

# Thinking about Payments – Technical Archive

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This is a technical paper that sets out the context surrounding decisions about reimbursement and remuneration for patient and public involvement in health research. It was written by Peter Bates, PPI lead at CLAHRC NDL to review current arrangements and draw out recommendations for local action. It may also provide the foundation for shorter and more accessible documents, such as (i) costed submissions to funding bodies, (ii) proposals for organisational change, (iii) information for PPI representatives. Most of this document was written in 2012, it was last amended on 3 August 2014, and it remains a working document and so parts of it may need further checking for accuracy or the addition of further information. To offer improvements or corrections, or to discuss the issues it describes, please contact [peter.bates@nottingham.ac.uk](mailto:peter.bates@nottingham.ac.uk) or tel 07710 439 677.

## Introduction – why a review is needed

Current arrangements at CLAHRC NDL<sup>1</sup> for making reimbursements and payments<sup>2</sup> to patients and the public<sup>3</sup> who get involved in co-producing health research are in need of review for the following three main reasons:

### 1. Looking back – the current system is not fit for purpose

CLAHRC NDL's host organisation, Nottinghamshire Healthcare NHS Trust (NHC) has a policy that is no longer fit for purpose and is incongruent with the advice from INVOLVE<sup>4</sup>. Recent requests for reimbursement or payment have come from people in a variety of circumstances not previously encountered or covered in the

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<sup>1</sup> [CLAHRC NDL](#) (Collaboration for Leadership in Applied Health Research and Care – Nottinghamshire, Derbyshire and Lincolnshire) is a health research collaboration between the University of Nottingham and NHS organisations across Nottinghamshire, Derbyshire and Lincolnshire. It is one of nine CLAHRCs in England that are funded by the National Institute for Health Research until September 2013.

<sup>2</sup> In this paper, I use the phrase 'reimbursement and payments' to mean any money that changes hands between CLAHRC NDL and PPI representatives. The choice of this phrase avoids the term 'remuneration' that might imply a contract of employment, or 'reward' that might imply a transaction or obligation rather than a free gift. These matters are discussed elsewhere in the paper rather than being bundled into a single phrase.

<sup>3</sup> The catch-all phrase 'patients and the public' is in common use in health research. It is understood here to mean people using health or social care services, their relatives and friends, other individuals and groups with an interest in the quality of care that is provided, and the wider public that helps to pay for it. The key issue here is that it is a 'lay' or external viewpoint that adds value to the professional clinical or academic team.

<sup>4</sup> INVOLVE is part of the National Institute for Health Research and has responsibility for promoting patient and public involvement in research.

policy, prompting a search for guiding principles. Attempts within NHC to update this policy over the past three years have stalled. An updated policy statement would guide decision making and protect both employees and people receiving these monies.

## 2. Looking round – a ready-made approach is not available from others

Other organisations that might have served as a guide adopt widely divergent practices. For example, attending a meeting at NHC attracts expenses only, while it attracts expenses plus a participation payment of £80 at the Mental Health Research Network Coordinating Centre. A similar degree of divergence is shown in payments to the PPI representative on the Board of different CLAHRCs. Representatives receive £25 at PenCLAHRC and £150 at Cambridge and Peterborough.

We might also consider whether published analysis and guidance meets our needs. Unfortunately, existing publications offer a partial view, such as:

- a discussion<sup>5</sup> of the ethics of donation and reward, which lacks detail on actual remuneration rates;
- a model procedure<sup>6</sup> for navigating the benefits and taxation system, which does not address the issues arising for people who are not in receipt of state benefits; and
- an historical account<sup>7</sup> of the challenges of creating a payments system for engagement, which lacks guidance on participation as a research subject.

## 3. Looking forward – there is a need to prepare for change

New organisations and research proposals under development will require a costed PPI component<sup>8</sup>, as well as practical approaches to implementation that learn the lessons from CLAHRC ND. Such new arrangements include the Academic Health Sciences Network and Healthcare Technology Cooperative. Part of the legacy of CLAHRC ND is to develop ethical and effective practices

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<sup>5</sup> Nuffield Council on Bioethics (2011) *Human bodies: donation for medicine and research*.

<sup>6</sup> INVOLVE (2010) *INVOLVE policy on payments and expenses for members of the public including INVOLVE group members* Eastleigh: INVOLVE. INVOLVE are also so focused on the coproduction of research that they appear to ignore the obvious links with payments for participation in research. While these two issues are very different for research managers, some citizens will see little difference between giving up their time to be interviewed as a research subject and giving up their time to share their experiences as a member of a study advisory group. The two activities become different when intrusive medical procedures are involved, but a comprehensive exploration of the ethics of payment should cover both kinds of activity.

<sup>7</sup> Rickard W and Purtell R (2011) Finding a way to pay in the UK: methods and mechanisms for paying service users involved in research *Disability & Society* Vol. 26, No. 1, January 2011, 33–48.

<sup>8</sup> INVOLVE have created a PPI cost calculator.

for rapid adoption by the new organisations. Furthermore, welfare reform<sup>9</sup> will affect some PPI representatives, and so it is important to be as clear as possible about arrangements for reimbursement and reward in advance of these changes. It can be difficult to obtain clear advice from the Department of Work and Pensions and HMRC<sup>10</sup>, although specialist advice is available<sup>11</sup>.

## What this paper will cover

The next section of this document offers some overarching principles and this is followed by an attempt to disentangle the ethical dilemmas involved in reimbursement and payments. I then attempt to apply this analysis to real life situations in order to generate practical working arrangements for daily use. This clarification of guiding principles should also help when the environment changes or novel situations arise.

Each section concludes with a number of recommendations that arise from the preceding argument, beginning with the items below. These recommendations are precise in terms of what might be done to address the issues that have been identified in the paper, but are insufficient to form the substance of specific proposals that should be put to the CLAHRC NDL Board (or any other Board) for immediate action. A proposal for the Board would need to review the strategic priority of each recommendation against other agendas, the place of that recommendation in relation to the others made in this paper, the amount of effort required in relation to the benefit accrued from the change, and the resources needed to implement the change. It will be quickly seen that this list of recommendations is far too long and would need pruning back to a manageable size. Nevertheless, the discipline of

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<sup>9</sup> Universal Credit is currently being piloted and will be rolled out to everyone in England during 2013. The rules about volunteering will change – see [here](#) for more information and [here](#) for DWP guidance. DWP wants to make sure that everyone affected by Universal Credit has access to the support they need. Work is taking place with partners including the Money Advice Service and Citizens Advice Bureau over the next few months to develop and refine the approach and processes. Partnership communications will start from January 2013 in the North West of England to support preparations for Universal Credit Pathfinder in April 2013. See [DWP - volunteering while getting benefis.pdf](#) and [DWP - Volunteering while looking for work](#) for more information.

<sup>10</sup> This is largely because the issues are complex and DWP and HMRC find the issues disproportionate, as they affect a small number of people and involve small amounts of money but take a great deal of time and effort to resolve.

<sup>11</sup> The Involvement Helpline is run by Milton Keynes Citizens Advice Bureau on behalf of the Social Care Institute for Excellence, the Care Quality Commission and Skills for Care. Advisors are trained in benefit conditions for involvement. [Steve.naylor@mkcab.org.uk](mailto:Steve.naylor@mkcab.org.uk) explains that the helpline operates 9am -5pm Monday – Friday; referrals are logged and clients are contacted at a time and method of their choice. Access to the Helpline is by subscription and is available across the UK. Subscriptions are preferably sold in blocks of referrals per annum, take an average of 6 hours each and cost £120-£130 each. This document sent to Simon Francis at DWP for comment 20 October 2012.

considering what action would logically follow from each stage of the discussion set out in this paper is helpful in pressing each issue through to its conclusion.

It is inevitable that this technical document is dominated by the details of the welfare benefits system, but it is important to note that many people who become PPI representatives are not dependant on state benefits at all. This paper seeks a consistent response to their circumstances alongside those who receive benefit payments.

Finally, this technical archive aims to bring all the relevant issues together in one place; it does not seek to distil these ideas into a tight and memorable framework. Indeed, the opposite is true. Thus it forms the basis of a subsequent piece of work that charted the next steps in the journey, thus:

- Form a technical archive and begin the process of seeking common themes and issues
- Distil this material into a survey and find out how people make sense of the issues in their own mind by running a factor analysis
- Consider the implications of the factor analysis as a framework for devising an ideal system.
- Return to the technical archive to find out how much of the ideal system can be implemented within the framework of guidance and policy that circumscribes the field.

## **Recommendations**

1. Use this paper to inform decisions about reimbursements and payments.
2. Subscribe to the Involvement Helpline at Milton Keynes Citizens Advice Bureau so that PPI representatives have access to specialist advice and advocacy, in order to provide accurate advice to PPI representatives, check this document and keep it up to date.

## **Overarching goals**

Our intention is to create a system that:

- Is legal, ethical and safe
- Promotes informed decision-making by providing accurate information
- Nurtures individual confidence, skills and ambition in all stakeholders
- Creates a range of opportunities from simple volunteering to paid jobs, and helps people move towards paid work if they wish to do so

- Is as simple as possible, so people understand it, can see that it is fair and avoid burdensome and excessive administration.

We note that the welfare benefit system is complex and rapidly changing, so individuals should check with their Jobcentre Plus<sup>12</sup>, Pension Service or Tax office rather than relying on this document for definitive and personalised interpretation of particular circumstances. This is especially important as financial penalties can now be incurred for failing to do so<sup>13</sup>.

## A contested area

Reimbursements and payments occupy a space where competing principles intersect, as shown in the following table<sup>14</sup>. Note that each of these items bleed into other cells in both the adjacent column and other rows, rather than being mutually exclusive, and so form a complex system of interlocking issues. This table provides an exhaustive summary of the values and principles that drive different parts of the payment and reimbursement system.

Theme	Will you take this approach...	Or this one?
<b>Focus on the person</b>		
1. Is the person vulnerable?	1a. Organisations have a duty of care towards people who offer to take part - to ensure that they are not exploited, placed under duress, or inadvertently harm their health, wellbeing or finances through involvement activities.	1b. People who take part in PPI activity do so as free citizens. As long as the circumstances are legal (including consideration of the Mental Capacity Act 2005) and ethical (including compliance with Ethics Committee advice <sup>15</sup> ), people make free and informed choices and bear responsibility for them.

<sup>12</sup> Additional information is available from [DWP Stakeholder Bulletins or e-zine](#).

<sup>13</sup> DWP introduced Civil Penalties on 1 October 2012 as part of the tougher penalties introduced in the Welfare Reform Act 2012. A £50 penalty can be imposed on claimants who receive a benefit overpayment. This could be as a result of the claimant's negligence in providing incorrect statements on their claim and not correcting it; or failing, without reasonable excuse, to notify DWP of changes to their circumstances.

<sup>14</sup> The idea for this table and some of its content came from NRES (March 2011) *Information Sheets & Consent Forms Guidance for Researchers & Reviewers* pages 127-128, but has been extensively adapted by the present author.

<sup>15</sup> Local NHS Research Ethics Committees follow guidance in DH (2011) *Governance Arrangements for Research Ethics Committees*. The national Social Care Research Ethics Committee is hosted by the Social Care Institute of Excellence.

Theme	Will you take this approach...	Or this one?
2. Is the person a volunteer?	<p>2a. The central purpose of PPI is to seek views from the wider public who are not employed through the organisation.</p> <p>2b. To be a volunteer is to bring an ineffable and precious quality to the activity, and this is lost as soon as money becomes involved.</p>	2c. PPI is an essential part of all research proposals, so it should be paid for in the same way as other essential components, such as data analysis.
3. Is the person altruistic?	3a. Participants are contributing to the public good and so should not be out of pocket or disadvantaged through their involvement.	3b. Avoid inducements as they may be experienced as coercion, bring the 'wrong' people forward, distort their evidence <sup>16</sup> and harm them.
4. Is the person of high status?	<p>4a. Being paid, whatever the level, is highly symbolic and expresses the value placed on stakeholders.</p> <p>4b. Payment (and status) is tied to the tasks that the person is employed to do now, rather than any other job they may have or job they may have done in the past.</p>	4c. Different people at any meeting are on widely differing salaries and hold varying status. Mutual respect should be achieved without manipulation of the financial arrangements.

<sup>16</sup> Deci reported evidence in support of the idea that unpaid volunteers offer the highest level of commitment. For example, "students were given three-dimensional cubes to play with. One group was paid to do it, the other was not. The paid ones lost interest sooner and were more likely to stop and read magazines that had been left lying about. Money changed the focus. The unpaid volunteers reported playing with the cube because it was fun or because they chose to; for the paid students the interesting, enjoyable, challenging aspect of the activity got lost." (James O (2007) *Affluenza* London: Vermilion p167, referring to Deci EL (1971) Effects of externally mediated rewards on intrinsic motivation *Journal of personality and social psychology* 18, 105-115.). In contrast, there is some more recent evidence that payment improves performance. Brase GL, Fiddick L & Harries C (2006) Participant recruitment methods and statistical reasoning performance. *Quarterly Journal of Experimental Psychology*. 59, 965-976 found paid respondents were better at maths problems than unpaid volunteers, while Sharp EC, Pelletier LG & Leveque C (2006) The double-edged sword of rewards for participation in psychology experiments. *Canadian Journal of Behavioural Science* 38, 269-277 unsurprisingly found unpaid volunteers more prosocial than their paid counterparts.

Theme	Will you take this approach...	Or this one?
5. Is the person a worker?	<p>5a. PPI activity helps people escape unemployment by offering training, vocational preparation, rehabilitation or a work trial.</p> <p>5b. PPI activity is a career development opportunity, through which the person contributes to the economy.</p> <p>5c. PPI activity is part of worktime employee supported volunteering<sup>17</sup>.</p>	<p>5d PPI activity is part of civil society, which encourages active citizenship in leisure time.</p> <p>5e. PPI activity is unlike work and so should not be used to show the person is fit for work<sup>18</sup> or to destabilise the person's welfare benefit status.</p>

<sup>17</sup> Employer Supported Volunteering is supported by the Government's Office of Civil Society. See [here](#).

<sup>18</sup> A model letter explaining this position to Jobcentre Plus is available in Appendix 4 of NIHR Involve (May 2010, revised 2012) *Payment for involvement: a guide to making payments to members of the public actively involved in NHS, public health and social care research*.

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## Focus on the money

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6. Is the money a gift?

6a. Funders can offer what they like and can afford, and participants can choose to accept or reject offers of reimbursement and payment<sup>19</sup>.

6b. Where participation is required by statute (e.g. in the NHS<sup>20</sup>) Jobcentre Plus set aside its notional earnings rule to let people reject the offer.

6c. In relation to agencies where participation is not a legal obligation, (e.g. some parts of universities) people are expected to be financially independent of the State wherever possible, and so offers which have been refused may be treated as if they had been paid<sup>21</sup>.

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<sup>19</sup> Department of Health (August 2006) *Reward and Recognition: The principles and practice of service user payment and reimbursement in health and social care* permits people to choose whether to accept a participation fee or not. Since a change in the law, benefits will not be affected by an offer of payment made by an NHS Trust that you decline entirely, or when you ask to be paid a lower amount or you ask for the payment to be donated to a charity. See MHRN (2012) *Model Payment Policy for Service Users and Carers for MHRN hubs hosted by NHS Trusts* para 4.4.4.

<sup>20</sup> This was established in section 242 of the National Health Service Act 2006. SCIE (2011) *At a glance 50: Reimbursements and payments for service user involvement* lists some of the public authorities that are required by law to involve service users and carers: local authorities, landlord authorities, NHS Trusts and health boards, Care Quality Commission, Social Care Institute for Excellence, university social work training courses and others.

<sup>21</sup> The notional earnings principle means that a person who refuses an offer that would have made them less dependent on state benefits is treated as if they had received it. See <http://www.dwp.gov.uk/docs/m-37-09.pdf> and also <http://www.dwp.gov.uk/docs/m-34-09.pdf>. Refusing to accept a payment for involvement as a service user is listed as an exemption from the notional earnings principle in the guidance for Universal Credit – see <http://www.dwp.gov.uk/publications/specialist-guides/advice-for-decision-making/paragraph H3225>. In other words, refusing a payment for involvement will not affect entitlement to Universal Credit.



7. Are public funds being used properly?	<p>7a. Minimise cost to the public purse. Do not 'double fund' – by making payments to people who are already in employment or who can have their costs covered from another source.</p> <p>7b. The organisation has a duty to actively promote wellbeing, recovery and employment, and develop skills and self esteem, hence reducing whole-system reliance on the public purse.</p>	<p>7c. Most PPI representatives are poor, so pay them as much as possible</p> <p>7d. Paying little or nothing may reduce participation by busy or well-paid people, while those who do engage may be unrepresentative of the wider community and driven by different priorities.</p> <p>7e. Most people who have the confidence and opportunity to become a PPI representative are well off and successful, so may be unrepresentative of the wider community.</p>
8. Is there a cap on the amount paid?	<p>8a. The state has set subsistence levels (e.g. (i) the maximum amounts of permitted work income that may be earned without affecting entitlement to welfare benefits; or (ii) loss of earnings rates for jury service) and this forms a precedent for the appropriate level of entitlement to public funds.</p>	<p>8b. Jobcentre Plus retains the right to review wider benefit entitlement under any circumstances, and large payments may trigger a review, destabilising the person's financial situation<sup>22</sup>.</p> <p>8c. Excessive payments will form an undue inducement to participate and breach ethical principles.</p>

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<sup>22</sup> While in theory there is no harm in a review, many people report that payments are suspended for several weeks while the review takes place and substantial efforts need to be expended to restore entitlements. Some people fear that their entitlement will be unjustifiably downgraded.

9. Is it a free market?	<p>9a. Use trial and error to discover the lowest offer that will successfully engage people in each distinct activity<sup>23</sup>.</p> <p>9b. If people are doing PPI in their usual worktime, they should be employed at the market value of their time, or reimbursed for loss of earnings.</p>	<p>9c. Aim for equity across PPI representatives or between representatives and paid staff, so equal activities attract equal rewards.</p> <p>9d. Wherever possible, PPI activity should be moved out of worktime into leisure time or another person found to serve as a PPI representative who will be cheaper.</p>
10. Are people entitled to the payment?	<p>10a. PPI activity involves clear expectations in terms of time and effort, obligations and conduct, productivity, outputs and remuneration, so it is employment.</p> <p>10b. Wage-earners must fund their own travel to work costs and other routine expenses.</p>	10c. PPI activity is a freely offered gift, which may yield a 'thank you' gift in response, but there is no entitlement or redress if either gift is withheld <sup>24</sup> .

Table 1: A map of principles that affect payment and reimbursement decisions

The following section of this paper identifies a number of real-world scenarios; attempts to interpret each one in the light of the principles set out above, and then suggests solutions. Whilst in theory, each of the principles set out in Table 1 could drive decision-making and several of them have shaped the response of other organisations, this paper suggests which principle should guide decision-making in the opinion of the author.

Where possible, an explanation is provided of why this principle has been selected rather than any other, but sometimes this is no more than a personal interpretation of fairness, rather than the result of more robust and explicit reasoning. The survey that followed the task of writing this technical archive provided a stronger way to select

<sup>23</sup> The Department of Work and Pensions acknowledges that different sectors of the community will respond to different levels of incentive to become involved. See Bacon J & Olsen K (2003) *Doing the right thing: Outlining the Department for Work and Pensions' approach to ethical and legal issues in social research* DWP: DWP Ethics Group

<sup>24</sup> As long as they are not made in exchange for work done and the person is not employed, one-off gifts are ignored by Jobcentre Plus (see Department of Health (2004) *Reward and Recognition* paragraph 54). INVOLVE sometimes give a 'once-off payment' as a thank you, but not more than once a year.

which principles *should* be used, as it is based on a factor analysis of many respondents, rather than the author’s personal preference.

## Simply attending a meeting and joining in

Attending the PPI Catchup meeting at CLAHRC NDL is an example of this situation. An examination of neighbouring services reveals the following examples:

Example	Which principles are at work
Although the NHC policy says that a participation fee can be offered, in practice, staff at the NHC Involvement Centre believe that engagement is at its most therapeutic when it is unpaid and voluntary, so never offer a participation fee.	The policy uses 6a – offer a gift The practice is 7b – promote recovery
General attendees at the East Midlands MHRN PPI meeting <sup>25</sup> at the Institute of Mental Health receive expenses only.	3a – not ‘out of pocket’
Attending the national meeting for carers that is hosted by the MHRN <sup>26</sup> will attract both expenses and an £80 participation fee	7c – pay as much as possible, along with 8b – stabilise benefit status

Table 2: A variety of responses to simply attending a meeting

### Recommendations

3. Apply Principle 3a to this situation – to treat this activity as an act of altruism from volunteers who freely give their time. People attend if they wish, and there are no obligations beyond common courtesy for absence or for conduct whilst present. As such, do not pay a fee for this kind of participation. This has been discussed with the PPI group and the general feeling is that this is the right principle to apply in this context.
4. Specify on the PPI webpages the financial arrangements for each meeting or event that includes PPI representatives, as shown on the PPI Volunteer Vacancy Board. In particular, general attendance at the PPI Catchup meeting and similar events is ‘expenses only’.
5. Include a footnote explaining the money ‘offer’ on the agenda of all meetings attended by PPI representatives.
6. Seek management approval to follow the guidance set out here in place of the NHC policy.

<sup>25</sup> Information from Debbie Butler

<sup>26</sup> Information from Bethan Thomas

## Expenses are incurred

People are expected to use the most economic and practicable forms of transport and most direct routes - and apply a similar approach to other expenses, whilst meeting their individual needs.

In line with the situation described in the previous section, the guide here is Principle 3a - that **the person should not be disadvantaged** through their involvement. However, some state benefit regulations are based upon competing principles, as we shall see.

If payments are received, Jobcentre Plus has regulations that help define what counts as expenses rather than earnings. They may consider any money received to be earnings rather than expenses if it does not match the exact receipted amount that was expended. For a payment to be considered as a reimbursement of expenses it must be incurred 'wholly, exclusively and necessarily' in the course of the volunteering activity.

Jobcentre Plus goes on to define what expenses may include. These may be: travel costs; child carer or replacement carer; personal assistant, support worker, interpreter or facilitator; necessary subsistence and accommodation; and stationery and telephone costs. If the person is receiving reimbursement of expenses and no other payments in relation to voluntary work, then such payments are disregarded by the benefits system.

In one NHS Foundation Trust<sup>27</sup>, mileage rates for PPI activity are set at the same level as that for staff, in accordance with Principle 2c (equity). Elsewhere, mileage payment levels are capped to keep them below the taxable level.

However, if a separate payment is made that might be considered earnings, then Principle 10b (work related costs) used to be applied. In this situation, Jobcentre Plus could treat any attendant reimbursement of expenses as part of the total earnings of the person, and the combined amount may be deducted from their benefit income or even disqualify them entirely from entitlement to benefits<sup>28</sup>. While this aligns with the common practice in the community by which a person in receipt of full time earnings is expected to meet their own travel to work costs, applying it to small payments can mean that the person suffers a net loss of income. The Universal Credit regulations now disregard expenses arising from involvement in 'service user activity'<sup>29</sup>.

Another variant occurs when the monies are paid by an NHS Trust<sup>30</sup>, in which case principle 6b is applied (PPI activity is required by statute), and expenses may be

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<sup>27</sup> Cambridge & Peterborough NHS Foundation Trust (2010) *Payments for Service Users and Carers Involvement*, paragraph 6.12. Available at <http://www.cpft.nhs.uk/Find%20help/documents-that-guide-practice.htm>

<sup>28</sup> This provision has been removed from the Universal Credit regulations due to be introduced in 2013.

<sup>29</sup> See <http://www.dwp.gov.uk/publications/specialist-guides/advice-for-decision-making/> paragraphs H3130, H3160-H3164.

<sup>30</sup> There are separate MHRN payments policies for NHS hosted and University hosted organisations. The key difference appears to be that the law demands PPI activity in the NHS, and therefore expenses that are paid alongside participation fees should be disregarded, but this is not the same for university settings. CLAHRC NDL is a joint venture hosted by NHC and payments are made by NHC finance office, so it qualifies under this

received alongside a participation fee. This provides greater protection than similar monies paid from a university<sup>31</sup>. Despite the fact that all payments for participation are made by the finance office at NHC, CLAHRC NDL is not included in this easement<sup>32</sup>.

Many of these difficulties fall away if the person:

- Is not claiming state benefits
- Receives reimbursement of expenses only
- Asks CLAHRC NDL staff to book travel tickets, taxis, hotels and similar expenses on their behalf and pay for them directly.

Until now, administrative arrangements have been cumbersome and could disadvantage the person. This is because the current PPI webpages<sup>33</sup> indicate that reimbursement will normally be made in cash on the same day as the activity to ensure that the person is not inconvenienced by cashflow problems. To do this, cash has to be ordered from NHC and then collected in person seven days prior to the event and the balance returned in person within seven days, involving up to four hours work<sup>34</sup>. Even with this effort, PPI representatives need to have the cash in hand to travel to the event before obtaining reimbursement on arrival.

A more practical arrangement is for CLAHRC staff to issue travel tickets and other items in advance where the cost is substantial and for the person to claim reimbursement through their bank account for smaller amounts.

## Recommendations

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provision. As government policy supports PPI activities across the whole of society and promotes public/private partnerships, this situation will become increasingly ambiguous. A second possibility here is that the law requires PPI in the service delivery of the NHS Trust, but this may not extend to health research activities. INVOLVE are negotiating with the Department of Health and the Department of Work and Pensions to clarify this matter and have been assured that the policy intent is to ease participation across all sectors (personal communication from Lucy Simons).

<sup>31</sup> In contrast, costs that are reimbursed by the university might be taken into account by Jobcentre Plus. If a person in receipt of benefits requires a personal assistant, facilitator, replacement carer or support worker or child carer for PPI involvement activities, any reimbursement of the costs may be treated partly or wholly as earnings by Jobcentre Plus. See the MHRN model policy for University-hosted organisations.

<sup>32</sup> Social Care Institute of Excellence (2011) *At a glance 50: Reimbursements and payments for service user involvement* page 5 explicitly states that CLAHRCs are excluded from these easements. At a meeting between the Department of Health and Department of Work and Pensions on 23 June 2010, it was confirmed by a DH official, Vince Roose (patient experience and engagement team), that research in the NHS does not fall under section 242 of the Health and Social Care Act 2006, and so does not benefit from these easements (personal communication from Lucy Simons at INVOLVE 19 Dec 2012).

<sup>33</sup> <http://www.clahrc-ndl.nihr.ac.uk/gettinginvolved/public-involvement-fags.aspx>

<sup>34</sup> Some auditors would expect two staff to transport money, a car or taxi to be used, and funds to be kept in a safe in order to protect the funds from theft and the staff from allegations of misappropriation. This adds further complexity and cost to the arrangements described above.

7. Ensure that PPI representatives are not disadvantaged by their participation by making expensive travel and other arrangements directly on behalf of the person whenever possible.
8. Amend the PPI web pages to indicate that the usual alternative where people do not ask for bookings to be made on their behalf is to pay the claim into the person's bank account within two weeks.
9. Emphasise on PPI web pages and individual documents that it is the responsibility of the PPI representative to choose whether to accept participation monies and to declare any funds received to Jobcentre Plus, the Pension Service and the Tax Office as required. A model letter is available to clarify whether participation payments are exempt from National Insurance and tax.<sup>35</sup>

## The person needs a personal assistant

While this situation is mostly covered by the expenses section above, paying for a personal assistant poses some unique challenges and so deserves a discussion in its own right.

The current NHC policy appears to be a variant on Principle 8 (cap the payment) as it sets a maximum of £20 per day for a personal assistant. The National Minimum Wage was increased in October 2012 to £6.19 per hour for people aged over 21, and the PPI representative would have to pay additional costs associated with their role as the employer of their assistant.

A payment of £20 per day suggests one of the following options:

1. The PPI activity is restricted to around two hours from 'door to door' – a very short 'day'.
2. The personal assistant is employed in breach of the National Minimum Wage regulations
3. NHC expects the person to combine this payment with funds from elsewhere to pay the personal assistant. This may be appropriate if the person already employs a personal assistant who supports them to do other activities at the time the PPI activity will be taking place. In this situation, the NHC payment is merely paying for the marginal additional cost associated with providing personal assistance to enable the person to engage in the PPI activity.

As options 1 and 3 above are uncommon and option 2 is unacceptable, a change to the policy is recommended.

The smallest change would be to retain Principle 8 (cap the payment) but revise the level by applying a variant of Principle 9 (allow a free market to set levels) by adjusting the cap to the average cost of personal assistants in the UK. NDTi<sup>36</sup> has

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<sup>35</sup> This is due to be published later in 2013 by INVOLVE and relates to HMRC guidance EIM71105, available at <http://www.hmrc.gov.uk/manuals/eimanual/eim71105.htm>

<sup>36</sup> The National Development Team for Inclusion is a non-profit organisation with a national overview. See [www.ndti.org.uk](http://www.ndti.org.uk)

advised that personal assistants receive varying pay rates across the UK, generally within the range £7-£9 per hour and, as mentioned above, on-costs would need adding to this figure to cover the employer's responsibilities. NDTi further note that paying £7 per hour is likely to reduce quality and increase turnover – an unsatisfactory situation for personal assistants and the people they support.

Abandoning Principle 8 (cap the payments), while retaining Principle 9 (free market), would align CLAHRC NDL with the INVOLVE policy, where the full costs and expenses of a Personal Assistant are reimbursed without setting a ceiling. As the sums are comparatively high, prior approval is needed. As we saw above, welfare benefits are unaffected by reimbursed expenses for either paid or voluntary involvement when it is an NHS Trust that is reimbursing the expenses, as is the case for CLAHRC NDL<sup>37</sup>.

Any payment is generally made to the person, rather than the personal assistant, as the contract between the person and their personal assistant is a private matter.

However, if there are difficulties, it may sometimes be appropriate to pay the Personal Assistant or other carer directly, in order to ensure that there is no impact on the state benefits of the person being supported. In this situation, advance arrangements must be made with the person or their carer to obtain their authority for paying the personal assistant or replacement carer directly, to obtain their contact details and set up payment arrangements.

The issues for interpreters are the same as for personal assistants and so both kinds of supporters should be treated in the same way<sup>38</sup>.

## Recommendations

10. The Board should to set aside NHC policy and follow INVOLVE policy by paying what it costs for people who need a personal assistant. The level of payment must be agreed in advance, be reasonable, and be supported by written evidence.
11. A model letter<sup>39</sup> is offered to the PPI representative for them to take to the Jobcentre explaining the arrangements.

## People in particular circumstances

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<sup>37</sup> In contrast, costs that are reimbursed by the university might be taken into account by Jobcentre Plus. If a person in receipt of benefits requires a personal assistant, facilitator, replacement carer or support worker or child carer for PPI involvement activities, any reimbursement of the costs may be treated partly or wholly as earnings by Jobcentre Plus. See the MHRN model policy for University-hosted organisations.

<sup>38</sup> This approach is taken from the Mental Health Research Network Heart of England Hub (2012) *Guidance for service user and carer payment*.

<sup>39</sup> Model letters are available in Appendix 4 of NIHR Involve (May 2010, revised 2012) *Payment for involvement: a guide to making payments to members of the public actively involved in NHS, public health and social care research*.

Children and young persons of compulsory school age<sup>40</sup> can be involved as long as this does not adversely affect their education, health and physical development. Consent from their parents or guardian and from the school is required, both for the involvement activities and the payment arrangements. Earnings from a part-time job do not affect their parent's entitlement to welfare benefits.

People with childcare or other caring responsibilities can claim a payment for the costs of the temporary carer. In one NHS Foundation Trust this is set at £7.50 per hour or a maximum of £30 per day and can be claimed for preschool children and those under 13 after school hours and during school holidays<sup>41</sup>.

People who are detained in medium secure (such as Arnold Lodge<sup>42</sup>) and high security hospitals (Ashworth<sup>43</sup>, Broadmoor<sup>44</sup> and Rampton<sup>45</sup>) and prisons<sup>46</sup> are exempted from the National Minimum Wage regulations and these establishments have rules on the amount of money that an inpatient or prisoner is allowed to receive<sup>47</sup>. These rules take precedence to ensure that inpatients and prisoners who engage in involvement activities are not paid at rates disproportionate to others

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<sup>40</sup> This paragraph has been adapted from Cambridge & Peterborough NHS Foundation Trust (2010) *Payments for Service Users and Carers Involvement*, paragraphs 6.4 to 6.9.

<sup>41</sup> Cambridge & Peterborough NHS Foundation Trust (2010) *Payments for Service Users and Carers Involvement*, paragraphs 6.14 to 6.17.

<sup>42</sup> Dr Najat Khalifa wrote (29/11/12): 'It is my experience that Arnold Lodge have no objections to paying participants, staff and patients. When we did our study, we opted to pay participants at Arnold Lodge a Tesco gift voucher, but we were told by the managers of Arnold Lodge that they would have had no objections to cash payments.'

<sup>43</sup> Ashworth has its own policy that allows a maximum of £20 to be paid into patients personal accounts held by the hospital for their participation in a research project. See Wilkins T (2005) *Payment to Service Users for Involvement in Research - High Secure Services*, MerseyCare NHS Trust. Robert McLean confirmed this is still in use (personal communication 4 Dec 2012).

<sup>44</sup> Email from Derek Perkins (5 Dec 2012) 'Patients within our trust are periodically paid for participation in research studies, this being included in discussions regarding local support and the R&D and ethics submissions. Were payment to be considered inappropriate for any reason, it would be picked up at this stage. Once agreement has been reached, the level of payment is included in the information made available to patients at the point of obtaining their consent. Because of necessary security protocols, payment within high security is made through the patients 'internal banking system' and we have protocols developed to enable this, which can be shared if of interest.'

<sup>45</sup> Dr Najat Khalifa wrote that: 'The managers at Rampton did not approve our proposal to pay Rampton participants for security reasons. Rampton patients no longer receive any reward payments but rely entirely on state benefits (Janga Singh, Senior Social Worker at Rampton, personal communication 16 Jan 2013).'

<sup>46</sup> This section has been adapted from Cambridge & Peterborough NHS Foundation Trust (2010) *Payments for Service Users and Carers Involvement*, paragraph 6.3.

<sup>47</sup> Payments to prisoners may be perceived as making prison more pleasant or enabling offenders to profit from their crimes, and so they are regulated by the Incentives and Earned Privileges Scheme. Prisoners who engage in approved work or learning in the prison start at a basic pay rate of 50p per day and can only spend a proportion of their savings. This may include payments from an outside body. See

[http://www.justice.gov.uk/downloads/offenders/psipso/ps0/PSO\\_4460\\_prisoners\\_pay.doc](http://www.justice.gov.uk/downloads/offenders/psipso/ps0/PSO_4460_prisoners_pay.doc).



within that environment<sup>48</sup>. Once these obligations are met, from the perspectives of CLAHRC ND, detained persons will be offered the same opportunities with regard to payments and reimbursements as other citizens.

The detained individual may be able to participate in PPI activities if they are escorted by a staff member. The clinical team have a duty to support therapeutic and community-based activities, such as PPI, while CLAHRC has a duty to make reasonable adjustments to enable disabled people to participate. Adjustments might include taking the activity to the person, rather than expecting them to attend meetings on our premises; or contributing to the costs of a staff escort. As both the clinical team and the research team benefit, then it makes sense to share the associated costs.

## Recommendations

12. Where the potential PPI representative needs a staff escort and the clinical team are unable to provide this without help, we should offer to cover half the costs, in recognition of the shared obligations between the clinical team and the research team.

## A brief non-recurring activity that requires considerable skill and/or commitment

Where the person is making a contribution that goes beyond the mutual obligations of citizenship, then a different arrangement is needed. The guide here is Principle 6a (exchange of gifts).

The state benefits system allows for people on means-tested benefits who undertake an activity within a single day in any year<sup>49</sup> to be offered one cash payment or cash voucher as an acknowledgement for their contribution<sup>50</sup>. Vouchers are treated in the same way as cash. Jobcentre Plus treats a single gift as capital, and so it will not affect entitlement to mean-tested State benefits as long as it does not take the person over the £6,000 savings threshold. No tax or national insurance contributions should be deducted and the tax office<sup>51</sup> does not need to be informed. There are further rules about alternative items that might be offered as a gift, such as computer equipment, registration for training courses, subsistence items such as food<sup>52</sup>, and in general these are more likely to be considered as income by Jobcentre Plus rather than gifts of capital in line with Principle 7a (do not double fund).

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<sup>48</sup> This principle is promoted in a Canadian discussion by Hanson R, Letourneau E, Olver M, Wilson R & Miner M (2012) 'Incentives for Offender Research Participation Are Both Ethical and Practical' *Criminal Justice and Behavior* Volume 39, Number 11, pp. 1391-1404.

<sup>49</sup> Starting 6 April.

<sup>50</sup> Mental Health Research Network (January 2012) *MHRN Service Users & Carers Payments Policy: Service user and carer participation: helpful benefit rules and benefit pitfalls to avoid where payments are made by an NHS Trust*.

<sup>51</sup> Her Majesty's Revenue and Customs.

<sup>52</sup> I have an old memory that subsistence items are more likely to be counted as income rather than luxuries, but this judgement may have been superseded by newer regulations. Advice welcome!

If Jobcentre Plus considers the amount excessive, then additional enquiries may be made, as the person may be considered to be engaged in remunerative work, thus invoking Principle 10a (it's a job). Jobcentre Plus staff would expect to see a formal letter from the giver confirming that this is a once-off gift given to thank the person.

Vouchers may be problematic in that they favour particular retailers, but may be more suitable for people who have a problem of diverting cash to harmful purposes and for staff who may feel more comfortable carrying them.

What should be the value of the voucher? A strict system of paying an hourly rate invokes Principle 10a (it's a job) rather than Principle 5e (it's not a job), but gifts also have a degree of proportionality, as we may give a birthday card to a superficial acquaintance and jewellery to a lover. The single-day per annum used by the benefits system prompts comparison with the day rate used in the courts. A maximum of £60 undercuts this, avoiding the implication that it is a day's work.

## Recommendations

13. Prepare a model letter for people to take to Jobcentre Plus.
14. Continue to offer vouchers rather than cash for this kind of participation.
15. A maximum voucher value of £60 may be offered to any one individual no more than once per year.

## The activity requires considerable skill and time

Attending an advisory group for a CLAHRC research study or sitting on the CLAHRC Board provides examples of this situation.

The suggested guide here is a version of Principle 6b (participation required by statute). The organisation has a duty to engage people and for these roles there is an obligation to undertake particular activities in particular ways (that may be set out in a role description<sup>53</sup>), and a participation payment is then owed to the person in all good faith.

A framework<sup>54</sup> for ranking different PPI tasks has been provided for mental health research activities, and this can be used as a guide to payment levels. It has been suggested<sup>55</sup> that failing to adequately describe the performance standards for each particular activity leads to inequity (as payment levels are unrelated to performance), reduces the value of PPI activity and damages the reputation of PPI representatives (as some people are poorly matched to the task and do not complete it to a satisfactory standard).

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<sup>53</sup> Sample role descriptions can be found in Appendix 1 of INVOLVE (2<sup>nd</sup> edition, 2004) *Involving the public in NHS, public health and social care research: Briefing notes for researchers*. Role descriptions are informal and not enforceable in the courts or covered by employment legislation, according to a ruling made 26 January 2011 by the Court of Appeal in *X v Mid Sussex Citizens Advice Bureau and others* [2011] EWCA Civ 28.

<sup>54</sup> 'MHRN Menu of Service User Engagement in Research' offers five levels of involvement for members. See [http://www.mhrn.info/data/files/FOR\\_SERVICE\\_USERS/Menu\\_Service\\_User\\_Involvement.pdf](http://www.mhrn.info/data/files/FOR_SERVICE_USERS/Menu_Service_User_Involvement.pdf)

<sup>55</sup> Mental Health Research Network Heart of England Hub (2012) *Guidance for service user and carer payment*.

We quickly note that the government's policy statements have carefully avoided any suggestion that engagement in involvement activities is a job and participation payments are wages. While the borderline between volunteering and contractual employment has been examined through the civil courts<sup>56</sup>, there does not appear to have been a similar test applied to payments for involvement<sup>57</sup>. In some ways, getting involved in these activities is more like work than any arrangement yet discussed in this paper. Support for this position is found in the following places:

- Department of Health guidance<sup>58</sup> suggests that “service users... [should be] paid according to open and consistent criteria that takes into account the level of involvement, the type of work and the skills and expertise required.” Such a statement would not be out of place in describing work duties, and others<sup>59</sup> have reinforced the idea that increasing time, commitment, skills and expertise should lead to increased levels of remuneration.
- INVOLVE make clear that paying for time, skill and expertise is best practice, in contrast with merely reimbursing expenses<sup>60</sup>.
- The amount of money that is offered also suggests that the concept of casual employment has been used as a guide. The current NHC policy offers £9.50 an hour, £19.50 for a 3 hour session and £10 for additional background work. These figures lie above the National Minimum Wage level<sup>61</sup> and below the £20 per week maximum rate of disregarded and permitted income set for some benefits<sup>62</sup>.
- Participation fees well above the National Minimum Wage are sometimes paid. INVOLVE use and recommend the NIHR committee rate of £150 per

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<sup>56</sup> In the case of *Migrant Advisory Service v Chaudri* UKEAT/1400/97 the Employment Appeal Tribunal upheld a finding that an individual who worked for four days per week for two years, was paid “expenses” of £25 per week, and subsequently £40 per week, even though no expenses were actually incurred and received holiday pay and sick pay, was an employee. In this case the finding that the payment of “expenses” was in fact pay for regular hours worked rather than reimbursement for expenses actually incurred was crucial.

<sup>57</sup> “I’m not aware of any caselaw on this particular area. I would expect that for a contract of employment to exist there would need to be other factors indicative of employment status, such as mutuality of obligation, in addition to payment of a fee and expenses.” (Personal communication 7 November 2012 from David Gray-Jones, Partner and Solicitor-Advocate, Thomas Mansfield LLP).

<sup>58</sup> Department of Health (August 2006) *Reward and Recognition: The principles and practice of service user payment and reimbursement in health* Dept of Health,

<sup>59</sup> McHarron, A & Nettle, M (1999) *Payments to Service Users: Guidance Paper 1* NHS Executive, West Midlands Partnership in Mental Health.

<sup>60</sup> NIHR Involve (May 2010, revised 2012) *Payment for involvement: a guide to making payments to members of the public actively involved in NHS, public health and social care research*. Page i.

<sup>61</sup> At one NHS Foundation Trust, the policy explicitly commits to paying an hourly rate for involvement activities that is at or above the National Minimum Wage. See Cambridge & Peterborough NHS Foundation Trust (2010) *Payments for Service Users and Carers Involvement*, paragraph 6.2. This may have been done because of a wish to pay a decent wage, or to avoid prosecution under the National Minimum Wage regulations in the event that these payments happen to be deemed as earnings.

<sup>62</sup> The level of earnings that is disregarded by Jobcentre Plus varies with the type of benefit, from £5 per week for people receiving Income Support (see [here](#) for details) up to £99.50 for Supported Permitted Work (see [here](#)). Advice should be sought from Jobcentre Plus for individual situations and disregarded earnings must still be declared.

day and the peer review rates of £50, £125 and £200 for documents, depending on their size. We note in passing that CLAHRC generally uses the NHC rate rather than that set by INVOLVE.

- The new Universal Credit regulations allow payments to be made for involvement that are below the National Minimum Wage level<sup>63</sup>. However, whilst reimbursement of expenses is allowed by the Income Support rules, participation payments are treated as earnings<sup>64</sup>.
- One organisation<sup>65</sup> offers three levels of payment in line with NHS Agenda for Change hourly payment levels, ranging from Band 4, Point 8 (£9.98 per hour), through Band 5, Point 8 (£15.62 per hour) to Band 8, Point 8 (£23.90 per hour) with each level being matched to clearly defined skills and duties. These are specified as follows:

#### Basic Rate

Assisting a research project with time; being asked views and opinions; conducting basic interviews etc.; attend research conferences/events as a delegate; attend conferences as additional support for the Hub or research teams; attendance at project meetings or consultation meetings; observe or shadow fellow member or colleague during specific tasks (i.e. meetings, research development proposals etc).

#### Standard Rate

Contributing to specific HUB research projects in a professional manner; conducting interviews, desktop research, report writing, designing questionnaires etc.; provide summaries of completed adopted studies; taking the 'lead' on some themes; lead Focus groups; undertake audits; being more proactive and more equal partner in the research project; assist with design of Heart of England led workshops/seminars; assisting or partly delivering workshops either independently or with another member of the MHRN Heart of England; represent and advertise the role of the MHRN Heart of England at various seminars (usually on behalf of the Service User Development Officer or Hub Manager); conduct local audit work/focus; assisting research community with Research proposal and development; membership of research development group (local level); sit on Recruitment Panels (local level); personally invited to respond to requests for expressions of interest on specific research topic areas; advised of employment opportunities within Heart of England Region

#### Advanced Rate

Represent service user and carers on local steering group, advisory group etc.; represent service users and carers at a regional and national level on behalf of the Heart of England; attend and present at local, regional and national workshops/seminars on behalf of or with members of the Heart of England Hub; design and deliver half day or one day workshops on behalf of the Heart of England; provide professional advice and assist the research community in

<sup>63</sup> <http://www.dwp.gov.uk/publications/specialist-guides/advice-for-decision-making/> paragraph H3241.

<sup>64</sup> See [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/303720/m-9-14.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/303720/m-9-14.pdf)

<sup>65</sup> This approach is taken from the Mental Health Research Network Heart of England Hub (2012) *Guidance for service user and carer payment*.

developing proposals; assist with the design of research proposal; design questionnaires; analyse audits; sit on Recruitment Panels (regional and national level); sit on or lead Research Development Group (local level); personally invited to respond to requests for expressions of interest on specific research topic areas; provide summaries of specific papers; mentor new members (with support of Heart of England Team); advised of employment opportunities in research within MHRN region.

- An example from elsewhere<sup>66</sup> is set out in the table below for comparison purposes.

Contribution	Payment
Chairing a meeting	£30
Co-facilitating a Focus Group	£25
Sharing personal experience and contributing to a teaching session taking up to half a day	£25-£35
Preparing and giving a short presentation of up to 30 minutes	£40
Preparing and giving a longer presentation of up to 60 minutes	£75
Planning, preparing and co-facilitating a half day training seminar	£125-£175
Planning, preparing and co-facilitating a whole day training seminar	£250-£350
Participation in high-level working groups and committees meeting at national level.	£75-£190

Administrative procedures further reinforce the status of PPI representatives as casual workers:

- Where the person is paid for their involvement, then any payments made in addition to this, such as reimbursed costs of travel (tickets, cabs, petrol, or mileage allowance) and carer costs are all added to the participation fee to arrive at a figure that is treated as total earnings by the welfare benefits system. There are no benefit rules for reimbursed costs of a personal assistant, facilitator or support worker so each person must ask Jobcentre Plus for a ruling.
- Payments can be averaged over a four-week period if Jobcentre Plus is notified well in advance.

<sup>66</sup> Cambridge & Peterborough NHS Foundation Trust (2010) *Payments for Service Users and Carers Involvement*, paragraph 3.1 and 6.3.

- In some settings<sup>67</sup>, payments are processed through the payroll system and the person is asked to complete a start of work (P46) form. Payroll staff send the completed document to the HMRC. Universities may be able to obtain exemption from the PAYE process for people who receive payments for their involvement in research<sup>68</sup>. HMRC copy the P46 form to Jobcentre Plus, who, if they have no prior knowledge of the arrangements, will assume that the person is working, stop their welfare benefit income and possibly pursue them for failing to notify them of a change in status.
- Some agencies treat the payments as if they are subject to employment law, such as the part time worker's regulations<sup>69</sup>, and count the income as taxable and subject to National Insurance obligations.

Although the Government have been clear that PPI activity is not employment, it may be considered a hindrance to taking up an ordinary job. Anecdotal evidence suggests that on some occasions Jobcentre Plus staff have deemed anyone who commits more than 16 hours per week to be unavailable for work, and so have reduced or withdrawn their entitlement to benefits<sup>70</sup>. Finally, we note that none of these welfare benefit considerations are relevant to a person who is not in receipt of such benefits but wishes to become a PPI representative.

## Recommendations

16. To pay a participation fee when specific roles<sup>71</sup> are defined in funding applications or organisational structures, and when the activity is performance managed.

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<sup>67</sup> King's College London have agreed that people claiming fees or expenses for involvement activities in the MHRN Coordinating Centre will not have to complete the usual Employment Status Assessment form. In all other cases, King's will only pay people who have demonstrated via this form that they are registered as self employed. Personal communication from Bethan Thomas.

<sup>68</sup> The British Universities Finance Directors Group have obtained agreement from the HMRC and so payments for involvement in research may be exempted from PAYE arrangements. See details at Appendix 5 of NIHR Involve (May 2010, revised 2012) *Payment for involvement: a guide to making payments to members of the public actively involved in NHS, public health and social care research*

<sup>69</sup> The Part-time workers (Prevention of Less Favourable Treatment) Regulations 2000 ensure that part-time workers are not treated less favourably in their contractual terms and conditions than comparable full-time workers unless it is objectively justified. This means part-time workers are entitled, for example, to: the same hourly rate of pay, the same access to company pension schemes, the same entitlements to annual leave and maternity/parental leave on a pro rata basis, the same entitlement to contractual sick pay and no less favourable treatment in access to training. See <http://www.legislation.gov.uk/ukxi/2000/1551/contents/made>

<sup>70</sup> The benefits regulations are clear that jobseekers must prioritise employment over volunteering, but there are no limits to the amount of time that can be given to volunteering. A widespread confusion has been to mistakenly believe that the 16 hour threshold for paid work – doing more paid hours leads to a reduction in benefits – applies to volunteering too. It does not. However, the status of people who take up more than 16 hours per week of PPI activity remains unclear. See <http://www.volunteering.org.uk/policy-and-campaigns/policy-blog/2355-universal-credit-regulations-restricting-volunteering> for more information.

<sup>71</sup> Is the participation fee payable where individuals are recruited to a group and anyone can engage, but a casual contract applies where there is an agreement with one named individual?

17. Equal opportunities requirements (advertise vacancy, invite applicants, transparent selection process and providing references) are less stringent than more substantial posts, but a proportionate response to these principles should be in place.
18. Endeavour to match individuals to appropriate tasks and provide training and support so that people build skills and confidence and can be provided with a reference delineating their performance.
19. Offer the NIHR committee rate for PPI representatives on the Board, allowing people to choose the alternative rates of £19.50 or expenses only if this suits them better<sup>72</sup>.
20. Check that the University of Nottingham has taken up the exemption arrangements offered by HMRC or encourage this to be done.
21. Offer a standard letter to the person for submission to Jobcentre Plus if required to explain the circumstances under which the funds are received and where relevant to request averaging over four weeks.

## Employment

Alongside the appointment of a PPI lead<sup>73</sup>, there are occasionally opportunities for CLAHRC NDL to create a new post. If the person specification includes personal experience of a health condition, use of health or social care services or expertise as a PPI representative, then this post forms an opportunity for advancement for PPI representatives. Such positions might range from a few days or hours a year up to full time employment. Our host organisation, NHC, employs Peer Support Workers specifically for their role as experts by experience, while in some organisations, person specifications for all posts include lived experience of mental illness as a desirable component of applications.

Within CLAHRC NDL, there are several examples. Firstly, the STEP-OUT study has recruited Community Link Workers and paid them on a casual basis for each person they have recruited to the study<sup>74</sup>. Secondly, the DISCO application led by Professor

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<sup>72</sup> A group of 8 PPI representatives polled on 19 October 2012 unanimously thought the £150 rate excessive for Board representatives and recommended that £19.50 should be offered.

<sup>73</sup> A survey in March 2012 of all nine CLAHRCs in England found PPI varying levels of investment in the PPI lead role, varying from 0.05 whole time equivalent (wte) staff member to 2.5 wte. In addition, CLAHRCs will vary in the extent to which other staff include PPI activity as part of their wider role. Similar variation was found in a September 2012 anonymous survey of the salaries of PPI lead staff. Sixteen responses were received, mostly from NHS employees, with a few exceptions. Exactly half of them were paid between £30,000 and £40,000 with others equally distributed from below £20k (NHS band 4) to above £50k (NHS Band 8B).

<sup>74</sup> Community Link Workers receive a total of £60 per completed respondent, paid in response to four stages of the data collection. One person has recruited 100 participants, so, if the Link Worker collects data at 4 time points from each participant, they will earn £6,000. They are paid via the University of Nottingham payroll as casual employees. NI and tax is deducted if appropriate to the current employment status of the Community Link Worker. They are treated as employees in as much as they have been recruited (albeit not via a formal interview process), trained for a specific role and supported in the carrying out of that role. They are not provided with office space at the university as this is not required. The Finance Director's concession from the

Schneider offers such a contract to two people who became co-applicants and PPI representatives to the research project<sup>75</sup>. Each employee would be paid £100 per day for 20 days per year, for five years.

We note that this sort of arrangement has the following consequences:

- It provides higher status, security and career prospects for the person who is employed rather than simply participating as an active citizen
- It acknowledges that the workforce already includes people with lived experience of disability or mental health issues and so reduces shame and secrecy
- It reduces the discrimination that shuts people with lived experience out of the labour market by acting as a Mindful Employer<sup>76</sup>.
- It adds to patient benefit by closing the gap between researcher and researched
- It increases the risk that the research team will think that they hold all the relevant knowledge and so do not need to consult with people outside their group.

## Recommendations

22. To sign up to the Mindful Employer Charter.
23. To encourage the University of Nottingham to consider adopting the Mindful Employer Charter.
24. Where possible, to create posts in which lived experience is a desirable part of the person specification.
25. To draw on that team member's expertise as well as consulting with the wider PPI constituency.

## Participation as a research subject

The standards of the 1947 Nuremberg Code<sup>77</sup> state that no persuasion or pressure of any kind should be put on research participants, and subsequent literature has drawn a distinction between the acceptable practice of offering inducements to encourage people to participate, and unacceptable coercion, which makes a threat of violating the person's human rights if they do not cooperate. Ethics Committees consider actions to be undue inducement if they distort people's judgements of the

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HMRC (see footnote 34) does not apply here as they are not being paid as research participants but rather to recruit research subjects.

<sup>75</sup> The rate is that paid to postdoctoral students employed on a consultancy or piecework basis. If supported, DISCO will start in the autumn of 2013.

<sup>76</sup> See <http://www.mindfulemployer.net/> for more information. NHC is signed up to the Mindful Employer charter, but the University of Nottingham is not (see [here](#) for a list), despite government encouragement to do so (DH (July 2012) *No health without mental health: Implementation Framework* page 35).

<sup>77</sup> [http://www.ushmm.org/research/doctors/Nuremberg\\_Code.htm](http://www.ushmm.org/research/doctors/Nuremberg_Code.htm) The Code forms the foundation of medical ethics in many countries.



risks and benefits of participation, interfere with their freely given and fully informed consent, and prevent people from refusing to answer questions or withdrawing from the study at any time without losing their payment. Internationally agreed guidance<sup>78</sup> ensures that these issues are treated with particular care when vulnerable populations are involved as the impact of threats or coercion may be disproportionately large.

Making a payment cannot be a threat, but may be considered to be undue inducement if the amount paid leads the person into a reckless disregard for risks or clouds their judgement of the costs and benefits of engaging in the research. However, one study<sup>79</sup> found that the offer of money led people to scrutinise the offer more thoroughly than otherwise and others<sup>80</sup> found no effect. Small payments have been found to encourage people to engage in healthy behaviour<sup>81</sup>. It should take account of the person's usual opportunities for earning this kind of sum.

Free prize draws and lotteries<sup>82</sup> are sometimes used to encourage participation as a research subject. Lotteries occur where participants have to pay to enter and prizes are allocated by chance, and are subject to the Gaming Act 2005.

The model policy<sup>83</sup> produced by the Mental Health Research Network says that people will not be paid for participation in research. Others<sup>84</sup> offer £60 for giving blood, or £120 for participating in a clinical trial. Some studies<sup>85</sup> offer a small payment and describe it as a thank you gift, emphatically not *in exchange for* participating. Similarly, reimbursements for expenses and inconvenience can be made. Meanwhile, in the Royal Northern College of Music, expert tutors who serve as research subjects are reimbursed for their time, with payments being made at the actual 'loss of earnings' rate – the hourly rate they charge for instrumental tutoring. Guidance does not seem to be available on setting payment levels<sup>86</sup>.

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<sup>78</sup> World Medical Association (2008) *World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects*. Ferney-Voltaire, France: Author. Available at <http://www.wma.net/en/30publications/10policies/b3>.

<sup>79</sup> Cryder CE, London AJ, Volpp KG & Lowenstein G (2010) Informative inducement: study payments as an indicator of risk *Social Science & Medicine* 70, 455-464.

<sup>80</sup> See, for example, Halpern SD (2011) Financial incentives for research participation: Empirical questions, available answers and the burden of further proof *American Journal of Medical Sciences* 342: 290-293.

<sup>81</sup> See [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(14\)60490-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)60490-6/fulltext)

<sup>82</sup> See <http://www.ethicsguidebook.ac.uk/Are-you-paying-participants-or-using-lotteries-or-prize-draws-192>

for more information on using prize draws and lotteries to encourage people to become research subjects. For example, the Royal Northern College of Music policy (2012) offers three Amazon vouchers in a prize draw (first prize £30, second prize £20 and third prize £10) for completed questionnaire returns.

<sup>83</sup> See MHRN (2012) *Model Payment Policy for Service Users and Carers for MHRN hubs hosted by NHS Trusts*.

<sup>84</sup> See, for example, Richmond Pharmacology at <http://www.trials4us.co.uk/registration/index.php>

<sup>85</sup> For example, the Impact of Injuries study in CLAHRC NDH offers £5 for each completed questionnaire.

<sup>86</sup> As examples, (i) the National Research Ethics Service expect applicants to justify how the payment amount has been calculated, but offer no guidance on how to do this. Clive Collett explains "There currently isn't any guidance on rates and I suspect the HRA or others would be wary of providing guidance on "rates" as it is not the role of the HRA to set such tariffs for research payments and even if they did the over time these would need to be updated. Thus, currently each proposal would be considered on its merits in the context of the complexity of the research and the specific participants to be recruited by each research ethics committee. The onus is always on the applicant to justify and clearly explain how the payment amount had been

## Recommendations

26. Develop a shared view about the guiding principles for reimbursement and reward for participation as a research subject. Continue to define individual arrangements prior to seeking Ethics Committee approval, and to ensure that subsequent actions follow the guidance of the Committee.

## PPI representatives who have a job

What happens if person wishing to engage in PPI activity has a job and the proposed activity falls in their normal worktime? We might ask the following questions:

- Is the employer willing to treat the PPI activity as part of the person's ordinary work, or perhaps label it as a training or career development opportunity, or as Employer Supported Volunteering?
- Is the employer providing equality of opportunity to all its employees, or are some grades or departments able to take up volunteer or PPI opportunities within their worktime, while others are not?
- Is it possible to vary the person's working hours so that the PPI activity falls into their leisure time or annual leave?
- Many people do a full time job and then use their leisure time to undertake voluntary work, without then using their earnings potential in the workplace as an argument for seeking payment in the volunteer setting. Should our arrangements work this way?
- Should the organisation take a view about work/life balance? It is worth noting that many UK companies ask full time staff to work 37 hours a week, while the European Working Time Directive sets a usual maximum working week at 48 hours. On this basis, up to 11 hours a week might be available without harming the person's leisure life.
- Is the person's contribution entirely unique, or could someone else provide a PPI perspective without these complications?

One NHS Foundation Trust compensates employed people for loss of earnings on a discretionary basis if arranged in advance<sup>87</sup>.

In contrast, the maximum reimbursement for 'loss of earnings' due to undertaking jury service is £64.95 per day for the first 10 days, increasing to £129.91, thereafter, and with a further increase after 200 days. This is only marginally higher than the National Minimum Wage and so most employed people find that this breaches

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calculated." (personal communication, 4 October 2012). (ii) Timothy Conway at DWP responded: "All I really know is what we do in terms of our research. We do pay, usually up to £20 for people to take part in qualitative research. A participant would sign for receipt of that and as long as the form (which the researcher should have designed) makes clear that it is a gift then the individual would not have their benefits affected. This has not changed." (personal communication 5 October 2012).

<sup>87</sup> Cambridge & Peterborough NHS Foundation Trust (2010) *Payments for Service Users and Carers Involvement*, paragraph 6.10.

Principle 3a (avoid disadvantaging the person) – perhaps on the basis that everyone and not just the government, should contribute to upholding the rule of law.

### **Recommendations**

27. Attempt to negotiate with the employer to have the PPI activity counted as part of their paid job. Check that the employer is offering opportunities consistently to all employees.
28. People who can choose their working hours should move their work so that involvement activity is part of their leisure time.
29. If the person is unable to adjust their working pattern, then seek a substitute rather than offering the person a casual contract of employment.
30. Where it can be shown that (a) the person will lose working time, (b) the level of their lost earnings can be established in writing, and (c) the contribution cannot be made by someone else who would be cheaper – then reimburse the loss of earnings or transfer the payment to the employer.