

Payments for Participation Report

Background

As part of the Royal College of Paediatrics and Child Health (RCPCH) revision of the Guidelines for the Ethical Conduct of Medical Research Involving Children (2000) the NIHR Medicines for Children Research Network were tasked with investigating young people's views on whether or not the offer of payment, (common in adults) to participate in research would influence their decision to take part in research. By payment we refer to cash sums, the most commonly form of payments for participation of which four main types have been described:

Reimbursement payments compensate participants for direct financial expenses of involvement in the study. Such costs will only be based on the *actual* expenses incurred by the participant as a result of participation and usually requires receipts.

Compensation payments similarly reimburse direct costs of participation, but also reward participants for the time-cost and effort of involvement in the study. The level of compensation offered depends on factors such as frequency of clinic visits, risks associated with involvement and length of hospital stay.

Appreciation payments are small tokens given after study completion to reward participants for their efforts. These may commonly take the form of gifts or vouchers, but money may also be offered.

Incentive payments are designed to directly encourage enrolment through the promise of financial gain above the direct and indirect expense of participation.

Young Persons Advisory Group Input

A workshop was designed and rolled out late 2012 across the MCRN National Young Persons Advisory Group, which has over 80 members aged between 8-18 years old. The Scottish Medicines for Children's Network also carried out the workshop with their members.

In total 54 young people aged between 9 and 18 years of age took part. This was broken down into 16 males and 38 female contributors.

Each group focussed on three case studies that involved varying degrees of testing ranging from clinical trials of medicinal products to non medical studies and invasive and non invasive studies. The technique of role plays was utilised to allow participants to explore the issue from different points of view. The group were asked to take on the role of three

characters that included a research nurse, parent and child and used set questions to facilitate the discussion.

- Would you participate if payment were offered?
- Why?
- What would be the most acceptable form of payment?

The group observed the discussions and shared their opinions based on the characters explorations of the issue. The feedback is measured against responses before and after payment was offered.

Key feedback

Invariably, young people had more reservations about accepting payment with invasive clinical studies that were the most serious as they felt they were being coerced into a situation without giving true consent. One young person commented that, “No matter how invasive the study is, no amount of payment would be considered appropriate.”

Regardless of how long the study would last, the children felt that money became more inappropriate as an incentive. The issue was clouded further by varying amounts of monetary incentives. For instance one young person said, “I am suspicious about why lots of money is being offered.” Another said that if a study was particularly invasive then, “a small amount of money would be insulting and not reflect how hard the trial is.” Most felt that no amount of money would make up for the intensity of a study. One young person suggested that they felt differently however and stipulated that a fixed payment should be made per individual visit because, “A lot of effort is required and the side effects can be horrible.”

However, their feelings towards simple, quick and non- invasive studies were quite different. 90 % of young people suggested that they would be happy to participate if it was aiding research and wouldn't expect any payments. One young person asked the question, “Do we really need to be paid if we want to help people anyway?” They were open to the idea of nominal vouchers retrospectively as a gesture of goodwill for their participation. One member said, “It is quite nice to receive a voucher or ticket to a show.” Members of the Scottish Network thought that vouchers should encourage a healthy lifestyle e.g. vouchers for swimming or sports centres. Some believed that if you know you are helping other people that should be enough.

A concern was raised regarding the general public opinion of offering payments to participants as it might send out the wrong message. In all circumstances, it was agreed that travel expenses should be reimbursed. Children understand the consequences of time, cost and inconvenience to parents accompanying young people on clinical studies.

Issues such as demographics also play a part in the difficulties offering payment. Children felt that low income families might feel they cannot say no to their child being involved, whilst other parents may not be able to guarantee that the money will go to the child. “Parents could force children to do something they don’t want to do for payment – it’s really wrong.” It was also felt that offering large payments may pressurise children to take part. In some cases it was recommended that the child be awarded a certificate or goodie bag as a way of recognition.

Conclusions

The general consensus was that it was acceptable and reasonable to give a small reimbursement or appreciation for participation, but under no circumstances should we offer any sort of incentive or compensation payment:

“Shouldn’t be used to bribe, better to be given at the end as thanks.”

The young people felt that offering incentive or compensation payments makes the decisions much harder to make and that there are so many variables it’s impossible to determine a fair rate of payment, which makes it unethical. Furthermore, it may cloud the issue of participation and often incentivise something a young person has not fully consented to. They felt that travel expenses should always be covered as a sign of goodwill to parents.