

Uncovering the values that motivate people in relation to payments for involvement in research

By Teresa Roca and Peter Bates

In the United Kingdom, more than £8 billion a year is invested in health research and much of this work relies on members of the public to come forward and volunteer to be research participants or advisers. Participants allow researchers to test drugs and other interventions on them, measure their reactions and report the findings; while advisers comment on documents and attend steering group meetings to share their views about the direction of research and its methods. In recognition of this contribution, both participants and advisers sometimes receive some money or gifts such as a shopping voucher, but this is highly contentious for a wide range of reasons.

Firstly, the history of research ethics, starting with the 1947 Nuremberg Code, outlawed coercion and emphasised the importance of free choice in whether to participate in research or not. While offering money may encourage some people to take a reckless approach to the risks involved, there is evidence that it also appears to act as a prompt to scrutinise the transaction more carefully. Secondly, people who rely on means-tested welfare benefits worry that receiving a payment for participation in research may destabilise their entitlement to benefit by drawing attention to the claimant, triggering a review, risking the application of obscure regulations that they know nothing about, and a loss of income. Where welfare benefit regulations are used to set payment levels, the resulting sum may be viewed as paltry or insulting to members of the public who are used to professional rates of remuneration. Thirdly, current national guidance is fractured and incomplete, as it largely relates to research advisers rather than participants, to welfare benefits rather than tax, to research rather than service delivery, to health rather than social care, and to statutory rather than voluntary organisations. This confused policy is then overlaid with inconsistent local interpretations and so fourthly, the procedures surrounding such payments are so complicated that some NHS Trusts have found them unworkable and simply abandoned the guidance, leading to a conflict between national policy and local practice.

These problems are longstanding, so why is action needed now? The Coalition Government has redesigned the welfare benefits system and the introduction of Universal Credit in 2013 will trigger reform of payment systems for involvement in health research. Further, the government has set ambitious targets for increasing participation levels in research. In response, the major body that supports public participation in research, Involve, will be issuing new guidance. So, in order to understand more about the ideas that drive payment and reward arrangements, the second author reviewed policy and guidance statements in Spring 2013.

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Reflection on this material generated a set of sometimes contradictory value statements that appeared to underpin different aspects of policy.

These value statements were then formed into the heart of an online survey that we ran in Spring 2013. This yielded 251 useful returns from a group of respondents that included a few more women, people over the age of 40 and people from ethnic minorities than the regional population overall. People received a variety of different types and amounts of reward, just as we had anticipated.

The main part of the survey asked respondents to tell us what principles they thought *should* drive any payments system. They were presented with 46 statements and asked to rate each one on a 5-point Likert scale to indicate the strength of their agreement or disagreement with it. The first author then conducted a factor analysis to look for themes that drove the scoring. The three main factors that emerged from these statistics are set out below.

Personal Development

The statements that clustered together to form this factor were:

- Involvement expands important personal and social skills
- Involvement should help participants to develop their skills
- Involvement develops work-related skills
- The involvement system should promote wellbeing, independence and employment
- Involvement supports people to express their views, experiences and concerns
- Arrangements for getting people involved should support people who are vulnerable to make a contribution alongside others

The personal development concept includes a pastoral responsibility for people who engage with researchers, ensuring that people are kept safe from exploitation and have opportunities to develop in confidence, assertiveness, knowledge and skills. A system that focuses on this agenda will establish mentoring relationships between researchers and lay advisers, offer coaching in relevant skills, and provide training and networking opportunities.

Volunteering

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From this perspective, involvement in research is a form of volunteering, as captured in the following statements:

- Payments can coerce and distort motivation
- To contribute to society at large is a good enough reward
- Unpaid people can challenge the system
- Paying for involvement may bring the 'wrong' people forward
- Volunteering is a way to give something back in exchange for the clinical care you have received
- Involvement is a leisure activity

Within this frame of reference, patient and public involvement in research is a contribution to civil society, a way for people who have used health services to recompense the community that has helped them and something that should not be distorted through financial rewards. A system that focuses on this agenda will advertise participation through volunteer centres, emphasise flexibility rather than obligation, invest in thanking people rather than paying for their time, and provide pathways into other opportunities to volunteer in the community.

Work and the market place

The third factor suggests that patient and public involvement should be like paid work in which skilled labour is exchanged for money in a capitalist market place. This is revealed in the following statements:

- The amount of money paid should relate to the actual tasks being done
- Payment levels should reflect the effort required
- Activities that are more intrusive (time consuming, invasive, dangerous or disruptive) should be paid at a higher rate
- Pay people according to the level of skill required
- It's work, so set out clear expectations

A system that focuses on this agenda will design participation opportunities around defined roles, feedback on performance and references as well as paying people on a scale that starts at the National Minimum Wage or above and then rises by increments of responsibility to consultancy rates.

How powerful are these factors?

There are two ways in which the relative power of these three factors may be reviewed. A simple comparison of the number of respondents who subscribed to the factors, place Personal Development as most important, followed by Work and

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the Market Place and then Volunteering. More importantly, one might consider the power of the factor to drive (or 'load') the results. Using this approach also places Personal Development as most important but switches the other two factors by placing Volunteering second and Work and the Market Place third.

Discussion

Having set out these findings, we hasten to give several reasons for caution. Firstly, findings are less certain if the sample size is small, as is the case here. Secondly, the statistical tests that were applied may establish a relationship between factors, but cannot comprehensively establish causality. Thirdly, we note that some other questionnaire items had a minor impact on the overall dataset, such as people wishing to promote fairness and equality in society.

Conventional guidance on payments for participation begins with the welfare benefit system and attempts to devise arrangements that will avoid punishing participants and will reward them for their engagement. However, payments for participation fall into an ambiguous space full of perverse incentives and inconsistencies that lies at the boundary of welfare benefits, taxation, employment law and safeguarding. The result is guidance that focuses upon people in receipt of means-tested welfare benefits and offers no help on how to engage with other groups.

The work reported here takes a very different approach. We have uncovered three broad sets of principles that our respondents regard as an ethical approach to payments and attempted to rank them in order of importance. This provides a new starting point for constructing a policy that will both address real need and recognise the contribution of participants in a way that makes sense to them. The resulting policy would then have to be shaped by the constraints of national law and procedure before it could be used, but it would have a more secure foundation and a broader reach than current arrangements. The reform of the welfare benefits system provides a spur to such a project.

The three core factors of personal development, volunteering and work – provide a framework for training and discussion amongst patient groups, Boards of Governors and Research Ethics Committees. The shared language will help participants in those discussions clarify their own ideas, negotiate with others and even 'agree to disagree' about the best way forward. It moves the discussion away from private morality into a conversation about how to respond to the specific drivers that have been revealed in our survey.

Our research found that Personal Development was the most popular and powerful factor. This presses those who plan opportunities for involvement to design

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effective support for personal development, such as pastoral support, initiatives to engage seldom-heard groups and training and coaching opportunities.

The sequence of the second and third factors may reflect a shifting social context. In our study, Work had more adherents, perhaps in line with ideas that are dominant in the present economic and policy context, whilst Volunteering, which drove the design of local policies in the past, seems to be less advocated by our current pool of participants. We would need to track changes in scoring over time to explore whether wider social changes are in fact influencing the values that motivate people in regard to payments for participation.

We might also learn more about each of the three factors by examining the wider theoretical or empirical literature on them to see if they have any application to the specific example of participation in research endeavour. For example, the work of Hardill and colleaguesⁱ who found four kinds of volunteering may illuminate the different motivations that drive people to volunteer as research participants.

Our work has made a start in relation to the values that people think should drive a payments system for participation in research activities. Much more work is needed to design an approach to payments that harnesses these insights and then charts a course through the welfare benefit, tax and other systems. Such a pathway would lead to the formation of a procedure that is respectful of the diverse values and priorities of individual participants, legal, and encouraging of participation. We hope that the analysis reported here provides a starting point.

ⁱ Hardill I, Baines S & 6 P (2007) Volunteering for all? Explaining patterns of volunteering and identifying strategies to promote it *Policy & Politics* Vol 35, No 3, 395-412.