for public involvement in health and care research: a guide for organisations on employment status and tax - Health Research Authority.](#)

⁵ NIHR Applied Research Collaboration North East and North Cumbria (July 2024) *Ethical Practice Guidelines for Public Involvement and Community Engagement*. Available at [Ethical-Practice-Guidelines-FINAL-July-24.pdf](#).

⁶ See Bates P (2021) [How to build an organising logic for structuring recognition payments for Public Contributors](#)

⁷ Bates P (2023) *How to set payment levels for research participants*. Available at <https://peterbates.org.uk/wp-content/uploads/2022/08/How-to-set-payment-levels-for-research-participants.pdf>. See also Winter DT, Geiger B, Day CA. A comment on participant reimbursement within Australian drug and alcohol research. *Drug and Alcohol Review*. 2022 Sep;41(6):1484.

⁸ *People in Research* may retain the expired adverts and so could perhaps analyse a much larger dataset, but there is no evidence on the website that they have done so. Since [Log In - People in Research](#) declares “The data we collect here is collected in the public interest” a Freedom of Information request for the 2024 dataset of adverts was submitted on 05/01/2025.

⁹ Recent years has seen an increase in online working, so it may be that the mistaken assumption that online contribution is always free of expense has led to fewer expenses offers being made.

¹⁰ The Equality Act 2010 requires organisations to make reasonable adjustments before people ask for them.

¹¹ NIHR (2024) [Guidance for Recognising and Addressing Ineligible Public Involvement in Health and Care research.](#)

¹² Fenandez Lynch and colleagues found no association between the size of the financial incentive being offered for participation in research and the number of fraudulent participants – see Fernandez Lynch H, Joffe S, Thirumurthy H, Xie D, Largent EA (2019) Association Between Financial Incentives and Participant Deception About Study Eligibility. *JAMA Net Open* 2(1):e187355. In contrast, the meta-analysis by Comachio et al found that, across a number of studies, increasing the incentive did increase the number of people willing to falsely claim eligibility – see Comachio J, Poulsen A, Bamgboje-Ayodele A, Tan A, Ayre J, Raeside R, Roy R, O’Hagan E. Identifying and counteracting fraudulent responses in online recruitment for health research: a scoping review. *BMJ Evidence-Based Medicine*. 2024 Dec 21.

¹³ Wang Y. (2024) Do participants lie? Imposter participants in online qualitative research. *Qualitative Research Journal*. Sep 30. There is also evidence to show that not all citizens are truthful in Kass et al (2007) where ten percent of participants in their sample admitted to dual enrolment in Phase 1 clinical trials, despite the clear prohibition within the trial management mechanism (known as TOPS) due to the risks of adverse drug interactions – see Kass NE, Myers R, Fuchs EJ, Carson KA, Flexner C. (2007) Balancing justice and autonomy in clinical research with healthy volunteers. *Clinical Pharmacology & Therapeutics*; 82:219–227.

¹⁴ See [Retraction Watch – Tracking retractions as a window into the scientific process](#). Also Fanelli’s analysis of 32 surveys found 2% of scientists admitted that they had fabricated, falsified or modified data or results at least once and up to 33% admitted other questionable research practices. See Fanelli D (2009) How Many Scientists Fabricate and Falsify Research? A Systematic Review and Meta-Analysis of Survey Data. *PLoS ONE* 4(5): e5738. <https://doi.org/10.1371/journal.pone>. Similarly, Phillips et al found that more than half of CVs submitted by academics applying for a job included one or more publications that were unverifiable or inaccurate in a self-promoting way. See Phillips T, Saunders RK, Cossman J, Heitman E. Assessing Trustworthiness in Research: A Pilot Study on CV Verification. *Journal of Empirical Research on Human Research Ethics*. 2019;14(4):353-364.

¹⁵ The use and misuse of vouchers is discussed in section 3.1 of Bates P (2023) *How to set payment levels for research participants*. Available at <https://peterbates.org.uk/wp-content/uploads/2022/08/How-to-set-payment-levels-for-research-participants.pdf>.

¹⁶ Some employers give their staff a shopping voucher from time to time. The voucher may be an attempt to signal that the employee has no contractual right to receive it.

¹⁷ NIHR (2024) [Guidance for Recognising and Addressing Ineligible Public Involvement in Health and Care research](#).

¹⁸ Judah et al assigned patients randomly to three arms of a study – invitation letter, £10 payment or a prize draw to win £1000. Those receiving a simple letter were most likely to attend a screening appointment, and those entered into the prize draw were least likely to turn up. Judah G, Darzi A, Vlaev I, Gunn L, King D, King D, Valabhji J, Bicknell C. Financial disincentives? A three-armed randomised controlled trial of the effect of financial incentives in Diabetic Eye Assessment by Screening (IDEAS) trial. *British Journal of Ophthalmology*. 2018 Aug 1;102(8):1014-20. Note that payment may be offered for a variety of motives, so paying may be the right thing to do, even if it does not increase recruitment.

¹⁹ See Table 1 of Bates P (2021) [How to build an organising logic for structuring recognition payments for Public Contributors](#)

²⁰ See [The 37 Test – Peter Bates](#).

²¹ See section 2.1 of Bates P (2023) *How to set payment levels for research participants*. Available at <https://peterbates.org.uk/wp-content/uploads/2022/08/How-to-set-payment-levels-for-research-participants.pdf>.

²² Bates P (2024) [How-to-write-in-public.pdf \(peterbates.org.uk\)](#).

²³ Feedback was gratefully received from Sanjana Choudhury, Barbara Molony-Oates, Rhianna Parsons and Tom Withers. All remaining errors and omissions are the sole responsibility of the author. The information is provided in good faith and so readers engage with the contents at their own risk and undertake not to hold the author liable for any injury, loss, or damage arising through reading or acting on its contents.