

The impact of paying users for their involvement – A discussion paper

1. Introduction

This paper discusses the issues around deciding when to pay users and the impact of paying people for their involvement (rather than the practical issues of how much to pay, managing the tax system and paying people on benefits). It mainly draws on information supplied by members of the User Involvement Shared Learning Group. A brief literature search (using Google and PubMed) found that there is very little published on the impact and experience of paying users for their involvement.

The views in the paper may not be shared by all members of the Shared Learning Group.

This paper was written in 2008. Some updates were added in May 2010. The paper is structured as follows:

- Section 2: When should users be paid for their involvement in the work of voluntary organisations?
- Section 3: When do users think they should be paid for their involvement?
- Section 4: What, in theory, are the benefits of paying users for their involvement?
- Section 5: What has been the experience of paying users for their involvement?
- Section 6: What do users say are the benefits of being paid?
- Section 7: Overall conclusions

2. When should users be paid for their involvement in the work of voluntary organisations?

One of the main problems for voluntary organisations is distinguishing user involvement from volunteering. This topic was covered in another paper produced by the Shared Learning Group – ‘*User involvement and volunteering*’. We concluded that:

- User involvement refers to any activity where the knowledge and experience of life affected by a health condition (or other disadvantage e.g. homelessness) is respected, valued and drawn upon to *influence* and shape the work of an organisation. Users are encouraged to share power, control and influence and therefore also share accountability and responsibility.
- The key aspect of ‘volunteering’ is the willingness of individuals to give their time freely to help an organisation to ‘do its job’. Anyone can be a volunteer. They are not necessarily affected by a health condition (or disadvantage) and may not require any particular expertise.

This distinction can sometimes help decisions about when a user should be paid for their involvement activity.

For all voluntary/charitable organisations, there is also the broader question as to whether it is appropriate to pay anyone for their time, when many people are willing to provide their time for free.

What do members of the shared learning group do?

Breakthrough Breast Cancer do not pay users for their involvement because they view volunteering as a core value for their organisation.

Breast Cancer Care developed and tested a policy on payment for UI. After piloting, they decided not to pay users for their involvement, mainly because of the problems of overlap with volunteering.

Diabetes UK do not to pay people to be involved because:

- user involvement sits in the volunteer department and the organisation has a culture and history of working with volunteers who are not paid
- they do not believe that money motivates people to do this kind of work
- they have some concerns about the effect of payment on the nature of involvement and the complexity of paying people in a way that doesn't effect their benefits.

Livability plans to offer people gift vouchers as they believe it is important to pay service users.

Macmillan Cancer Support stopped paying users for their involvement, partly because they concluded this was not an appropriate use of their charitable funds. They also used to pay their CancerVOICES regional contacts but have now stopped. No one has stopped being a regional contact as a result.

The National Council for Palliative Care does not pay users for their involvement, because they do not see this as a good use of their limited resources. People still choose to get and remain involved.

The Papworth Trust makes a £40 gift payment service users who work with other service users.

At **Shelter**, peer educators are rewarded with vouchers on a regular basis. However, there is some concern that this could be seen as payment and that it creates an implied contract.

Non-charitable organisations

Much of the external debate around paying users relates to involvement in the NHS and research organisations, where payment may be more appropriate since it does not conflict with volunteering. However, if different policies operate in different organisations, this clash of cultures can cause problems for collaborative projects. Macmillan experienced this in a joint project evaluating National Consumer Cancer Research Panels. It can also be confusing for users who work across the different arenas¹. The lack of a consistent policy can make it seem that decisions about paying users are arbitrary.

Paying expenses

There is no question about paying people's expenses. All members of the Shared Learning Group agreed that offering to pay people's expenses and paying them promptly (or even in advance) is essential. Expenses should include carer's costs, childcare and PA costs if required. A difficult issue is whether losing a day's pay through involvement should count as an out of pocket expense.

In all cases, it is important to be clear about which expenses will and will not be paid, and what level of involvement is expected in return.

3. When do users think they should be paid for their involvement?

Very little has been published on this topic. In a SCIE project on payment and the benefits system, users said they wanted payment so they would be seen as equal partners with everyone else 'working around the table'¹. In this context of influencing health and social care service development, the majority of service users did want payment. As one user described:

"I'm being paid the minimum wage for attending meetings where I am giving advice that has the potential to change people's lives and change policies. I've been in the mental health system for 20 years and I've got a damn sight more experience than a lot of the professionals I know".

In the same study, the service providers also reported that paying users gave them the right to expect things in return – for example reliability and appropriate behaviour.

In contrast, in a survey of users and volunteers carried out by **Macmillan Cancer Support**, the majority thought they should be paid for their travel, but were ambivalent about being paid for their time.

Similarly when carers in Sunderland were asked whether they should be paid for their work as carer representatives on local NHS/social care committees and forums they concluded that they shouldn't receive payment for their time. This was because:

- They felt payment would turn them into 'professional' representatives and give them a different perspective from the unpaid carers who freely give their expertise.
- They were concerned they might start to depend on this payment as a source of income, which would not be to their advantage.
- They were concerned about the impact on their benefits.

The **British Heart Foundation** (NHF) asked some of their users in Scotland for their views on payment for involvement and found the following:

- People distinguish user involvement from volunteering on the basis that it requires drawing on their personal experiences.
- Most people working with the BHF recognise that they are working for a voluntary sector organisation and don't want to take publicly donated funds away from research and education.
- Most people do not want to be paid for their involvement. However, some people believe that if they are asked to play a major role requiring a lot of input, then a token of appreciation would be appropriate. This could take the

form of a voucher, perhaps given once a year. It is important that people feel their involvement is appreciated.

4. What, in theory, are the benefits of paying users for their involvement?

In theory some of the benefits of paying for users for their involvement include:

- ⇒ Demonstrating that the input and expertise of users is valued by the organisation
- ⇒ Allowing a greater level of responsibility and participation and therefore accountability to be asked of people who are involved
- ⇒ Creating a more equal relationship between staff and users
- ⇒ Encouraging a more diverse group of people to get involved
- ⇒ Providing motivation for people to get involved for the first time

Based on Roger Steel's experience at INVOLVE, it can be very difficult to get diversity amongst involved users, and this may be made even more difficult if no payment is offered. People from marginalized communities have other priorities (sometimes just day-to-day survival), so they may need incentives other than 'goodwill' and 'a desire to influence and learn' to motivate them to get involved.

For this reason, the **Prostate Cancer Charity** planned to pilot paying users in a project that is aiming to engage men aged over 70 from BME communities, to see if this encourages their involvement.

In addition, some people may not be able to get involved unless they are paid. People that work may have to take annual leave or reduced pay to take part. This might mean that only certain groups of people are able to afford to participate. This was the reason that Macmillan Cancer Support originally agreed to pay their users. They hoped it would support the involvement of people beyond the 'usual suspects' – those people who were sufficiently well-off to be able to give their time for free.

5. What has been the experience of paying users for their involvement?

Organisations that have piloted policies for paying users have reported the following experiences, though this is largely based on individual perceptions rather than systematic evaluations:

- It is very difficult to set fair and clear policies on payment for user involvement in organisations where there are large numbers of volunteers, as the boundaries can get very blurred.
- There can be problems with people who want to become 'professional' users. Some people, who have lost their jobs as a result of their health condition, have found UI to be a way to restore their earnings. They may also develop new skills and confidence, e.g. in becoming a trainer, which they may not have developed in their previous careers. These people can easily take advantage of the system where they are getting paid, and monopolise any involvement opportunities.
- For some organisations, payment has not had an impact on increasing the either the number or the range of people who get involved. The people who

benefit most from any payments are often the people who know how to work the system, who are often very far from the people most in need.

- For other organisations, payment does seem to provide an incentive, is valued by the users and plays an important part in ensuring diversity.
- The practical issues around paying tax and avoiding loss of benefits can be a challenge. It is really important that payment is offered as a choice and individuals are given the right advice and support to manage the consequences of being paid.

At **Rethink** it seems that carers are more likely to be motivated by a payment. This might be because they are less likely to suffer benefit problems. Service users seem to be more cautious about payment and are just as likely to get involved without being paid. In fact the vast majority of people who work with Rethink do not get paid.

6. What do users say are the benefits of being paid?

There is some anecdotal evidence of the impact of payment on users. One woman who was paid for her involvement as a user at **Breast Cancer Care** as well as giving her time freely as a volunteer, described how being paid had made a difference to her and the staff she worked with:

"If you're paid, you're a member of the team. The staff attitude is different if users are paid, otherwise it can be a bit 'you don't have anything else to do, you've got lots of spare time' etc... It's about valuing people. People speak down to you otherwise. It's like once you get cancer you don't get paid for your contribution, even if it's a business meeting."

7. Overall conclusions

Payment for user involvement can address some of the other challenges of involvement - namely ensuring a diverse group of people get involved, and ensuring people's views are listened to, valued and acted upon. However, there are other ways of meeting these challenges. It is still not clear whether payment is an *essential* part of this process. If user involvement is *managed* well, some of these challenges would not appear.

There are also other benefits to involvement, not just from getting paid. For example, Breakthrough Breast Cancer's strategic objective for UI is "*To change the way we relate to stakeholders in order to engage them, maximise contributions, and deliver greatest benefit to them and to us*". UI therefore operates on a principle of "mutual benefit", which is thought to replace the need to pay users.

One area that could be developed is supporting people who want to move on from user involvement, to use their new found skills in paid positions. More attention could be given to supporting people along a 'user involvement pathway' e.g. by developing new employment opportunities that enable organisations to reap the benefits from the investment they have already made in developing people. For example:

Action for Blind People is beginning to look at a route for service users to become employed.

Diabetes UK is starting to look at helping people turn their involvement into experience on their CV.

Breakthrough Breast Cancer is looking at people gaining accreditation for the training they attend.

The User Involvement Shared Learning Group
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References

1. M Turner and P Beresford. (2005) *Contributing on equal terms: Service user involvement and the benefits system*. London: SCIE.