

Developing a Regional Approach to Remuneration for Public Involvement in Health and Care Research

Introduction

There is a long-standing commitment to ensure that there is reward and recognition for public involvement in health and care research and most funders (NIHR, HRA etc.) now expect remuneration to be costed into research proposals. This is NOT being a research participant (taking part in an interview, focus group or completing a survey, trial etc.) this is for being a member of the research team or, what is known as a PPI (patient, public involvement) group. Remuneration for being what is known as a 'public contributor' (service user, expert by experience, lay member) means financial recognition for a public contributors' time, skills and expertise. In addition all out of pocket expenses should be covered in full.

A North East North Cumbria Remuneration Working Group has been meeting since 2021 to share good practice, address challenges and to work towards developing a regional approach. This group has involved representatives from each of the regional university finance teams as well as NIHR research infrastructure organisations, public contributors and has been chaired by the Director of the NIHR ARC (Applied Research Collaboration). This summary has been agreed and produced by the working group (see below for membership).

Minimum Standards

- The UK Standards for Public Involvement should underpin all remuneration policies and procedures [UK Standards for Public Involvement](#)
- Remuneration should be simple, straightforward and easily understood
- Payments should be made quickly and efficiently
- Public contributors should not be worse off financially as a result of being involved in research
- Actual expenses should be paid up front wherever possible
- Public contributors should not encounter additional barriers to involvement, including financial or bureaucratic barriers
- There should be a choice of different ways of recognising and rewarding involvement (other than financial reward) and should be readily available

In March 2024 the NIHR renewed its commitment to Public Partnerships and stated clearly its intention with regard to remuneration. [Renewing the NIHR's commitment to public partnerships | NIHR](#)

Make systems of reward and recognition for the involvement of people and communities more equitable, efficient and consistent across NIHR coordinating centres, infrastructure and research.

National Guidance

The NIHR has developed national guidance on Payment for Public Involvement in Health and Care Research (August 2024).

[Payment guidance for researchers and professionals | NIHR](#)

There is also guidance to help organisations (Universities, NHS Trusts etc.) decide on the most appropriate remuneration approach including issues around employment status & the impact on tax or welfare benefits, including guidance for organisation to determine tax and employment status (April 2023).

[Payment for public involvement in health and care research: a guide for organisations on employment status and tax | NIHR](#)

Remuneration methods

There are many types of public involvement activities, and public contributors can be involved in all stages of the research cycle. There is no 'one size fits all' approach to public involvement, nor indeed recognition and reward. Consequently, a flexible approach to remuneration is required and tailored support is needed to meet specific circumstances. Involvement in research activities is NOT employment (does not include employment rights) and is also NOT volunteering (requiring DBS clearance, induction training).

Some individuals may have short term and infrequent involvement with one research study, whilst others may be involved in numerous studies across different institutions. It is important to make distinctions between these different levels of involvement.

The NIHR guidance offers suggested amounts for different activities (involvement in research steering groups, PPI groups, reading/reviewing documents, taking part in workshops, seminars or training, and being a co-applicant). Each institution will have its own policies and procedures for remuneration as well as their own payment amounts and processes.

These may include:

- Reimbursing expenses (travel, accommodation, subsistence, childcare, personal assistant etc.) at cost. Some institutions will arrange travel/accommodation etc. on behalf of public contributors so that they are not out of pocket if they are significant amounts
- Payments direct into an authorised personal bank account via BACS
- Shopping vouchers
- In-kind support (offering training, skills sharing etc.)
- Certificates and references

- Access to facilities such as a library or spaces
- Access to training opportunities
- Honorary appointment
- Payment to a VCSE organisation that has facilitated public involvement
- Individuals signing up as sessional workers/volunteers
- Remote/home working costs

It is important to note that both HMRC and DWP may consider **any** payment (including shopping vouchers) as 'income' and this may have a consequence for anyone who is a taxpayer and/or welfare benefits claimant. It is really important that public contributors are made aware of any implications and will need to check out their own circumstances. Each institution will make clear to public contributors that they are responsible for notifying the HMRC or Job Centre Plus. Most institutions will not deduct income tax or national insurance at source and will expect individuals to declare the amounts that they receive as remuneration and as reimbursed expenses. It is important to make sure individual public contributors are aware of this requirement and are supported to declare payments of both expenses and for their time.

Specific advice is outlined in the NIHR National Guidance and there is a sample letter for individuals in receipt of welfare benefits to present to their Job Centre/Job Coach. [Welfare Benefits Jobcentre Letter | NIHR](#)

Remuneration process

Each circumstance will be different and the researcher/PPI Lead will need to agree in advance what the remuneration policy is within their own institution and what the claims process is for each individual.

NIHR has produced guidance for public contributors to help them to navigate the system (August 2024). [Payment guidance for members of the public considering involvement in research | NIHR](#)

This guidance includes access to a free confidential personalised Benefits Advice Service that can be accessed by any public contributor. There is a specific section in the guidance for people who are in receipt of Welfare Benefits (last updated July 2024). [Payment guidance for researchers and professionals | NIHR](#)

Payments for people with 'no recourse to public funds'

There are some specific circumstances which have proved problematic and in which payments have been withheld, this included people designated as having 'no recourse to public funds' specifically asylum seekers and refugees. We have taken advice:

Our understanding of the DWP documentation is that "no recourse to public funds" is a condition placed on visa holders meaning they are not eligible for benefits, homelessness assistance and social housing. PPI payments do not fall within the official definition of public funds and it would therefore seem that asylum seekers or refugees who are subject to "no recourse to public funds" may still receive PPI payments. (I would add that in my own

view, since universities are in any case private institutions there should be no question of any payments made by them counting as public funds). The Refugee Council agrees with this interpretation, saying that "no recourse to public funds" is widely misunderstood. They say that it can actually be "safer" for these people to receive PPI payments, as there are no benefits to be affected.

Jeremy Taylor, NIHR Director for Public Voice, NIHR Coordinating Centre. August 2024

Conclusion

Each institution will have its own systems and processes and, although steered by the NIHR national payments guidance this is not mandatory. Discussions have taken place at a national level between NIHR Centre for Engagement & Dissemination, HMRC and the British Universities Finance Directors Group. Discussions are also underway at a national level with the DWP.

The Regional remuneration working Group hope that this document provides some useful information in an attempt to make the process more manageable for everyone.

Felicity Shenton

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Regional Remuneration Working Group Membership

Chair: Professor Eileen Kaner, ARC Director & Professor of Public Health, Newcastle University

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