

How to set payment levels for research participants



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1. Introduction and summary of findings

This is one of a series of guides¹ addressing issues that relate to payments for members of the public involved in research. Most of the others relate to engaging Public Contributors as coproducers of research, while this guide is concerned with payments made to Participants¹ – perhaps for being interviewed, completing questionnaires or undergoing treatments and tests. Participants may be healthy volunteers or people who live with the condition under scrutiny, but the defining aspect of the role is that they are participants (the people who were previously called ‘research subjects’). Such payments are usually made to everyone who contributes data to the study, although in some cases, willing participants are entered into a prize draw².

¹ A note on language. In this paper, the roles of Research Participant and Public Contributor are capitalised as individuals are under consideration, while the activities of research participation and public contribution are not.

Payments should be only one part of a broad approach to ensure that participation in research is accessible to all by investing in public understanding of science, locating participation sites on public transport routes or online, making reasonable adjustments to enable excluded groups to participate, fitting around work and family duties and reducing the demands of participation³.

A great deal of care should be taken to ensure that such payments are not so low that they exploit⁴ participants nor so high that they amount to coercion or undue inducement⁵ (obstruct the person's free choice to resist, start, complete, or abandon their participation⁶); distort the person's evaluation of risk⁷; erode trust in the overall research, downgrade data quality; or precipitate attempts to secure the payment by deception⁸. This paper is mainly about the level of payment and explores ethical concerns briefly en route.

Ethical issues include the question of who decides on the level of payment that is proposed in the original funding application; how it is amended if the funder requires economies to be made prior to approval; and how it is offered to specific individuals in relation to identified activities. The principle of coproduction indicates that these decisions should be made in partnership with Public Contributors, but it is not always clear whether this has been done or not. In example 3.2m below, a group of Public Contributors:

- were given a budget and then devised different ways of distributing it over the course of the trial for each research activity completed by participants
- voted on the different approaches
- Sought feedback on the most popular approach from independent focus groups
- Settled on the final arrangements in collaboration with the research team.

Similarly, in example 3.2g, the research team undertook an initial study where they asked people their opinion on the amount of money to offer in later research and settled on a figure that was appreciated by participants but was not of such a value that it may be construed as an undue inducement to take part.

Relevant literature and real examples of payment levels are used to explore some of the issues involved, provide benchmarks for comparison⁹ and meet the obligation for transparency¹⁰. The tables below contain examples selected to highlight the range of payments that have been deployed in a selection of studies. Further work would be needed to find out how often each option is used and whether payment rates are correlated with other factors. The discussion after each table presents the explanation provided by a member of the research team in response to a simple inquiry¹¹, annotated with reflections by the author¹². Research teams mentioned in the text were then invited¹³ to review what has been written about them and suggest improvements. The project is ongoing and saturation will be achieved when no new payment rates are found and no new justifications offered¹⁴. The aim is not to narrow down onto shared viewpoints, but to expand possibilities by reporting on both common and unusual levels and justifications for payment. The result can bombard readers with multiple possibilities, so this document is perhaps best viewed as a resource from which more concise and thematic arguments can arise. This Guide applies to the United Kingdom only, as there are significant differences in the legal context elsewhere¹⁵.

The evidence gathered during this exploration is set out in sections 2-6 below and the findings can be summarised in the following six statements:

1. The voice of patients and the public is rarely heard in this debate¹⁶, so Research Participants are often cast into the role of grateful recipients of a pre-ordained system rather than as Citizen Ethicists¹⁷ who know the right thing to do.
2. Most attention to date has been given to avoiding undue inducement, with little time spent on the ethics that might shape levels of payment considered safe.
3. There are no industry norms and few guidance documents to inform the decision about how much to pay, or how to pay Research Participants. The vacuum is filled with folklore and diverse practices.
4. Many different arguments are used to justify both payment and non-payment decisions, sometimes with little rigour.
5. There is little evidence to show that payment increases recruitment and retention of Research Participants, and this is not always why payments are made anyway.
6. Payments for research participation overlap with payments for some other activities. Applying the payment rates designed for Public Contributors to Research Participants could treat people well and increase the cost one hundredfold.

2. Alternative arrangements

2.1 Unpaid participation

The examples in the following table show that researchers can ask for information ‘for free’ in a variety of formats on a range of topics and involving diverse time commitments. While non-payment is acceptable¹⁸, international commentators suggest that the use of unpaid participants in health research is in decline and payment is displacing non-payment¹⁹. In Karagic et al’s survey²⁰, only 6.3% of the public thought that researchers should eschew offering payments to research participants.

There may also be effects between payment options, so offering a payment in one study may deter participants from engaging with a subsequent study where payment is not offered. A longitudinal study to examine these mechanisms might discover the opposite effect too: participants who were paid at first realise the benefits and engage in a second study for altruistic reasons.

Examples of research studies that did not offer a payment for participation

	Format	Topic	Duration (mins)	Source
2.1a	Online questionnaire	Apps for anxiety	10	21
2.1b	Online questionnaire	Loneliness	20	22
2.1c	Online survey	Disabled children’s education	20	23
2.1d	Online tests	Pattern recognition	60	24
2.1e	Daily app use	Mood	12 weeks	25
2.1f	Telephone interview	Hospital discharge	15	26
2.1g	Online questionnaire	Carers	30	27

Several writers²⁸ have made the case for non-payment to participants as an ethical position. Arguments often combine several of the following:

Prohibitions. One research team declared, ‘we are guided by ethical principles, in that we are unable to pay study participants to take part in studies.’²⁹ No such prohibitions have yet been found, but it is quite possible that local policies may exist which prohibit payment, or that organisational folklore exists which leads staff to believe that a written policy exists when there is actually no such document.

Supply of volunteers. If citizens fitting the study requirements are in plentiful supply and it is easy to achieve a sufficiently diverse sample, funding is not needed as an additional incentive to drive recruitment. Other citizens may be unwilling to volunteer and feel exploited by the lack of payment offer.

Minimal burden on participants. The brevity of the survey was given as a rationale for non-payment in example 2.1a. Some potential respondents will be content to participate if they remain anonymous³⁰, while others will find that the minimal burden is still too great to bear.

Minimal burden on researchers. Collecting addresses and bank account information and administering payments is laborious and can be avoided by simply not offering to pay. This issue is amplified when the target number of respondents is high, such as in example 2.1c where the goal is 1500 returns. Participants are pointed to the study webpage where findings will be published in due course.

Time pressure. If the results of the study are needed urgently, all processes that delay completion are stripped away, and this includes administering payments.

Stewardship of funds. Money should be assigned where it is most needed, and so if the research can be successfully completed without making payments for participation, then the funds should be diverted to a more useful purpose³¹. Sometimes the budget for the study does not allow for such payments, but this is rather a spurious argument if the research team are the very people who wrote the funding application in the first place³². In example 2.1g, the researcher asked for funds to make a payment to participants who completed a questionnaire, but this was refused by the funding body. Example 2.1f illustrates another stewardship issue, since all the respondents are already salaried, and will be expected to complete the interview as part of their work duties. This viewpoint is strengthened when staff salary is funded from the public purse.

Science as a motivator. One respondent commented that ‘we believe that participation in research alone should be reward enough instead of monetary compensation’. Some might ask if these researchers also decline their salary cheque or, if pressed would admit that most people’s daily lives are shaped by a forcefield of diverse motivations.

Altruism and service as motivators. In example 2.1c, altruism was regarded as a more powerful incentive than money, so potential participants are assumed to believe that this research will lead to improvements in the education, health and care of disabled children. Jonas³³ argues that volunteering to undergo risk and possible injury for the sake of the community is a noble sacrifice that cannot ever be demanded nor adequately rewarded. Lynch et al (2020)³⁴ recommend that researchers ‘welcome altruists, while resisting approaches that rely heavily on altruism’ (p14), and in fairness, compensate altruists rather than expecting them to participate for nothing.

Data quality. Offering payment (or sometimes excessive payment) might draw in respondents who are more interested in receiving the payment than in telling their story, rendering their responses superficial rather than reflective, depersonalised rather than engaged, brief rather than exhaustive, and slapdash rather than accurate³⁵. Lynch et al (2020)³⁶ observe that data drawn from altruists may not be all that different from data drawn from participants motivated by financial considerations.

Benefits of participation. In example 2.1d, the research team expected participants to benefit from using the smartphone app since they would gain insight into their own mental health. The team decided that this benefit cancelled out their obligation to provide financial reward. In healthcare services that are free at the point of use, the offer of a payment can signal that this is research and so help to prevent the participant from falling into 'therapeutic misconception' – the error of imagining that activities designed to advance research for the general population are actions designed to improve their own personal care and treatment³⁷. The team that wishes to offer non-monetary 'benefits of participation' as an alternative to a payment needs to ensure that participants understand what they are getting into. Alternative non-monetary benefits are offered from time to time, such as sending participants a Christmas card, which has been found to make no difference to retention³⁸ but may have delivered other benefits.

Proportional rates. As well as their consideration of the benefits of participation, the team in example 2.1d constructed a ladder of payment rates, with the task of completing a short online questionnaire placed on the lowest rung and so yielding no payment, and payments rising for activities such as attendance as a Research Participant at a focus group and rising again for activities as a Public Contributor, such as membership of a Lived Experience Advisory Panel and serving as a Public Co-Applicant³⁹.

Uneven impact. Some researchers worry that payments cannot be delivered evenly. Fairness demands that every participant is given the same offer of payment, but each person's circumstances will be different, so the offer will be experienced in different ways. Thus, for example, an offer of £50 will be trivial to a wealthy person but might be life-changing for a person living in secure accommodation on low income. For the latter, the offer may be an undue inducement that invalidates consent - and so perhaps it would be better to avoid this problem by paying nobody. This argument is flawed in three ways. First, while payment influences the decision to participate, it does not amount to coercion (see below). Second, there is no empirical evidence to support the view that payments are more likely to generate undue inducement in economically deprived communities⁴⁰, while there is evidence to support the view that stereotypes can shape opinions⁴¹. Third, while it correctly shows that selecting the correct level of payment to offer is hard, the same arguments apply to non-payment, which will also have an uneven impact.

2.2: Payments to others

This section provides some examples of payments where the money is assigned to another agency or individual rather than the research participant.

The Afri-c study is recruiting ten care homes in England to participate in a study where air is filtered to find out if this reduces the incidence of coronavirus. Care homes in the intervention group are offered £1,000 for involvement in the set-up and £3,500 for the

closedown of the research, while care homes in the control group were offered £750 for the set-up and £2,250 for the closedown. The payment is offered to the proprietor or the home along with the consumables - primarily the air filters – and each home is involved for one winter period, usually September to April⁴². Since a substantial proportion of care homes are for-profit establishments led by an owner/manager who has no other residential units, payments to the proprietor equate to payments to the research participant.

This example may be considered as a neat reversal of the practice of full cost recovery by the NHS for its involvement in commercially funded research. This approach precisely costs the additional tasks undertaken by the care provider (the NHS) that are necessary for the research to proceed and ensures that they are fully recompensed without making a profit or loss on the transaction. The fact that the commercial funder hopes to eventually make a profit from the research is used to justify a full cost recovery approach in contrast to the partial cost recovery system⁴³ that is used for non-commercial studies. In the above example, the care home is the service provider and the research team is positioned as the funder, so a precise calculation of the additional costs incurred by the care home as a result of its participation in the research could lead to a payment to the organisation. An algorithm has been devised⁴⁴ for making such a calculation, although we must wonder if it has ever been used to calculate the appropriate level of payment to a care home in acknowledgement of their involvement in a research study.

In another study of care homes⁴⁵, the research team offered £1500 to each participating care home. Staff film mealtimes where alcohol plays a part and both staff and residents are invited to engage in online interviews. In granting approval, the Research Ethics Committee must have considered where the money goes and how it affects the engagement of staff and residents in the research as well as addressing staff workload and resident privacy considerations⁴⁶. The payment was accompanied by a recommendation that it could be donated to the home's activities fund or to pay for something that residents will benefit from. This decision was based on a previous study which found that most care home residents preferred this arrangement and did not want to receive payments for themselves⁴⁷.

Some research funders allow applicants to include the costs borne by the care home who then reclaim expenditure incurred for attending meetings and other activities attributable to the research⁴⁸.

A research study conducted in 2021 by Ipsos MORI on behalf of Elsevier called "The Clinician of the Future" aims to explore trends and changes that will impact the future of healthcare⁴⁹. Participants complete a 15-minute online questionnaire, receive a copy of the final report and indicate which charity from a predetermined list will receive a donation of US\$5.

3. Payments for specific activities

Some researchers pay differing amounts to participants assigned to each arm of their study, especially when the demands of being involved vary considerably. However, the decision to offer participation in a particular arm, and therefore the level of payment, is decided for

clinical and research reasons, rather than as delegated for the participant to choose and possibly be accused of 'chasing the money'.

3.1: Payments for completing a survey or questionnaire

Surveys and questionnaires offer the least demanding option for data collection, especially online, brief surveys. Evidence on payments for research is largely drawn from studies of these tasks⁵⁰, with few studies exploring the effects of payment offers upon recruitment or retention when other data collection mechanisms are used. In relation to brief, online and or postal surveys, the British Psychological Society advises that payments should not be so low that they exploit participants⁵¹, but does not go on to indicate what a threshold figure might be.

Sometimes a questionnaire is combined with other activities, such as watching a short online video before answering the questions. As the principles underpinning payment for these complex approaches are more difficult to discern, the majority of entries in this document will be simple rather than compound approaches.

Payment is usually made in retrospect to those who have completed the survey, but can be made in advance, as was the case with a survey of Ethics Committee chairpersons⁵².

The payment is sometimes made by bank transfer⁵³. Several of the payments are made by voucher, which is perhaps intended to emphasise that it is a gift, although declaring it in marketing materials reframes it more as an obligation which, if withheld, would result in participants feeling reasonably aggrieved. The wide range of purchases that can be made suggest that it could be used for extras rather than weekly food shopping⁵⁴. Some teams check the National Living Wage⁵⁵ hourly rate before deciding on the value of the participation payment which they will offer.

Grady⁵⁶ observes that people may value cash and gifts in kind differently depending on their preference. Respondents in receipt of welfare benefits may erroneously believe that a cash payment will lead to a review of welfare benefit entitlement in contrast to a gift which will be ignored⁵⁷ and it can be difficult to reassure people who have had negative experience with the benefits system in the past. Welfare benefit reviews are more likely to happen if the value of the cash or voucher is greater than £30⁵⁸. Similarly, research teams may believe that offering a voucher to an employed person will have fewer tax implications than payment in cash.

Vouchers are also a useful option for people who don't want to give out bank details, while others are unable or don't want to open an account with the company that issues the voucher. Research staff can help participants to set up such an account or make orders, but this can be very time consuming.

Paternal attitudes can lead to the use of vouchers rather than money as a way of controlling the participant. For example, people who use illicit drugs have been given vouchers in the past to try and prevent them using the payment to buy drugs, despite the evidence showing that paying cash does not lead to the purchase of drugs or relapse. The UK Health Research Authority⁵⁹ has declared that, unless there is clear evidence to the contrary about the specific recipient, research participants should be treated as autonomous persons and not treated differently to others. A further example in which payments are provided in a restrictive manner is provided when patients are issued with a rechargeable MasterCard

loaded with monetary value by the research team, while a merchandise category code prevents it being used to purchase alcohol or tobacco⁶⁰.

Research studies that offer a participation payment for completing a survey

	Format	Topic	Duration (mins)	Type	Value	Source
3.1a	Online	Diabetes and activity	15	Voucher	£10	⁶¹
3.1b	Survey	Venous leg ulcer	?	Voucher	£10	⁶²
3.1c	Online	Chronic pain	30	Prize draw	£15	⁶³

In example 3.1b, the research team reviewed evidence on the effect of payments on retention before designing their approach and are also testing whether the additional provision of a thankyou card and a newsletter about the progress of the study reduces attrition. Participants are asked to complete a questionnaire at four time points and then they receive the single voucher at the end of the entire period. Sending the Research Participant a voucher at the end of the whole study precludes testing whether receiving the voucher has an impact on recruitment or retention, although the promise of its subsequent arrival may have an impact.

In example 3.1c, participants are given the option of being entered into a prize draw to win a £15 voucher⁶⁴ and told that there was approximately a 1 in 50 chance of winning.

3.2: Payments for being interviewed

The following examples suggest that payment levels vary considerably between studies, and the amount does not appear to be systematically affected either by the duration of the interview or the sensitivity of the topic.

Research studies that offer a payment for participants who were interviewed

	Format	Topic	Duration (mins)	Type	Value	Source
3.2a	Phone questionnaire with a parent and their child	Draft text of a questionnaire	45	Money	£70	⁶⁵
3.2b	Online Interview	Dental care	120	Voucher	£50	⁶⁶
3.2c	Online interview	Contraception	?	Voucher	£30	⁶⁷
3.2d	Online Interview	Covid bereavement	60	Voucher	£25	⁶⁸
3.2e	Interview	Communication with social services	?	?	£25	⁶⁹
3.2f	Interview	Starting insulin	?	Voucher	£20	⁷⁰
3.2g	Interview and breath test	Smoking	?	Voucher	£15	⁷¹
3.2h	Interview	Continence care	45	Voucher	£10	⁷²
3.2i	Online interview	Bowel cancer and sex	60	Voucher	£10	⁷³
3.2j	Online interview	Sexual violence	120	Voucher	£50	⁷⁴

	Format	Topic	Duration (mins)	Type	Value	Source
3.2k	Telephone interview	Carers experiences	60	Voucher	£20	⁷⁵
3.2l	Interview	Social citizenship	90	Voucher	£?	⁷⁶
3.2m	Interview	Condom use	Not given	Vouchers	£85	⁷⁷
3.2n	Online interview	MHA Detention	60	Voucher	£20	⁷⁸

In example 3.2a the money is to be shared between the two family members, bringing the payment per person closer to other payments cited here.

In example 3.2b the time needed for the interview itself was considered along with the fact that participation would require no preparation. The rate of £25 per hour reflects that offered to Public Contributors, which stands at more than two and a half times the National Living Wage⁷⁹ and well above the ‘average for similarly unskilled and burdensome work’⁸⁰.

Example 3.2c invited adults with learning disabilities to talk about their involvement in decisions about contraception, a sensitive topic that can lead to people feeling vulnerable. This group of adults may be more susceptible to coercion and so it is even more important than usual to ensure that the payments do not undermine informed choice⁸¹. If the person is deemed to lack capacity to give consent, then in most other areas of life, another person will act as the Decision Maker. This would increase risk if the Decision Maker does not personally face the discomforts and risks associated with participation in the research but does receive the payment or other benefits, and so participation payments for research participants aged under 16 and for adults who lack capacity appears to be limited to reimbursement of expenses only⁸².

In example 3.2d, the research team explain their offer of payment by simply declaring that it has been approved by the Research Ethics Committee as a small token of appreciation. Since all the payments featured in this paper are taken from real world research projects, every single option has received a favourable opinion from a Research Ethics Committee, leading one to wonder how these Committees interpret their role in relation to the ethics of participation payments and whether ethical payments are a lavish smorgasbord of options. Transferring responsibility for the mode and level of payment may occur for a variety of reasons, such as where an investigator pointed to payment norms in vogue in their institution and was personally unaware of the rationale for them. There are so many ethical challenges in conducting responsible research that adopting the conclusions of others is a reasonable way to proceed – at least in the short term.

Examples 3.2c and 3.2e have not provided an estimate of the duration of the interview.

In example 3.2e, Disabled co-researchers⁸³ work alongside academics to explore the use of digital communication between social workers and people using services. Respondents receive £25 and the Disabled Co-researchers £30 an hour, reflecting the greater obligation owed by the researchers in terms of hours per week and duration of their commitment to the study, although as they are freelance this is not a legally enforceable obligation. Any payment at all changes the nature of the relationship between staff and Research Participants, as it does between staff and Public Contributors, and discussing the amount of money to be paid adds to staff discomfort by inviting them to reframe their distinctive role and renegotiate their relationship with others⁸⁴.

In example 3.2h respondents are care home staff who are already paid, emphasising that this payment is a thankyou rather than payment in exchange for completing the task. In contradiction to this position, Lynch et al (2020, p41) argue that participation payments should be made without regard to whether respondents are being paid by their employer for the time involved, while Grady⁸⁵ identifies an aspect neglected in the Lynch et al model (see section 10 below), which is to treat the payment as an unconditional gesture of thanks and appreciation.

Examples 3.2i and 4a both involve intimate topics, yet the comparatively impersonal questionnaire in 4a pays five times the rate of the more demanding interview in 3.2i.

In example 3.2j, the researcher aimed to strike a balance between valuing participants' time and ensuring that money did not become the main motivation for people to participate. She was concerned that higher payments might bring in people who would turn out to be less comfortable talking about their experiences. For this reason, and because the payment is conceived as a thankyou gift rather than a reciprocal transaction for work done, the researcher would have preferred to conceal the value of the participation payment. In Example 3.2l, a voucher of unspecified value is offered to participants. The National Institute of Health Research has (perhaps inadvertently) taken the same approach by publishing information about opportunities for research participation without explaining payment arrangements⁸⁶.

In example 3.2k, participants were offered a £20 voucher as a thank you for their time, together with £20 towards the cost of any substitute care that is required to enable them to take part in the interview.

In example 3.2m, trial participants complete four questionnaires and provide two self-samples over a twelve-month period. Some participants may also be invited to take part in an interview if they express interest, are invited to take part, and then complete the interview. Not all participants will want to take part and not all those who express interest will complete the interview. Vouchers are offered to thank participants for each completed task, up to a total of £85.

3.3: Payments for attending a workshop or group interview

All the following examples describe group interviews that take place online⁸⁷; in-person meetings have not yet been identified which is probably an enduring consequence of the coronavirus pandemic. Some participants might feel that disclosing information to other group members demands a greater level of trust compared to speaking one to one with a trained interviewer. There is no evidence to suggest payment rates increase as the level of trust increases.

Research studies that offer a payment to participants who attended a group interview

	Topic	Duration (mins)	Type	Value	Source
3.3a	Experience of pain	120	Money	£50	⁸⁸
3.3b	Predicting pain	90	Money	£42.50	⁸⁹
3.3c	Avoidable harm	?	Voucher	£25	⁹⁰
3.3d	Unnecessary medication	90	Voucher	£20	⁹¹
3.3e	Views of Covid certificates	90	Voucher	£15	⁹²

	Topic	Duration (mins)	Type	Value	Source
3.3f	Nurses' wellbeing	240	Voucher	£110	⁹³
3.3g	Healthcare technology	90	Not stated	£75	⁹⁴

In example 3.3a, the total is made up of £30 for time, £5 for internet related costs and £15 for food. The rates suggested by NIHR for Public Contributors⁹⁵ were copied by the research teams and offered to Research Participants in examples 3.2b, 3.2f, 3.3a, 3.3b, 3.3d and 3.3g.

In example 3.3b, the total offer is made up of £25 per hour plus a £5 contribution towards broadband costs⁹⁶. The researchers also asked participants what kind of refreshments they liked and then sent sachets of tea, coffee or hot chocolate and some biscuits through the post as a treat to thank them. This example enables us to distinguish between compensating the person for subsistence costs (such as providing a meal for a Research Participant who is required for more than four hours) and an appreciation payment⁹⁷, which is more like a gift in that it is unnecessary but makes the person feel valued. Care is needed to ensure that the attempt to communicate appreciation does not backfire and leave the person feeling devalued⁹⁸.

Example 3.3c involves a range of opportunities, in which participants in an online survey were offered nothing, focus group participants were offered a £25 shopping voucher and Public Contributors received £150 per 90-minute meeting, so non-payment was part of a wider scale of payments.

In example 3.3d, vouchers were offered as this was considered to be the simplest way to manage these transactions during the pandemic.

In example 3.3e, the rate was set by comparison with an industry benchmark provided by the Prolific company, which recommends £7.50 per hour⁹⁹ and so the time required was presumably rounded up to two hours.

Example 3.3f seeks registered nurses willing to attend two workshops each lasting two hours and offers £55 per workshop. The team had previously used a rate of £25 per hour, having received approval for this rate from the Ethics Committee and from an advisory group of care home nurses. An additional £5 per workshop was offered in alignment with recommendations from the Applied Research Collaboration East of England in recognition of the online nature of research during Covid¹⁰⁰. Workshops are offered at different times of the day to provide choice and enable the nurse to undertake the workshop outside their working hours and so avoid any loss of earnings.

In example 3.3g, the figure was based on an hourly rate of £25, allowing 1.5 hours for the focus group and then adding a generous 1.5 hours for administration time around this, such as gaining consent, solving technical challenges to online participation etc. As has been shown in this section, there is some room for discretion in how times are calculated and other benefits provided, which can lead to variations in the offer made by different studies.

3.4: Payments for using a smartphone app or wearable device

In the table below, the duration refers to the number of days over which the research participant is expected to wear the device or use the smartphone. In some trials, simply wearing the device is sufficient and data is transferred without further action being needed, while in other studies, the user will have to open an app, select between a menu of options and send their response. These tasks are often combined with other activities to capture feedback on the experience or additional information, so the person may have to complete a questionnaire or attend an interview too.

Research studies where a payment is offered to the participant for using a app or device.

	Format	Topic	Duration (days)	Type	Value	Source
3.4a	Questionnaires, 60-minute interview and daily app reports	Mood and emotions	28	Voucher	£50	¹⁰¹
3.4b	Two questionnaires and daily app reports	Experiences of pain	30	Money	£20	¹⁰²
3.4c	Online 40-minute interview	Experience of wearing device	14	Voucher	£20	¹⁰³

Example 3.4a was made up of £20 for an hour-long phone interview and £30 for earning badges by using the smartphone app over a four-week period.

3.5: Payments for invasive procedures

In all research involving human subjects, the burden of participation should be minimised as far as possible, and payments must not be used to persuade participants to endure unnecessary procedures or take unnecessary risks. Around a third of research institutions surveyed in 2005 increased payment levels for participants in studies where risk was unavoidably high¹⁰⁴, which mirrors employment situations where staff are paid ‘danger money’ and this approach was reflected in the survey of patients where 62% wanted the payment system to include a sum to ‘make up for risk’¹⁰⁵.

Some potential participants who are given scant information about possible harms and side effects of experimental medication are more likely to use the payment amount as a proxy and conclude that large payments are to compensate for large risks¹⁰⁶, while the level of payment is less likely to be used in this way in circumstances where good quality information is provided about medical risks and outcomes. Indeed, evidence suggests that large payments encourage participants to carefully scrutinise the risks rather than ignore them¹⁰⁷, and while there is a real concern that some participants submit misinformation at the screening stage in an attempt to secure entry or during the study to avoid being stood down, there is no evidence to suggest that this effect is more pronounced when payment rates are high¹⁰⁸. Some studies requiring invasive procedures are run by a commercial organisation (perhaps pharmaceuticals or medical devices), so may be able to pay more than studies funded from the public purse¹⁰⁹.

A survey of American payment levels published in 2012 provided data on amounts paid for specific procedures¹¹⁰ and contemporary UK examples are given in the table below.

Research studies where a payment is offered to the participant for an invasive procedure.

	Organisation	Procedure	Number/duration	Type	Value	Source
3.5a	hVIVO (part of Open Orphan plc)	Flu Camp (injected with virus, details not given)	Number of interventions unknown, camp lasts up to 14 days	Not given	<£4200	¹¹¹
3.5b	London Trials				<£4000	

In example 3.5a, the opportunity is open to healthy participants rather than people with a particular health condition. The risk to participants¹¹² is increased, as they undergo discomforts and invasive procedures such as blood tests and are infected with the virus. However, in this case, it is unlikely that significant harm will ensue leading to the person needing long-term medical treatment.

These stark examples of risk also carry additional freight that may apply to less intrusive approaches. For example, the burden and inconvenience placed on volunteers is high as they are required to live away from home for a sustained period of isolation and confinement, which might also incur additional costs requiring reimbursement if they serve as carers to other citizens. If the induced infection is contagious, the volunteer will be unable to withdraw until the quarantine period is complete. They will be deprived of home comforts and will probably have to tolerate extensive periods of boredom. Medical tests undertaken for the research may reveal incidental findings, and this can be a source of anxiety to participants as they anticipate the test or respond to its results. In the same way, some people may find that the anticipation and aftermath of an interview generates distress¹¹³, especially if it concerns a sensitive topic, which could be a justification for compensating participants financially.

4. Neighbours

The topic of payment for research participation is discrete but there are several similar practices that are used in neighbouring activities and may shed light on payment arrangements, helping us to understand what is happening or how to calibrate payment levels. Largent & Lynch convincingly argue¹¹⁴ that payment rates for Research Participants can be set in the light of comparisons with similar opportunities beyond the world of research, and that the case for research to be treated as entirely different from these other activities ('research exceptionalism') cannot be sustained. Similarities and differences between research participation and the following activities are discussed below.

4.1: Payments to Public Contributors

Leaders in the field explain that a Research Participant is providing evidence to be analysed and interpreted by researchers, while a Public Contributor is on the other side of the desk, co-designing and co-delivering the research alongside academics. However, the binary distinction of roles works most of the time but collapses under pressure and the distinction

may be opaque to some citizens. The case has been clearly articulated for paying Public Contributors¹¹⁵, and many of the arguments would apply equally well to payments for participation. For example:

Description. Opportunities are listed on websites and explained on Participant Information Sheets¹¹⁶, but these descriptions do not always make clear whether the role is Research Participant or Public Contributor. For example, the NIHR website *People in Research* includes a data field ‘involvement type’ in which the option ‘undertaking’ means to take up the role of Research Participant. In examples 2.1d, 3.3a, 3.3d, 3.4a and 3.4b above, the *People in Research* website is seeking participants but does not list the activity as ‘undertaking’ research. Conversely, activities that are clearly designed for Public Contributors are listed as ‘undertaking’ research¹¹⁷. Other listings are even more confusing, such as example 2.1e where the opportunity is classed as ‘all of research’ and its flyer¹¹⁸ invites people to ‘shape how researchers store and use mental health data’, which hints that the role is Public Contributor, but on closer inspection, the opportunity turns out to be for a Research Participant. This is not to suggest, of course, that Research Participants do not shape research and practice, but merely that these statements do not help readers clarify whether they are being invited principally to participate in or coproduce research¹¹⁹.

Ethical review. Participants are perceived as vulnerable and so are protected by the scrutiny of a Research Ethics Committee, while in contrast, as free agents, Public Contributors are not. Perhaps the best way to find out if the activity falls under payment arrangements for Research Participants or Public Contributors is to check whether the research has been approved by a Research Ethics Committee. This falls down when the advert declares that the overall study has been approved, but the specific activity is part of the governance of the study and so people are involved as Public Contributors but may think that the reference to ethical review means that they are engaging as participants. Furthermore, some research teams announce the fact that their proposals have been evaluated by the Research Ethics Committee as a way to indicate to Public Contributors that the study has been thoroughly planned, or because they have obtained a favourable opinion from the Research Ethics Committee about the public involvement aspect of their plans.

Research method. Studies using Participative Action Research or a similar method adopt approaches in which all stakeholders, including participants, have a role in steering the research. Example 3.3g asserted that drawing research participants into the co-design process blurred the distinction between the two groups and justifies parity between the payment rates offered to Public Contributors and those offered to Research Participants.

Research topic. Some studies investigate the practices of coproduction and so the research team recruit Public Contributors as Research Participants. Where the research team includes Public Contributors and the research methods are based on coproduction principles, it can be extremely difficult to disentangle the roles of Research Participant and Public Contributor.

Burden. The brevity and demands that are required are no indication, since both Research Participants and Public Contributors may be involved for a single event, such as a focus group, or may have a long-term connection with the study with many contacts over the duration of the work.

Data capture. The tools used to capture information previously gave a hint, as participants were more likely to be recorded than Public Contributors. Since the arrival of the Covid-19 virus, recording the deliberations of management and advisory groups is increasingly common.

Payment rate. Since a number of research teams apply the payment rates set out in the NIHR guidance on payments to Public Contributors to Research Participants¹²⁰, this cannot be used to discern whether the invitation is to be a Research Participant or a Public Contributor.

So despite a kind of exceptionalism favoured by some Public Contributors who argue that payments for Public Contribution are not comparable to any other transaction, the result is that some activities, to all intents and purposes, are experienced as identical by the member of the public whether they are considered to be research participation or public contribution. The following table provides some examples.

Activity	Research Participant	Public Contributor
4.1a Questionnaire		Topic – scrotum pain. Payment offered - £50 ¹²¹
4.1b Online focus group lasting 60 minutes	£10 ¹²²	Unpaid ¹²³

4.2: Discounts

Where patients are paying for healthcare, the fee can sometimes be reduced if they agree to participate in research. For example, some women in the UK who are seeking fertility treatment must pay more than £6,000 per cycle of treatment, but this falls below £1,000 if the woman shares some of her eggs with laboratory researchers¹²⁴. The sector is highly regulated¹²⁵ with detailed access arrangements varying from place to place¹²⁶.

In this example, no payment is offered to research participants, but the discounted fee serves a very similar function. Indeed, this research illustrates five points which may have broader application to the field of participation payments, as follows:

- **Informed consent.** The notion that informed consent to participate in research is given in a calm, placid environment by a person who has perfect grip on their powers of reason and emotion is found wanting. Women and men involved with these decisions are of necessity immersed in a highly charged context, as will many participants in other research areas, since most decisions are made in the heat, dirt and noise of real life. Furthermore, the fees involved are substantial, and so the risks of slipping over from acceptable ‘mere inducement’ to unacceptable undue inducement increase accordingly and so staff are doubtless highly sensitised to the need for fully informed and free consent. In other areas of research, the stakes are not so high but the issues remain.
- **Acceptable research.** Unnecessary risk must be eliminated from research studies rather than retained and ‘paid for’ by offering large incentives for participation. In this example, women who are receiving fertility treatment and also wish to share

their eggs with another woman may endure the risks of surgery, while those are not receiving treatment but wish to share their eggs with researchers may not. Perhaps some research teams would benefit from similarly clarifying the research that they will not do, the forbidden city that they must not enter.

- **Precious gift.** Participation in research can be a costly sacrificial action. In the case of fertility treatment, the woman who chooses to share her eggs with the researcher is reducing her own chances of becoming a parent. The detailed arrangements mitigate this as far as possible, but nevertheless, the sacrifice is a costly one and so it is no surprise that Jonas¹²⁷ suggests that this is holy ground. In other research areas too, researchers do well when they recognise the significance of the gift that they are being given when the respondent gives access to their body or speaks about their life.
- **Payment benchmarks.** The scale of the discount is calculated by reference to the unit cost of each item that makes up the treatment – tests, drugs, equipment use, staff time and so on. This is easy for the health economist, but more difficult for the patient who is used to NHS care being free at the point of use, so she is less likely to consider the sums involved in the light of these wider calculations. Indeed, the woman may think about the fee waiver of £5,000 in comparison with her weekly wage, savings or bank loan. As discussed with example 3.3e, research teams may wish to explain which benchmarks have been used to derive the level of fee waiver or participation payment.
- **Public understanding.** Whilst medical ethicists repeatedly underscore their view that this transaction is egg sharing followed by a fee waiver, we do not know how many women feel as if they have sold their eggs - or taken a noble and selfless decision. In a broader context, it is helpful to find out how participants are conceptualising what they give and what they get, rather than confining our understanding to the language, metaphor and significance of the payment as set out by the research team.

4.3: Payments for behaviour change

Professor Michael Ussher's team is studying the impact of offering financial incentives to young mothers to help them avoid postpartum relapse back to smoking¹²⁸. These payments are quite different from payments for research participation as they aim to incentivise specific lifestyle or behaviour change rather than incentivise or reward participation in research. Indeed, to keep things simple, this team do not offer research participation payments. Their incentive payments for smoking cessation amount to a total of £300 in the most expensive arm of the study, the money being distributed in tranches between the mother and an informal supporter if the supporter remains abstinent for three months postpartum and the mother remains abstinent for a year. There is evidence to show that such payments have the potential to support behaviour change¹²⁹.

Payments intended to incentivise behaviour change trigger three useful questions for our investigation of payments for research participation. First, we might ask if the payment is looking back or looking forward. Payments for research participation are intended to be

entirely retrospective as they simply acknowledge the tasks already completed by the participant in the past in service of the research project, while payments that incentivise behaviour change are prospective, intended to influence future lifestyle and conduct. In the smoking study, while payments are made in recognition of abstinence in the recent period, this is with a goal of sustaining smoking abstinence into the future. The payment is the intervention that is being tested, to see if it delivers an outcome in terms of future behaviour change.

Second, we might ask about inducements. Some payments for research participation consist of nothing more than reimbursement of out-of-pocket expenses and compensation for time, burden and harm (see below), while others set the payment level at a higher rate to induce people to participate. In a study where there is a shortage of potential participants, for example, a larger payment may be offered to encourage the hesitant to re-evaluate their decision and choose to participate¹³⁰. In this case, the research team, along with the Research Ethics Committee, need to be satisfied that the payment acts as a 'mere inducement' that reasonably encourages people to act on their best intentions, rather than an 'undue inducement'¹³¹ wherein the payment is so large that the participant sets aside their principles and deeply held preferences, makes a decision based on clouded judgement and takes an action that leaves them feeling compromised. Both the team offering payments for research participation and the team offering payments for behaviour change must identify this threshold and avoid undue inducement¹³².

Third, we might ask about public understanding. These are rather complex arguments, and it is far from clear that the recipient will recognise the distinction between a payment for research participation and one intended to incentivise behaviour change. Indeed, it is possible that a payment for research participation which is not intended to urge the recipient to adopt any specific behaviour or attitude may be interpreted as an incentive or even a bribe¹³³ to do so. Nor is it clear what research teams can do, if there is anything more than simply offering a clear explanation, to ensure that people receiving a payment for research participation know why it is being offered and what is required of them.

4.4: Consultancy

Some research studies resemble Consultancy, in that they ask about the acceptability, accessibility and effectiveness of a specific healthcare service. In this case, research participants are occupying a role that resembles that of a Consultant or a Regulator, where they would be paid accordingly¹³⁴.

4.5: Employment and Performance-related Pay

There are numerous opportunities to be paid outside the research world¹³⁵, whether that be casual, unskilled work or more demanding commitments, and several commentators have recommended that payment rates for research participants should be benchmarked against alternatives opportunities to earn a casual or regular income. See, for example, the catalogue *Experience Pays*¹³⁶ that lists ways to use one's lived experience to generate income.

A specific aspect of the employment field that bears comparison with payments for research participation is performance-related pay. This can be used in two ways. First, the economic theory and empirical evidence available to support workplace practices where wage incentives are used to modify the behaviour of workers may reveal some mechanisms that operate beyond the workplace and so shed light on the effect of offering money to research participants. Second, the problem of insufficient recruitment to clinical research could be located with passive recruiters, such as family doctors or research nurses, rather than with hesitant patients, and so offering the doctor or nurse an incentive payment may mobilise them. This latter option has been explored by Parkinson et al¹³⁷ but is beyond the reach of this *How To Guide*.

4.6: Volunteering

Opportunities to volunteer, either with or without the payment of an honorarium, may be viewed as analogous to becoming a research participant. Lynch et al (2020)¹³⁸ note that enduring discomfort as a research participant for altruistic reasons might be compared with donating blood, skin or tissue samples.

4.7: Other research participant roles

There are other research studies where one might receive payment as a Research Participant – the subject of this whole paper and the approach used specifically in example 3.3e. Interestingly, while some websites that list opportunities include payment rates in their profile of each role, some do not. Furthermore, these comparisons do not need to be limited to clinical research, so completing a survey for a health research team might be compared with a similar exercise carried out by a marketing company.

5. Distinguishing reimbursement, compensation and incentive

Lynch and colleagues¹³⁹ divide payments into three categories, as set out below.

Reimbursement for out-of-pocket expenses. This lowers financial barriers that may exclude people who cannot otherwise afford to participate and ensures that participants are not financially disadvantaged¹⁴⁰. Payments should always be prorated, so that actual costs incurred are reimbursed if the participant withdraws before the end of the study.

Prepayment is even better than reimbursement, as it shifts the outlay on to the research organisation and includes people who would otherwise lack the necessary funds to engage in the first place.

Compensation for time¹⁴¹, burden, and harm. Everyone who participates contributes time and shoulders the burden of participation, but harm is avoided wherever possible and so compensation for injury caused by participation is rarely paid and is the subject of separate guidance¹⁴². The burden may include a flat-rate payment in recognition of lost earnings¹⁴³, set by comparison with similar ways of earning a casual income outside the research sphere.

There are several difficulties with enacting this principle. Take as an example, a hypothetical research study which decided to offer £25 for participation in an online survey that took an

hour to complete. While this payment level is similar to that offered to Public Contributors, it amounts to a much more generous hourly rate than that paid to most health and social care staff¹⁴⁴. If the staff complete the survey within their normal working hours, such a payment would obviously be due to their employer rather than the employee.

Incentives to promote recruitment¹⁴⁵ and retention¹⁴⁶, including in the face of risk and uncertainty. In Karagic’s survey, people over 60 were less in favour of incentive payments than their younger counterparts. Participation in some research projects offers other rewards¹⁴⁷ too, such as the prospect of direct medical benefit, but payment levels should not be reduced in the light of these attractions, since reimbursement and compensation are still due, and such rewards are often delayed and cannot be guaranteed. Enrolling in a vaccine study, for example, may provide early access to protection during a pandemic, but still demands time, involves discomfort and the person may be given a placebo or the intervention may turn out to be ineffective. A completion bonus may be offered with the goal of increasing retention and reducing attrition, but this is discouraged in the UK¹⁴⁸, and anyone who is removed from the study by the research team for clinical or welfare reasons (rather than for deception) must be paid as if they had completed it. The bulk of the funds should be prorated and assigned to reimbursement and compensation with smaller amounts used to incentivise completion so that participants who wish to withdraw are not unduly discouraged from doing so.

Lynch et al summarise these recommendations into the following table.

Reimbursement	Compensation	Incentive
Goal		
Full coverage of reasonable expenses	Fair payment for time and burden (may be more or less than a participant might earn outside research, depending on individual earning capacity Compensation for risk may be permissible, but not needed as a matter of fairness Compensation for harm	To encourage enrolment and retention in important, ethical research of participants for whom reimbursement and compensation are insufficient motivations
Variability		
Amounts will vary per participant depending on expenses incurred Prorate payment for early withdrawal	Rates should be uniform across participants (do not consider individual lost wages) Amounts will vary per participant depending on number of visits, length of isolation & confinement, applicable procedures and tasks Prorate payment for early withdrawal	Aim for uniformity across participants, but differential incentives may be appropriate Offer completion bonus only for those who complete
Coverage		

Reimbursement	Compensation	Incentive
<p>Transport to and from visits</p> <p>Meals for outpatient visits >4 hrs¹⁴⁹</p> <p>Lodging covered for inpatient stays, not otherwise - enrolling nonlocal participants is not advised</p>	<p>Outpatient visits (hourly)</p> <p>Self-isolation (hourly or per day)</p> <p>Inpatient confinement (hourly or per day)</p> <p>Study procedures and tasks</p>	<p>Amount needed to motivate participant</p>
Factors to consider		
<p>Pre-payment (e.g., vouchers, expense card) or refund of out-of-pocket expenses</p> <p>Involvement of participants with dependents</p>	<p>Duration (including full duration of isolation/confinement regardless of remote work, employment)</p> <p>Visits on weekends, evenings, holidays</p> <p>Boredom, degree of social isolation</p> <p>Inconvenience including in relation to lockdowns</p> <p>Discomfort</p> <p>Intensity of confinement i.e. with participant group or solitary quarantine</p> <p>Cumulative impact (overall length of participation, total number of study visits, total length of confinement, etc.)</p> <p>Optional procedures</p> <p>Potential for payment-induced deception and available safeguards</p> <p>Do not consider prospect of medical benefit</p>	<p>Study importance (social value) and urgency of recruitment</p> <p>Study budget</p> <p>Type of participant sought, alternatives available to them, reasons for not enrolling</p>
Relevant benchmarks		
<p>Reimbursement rates and coverage for expense account expenditures of businesses, universities, and government</p> <p>Wage rates of household help for child and elder care (at least minimum wage)</p>	<p>Payment in comparable research involving healthy participants (e.g., phase I, vaccine trials), if fair</p> <p>Typical payment rates for study procedures</p> <p>Range between minimum wage (potentially in some multiple) and pay scales of analogous occupations involving similar social value and burden (e.g., firefighting)</p> <p>Differentials between ordinary pay and pay for inconvenient shifts (e.g., “time and a half”), ‘sea’ pay for sailors away for extended periods</p>	<p>Incentives offered in other similar research, with adjustments as needed to attract desired number and type of participants</p> <p>Hazard pay offered in various fields, e.g., combat pay to soldiers</p>

This framework appears comprehensive, but does not address appreciation payments¹⁵⁰, the issues discussed in section 4 on neighbours and in particular the boundary between payments for participation and payments to Public Contributors.

6. Finding opportunities

NIHR runs an online database of around 4,000 research studies called [Be Part of Research](#) that is publicly available and shows which studies are recruiting participants. Entries do not generally include payment information and are not written in an accessible format. In addition there are several online registries where the public can sign up to be notified about opportunities to either participate in or contribute to relevant research, including:

- [People in Research](#), serving England
- [Share](#), serving Scotland
- [HealthWise](#), serving Wales
- [Patient and Client Council](#), serving Northern Ireland
- [Research for the Future](#) serving Manchester
- [Discover](#) is based in northwest London.
- [Join Dementia Research](#)
- [Voice](#) lists opportunities in research into ageing.

These are generally ephemeral services, as entries are deleted once their active recruitment phase is over and no record is kept¹⁵¹. As well as rendering several of the endnotes in this paper obsolete, this practice inhibits review of trends and patterns in payment practices.

[PaidFocusGroup](#) is part of the private company MIS Group that is based in London and offers a service to the marketing industry. It is free to register, activities can be tracked on their Facebook page and people who sign up are notified of suitable opportunities to participate. Participants are offered payments via vouchers from Love2shop or Amazon¹⁵², or as cash via Paypal transfer. Other commercial organisations include [Survey Compare](#) and [Prolific](#).

It has been asserted¹⁵³ that some research teams are willing to pay a fee to these organisations for providing a participant-finding service, but are unwilling to pay community groups for the same service.

7. What is the status of this paper?

Most of the documents we read are finished pieces of work, carefully crafted and edited in private before being shared with anyone else. This is a different kind of paper – it was shared online [here](#) from the first day, when the initial handful of ideas were incomplete, poorly phrased and tactless. The work has been edited many times, and on each occasion a revised version has replaced the earlier material online. Despite this, the paper may still be lacking crucial concepts, evidence, structure and grammar¹⁵⁴. As readers continue to provide feedback¹⁵⁵, further insights will be used to update it, so please contact the author with your contributions.

It is one of a suite of documents that try to open up debate about how to empower disabled people and share decision-making in health and social care services – in research, implementation and evaluation.

This way of writing is risky, as it opens opportunities to those who may misunderstand, mistake the stopping points on the journey for the destination, and misuse or distort the material. This way of writing requires courage, as an early version can damage the reputation of the author or any of its contributors. At least, it can harm those who insist on showing only their ‘best side’ to the camera, who want others to believe that their insights appear fully formed, complete and beautiful in their simplicity. It can harm those who are gagged by their employer or the workplace culture, lest they say something in a discussion that is not the agreed party line. It can harm those who want to profit from their writing, either financially or by having their virgin material accepted by academic journals.

In contrast, this way of writing can engage people who are not invited to a meeting or asked for their view until the power holders have agreed on the ‘right message’. It can draw in unexpected perspectives, stimulate debate and crowdsource wisdom. It can provide free, leading-edge resources.

Using this process with this topic has surfaced five linked dilemmas, explored in a separate discussion¹⁵⁶.

¹ Bates P (2015, revised 2021) [How to make sense of payments for Public Contribution](#). Also Bates P (revised 2021) [How to estimate the costs of public involvement](#). Also Bates P (2021) [How to build an organising logic for structuring recognition payments for Public Contributors](#).

² For example, the study ‘Developing a Measure of Beliefs in Hoarding Disorder’ led by Kathryn Ragan at Newcastle University is offering four prizes consisting of an Amazon voucher worth £25 via a prize draw. The method of action may be quite different for prizes, since the thrill of gambling is engaged, although Mantzari’s team found no difference in impact of a payment offer for everyone and a prize draw - Mantzari E, Vogt F, Shemilt I, Wei Y, Higgins JPT, Marteau TM (2015) Personal financial incentives for changing habitual health-related behaviors: a systematic review and meta-analysis. *Prev Med.* 75:75–85.

³ Wang Ck (2021) Paying participants isn’t the way to improve clinical trial recruitment *StatNews* Sept. 28. Published at <https://www.statnews.com/2021/09/28/paying-participants-isnt-way-to-improve-clinical-trial-recruitment/>.

⁴ Exploitation occurs when one section of society bears the risks of research participation and another section benefits from the findings.

⁵ Precise definitions of coercion and undue inducement vary but usually contain some or all of the following factors: (i) the person’s ability to resist, (ii) free choice to join the study; (iii) a decision to withdraw or continue and complete; (iv) threats to violate the person’s rights or deny them opportunities if they do not comply; and (v) disproportionate rewards that overwhelm the person’s freedom of choice. Largent EA & Lynch HF (2017) Paying Research Participants: Regulatory Uncertainty, Conceptual Confusion, and a Path Forward, 17 *Yale Journal of Health Policy, Law & Ethics*. Available at: <https://digitalcommons.law.yale.edu/yjhple/vol17/iss1/2>. They have suggested that the amount paid to participants in the disastrous trial of BIA-2474 (€1900) was perceived as excessive after the tragedy occurred. The abuses that arose in the Tuskegee syphilis study may have been exacerbated by the payment that was offered.

⁶ Lynch et al (2020) notes that payments may lead to the person recalibrating various activities and therefore deciding to participate or not, but this does not amount to coercion unless the person is under such duress that their judgement is impaired and the payment becomes an undue inducement rather than an legitimate incentive. See Lynch HF, Darton T, Largent EA, Levy J, McCormick F, Ogbogu U, Payne R, Roth AE, Shah AJ, & Smiley T (2020) Ethical payment to participants in human infection challenge studies, with a focus on SARS-CoV-2: Report and recommendations. Downloaded from <https://ascopubs.org/doi/full/10.1200/JCO.19.00250>

⁷ Leuker’s team manipulated their offer of payment to investigate people’s responses. They found that a subgroup, who they dubbed ‘doubtful respondents’ predicted more harmful side-effects of participation when the payment offer was large than when it was modest. Leuker C, Samartzidis L, Hertwig R, Pleskac TJ (2020) When money talks: Judging risk and coercion in high-paying clinical trials. *PLoS ONE* 15(1): e0227898. <https://doi.org/10.1371/journal.pone.0227898>.

⁸ Simply reducing the amount of money offered as an incentive is unlikely to be a satisfactory approach to protecting against deception by would-be participants. For seriously ill patients, the possibility of personal therapeutic benefit may be much more tempting than cash. Other mechanisms are needed to ensure that only legitimately eligible people participate and that the information they submit is accurate. For a discussion about patients concealing information, see Bentley JP, Thacker PG (2004) The influence of risk and monetary payment on the research participation decision making process. *J Med Ethics*. 30(3): 293–8.

⁹ In September 2021, Silvia Bortoli explained that ‘internally within NIHR we are starting a payment rate benchmarking exercise with the aim of increased consistency across the board, so rates for participation is something I can bring to those discussions.’ Personal correspondence 2/9/21.

¹⁰ Payment levels should be included in marketing materials – see Gelinias L, Lynch HF, Largent EA, Shachar C, Cohen IG, Bierer BE (2018) Truth in Advertising: Disclosure of Participant Payment in Research Recruitment Materials. *Drug Inf J* 52(3):268–74. The HRA is clear that payments should be detailed in the Participant’s Information Sheet – HRA (2014) Ethics Guidance: *Payments and Incentives in Research* Health Research Authority, paragraph 9.1. Available at <https://s3.eu-west-2.amazonaws.com/www.hra.nhs.uk/media/documents/hra-guidance-payments-incentives-research.pdf>.

¹¹ Research studies were identified by registering with People in Research, Voice and NSUN from August 2021 and watching for studies that appeared to offer payment arrangements not yet reported in this guide. If this appeared to be a new contact, the research team were then sent a personalised version of the following email. The aim was to reach new respondents rather than bombard the same people with multiple inquiries, especially as requests for information were sometimes forwarded to another person. The inquiry ran thus: “I have seen some information about your study and wonder if I might ask a question about it. I am exploring payments to research participants and wonder if you would be willing to share with me your rationale for your offer. Please understand that I do not take a view on which arrangement is the best thing to do, but I am simply trying to understand why research teams come to their decision about the level, format and rationale for these payments. If you can spare a moment to share your thinking with me, I’d be grateful.”

¹² The text normally indicates which team provided the information, especially where a team is being complimented. On a few occasions, the author’s reflections are critical of the team, so these points are made without revealing the source, since the goal of this paper is to stimulate reflection rather than to undermine individual research projects.

¹³ A personalised version of the following email was sent to research teams who responded to the previous inquiry. “Thanks for your helpful reply. This is to inform you what I have done with your response and to give you an opportunity to correct any errors or misunderstandings. For my own amusement, I am writing some unfunded, free, online notes about payments for participation which can be seen at <https://peterbates.org.uk/wp-content/uploads/2021/06/How-to-set-payment-levels-for-research-participants.pdf>. This resource is a live document that will be changed frequently over the next few weeks as new information comes in. It is part of a larger family of resources on research coproduction that you are free to examine, mostly at <https://peterbates.org.uk/home/linking-academics-and-communities/how-to-guides/>. Your study is briefly mentioned and your help is acknowledged by including your name in endnotes. If there is anything that you want amended, added or excised, or if you know of other useful resources on this topic that I have missed, just get in touch and I will make the corrections straight away. I hope that I have treated everyone with respect, but the way to be sure is to invite feedback! Thanks again.”

¹⁴ The author read some of the available literature first and then started asking researchers for their rationale. It was interesting to note that asking researchers generated a much wider set of explanations for payment decisions than were found when searching the literature.

¹⁵ In the USA, the Anti-Kickback Statute is designed to deter fraudulent claims for Medicare and Medicaid. In theory at least, any payments made to research participants may be viewed as falling foul of these rules. See Largent EA, Heffernan KG, Joffe S, Lynch HF (2020) Paying Clinical Trial Participants: Legal Risks and Mitigation

Strategies *Journal of Clinical Oncology*. 38:6, 532-537. Download from <http://ascopubs.org/doi/full/10.1200/JCO.19.00250>.

¹⁶ So, for example, this protocol for a new study provides no information about the involvement of Public Contributors - Dunn A, Alvarez J, Arbon A et al (2023) 'Investigating the effect of providing monetary incentives to participants on completion rates of referred co-respondents: An embedded randomized controlled trial. Study within a trial (SWAT) protocol' *Contemporary Clinical Trials Communications*, Volume 32. <https://doi.org/10.1016/j.conctc.2023.101090>.

¹⁷ See Bates P (2021) [How to make the case that Public Contributors are Citizen Ethicists](#). Also Bates P (2021) [How to engage Public Contributors as Citizen Ethicists](#).

¹⁸ HRA (2014) Ethics Guidance: *Payments and Incentives in Research* Health Research Authority, paragraph 3.7. Available at <https://s3.eu-west-2.amazonaws.com/www.hra.nhs.uk/media/documents/hra-guidance-payments-incentives-research.pdf>.

¹⁹ Largent & Lynch (2017) op cit.

²⁰ The team surveyed 440 patients at a health centre to discover their views about payments for research participation. Karagic M, Chin J, Lin JH, Silverberg N, Lee-Wong M (2020) A cross-sectional survey on patient perception of subject payment for research. *Journal of Hospital Administration* 9(2).

²¹ <https://qmul.onlinesurveys.ac.uk/willingness-motivators-barriers> - rationale given via personal communication with Amy Dowse, 23/8/21.

²² <https://www.peopleinresearch.org/opportunity/the-psychology-of-loneliness/?topic=&involvement=&location=&beginner=&home=> . Explanation requested 22/8/21.

²³

https://www.ucl.ac.uk/psychiatry/sites/psychiatry/files/information_sheet_school_attendance_home_learning_study.pdf

²⁴ <https://uor-redcap.reading.ac.uk/surveys/?s=qqZyCNrt86>. Explanation requested 22/8/21.

²⁵ <https://www.peopleinresearch.org/opportunity/mindkind-study/?topic=&involvement=&location=&beginner=&home=>. Explanation provided by Blossom Fernandes, personal communication 24/8/21.

²⁶ SafeST study details requested from Kate Byrnes 13/9/21.

²⁷ See [Carer Recovery Questionnaire \(CRQ\) Study - People in Research](#). Details provided by Claire Hilton 14/10/21.

²⁸ McNeill P (1997) Paying people to participate in research: why not? *Bioethics* 11:390–396. Also Chambers T, (2001) Participation as Commodity, Participation as Gift, *American Journal of Bioethics* 40, 40.

²⁹ Although this point is made in a list of justifications for non-payment, the team quoted here had reframed payments as expenses and paid participants anyway!

³⁰ Some sensitive topics, such as illegal activities, will be concealed if contact details are required, and this may make it impractical to transact payments.

³¹ Commentators on the ethics surrounding payment of research participants have tended to focus on matters of informed consent to the neglect of broader observations about the ethics of the research, such as stewardship of funds and environmental impacts. See Bates P & Ward C (2021) [How to avoid doing bad research](#).

³² Many doctoral students are not assigned sufficient funds to enable them to offer participation payments. Reflection by Pawel Lucjan, personal communication 28/8/21.

³³ Jonas H (2001) Philosophical reflections on experimenting with human subjects. In: Tomossy GF and Weisstub DN (eds) *Human Experimentation and Research*. London: Routledge, pp. 219–247.

³⁴ Lynch et al (2020) op cit.

³⁵ Ideally, the respondent fully inhabits their story, just as they do in teaching out of lived experience (see Bates P (2017, revised 2020) [How to choose between an actor \(or simulated patient\) and an expert by experience](#). In these situations, researchers need to take care to avoid unwanted and unnecessary distress (see Bates P (2021) [How to respond to distress](#)).

³⁶ Lynch et al (2020) op cit.

³⁷ HRA (2014) paragraph 5.2.

³⁸ Coleman E, Arundel C, Clark L, Doherty L, Gillies K, Hewitt CA, Innes K, Parker A, Torgerson D & Treweek S (2021) Bah humbug! Association between sending Christmas cards to trial participants and trial retention: randomised study within a trial conducted simultaneously across eight host trials. *BMJ*, 375, [e067742]. <https://doi.org/10.1136/bmj-2021-067742>

³⁹ See Bates P & Koon E (2014, revised 2021) [How to engage people as research co-applicants](#).

⁴⁰ Poverty does increase ‘temporal discounting’ by which people welcome short-term gains at the expense of longer-term outcomes, but may also increase worry about harm, mistrust of authority and other factors, so there is no evidence to indicate that research participation payments are a particular risk to informed consent in economically deprived communities. See Gelinias L, White SA, Bierer BE (2020) Economic vulnerability and payment for research participation. *Clinical Trials*. 17(3):264-272. doi:10.1177/1740774520905596. In a study by Jennings et al, offering £100 as payment to research participants increased recruitment in general but did not do so amongst aged or economically deprived patients - Jennings CG, MacDonald TM, Wei L, Brown MJ, McConnachie L, Mackenzie IS (2015) Does offering an incentive payment improve recruitment to clinical trials and increase the proportion of socially deprived and elderly participants? *Trials* Dec;16(1):1-9.

⁴¹ Karagic et al (2020) op cit found that comparatively affluent people were more likely to believe that economically disadvantaged people would be influenced by the offer of a payment, while in reality, the poorer people in their survey were more likely to recommend that researchers should offer no payments for to participation.

⁴² Details from Claire Woodall, 15/10/21, afric-study@bristol.ac.uk

⁴³ The NHS recovers a proportion of its additional costs of involvement in an NIHR non-commercial research study through the mechanism often referred to as Excess Treatment Costs. Details are available at [Attributing the costs of health and social care research - GOV.UK \(www.gov.uk\)](#). We cannot assume that privately owned residential care homes will be willing to invest their effort, labour and expense to engage in research to the same extent as the NHS does, and so full cost recovery is the appropriate model as indicated above. This is reinforced by the following remarks (i) Many care homes are run by very small organisations, so would be overburdened by the obligation to subsidise research; (ii) only a proportion of residents in many care homes are publicly funded, and so the public service ethos is weakened and commercial thinking prevails in boardrooms; (iii) welcoming research demands openness and this requires some private residential care establishments to overcome a problematic ‘closed culture’, so properly funding them will help – see Care Quality Commission (2019) *Identifying and responding to closed cultures* available at [Microsoft Word - 20191031 Supporting information - closed cultures cross sector FINAL FOR PUBLICATION.docx \(cqc.org.uk\)](#).

⁴⁴ See the NIHR *Interactive Costing Tool* available at [interactive Costing Tool \(iCT\): Getting started \(nihr.ac.uk\)](#). The iCT is expressly designed to cost NHS input to commercially funded research so that full costs can be recovered and is not approved as a mechanism for costing other activities. However, it would be entirely consistent to apply an identical methodology in reverse for the purpose of calculating the real cost to the commercial care provider of engaging in research that was publicly funded. The iCT is comparatively easy to use when the NHS is the care provider, since it is preloaded with data such as staff salary costs that may be unsuitable for a commercial care provider, but the iCT does provide for non-tariff items and offers a tried and tested method for making the calculation of the extra costs involved in supporting a research study.

⁴⁵ The study is called ‘Keeping the spirits up?’, funded by NIHR School for Social Care Research – see [Keeping the spirits up? A study about promoting good practice in relation to alcohol use in care homes for older people | ENRICH \(nihr.ac.uk\)](#).

⁴⁶ Bates, P. and McLoughlin, B. (2019), Respecting privacy in care services *The Journal of Adult Protection*, Vol. 21 No. 6, pp. 276-284. <https://doi.org/10.1108/JAP-06-2019-0020>.

⁴⁷ NIHR (2013) *Public Involvement in Care Home Research Workshop Report*. Research Design Service Yorkshire and the Humber, downloaded from [PPI-in-care-home-report-v3-04-11-141.pdf \(nihr.ac.uk\)](https://www.nihr.ac.uk/files/PPI-in-care-home-report-v3-04-11-141.pdf). Notice (i) this finding was about the preference of care home residents for where payment should be directed and said nothing about the payment level; (ii) it concerned payments for public involvement, not research participation, so the study team that used the finding form another example of the application of public involvement approaches to research participation; (iii) elders may experience less normative pressure to raise an income than people of working age; (iv) care home residents as a group may feel less financial pressure than other groups in society as they have their survival needs met and fewer opportunities to spend; (v) care homes are a distinctive environment characterised by more intense relationships between residents than would be the case for independent citizens, which may generate anxiety from some individual recipients about gaining an advantage over peers, as well as altruistic responses, through which residents unable to participate due to dementia or other barriers could benefit from a payment to the group; and (vi) a payment that benefits everyone is more likely to win the support of staff than confining payments to a few individuals, which in turn will facilitate study success.

⁴⁸ Message on the CHAIN network 28/10/22 from Justine Schneider ““In the course of working with the Clinical Research Network (CRN) on a portfolio study taking place in care homes, we became aware that there is a possibility for care homes to be paid study support costs (SSCs) by NIHR, depending on what they do in a study. Activities like care home personnel attending meetings to set up a new study and or sitting in on group interventions delivered by external people can be recompensed through the SSC system. To do this a researcher needs to complete a [schedule of events cost attribution template](#) form – usually with advice from the local CRN administrators. If approved, care homes enter into a contract with the CRN for payment of SSCs.”

⁴⁹ Information from Reena Sangar, Global Head of Digital & Connected Health – IPSOS and Adrian Mulligan, Research Director - Elsevier. Contact email is CliniciansoftheFuture@ipsos-online.com.

⁵⁰ Brueton V, Tierney J, Stenning S, Meredith S, Harding S, Nazareth I, et al. (2014) Strategies to improve retention in randomised trials: a Cochrane systematic review and meta-analysis. *BMJ Open* 4:e003821.

⁵¹ British Psychological Society (2021) *Ethics guidelines for internet-mediated research* Download from <https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Ethics%20Guidelines%20for%20Internet-mediated%20Research.pdf> Page 17.

⁵² See Weissman JS, Campbell EG, Cohen IG, Lynch HF, Largent EA, Gupta A, Rozenblum R, Abraham M, Spikes K, Fagan M, Carnie M. IRB oversight of patient-centered outcomes research: a national survey of IRB Chairpersons. *Journal of Empirical Research on Human Research Ethics*. 2018 Oct;13(4):421-31.

⁵³ Becky Anderson at St George’s University of London has offered bank transfers to research participants who have learning disabilities, and added an alternative option of vouchers for those who prefer that.

⁵⁴ Cultural norms influence the choice of gifts, with some people preferring to give or receive a gift that is considered a luxury rather than a subsistence item, so a gift of toothpaste would be viewed as odd in the UK, while Chinese New Year is celebrated with gifts of money. For a discussion of the meaning of gifts, see Otnes C, Beltramini RF (1996) *Gift giving: A research anthology*. Popular Press.

⁵⁵ There are two forces at work here that compete for influence. First, the UK minimum wage regulations drive research organisations to pay more than the minimum rate and so avoid potential legal challenges. In contrast, Dickert & Grady have argued that payment rates for research participation should reflect rather than significantly exceed fair wage levels for unskilled, similarly burdensome work that contributes social value to the local area where they are paid. See Dickert N & Grady C (1999) What’s the price of a research subject? Approaches to payment for research participation. *N Engl J Med* 341(3):198–203.

⁵⁶ Grady C (2005) Payment of clinical research subjects *Journal of Clinical Investigation*. 115:1681–1687. doi:10.1172/JCI25694.

⁵⁷ This belief was held by one of the participants in a study undertaken by Becky Donne and also by the research team in example 3.3d.

⁵⁸ While the example given in the body of the text refers to respondents who are employed, some research teams and some research participants think that the UK welfare benefits system is more likely to discount a luxury item, while providing subsistence items might be considered as income in kind and be more likely to

trigger a review of entitlement to means-tested benefit payments. See Bates P (updated 2021) [How to make sense of our payments offer](#).

⁵⁹ HRA (2014) op cit, paras 6.1 and 6.2.

⁶⁰ This method is used as one arm of the *Diabetes My Way* study – see [Be Part of Research \(nhr.ac.uk\)](#). This arm of the study uses payments to reward clinic attendance, an approach discussed in section 4.3 of this paper.

⁶¹ <https://www.peopleinresearch.org/opportunity/gestational-diabetes-mellitus-physical-activity-exploring-issues-among-asian-populations-uk/?topic=&involvement=&location=&beginner=&home=>. Explanation requested from Hadeel Alaslani 22/8/21.

⁶² <https://www.isrctn.com/ISRCTN67321719>. Explanation provided by Katherine Jones 1/9/21.

⁶³ https://nclpsych.eu.qualtrics.com/jfe/form/SV_cwpHJuAcAbifzPA. Information requested from Claire Borthwick 2/9/21.

⁶⁴ Commonly used voucher schemes include Amazon, Love2shop and [Voucher Express](#).

⁶⁵ <https://www.peopleinresearch.org/opportunity/interviews-paediatric-pro-ctcae-childhood-cancer-care/>. No further explanation given by Siobhan Kelly 23/8/21.

⁶⁶ <https://www.peopleinresearch.org/opportunity/interview-experiences-dental-care-england/?topic=&involvement=&location=&beginner=&home=>. Explanation provided by Katherine Carr by personal correspondence 25/8/21.

⁶⁷ This study is based at the Department of Psychiatry, University of Cambridge and supervised by Dr Isabel Clare. See www.repro.cam.ac.uk/staff/ms-jodie-rawles.

⁶⁸ <https://www.peopleinresearch.org/opportunity/palliative-end-life-care-experiences-people-african-caribbean-descent-peace/?topic=&involvement=&location=&beginner=&home=>. Explanation provided by Marie Poole 1/9/21.

⁶⁹ <https://www.sscr.nihr.ac.uk/projects/p183/>. Rationale given by Dr Sophie Sarre, personal communication 30/7/21.

⁷⁰ <https://www.peopleinresearch.org/opportunity/research-call-older-type-2s-moving-insulin/>. Explanation requested from Chaya Langerman 22/8/21.

⁷¹ <https://www.isrctn.com/ISRCTN70307341>. Explanation provided by Caitlin Notley 13/10/21.

⁷² Care assistants and nurses are invited to complete one interview lasting between 30 and 45 minutes via MS Teams or telephone. The researcher will ask respondents about their experiences of providing continence care, along with thoughts, feelings and opinions they have about those experiences. All participants that complete the interview will receive a £10 Amazon voucher as a thank you for taking part. Study ERGO II reference 55504.A4.

⁷³ <https://www.peopleinresearch.org/opportunity/impact-bowel-cancer-sexuality-intimacy-experiences-sexual-minority-men/?topic=&involvement=&location=&beginner=&home=>. Explanation requested from Hannah Ward 26/8/21.

⁷⁴ Details taken from NSUN Newsletter 31 August 2021. Explanation provided by Emma Yapp 1/9/21.

⁷⁵ <https://www.voice-global.org/public/opportunities/carers-supporting-partners-living-with-dementia-at-home-during-the-covid-19-pandemic/>.

⁷⁶ The Euroship study is funded under the European Union's Horizon 2020 research and innovation programme, grant agreement No 870698. The advert and Participant Information Sheet ([Participant Information Sheet life course interviews.doc](#)) offer a gift voucher of unspecified value. Rationale requested from Ann McDonnell 10/9/21.

⁷⁷ <https://www.isrctn.com/ISRCTN17478654>. Explanation provided by Lauren Schumacher, 14/9/21.

⁷⁸ Experiences of being a mental health inpatient unit on 'section' in the last five years? A virtual one hour interview to learn about your experiences. Explanation requested from dop.finch@ucl.ac.uk 21/9/21.

⁷⁹ In August 2021, the UK National Living Wage for people aged over 25 is £8.91 per hour, with lower rates for younger people. The recommendation by the NIHR Centre for Engagement and Dissemination of £25 is therefore 2.8 times this figure. See <https://peterbates.org.uk/wp-content/uploads/2021/02/How-to-build-an-organising-logic-for-structuring-PPI-payments.pdf>.

⁸⁰ The National Living Wage is the legal minimum, while the average hourly pay gives the median, which in 2018 stood at £11.82, meaning that the payment rate for Public Contributors is 2.1 times the median hourly rate for all employees. See <https://www.ethnicity-facts-figures.service.gov.uk/work-pay-and-benefits/pay-and-income/average-hourly-pay/latest>. Gelinas et al (2020) op cit, argue that payment rates to research participants should be close to the average fair wage for occupations that deliver social value, and any excess funds available should not be assigned to participants, where they might result in undue inducement, but they should rather be devoted to benefiting the whole community. This might take the form of ensuring that the community where data was collected benefit from the health benefits deriving from the findings.

⁸¹ Bates P & Ward C (2020) [How to gain informed consent](#).

⁸² HRA (2014) op cit, paragraphs 7.1 to 7.3 are quoted here in full. “The Medicines for Human Use (Clinical Trials) Regulations (2004) explicitly prohibit the giving of incentives or financial inducements (except provision for compensation in the event of injury or loss) to children (under 16 years of age), incapacitated adults or their parents/legal representatives to participate in clinical trials of investigational medicinal products (CTIMPS). For other (non-CTIMP) research involving children the Royal College of Paediatrics, Child Health: Ethics Advisory Committee “Guidelines for the ethical conduct of medical research involving children” (2000) similarly state that researchers must “offer families no financial inducement, although expenses should be paid”. The MRC ethics guide “Medical research involving adults who cannot consent” (2007) notes that, whilst incentives or financial inducements should not be used, “MRC policy is that, as in other research, payment of legitimate expenses of participants or representatives directly related to participation in the trial is generally considered acceptable.”

⁸³ The Disabled co-researchers conduct interviews and work with academic colleagues on analysis and dissemination.

⁸⁴ Codsì M, Karazivan P, Rouly G, et al (2021) Changing relationships: how does patient involvement transform professional identity? An ethnographic study *BMJ Open* 11:e045520. doi: 10.1136/bmjopen-2020-045520.

⁸⁵ Grady C (2005) op cit, extending the classification first set out by Dickert N & Grady C (1999) op cit.

⁸⁶ The National Institute of Health Research and the Health Research Authority expect payment arrangements to be clearly presented, whilst avoiding undue prominence – see HRA (2014) op cit. page 5 and paragraph 9.1. On 5 November 2021 there were 4,021 studies published by the National Institute of Health Research at [Be Part of Research \(nih.ac.uk\)](#). Searching for the following key words founds only four study descriptions that mentioned payments for research participants: compensate, compensation, inconvenience, payment, reimburs, voucher, £.

⁸⁷ A variety of terms are used to describe a meeting where several research participants get together and talk, with the researcher collecting data that arises both in their own dialogue with each participant and in dialogue between respondents. Sometimes these terms, such as Focus Group or Workshop are used to mean a very precise way of running these encounters, but here the terms are used interchangeably.

⁸⁸ <https://www.peopleinresearch.org/opportunity/workshop-improving-pain-measurement-manchester-digital-pain-manikin-mdpm-study-2/?topic=&involvement=&location=&beginner=&home=> . Explanation provided from Mustafa Ali by personal communication 23/8/21.

⁸⁹ <https://documents.manchester.ac.uk/display.aspx?DocID=56024> Explanation provided by Claire Little 23/8/21.

⁹⁰ Sarah Carr, personal correspondence, 18 August 2021. This relates to the NIHR SSCR funded study ‘Avoidable harm in mental health social care’.

⁹¹ <https://www.peopleinresearch.org/opportunity/safely-stopping-unnecessary-medicines/>. Explanation provided by Daniel Okeowo 22/8/21.

⁹² <https://www.peopleinresearch.org/opportunity/use-covid-19-certificates-indoor-events-theatre-clinically-vulnerable-people-online-workshop/>. Explanation provided by Cecilia Landa-Avila 23/8/21.

⁹³ ‘Supporting care-home nurses’ well-being during the COVID-19 pandemic (THRIVE Study). Explanation provided by Diane Bunn, 30/9/21 and 18/10/21.

⁹⁴ This research team wished to remain anonymous.

⁹⁵ See NIHR (version 6.0, April 2021) *Reward and recognition for public contributors - a guide to the payment of fees and expenses*. Available at <https://www.nihr.ac.uk/documents/reward-and-recognition-for-public-contributors-a-guide-to-the-payment-of-fees-and-expenses/12248>

⁹⁶ A flat rate payment (rather than exact reimbursement of receipted expenses) for remote working may fall foul of welfare benefit rules – see Bates P (revised 2021) *How to make sense of our payments offer*.

⁹⁷ SACHRP (2019) *Addressing ethical concerns regarding offers of payment to research participants*. See <https://www.hhs.gov/ohrp/sachrp-committee/recommendations/attachment-a-september-30-2019/index.html>.

⁹⁸ Managing expectations is key, as inflated expectations could be dashed and leave the person feeling cheated and undervalued. Even something as simple as providing home-made cake at a meeting could flatten hierarchies or exacerbate differences, depending on who chooses the flavour and pays for the ingredients, who bakes and brings it, and who cuts and distributes it – see NIHR (2019) *Co-production in Action* at https://www.invo.org.uk/wp-content/uploads/2019/07/Copro_In_Action_2019.pdf. Deci found that payment can reduce intrinsic motivation to volunteer, while McCarron’s team found that it could have the opposite effect. Deci EL (1971) Effects of externally mediated rewards on intrinsic motivation. *J Pers Soc Psychol*. 1971;18(1):105-115. Also McCarron TL, Noseworthy T, Moffat K, et al (2019) Understanding the motivations of patients: A co-designed project to understand the factors behind patient engagement. *Health Expectations*. 22:709–720. <https://doi.org/10.1111/hex.12942>.

⁹⁹ See <https://www.prolific.co/pricing/>.

¹⁰⁰ It is worth noting that the NIHR CED offer £5 to Public Contributors in recognition of home office costs related to online activities.

¹⁰¹ <https://www.peopleinresearch.org/opportunity/ecoweb-plus/?topic=&involvement=&location=&beginner=&home=> Explanation provided by Holly Bear, personal communication 24/8/21.

¹⁰² <https://www.peopleinresearch.org/opportunity/smartphone-based-pain-measurement-manchester-digital-pain-manikin-mdpm-study/?topic=&involvement=&location=&beginner=&home=>. Explanation provided by Mustafa Ali.

¹⁰³ See <https://www.voice-global.org/public/opportunities/using-digital-technology-in-the-early-detection-of-neurodegenerative-diseases/>. Rationale requested 26/8/21.

¹⁰⁴ Grady C (2005) op cit.

¹⁰⁵ Karagic et al (2020) op cit.

¹⁰⁶ Any offer payment can lead participants to conclude that discomfort or unpleasantness must be endured. Gneezy U, Rustichini A (2000) Pay enough or don’t pay at all. *Q J Econ* 115(3):791–810

¹⁰⁷ Leuker et al (2020) op cit. Also Grimwade O, Savulescu J, Giubilini A, et al. (2020) Payment in Challenge Studies: Ethics, Attitudes and a New Payment for Risk Model. *J Med Ethics*. Also Millum J, Garnett M (2019) How Payment for Research Participation Can Be Coercive. *Am J Bioethics* 19(9):21–31. Also Largent EA, Emanuel EJ, Lynch HF (2019) Filthy Lucre or Fitting Offer? Understanding Worries About Payments to Research Participants. *Am J Bioethics* 19(9):1–4. Also Gelinias L, Largent EA, Cohen IG, Kornetsky S, Bierer BE, Fernandez Lynch H (2018) A Framework for Ethical Payment to Research Participants. *N Engl J Med* 378(8):766–71. Also Halpern SD, Karlawish JHT, Casarett D, Berlin JA, Asch DA (2004) Empirical assessment of whether moderate payments are undue or unjust inducements for participation in clinical trials. *Arch Intern Med* 164(7):801–3. Also Cryder CE, John London A, Volpp KG, Loewenstein G (2010) Informative inducement: Study payment as a signal of risk. *Soc Sci & Med* 70(3):455–64. Also Singer E, Couper MP (2008) Do incentives exert undue influence on survey participation? Experimental evidence. *J Empir Res Hum Res Ethics* 3(3):49–56. Also Slomka J, McCurdy S, Ratliff EA, Timpson S, Williams ML (2007) Perceptions of financial payment for research participation among African-American drug users in HIV studies. *J Gen Intern Med* 22(10):1403–9.

¹⁰⁸ Fernandez Lynch H, Joffe S, Thirumurthy H, Xie D, Largent EA (2019) Association between financial incentives and participant deception about study eligibility. *JAMA Net Open* 2(1):e187355. One way to manage deception is to create a register for participants to regulate concurrent participation in multiple studies, such as TOPS – see Bates P (2019, last updated 2021) [How Public Contributors can manage overlapping roles in health research.](#)

¹⁰⁹ There are significant ethical and practical differences between research that is publicly and commercially funded and this will affect both participants and Public Contributors who are involved in coproducing the research. See Bates P (2020) *How to decide whether to support public involvement in commercial projects.* Downloaded on 9 August 2021 from <https://peterbates.org.uk/wp-content/uploads/2020/01/How-to-decide-whether-to-support-public-involvement-in-commercial-projects.pdf>.

¹¹⁰ Urine sample \$10, blood test \$3-25, clinic visit \$30-75, lumbar puncture \$50-100, MRI scan \$50-200. See Dominguez D, Jawara M, Martino N, Sinaii N & Grady C (2012) Commonly performed procedures in clinical research: a benchmark for payment. *Contemp Clin Trials* 33(5):860–8. Similar amounts were found by Ripley E et al., (2010) Why Do We Pay? A National Survey of Investigators and IRB Chairpersons *Empirical Research on Human Research Ethics* 43, 54. An older study found no consistency and no rationale justifying variations in payment for specific procedures – see Grady C, Dickert N, Jawetz T, Gensler G, Emanuel E (2005) An analysis of U.S. practices of paying research participants. *Contemp Clin Trials* 26(3):365–75.

¹¹¹ https://flucamp.com/our-trials-new/?utm_source=google&utm_medium=cpc&utm_campaign=Generic%20-%20England%20-%20Non%20Study%20Specific%20Terms%20-%20Exact%20-%20Flucamp&gclid=EAlalQobChMIpuqljf_8AIVmfhRCh3zmwmg3EAAAYASAAEgLy_D_BwE&gclsrc=aw.ds

¹¹² Potential participants may wish to satisfy themselves that they will not be considered to have taken wilful and reckless actions by joining the study and so invalidated their personal insurance cover.

¹¹³ Bates P (2021) *How to respond to distress.* Op cit.

¹¹⁴ Largent & Lynch (2017) op cit.

¹¹⁵ Richards DP, Jordan I, Strain K & Press Z (2018) "Patient partner compensation in research and health care: the patient perspective on why and how," *Patient Experience Journal*: Vol 5, Iss 3, Article 2. DOI: [10.35680/2372-0247.1334](https://doi.org/10.35680/2372-0247.1334)

¹¹⁶ HRA (2014) op cit, page 5 directs that the "Payment amount should be discreet and not prominent within the advertisement i.e. it should not be the headline or very first line of the advert."

¹¹⁷ For example, <https://www.peopleinresearch.org/opportunity/national-audit-seeks-patient-public-involvement/?topic=&involvement=undertaking&location=&beginner=&home=> is listed as 'undertaking' research. In general, it seems curious that this database uses alternative category labels rather than the Research Participant' and 'Public Contributor' labels in use elsewhere. Similarly, on the Voice website, the description of a study on care planning after emergency hospital admission is unclear about whether the opportunity is for a Research Participant or a Public Contributor – see <https://www.voice-global.org/public/opportunities/encouraging-future-care-planning-in-later-life-after-an-emergency-admission-to-hospital/>.

¹¹⁸ https://www.peopleinresearch.org/wp-content/uploads/2021/08/Recruitment-poster-FR_QR.pdf.

¹¹⁹ People in Research commented, 'We agree that it would be interesting to explore more about how people categorise their involvement opportunities on People in Research and it is something we will consider in future updates and projects.' Personal correspondence from Sophie Jarvis, 2/9/21.

¹²⁰ In 2020/21, 1,390,483 people participated in clinical research (<https://www.nihr.ac.uk/about-us/what-we-do/our-research-performance/annual-statistics.htm>). Five studies recruited a total of 800,820 participants, leaving the remaining 589,663 participants who were involved in a total of 3,164 studies, an average of 186 people per study. Information from Andrew Walker, NIHR, personal correspondence 3/9/21. If we guess that the average study has two Public Contributors, then this generates the ratio of 100 Research Participants for each Public Contributor. Replicating the rates that are offered to Public Contributors could have very substantial consequences for individual participants and for research funders, although no examples have

come to light so far where payment rates for Research Participants replicate the higher rungs of the payment ladder offered to NIHR Public Contributors.

¹²¹ <https://www.peopleinresearch.org/opportunity/point-care-doppler-ultrasound-prior-emergency-scrotal-exploration/?topic=&involvement=&location=&beginner=&home=>

¹²² [Workshop - Occupational therapy for self-managing rheumatoid arthritis - People in Research](#)

¹²³ <https://www.peopleinresearch.org/opportunity/focus-group-study-covid-19-variants-individuals-persistent-infection/?topic=&involvement=&location=&beginner=&home=>. There is no indication that this work has been reviewed by a Research Ethics Committee.

¹²⁴ Some women are offered a limited amount of IVF treatment funded by the NHS and so payment arrangements apply outside of this free healthcare. In Professor Hartshorne's study, if the woman has six or more eggs, she may share up to half of them with the research team. If she has fewer than six, she may not share any. All payments relate to treatment costs and are not intended to generate surplus income or profit for the NHS. The woman can enjoy the same reduction in fee if she shares up to half her collected eggs with another woman. When eggs are shared with a research funder or another woman, the sum she pays falls significantly and the recipient pays the outstanding cost. The exact fees a particular woman pays will vary substantially according to the precise basket of tests, drugs and fertility interventions that she needs. There are separate arrangements for egg donors which are not addressed here. As an example of egg sharing with researchers, at the Centre for Reproductive Medicine, University Hospitals of Coventry and Warwickshire NHS Trust, the fee schedule effective from 14/7/20 means that some egg sharers pay £380 and recipients pay £6320.90 per cycle. Personal correspondence with Professor Geraldine Hartshorne 31/8/21.

¹²⁵ The regulatory body is the Human Fertilisation and Embryology Authority.

¹²⁶ Individual NHS commissioners take local decisions about eligibility for free NHS fertility treatment in the UK, with some offering three cycles to eligible women in line with HFEA guidance, while others limit it to just one or two cycles and yet more fund none whatsoever. Details of different areas' rules can be found at <https://fertilitynetworkuk.org/access-support/nhs-funding/england/>.

¹²⁷ Jonas (2001) op cit.

¹²⁸ <https://www.isrctn.com/ISRCTN55218215>. Explanation provided by Michael Ussher 23/8/21.

¹²⁹ Notley C, Gentry S, Livingstone-Banks J, Bauld L, Perera R, Hartmann-Boyce J (2019) Incentives for smoking cessation. Cochrane Database of Systematic Reviews 2019, Issue 7. Art. No.: CD004307. DOI: 10.1002/14651858.CD004307.pub6. Also Paul-Ebhohimhen V, Avenell A. Systematic review of the use of financial incentives in treatments for obesity and overweight. *Obes Rev Off J Int Assoc Study Obes*. 2008;9(4):355–67. See also [Financial incentives help pregnant women quit smoking \(healtheuropa.eu\)](#).

¹³⁰ While offering more money is effective in persuading more people to enrol on the study, it is not the only motivator. Jonas (2001) op cit, argues that research participants should be seen as volunteers to clinical research, going beyond a financial contract that includes the right to claim damages when things go wrong to potential martyrs who willingly risk death in noble service for others. The coronavirus pandemic prompted over 800,000 people to volunteer as study participants in 2020-21, despite the frightening death rates and lack of monetary reward.

¹³¹ Largent EA & Lynch (2017) op cit, page 107 for a discussion of mere inducement versus undue inducement.

¹³² Halpern's team tested incentive payments up to \$500 and found no undue inducement and an increase in recruitment in one group but not the other. See Halpern SD, Chowdhury M, Bayes B, et al (2021). Effectiveness and Ethics of Incentives for Research Participation: 2 Randomized Clinical Trials. *JAMA Intern Med*. Published online September 20. doi:10.1001/jamainternmed.2021.5450.

¹³³ The general principles of the Bribery Act 2010 may shed some light on the issues in play here. However, 88% of Karagic's survey (op cit) respondents thought that payments for research participation should not be considered to be a bribe.

¹³⁴ For example, the Care Quality Commission inspects healthcare services, including lay members and experts by experience on their inspection teams and paying them £200 per day. See Bates P (2018, last updated 2021) *Experience Pays* op cit.

¹³⁵ For a discussion of the principle of comparisons between participation payments in research and alternative sources of income, see Dickert N & Grady C (1999) op cit.

¹³⁶ Bates P (2018, last updated 2021) *Experience Pays: How to make money from your lived experience*. Downloaded on 9 August 2021 from <https://peterbates.org.uk/wp-content/uploads/2018/03/Experience-pays.pdf>.

¹³⁷ Parkinson B, Meacock R, Sutton M, Fichera E, Mills N, Shorter GW, Treweek S, Harman NL, Brown RC, Gillies K, Bower P. (2019) Designing and using incentives to support recruitment and retention in clinical trials: a scoping review and a checklist for design. *Trials*. Dec;20(1):1-4.

¹³⁸ Lynch et al (2020) page 16.

¹³⁹ Lynch et al (2020) op cit.

¹⁴⁰ Gelinas L et al (2020) op cit.

¹⁴¹ Guidance from the Pharmaceutical Research and Manufacturers of America (2020) *Principles on Conduct of Clinical Trials Communication of Clinical Trial Results* page 13 suggests that payment for time and reimbursement of reasonable expenses are the only two legitimate foundations for setting a payment rate. Download from <https://www.phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/P-R/PhRMAPrinciples-of-Clinical-Trials-FINAL.pdf>.

¹⁴² As an example, the six victims of the 2006 TGN1412 trial lost fingers and toes, as well as suffering other medical insults and subsequently received an undisclosed sum in compensation, reputed to be at least £2 million. For general guidance on compensation for harm, see ABPI (2014) *Clinical Trial Compensation Guidelines*. Available at https://www.abpi.org.uk/media/1607/compensation_guidelines_2014.pdf. Proper arrangements ensure that compensation for harm can be made when required, which is an obligation in all member states of the European Union – see Pike ER (2012) Recovering from research: A no-fault proposal to compensate injured research participants. *American Journal of Law & Medicine* 38(1):7– 62. See also Resnik DB (2006) Compensation for research-related injuries: Ethical and legal issues. *J Leg Med* 27:263-287.

¹⁴³ Lynch et al (2020) op cit advises research teams against compensating participants for their actual lost earnings as this would reproduce wage differentials and so create unfairness between participants. Rather, the compensation payment should be set by reference to the value of the participation to the research.

¹⁴⁴ For comparison, in 2021-22, NHS nursing Band 8A on a 1st pay point has an annual salary of £47,125.59, meaning that their gross (total) hourly income before deductions is £24.11 per hour. If net income is more relevant, then NHS Band 8D on the 1st pay point equates to an annual salary of £78,191 or a take home pay of £24.40 per hour. See www.nhspay.co.uk/NHS-Hourly-Pay.php.

¹⁴⁵ Parkinson et al (2019) op cit. note that recruitment is often a problem in research studies with 45% of randomised controlled trials failing to reach their target number of participants within the timeframe, and this proportion proving resistant to change. They find that there is evidence to support the use of payments to research participants, but it is incomplete and weak. Largent and Lynch (2017) op cit review the evidence to date and conclude that payment does improve recruitment to research studies. See also Mahmud A, Zalay O, Springer A, et al (2018) Barriers to participation in clinical trials: a physician survey. *Curr Oncol*. 25(2): 119-25. <https://doi.org/10.3747/co.25.3857>. Also Manton KJ, Gauld CS, White KM, et al (2019) Qualitative study investigating the underlying motivations of healthy participants in phase I clinical trials. *BMJ Open*. 2019; 9(1): e024224. PMID: 30647042. <https://doi.org/10.1136/bmjopen-2018-024224>. Also van Gelderen CE, Savelkoul TJ, van Dokkum W, et al (1993) Motives and perception of healthy volunteers who participate in experiments. *Eur J Clin Pharmacol*. 45(1): 15-21. PMID: 8405024. <https://doi.org/10.1007/BF00315344>.

¹⁴⁶ Gillies K, Kearney A, Keenan C, Treweek S, Hudson J, Brueton VC, Conway T, Hunter A, Murphy L, Carr PJ, Rait G, Manson P, Aceves-Martins M (2021) Strategies to improve retention in randomised trials. *Cochrane Database of Systematic Reviews* Issue 3. Art. No.: MR000032. <https://doi.org/10.1002/14651858.MR000032.pub3>. Also Edwards L, Salisbury C, Horspool K, Foster A, Garner K, Montgomery AA (2016) Increasing follow-up questionnaire response rates in a randomized controlled trial of telehealth for depression: three embedded controlled studies. *Trials* 17(1):107. <https://doi.org/10.1186/s13063-016-1234-3>. The Trial Methodology Research Partnership has a working group on Trial Conduct chaired by Katie Gillies but this group has not done any work on payments to research participants. Personal correspondence from Katie Gillies, 6/9/21.

¹⁴⁷ These other rewards might be separated into the things that motivate people to enrol in a study and the benefits that they report afterwards. Possible motivations include the following: curiosity, altruism, sensation seeking, desire for attention provided by physicians (perhaps because they believe that care and treatment will be more carefully shaped and delivered while ‘treatment as usual’ will be hurried and slapdash) and personal therapeutic benefit, perhaps through access to innovative treatments. See Grady C (2005) op cit. When Dr Abigail Moore’s team at the University of Oxford were recruiting staff as participants in the uCARE study, they offered a certificate of participation alongside a voucher and reminded staff that the certificate could be used as evidence of Continuous Professional Development, thus helping to secure approval for continued practice.

¹⁴⁸ HRA (2014) op cit, para 9.1 “completion bonuses...should not normally be permitted.”

¹⁴⁹ Notice that a meal eaten out in the course of research participation may be more expensive than the person would have enjoyed at home, and the quality of the food may be better. Nevertheless, reimbursement of these expenses is considered reasonable as these differences are unlikely to impair decision-making and reimbursing these costs means that the person is not worse off by participating in the research. See SACHRP (2019) op cit.

¹⁵⁰ This reference to hospitality is intended to refer to the provision of tea and biscuits (for example) that is not a direct reimbursement of expenses necessarily incurred by the participant but is a mark of generosity and welcome – items that have been termed ‘Appreciation Payments’. Such tokens are considered to bear no risk of undue inducement – see SACHRP (2019) op cit.

¹⁵¹ Information from Gwen Isaacs at the NIHR Centre for Engagement and Dissemination, personal correspondence 31/8/21.

¹⁵² Other voucher and discount code suppliers have been used too, including Marks and Spencer (which is being used by Olesya Ajnakina at UCL).

¹⁵³ Tweet from Lynn Laidlaw, 28 September 2021.

¹⁵⁴ As a result, the author assumes no responsibility or liability for any errors or omissions in the content of this paper. The information contained is provided on an “as is” basis with no guarantees of completeness, accuracy, usefulness or timeliness.

¹⁵⁵ A request for input has been sent to Kate Byrnes, Jim Elliott and Caitlin Turner. Helpful conversations and email exchanges have taken place with Syed Mustafa Ali, Becky Anderson, Holly Bear, Silvia Bortoli, Diane Bunn, Katherine Carr, Sarah Carr, Becky Donne, Amy Dowse, Blossom Fernandes, Katie Gillies, Geraldine Hartshorne, Claire Hilton, Georgie Hudson, Karen Hughes, Gwen Isaacs, Katherine Jones, Siobhan Kelly, Nancy Kouroupa, Cecilia Landa-Avila, Claire Little, Pawel Lucjan, Holly Fernandez Lynch, Michelle McCann, Caitlin Notley, Daniel Okeowo, Marie Poole, Sophie Sarre, Lauren Schumacher, Ruth Stafferton, Michael Ussher, Andrew Walker, Claire Woodall and Emma Yapp, although all errors and weaknesses that remain in this document are the responsibility of the author.

¹⁵⁶ Bates P (2021) *Dilemmas of writing in public*. Available at <https://peterbates.org.uk/dilemmas-of-writing-in-public/>.