

Paying people with lived experience for their participation

A review of legislation, literature, and practice

Authored by **Rhiann McLean** for the **Scottish Human Rights Commission**

March 2021

The **Scottish Human Rights Commission** was established by the Scottish Commission for Human Rights Act 2006, and formed in 2008. The Commission is the National Human Rights Institution for Scotland and is independent of the Scottish Government and Parliament in the exercise of its functions. The Commission has a general duty to promote human rights and a series of specific powers to protect human rights for everyone in Scotland.

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Foreword

The Commission is pleased to publish this important research into the benefits and challenges of paying people with lived experience of human rights issues to participate in research, policy making, and other processes that affect them. We strive to learn from, contribute to, and promote best practice in human rights.

Participation is fundamental to taking a human rights based approach, and to the work of the Commission. Across Scotland, people with lived experience of human rights issues are contributing their time, energy, and vital expertise to inform how the Commission, and other public bodies, work to protect and promote human rights.

It is important that these contributions are recognised as a core part of effective human rights work – and valued on an equal footing with professional efforts and expertise. Payment – whether monetary, or in the form of vouchers or ‘in kind’ resources – can help to acknowledge the value of these contributions. It can enable people to participate, particularly those who may face financial hardship. And it can help address inequalities in the status and relationship between professional and lived experience expertise.

Currently, in our own work, the Commission routinely covers participants’ expenses and the access costs which enable them to take part. However, we do not currently provide financial recognition to participants with lived experience for the time, energy and expertise they contribute to the Commission’s work. Payment for participation is not without its risks and challenges, so we commissioned this research to thoroughly explore existing guidance and practice, to help inform our approach to this issue.

The Commission welcomes and accepts the findings and recommendations of

this research, and we hope this publication can help guide others seeking to develop their own approaches in this area.

We note that participation can take many forms. We also know that a range of practices are emerging across Scotland which recognise the importance of involving rights holders in decisions that affect them. This research explores different models of providing payment for people's time, and supports what people themselves tell us: that one size does not fit all. Given the complexities involved, we hope this research will help to inform a range of nuanced approaches to supporting more meaningful participation across Scottish public life.

The Commission will now begin to take steps to implement the report's recommendations for our own work. This will include:

- ◆ Developing a values-based statement and a policy around payment for participation, working alongside our Lived Experience Leadership Group.
- ◆ Seeking specialist advice on the relationship between participation and employment law.
- ◆ Scoping out options for provision of individual financial advice for participants to fully understand the impacts of payment in their own specific circumstances.

We welcome opportunities to share our experiences with others embarking on similar journeys, and to hear from those with learning we might benefit from.

To discuss this research, for more information about this work, or for alternative formats of this publication, please contact isla.mcintosh@scottishhumanrights.com.



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Introduction

Commissioned by the Scottish Human Rights Commission, this research explores different approaches to paying people with lived experience of human rights issues for their time and expertise. In the context of this work, the term “people with lived experience” describes people who contribute to the Commission’s work in their capacity as individuals, rather than as paid representatives of organisations. The Commission’s work takes a human rights based approach to empower people to know and claim their rights¹. A key principle of a human rights based approach is peoples’ right to participate in decisions that affect their lives, and the participation of people with lived experience in the Commission’s work is vital to its operations.

Across the Commission’s work, people with lived experience have an important role as expert contributors across a range of activities including:

- ◆ taking part in meetings and events with the Commission;
- ◆ contributing experience and expertise to Commission research, evidence-gathering and policy development;
- ◆ taking part in a range of other short, medium, and longer-term projects and programmes.

Currently, people with lived experience do not receive any form of payment or financial recognition for their participation in the Commission’s work, other than reimbursement of their out-of-pocket expenses. It is important for the Commission to recognise the value of lived experience, and to position people with lived experience as equal stakeholders.

However, the Commission recognises a multitude of barriers to paid participation for people with lived experience, including

1. Potential impact on benefits entitlement;
2. Potential tax implications;
3. Potential employment law implications;
4. Internal auditing system compliance.

This project seeks to explore the best path forward for the Commission in their journey to paying participants with lived experience for their contribution. The research is not presented as a “how-to” guide, but offers detailed exploration of some of the most challenging considerations in this area. [The National](#)

[Institute of Health Research's latest guidance](#), published since this research was conducted, provides a helpful practical overview that complements the analysis in this report.

Methods

This project used a mixed-method approach to evaluate approaches to paid participation.

Desktop research

During the desktop research phase, details on legislation, regulation and guidance were sourced from the responsible government departments, with supporting information from leading professional and advisory organisations, and those national organisations with a longstanding background in paid participation. Guidance in relation to benefits entitlements is more challenging to source and is regularly changing as Universal Credit undergoes near-constant revisions. Employment law evolves with case law, especially in the relevant area of gig economy workers, and because of the UK's departure from the EU. The information given in the desktop research phase was (unless otherwise specified) the most up-to-date available in February 2021.

Semi-structured interviews

The researcher undertook nine semi structured interviews (see Appendix A) with organisations with experience of paid participation and/or specific experience working with marginalised groups. Each individual interview is summarised in a case study which explores the nature of the organisation, its target population and known barriers to participation, the organisation's approach to paid participation and learning from the process of paid participation. To enable organisations to be candid in their responses, all case studies have been anonymised. Key features of these case studies were analysed and evaluated in relation to legal and regulatory constraints.

Recommendations

Recommendations for the best course for the Commission take into account learning from case studies and the wider legislative and regulatory context, whilst acknowledging that developing a policy for paid participation is likely to be an ongoing, iterative process.

Scope of inclusion

Nine organisations, including charities, publicly-funded arms length organisations and limited companies were interviewed. Some of these organisations were suggested by the Commission, while others were sourced from the researcher's own networks.

There was a broad scope of inclusion of organisations working with people with lived experience from different backgrounds, including:

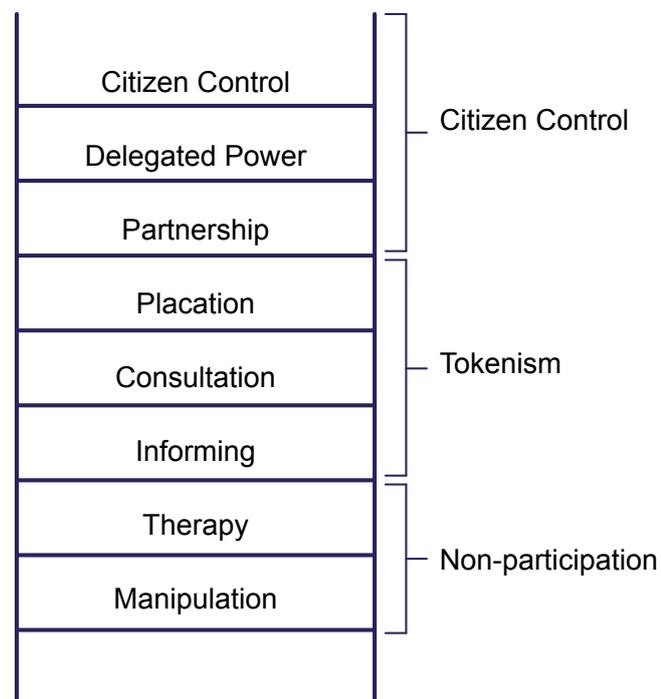
- People who are excluded, marginalised, or face structural barriers when it comes to participating in public policy and public life
- People who have no fixed address
- People who do not have standard financial arrangements (including those without bank accounts and those at risk of financial abuse)

Limitations

The researcher has drawn on available legislation and regulatory guidance and has experience of working in this field and of working with qualified finance and HR colleagues on the delivery of paid participation. However, the researcher is not a qualified employment law professional, tax advisor or benefits advisor. As such, the desktop review of available information should be viewed as a summary and interpretation of available evidence rather than an expert position. The researcher was unable to interview an organisation who worked exclusively with asylum seekers but did interview an organisation who had explored the option as part of a short-term project. There was also no formal interview with an organisation who paid people deemed by law not to have capacity. These are gaps for future research and consideration.

Defining participation

Case studies explore paid participation for people with lived experience across a range of projects and engagement methods. Using Arnstein's Ladder of Participation² as a framework, case studies covered a range



Arnstein's Ladder (1969)
Degrees of Citizen Participation

of degrees of citizen participation, from consultative market research to citizen control movements for victim-survivors of genocide. The organisations engaged in these interviews had relevant experience of research, policy development and co-production. Projects ranged from one-off engagement activities to long-term work.

Key legal, regulatory and other constraints

Establishing the true status of a participant under employment law

A variety of legislation affects the remuneration of participants. An appropriate starting point is to consider whether an organisation should, in fact, be employing its participants and therefore treating them in the same way it would treat employees.

The Chartered Institute for Personnel Development's (CIPD) factsheet on employment status explains that in UK employment law, there are three main categories of employment status:

- ◆ Employees working under a contract of employment, who have full employment rights;
- ◆ The genuinely self-employed, who are independent contractors;
- ◆ Workers, who have a status in between employment and self-employment.

The Chartered Institute for Personnel Development have a [factsheet](#) and [Q&A](#) which can help to determine whether participants should be treated as employees, workers, self employed, or none of the above.

Specialist employment law advice is recommended if there is any doubt around the employment status of a participation role.

For one-off engagements which involve a small piece of work and limited remuneration, it is highly unlikely that the participants, unless they are involved in other projects with the organisation, would qualify for worker or employee status, but it is important to be aware of the distinctions when considering how to engage with participants. The different statuses confer different rights upon an individual, and different responsibilities upon the organisation with whom they are working, as well as having cost implications for participation budgets.

The CIPD notes the following rights for employees, workers and the self-employed:

Employees have the right to:

- ◆ Protection against unfair dismissal;
- ◆ A statutory redundancy payment after two years' service;
- ◆ Minimum statutory notice;
- ◆ Statutory maternity, paternity, adoption, and shared parental leave and pay, and statutory sick pay;
- ◆ TUPE protection (provided TUPE applies to the transfer of undertakings concerned);
- ◆ Request flexible working;
- ◆ Paid time off for trade union duties and for ante-natal care, and unpaid time off to deal with emergencies for a dependent.

Both employees and workers are entitled to:

- ◆ National Minimum Wage/National Living Wage;
- ◆ A written statement of terms on the day the contract starts;
- ◆ An itemised pay slip on or before the day payment is made;
- ◆ Working time rights, such as weekly and daily statutory rest breaks, and a 48-hour maximum working week (although they can choose to opt out and work for longer);
- ◆ A companion during a disciplinary or grievance hearing;
- ◆ Protection from discrimination and from mistreatment following whistleblowing;
- ◆ Protection from unlawful deduction from remuneration;
- ◆ Health and safety protection;
- ◆ Auto enrolment on to a pension scheme;
- ◆ Paid annual leave.

Self-employed contractors have no employment rights, apart from:

- ◆ Health and safety protection;
- ◆ Protection from discrimination (in some cases) and from mistreatment following whistleblowing.

There is much confusion over the term ‘worker’, which is a concept relevant in employment law³ but not in tax law (workers may be taxed in the same way as employees, but not have the same employment rights). Employees “work under a ‘contract of service’; the self-employed work under a ‘contract for services’, [and] workers provide services personally to an organisation but under an arrangement that is looser than employment.”⁴ The term worker does have a distinct legal meaning, which the CIPD elucidates as follows:

A worker is any individual who undertakes to do or perform personally any work or service for another party, whether under a contract of employment or any other contract. It does not matter if the contract is express or implied, verbal or in writing, provided the individual undertakes to perform the work or services personally, for an end-user who is not a client or customer. This normally excludes those who are self-employed.⁵

Participants might also be considered temporary workers and be employed or remunerated by a third party, in which case Agency Workers Regulations 2010 (SI 2010/93) should be considered.⁶

Case law has determined the common law tests for whether an individual is a worker, an employee, or self-employed. According to the CIPD, the following factors indicate that an individual is an employee:

- ◆ Having to perform the work personally;
- ◆ Having to carry out the work when required (and the organisation must also be obliged to provide it);
- ◆ Being integrated within the business (for example, by being part of a team);
- ◆ Being controlled by the organisation in the way the work is done.

Boundaries between employment and self employment are often unclear. The CIPD advises the following factors suggest that self-employment status is most appropriate for an individual:

-
- ◆ Actively marketing their work outside the organisation, being able to decide how it is done, and (possibly) providing a substitute to carry it out;
 - ◆ Not being integrated within the business, or subject to a high level of control;
 - ◆ Supplying their own equipment;
 - ◆ Accepting the risk of not being paid if the work is not done;
 - ◆ Submitting invoices for payment;
 - ◆ Having no obligation to accept work⁷.

Workers will often have characteristics of both of these types of employment, and with the growth of the gig economy, case law is rapidly evolving in this area (e.g. Uber and Pimlico Plumbers). Furthermore, UK employment law may change due to the UK's exit from the EU, which provided the majority of UK employment law.

A lack of clarity over employment status may have both significant tax implications and result in claims to an Employment Tribunal. It is recommended that advice be sought from an employment law specialist if there is any doubt in respect of whether a participant should be engaged as an employee. Any organisation must be aware that courts will consider how the relationship between an individual and an organisation works in practice, not only what a written contract says (e.g. *Aslam v Uber BV* 2018). They will also take into account the “nature, length, and pay and benefits of the engagement”⁸ and how consistent or otherwise these are with other employees in the same organisation.

It is possible that participants in longer and even some relatively short-term projects (i.e. that are not one-offs) should be considered as workers under the definitions given. NHS England touches on the issue of prolonged engagement with participants in its paper *Working with our Patient and Public Voice (PPV) Partners*:

If the participation of a PPV Partner expands over time, for example the nature of the involvement work increases and / or their expertise is required for multiple programmes of work, then advice should be taken on whether the status of their engagement requires re-evaluation. Consideration may need to be given as to whether the role should constitute an NHS England job role.

Correctly establishing whether an employment relationship exists is key to

ascertaining whether payment should be handled under PAYE and incur employer's national insurance contribution (ER NIC). Where an individual is an employee or a worker, the employer must pay ER NIC, and deduct employees' NIC (EE NIC) and income tax from their pay (depending on where the individual is on their tax thresholds).

HMRC provides a [tool to check a person's employment status for tax](#).

HMRC's [employment status manual](#) may also be useful in correctly establishing a participant's status.

Note, if participants qualify as employees or workers, then the organisation engaging them is required to undertake [Right to Work checks](#) to ensure the individual has the right to work in the UK. Failure to undertake and keep a record of these checks can result in substantial fines.

Tax implications for paying participants

It is important to be aware of, and support participants in understanding, the potential tax implications of paid involvement. In its Employment Income Manual, HMRC includes the section EIM71105: *Research volunteers, lay participants and participants in clinical trials*⁹. Although this guidance was originally issued for universities, it is widely relied upon by other organisations who pay participants and the definition of “lay’ people or ‘users’ in research”¹⁰ is broad:

The people in question are invited to attend meetings to give their views on various matters to inform the research process and direction. Often they will be former or current patients, representatives of particular groups such as retired people, or representatives from charities. Payment is made to them for their participation in the meetings.

Returning to the subject of whether or not participants should be considered employees, HMRC advises that, as long as no employment relationship exists, “HMRC agrees that the amounts paid to those concerned are unlikely to fall within the definition of “earnings” for PAYE or NI purposes,”¹¹ and as such PAYE and NIC do not apply. This means there are no tax implications for the organisation engaging with the participants. The guidance does note that HMRC “is entitled to ask for details of payments to non-employees at their

discretion; but they would not routinely ask for details for small payments such as these”¹² and so a robust record keeping process for any payments must be in place.

In terms of tax implications for the recipients of any payments, EIM71105 states:

There will be no tax or NIC liability arising on the individual if the sums received do no more than reimburse the individual’s reasonable costs of participating in the trial or research, including costs of travel and subsistence.

However, in terms of sums that exceed the reimbursement of reasonable expenses, and contrary to the advice of some institutions¹³, HMRC states that the amount in excess of expenses reimbursement may be classed as Miscellaneous Income, and as such may be subject to a tax liability for the participant, “which should be notified to the HMRC under Self Assessment”¹⁴. It is worth noting that individuals can earn up to £1000 per year (from self-employment or miscellaneous income) before they have to register for tax self-assessment (this is known as a [trading allowance](#)).

Note that the use of vouchers to reward participants does not negate tax or benefits implications, though anecdotally vouchers have been used to avoid these. More recent guidance from the National Institute of Health Research states that:

“High street or gift vouchers may be treated as earnings, and viewed by the benefits authorities in the same way as other forms of payment.

Regardless of participants’ employment status, any income from participation – including in the form of vouchers - can be classed as ‘miscellaneous income’ and subject to tax, as well as potentially impacting on benefits. [The National Institute for Health Research](#) advises that organisations wishing to give vouchers as a non-taxable gift can request a ruling on this from their local tax office.

These payments need to be declared in the same way as cash, cheques or bank transfers. However in some circumstances HMRC will treat vouchers as a gift and not subject to NI or tax deductions. In this case the Department for Work and Pensions follows suit and treats the vouchers as a gift that does not affect benefits. The vouchers can be used to obtain goods in supermarkets. An organisation that wishes to be able to provide vouchers for service user involvement that will be treated as gifts should contact their tax office to request a ruling. Low amounts such as a £30 voucher will be more likely to be agreed.”

Similarly, some organisations assert that payments to participants are honorariums, and therefore not subject to tax. HMRC’s guidance disagrees with this, advising that honorarium payments are classed as earnings and are subject to tax, as well as NIC where relevant¹⁵. (Workers and employees should have NIC deducted if they exceed income of £183 per week or £792 per month in 2020-1)¹⁶. Payments labelled honorarium payments would also be classed as earnings for benefits purposes.

In addition to considering a paid participant’s employment status, an organisation should also be mindful of the off-payroll working rules, also known as IR35¹⁷. These regulations are intended to prevent organisations having individuals who are to all intents and purposes employees avoid PAYE contributions by contracting them via an intermediary (which can be the individual’s personal service company). HMRC offers a tool to determine whether contractors fall under IR35. Currently, public sector organisations are responsible for determining whether a contractor falls within IR35 and ensuring the relevant deductions are made and ER NIC paid. From 6 April 2021, this will also be the case for medium and large-sized private sector clients.

Where participants are being paid outside PAYE or IR35, they must pay tax on this income themselves if their total income for the year exceeds their personal allowance. If participants do exceed their personal allowance, they will need to complete a tax return form (also known as a self-assessment form). In Scotland, the standard personal allowance for 2020-21 (the amount which an individual can earn before income tax) is £12,500¹⁸. Those earning over £125,000 do not get a personal allowance. Note that many benefits are taxable¹⁹, i.e. they count towards this allowance. It should be borne in mind that even where an organisation is certain of the relevant threshold for an individual, many factors can affect their tax liability that they themselves may not be aware of, and so no assurances should be offered to participants in

terms of their liability. Many participants may find navigating the tax system challenging. Help for participants completing tax returns and understanding liabilities can be obtained from [the TaxAid website](#) and the [Low Incomes Tax Reform Group website](#).

Benefits implications for participants

Consideration of the complex UK benefits system is a crucial element in ensuring positive engagement with participants. Unfortunately, there is a lack of clarity from the Department for Work and Pensions (DWP) on how individuals might be impacted by paid participation. The participation specialist organisation INVOLVE has a detailed guide of how benefits may be affected, but it is now out of date due to ongoing revisions to Universal Credit (UC) and changes in allowances²⁰.

Any additional income may impact an individual's benefits and it is important that participants understand the potential impacts, and their responsibilities on reporting income to the DWP. Income from participation is likely to affect Universal Credit and the calculations can be complex with details not easily available as the UC system continues to undergo revision. For some, income from participation if dealt with correctly will simply mean an adjustment to their Universal Credit payment which will not disadvantage them. Potential participants can be supported to navigate the system correctly, and benefit from their participation, rather than being discouraged by the bureaucracy and fear of sanctions or income loss. However, minor issues (whether by error or omission of the individual, or a mistake at the DWP's end) can cause sanctions which may have a disastrous impact on a participant. There is much evidence that many claimants find these issues very challenging to navigate on their own²¹. Despite the risks associated with misinforming people, sensitively supporting individuals to navigate the benefits system to enable them to participate without fear of sanctions is considered best practice, especially when seeking to increase participation among seldom heard groups²².

One-off payments (once 'ignored' by the DWP), including vouchers, are now treated as earnings by the DWP²³. If a participant wishes to donate their fee to a charity and not receive it themselves, the DWP may also consider this as a payment to a third party and still treat it as though it were earnings for the participant.

Reimbursement of genuine expenses incurred in public involvement is now allowable by the DWP and not considered to be earnings, but it is essential these are properly documented. If expenses are included in a single sum for participation, then the full amount will be treated as earnings by the DWP²⁴. It is therefore very important for participants who receive benefits that their expenses are reimbursed accurately and clearly separated from any payment for involvement.

It should be taken into account that even if a participant wishes not to take a payment, their willingness to participate may be considered by the DWP as availability to work and as such may incur a sanction or complete removal of a benefit, such as Employment Support Allowance (ESA), if not handled correctly. The DWP does acknowledge the importance of people who are deemed to have limited capacity for work undertaking small amounts of work where they are able to, and may allow this in terms of being a paid participant²⁵. However, it is essential that the participant in question makes enquiries with their work coach in advance about whether the work to be undertaken is permitted²⁶. The DWP is strict on what it defines as permitted work for people in groups who are deemed as having low capacity for work and potential participants are likely to need support to navigate this. The completion of a Permitted Work Form (PW1)²⁷ will be necessary, and should specify “service user involvement” which is the language the DWP needs to see to understand that the individual is contributing their expertise by experience and being recognised for this. Where appropriate, the form should also make clear that the organisation working with the participant is providing any support needed to enable the participant to take part. There are limits on earnings and hours depending on how the DWP assesses an individual and which ESA group they are in. The current upper limit is £143 per week in earnings and no more than 16 hours of work per week (this is essentially the

NIHR provides an [example letter](#) organisations can adapt and send to Job Centre Plus staff alongside participants’ PW1 form, detailing the nature of the ‘service user involvement’ as distinct from employment, and noting what support the organisation is providing to enable this participation.

minimum wage for those aged 25 and over for 16 hours). The lower limit is £20 but with no limit on the hours undertaken. Rules for Universal Credit claimants are different and work coaches should be consulted.

NIHR guidance warns that for those receiving 'New Style ESA' together with Universal Credit for Housing costs: "Earnings up to full amount allowed for ESA of £143 week, will reduce the Universal Credit monthly payment for the costs of the rent. The Universal Credit monthly work allowance of £293 is the amount that can be received before Universal Credit is reduced by 63pence for every £1 over the work allowance". It also warns that anyone in receipt of a mortgage interest loan can have these payments stopped for 9 months if they receive any other payments at all.

Payments for asylum seekers

Most asylum seekers are not permitted to work whilst their application is being considered²⁸. Where people seeking asylum have been given permission to work, they are not permitted to be self-employed, and are only permitted to take up a job which is included on the list of shortage occupations published by UK Visas and Immigration. Asylum seekers who wish to contribute voluntarily must still speak to their case owner to ensure there is no detrimental impact on their claim.

Payments for Non-UK citizens

Non-UK citizens (excluding those from the Republic of Ireland) who do not have settled status or leave to remain are likely to require a visa to work legally in the UK. Visa restrictions may affect a person's ability to be paid for their participation, and advice should be sought from the Home Office.

Due to the complex and fast changing rules around benefits and permitted earnings, it is strongly recommended that individuals be supported to access specialist, comprehensive financial advice to ensure that payment for participation does not leave them financially worse off.

Payments to young people

As part of establishing work with young people (ie. those under 16 years old), their guardian should be consulted alongside the young person about the appropriateness of payment and how it should be made.

Payments to people serving a custodial sentence

Payments can generally be made to the bank accounts of people serving custodial sentences as they would be to any other person with a bank account, but the individual will have a maximum weekly allowance that they may draw on whilst they are in prison.

Private health insurance/pension incapacity payments

People who receive income from medical insurance (individually or as part of their employment) should be made aware that participation may breach the terms of any payments they are receiving, and so they should make enquiries with their insurance provider or employer.

Reporting and audit requirements

Regardless of organisation size, structure, governance, charitable or non-charitable status, and what standard of accounting is required, a robust process for recording the disbursement of funds, in whatever form, must be in place²⁹, including a system for the recipient to acknowledge receipt of their payment (unless this is made by BACS to an account they have agreed upon in advance). Such a process should be drawn up in line with the organisation's existing policies and reporting requirements³⁰. A robust procedure ensures a good audit trail both internally and externally should one be needed, allows for payments to be checked and tracked, and assists with budgeting³¹. It is also essential in supporting recipients who may be anxious about their payments, and the time needed for this should not be underestimated. As previously noted, under EIM71105, HMRC advises that they may request details of any such payments made³².

Despite the widespread use of electronic payments, cash may also be an appropriate option for payment when properly recorded with a process in place for authorising disbursements, and when safely transported/stored in accordance with the organisation's insurance³³. As explored in the case

studies that follow, the use of cash payment is often a judgement made based on an organisations' perceptions of the risks associated with cash. Cash payment may be a particularly practical option for those who may not have standard financial arrangements: e.g. people who do not have a bank account, do not have an easily accessible non-UK account, and those subject to financial abuse who may not benefit from money paid into an account controlled by an abuser. As outlined in the above guidance on benefits and tax implications, payments in cash do not absolve the receiver of any tax implications or the responsibility to report the payment to their benefits advisor, nor does it absolve an organisation of any liabilities under PAYE or IR35³⁴. Vouchers should be treated in the same manner as cash and all of the above applies.

Organisations can ensure a robust audit trail for themselves and for participants, by disbursing payment slips for participants to sign, or pro-forma invoices, detailing the amount and what the payment is for. Payment slip or invoices should record:

- ◆ Full name;
- ◆ Tax Date (this is the date the invoice is issued);
- ◆ Home address (if available, those without a fixed address should give, if possible, the best place at which to contact them);
- ◆ Bank details or desired method of payment, e.g. cheque, voucher, cash.

The individual should sign the payment slip or invoice before submitting it (in person or digitally) and be given a copy for their records. A recording system should be established for recipients to confirm receipt where payment is made in any form that is not a bank payment. Wherever possible, this should be done face to face and signed in person. If posting vouchers or cash, a tracked and insured method should be used. Voucher numbers and who they are issued to, should be recorded so that they can be cross-checked should a

It is important that expenses reimbursement is documented clearly and separate from any participation payments, to avoid the reimbursement being treated as earnings and impacting benefits

participant report the non-arrival or failure of a voucher.

Where a participant falls under IR35³⁵ or should be an employee, the organisation's (or its intermediary's) standard practices around adding an individual to its payroll, including the checking of documents, will apply.

For people in receipt of benefits, it is important that expenses reimbursement is well documented, as not doing so may risk the reimbursement being treated as earnings and impacting benefits³⁶. To reduce financial impact on individuals, it may be useful to pay for expenses in advance (e.g. pre-booked tickets). Where there are no receipts, e.g. for mileage, rates should be paid in accordance with HMRC guidance³⁷.

All records should be retained in accordance with the organisation's document retention policy, with due attention given to GDPR, confidentiality and secure storage of potentially sensitive information.

Wider ethical considerations

Ethical considerations are paramount in any research and engagement context, however they can be complex and multifaceted in social research where risk cannot always be quantified. It is challenging to capture precisely how payment can impact on decisions to participate in research, but particularly so in research where individuals may be motivated by a drive to help their communities and achieve greater social benefit³⁸.

While it is not uncommon to pay research participants for their time, the practice is inconsistent and the impact on participation and ethical practice is debated³⁹. Mirroring the same complexities seen in the regulatory frameworks above, much of the academic guidance on ethical considerations of paid participation is unclear and depends on the judgement of individual institutions and researchers⁴⁰. There is some suggestion that traditional research governance is not fit to consider the complexities of co-produced research⁴¹. However, there are increasingly more co-produced approaches to understanding ethics in community based, participatory research⁴². In addition, best practice approaches to research ethics utilise human rights legislation to inform professional ethics.

Good practice research focuses on the concept of 'freely given informed consent', outlined by the Economic and Social Research Council (ESRC) as:

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- ◆ giving sufficient and appropriate information about the research, to allow participants to make a meaningful choice about whether or not to take part;
 - ◆ ensuring that there is no explicit or implicit coercion, so prospective participants can make an informed and free decision on their possible involvement.⁴³

Principles of freely given informed consent also note that participation should not be coerced (through threat of harm, or withdrawal of services). There is also concern about the role of inducement in research. Inducement is an offer, whether financial or social, of benefit for participation. Inducement itself is not likely to be an issue in research where there is no significant risk of harm to individuals⁴⁴. However, payment for participation is at risk of being seen as undue inducement, particularly when participants would be influenced to participate in research that they would otherwise not participate in with a smaller incentive or with no incentive at all⁴⁵.

The Market Research Society (MRS), a UK professional body for market and social research outline principles for incentives and prize draws by stating that incentives must be proportionate to the task, and that participants must be made aware of:

- ◆ What the incentive will be;
- ◆ When participants will receive the incentive;
- ◆ Whether conditions are attached e.g. completion of a specific task⁴⁶.

This third consideration is particularly relevant where withdrawal from a process means a participant will not receive payment. It should be clear what conditions must be met for payment to be administered.

It is important to recognise the fine balance of these potential risks against the very real issues of enabling the engagement of seldom-heard groups, and those in financial hardship who otherwise would be unable to participate, as well as the importance of genuinely valuing the experience of participants and ensuring that they know their experience has value. An important part of balancing such concerns against the benefits is understanding that, largely, participants are, as much as any employee, capable of weighing up their situation and making an informed choice provided they are given the necessary information in an accessible way, and supported appropriately to understand its meaning.

Ethical considerations raised in the case studies detailed in this report include the risks of:

- ◆ People feeling compelled to participate in work that may harm them emotionally, whether they are cognisant of this risk or not;
- ◆ People participating in work because they are in financial hardship.

Other social considerations

Paying people who are legally deemed to lack capacity

This is a legally technical area which requires a careful individual assessment of the benefits of an inclusive approach against the potential risks to the person.

Paying people with substance misuse issues

People with substance misuse issues are often viewed as more vulnerable to personal financial risk or exploitation. However, evidence does not suggest that paying people who misuse substances to participate in research has links to relapse or additional substance misuse⁴⁷. While organisations may seek to offer remuneration in the form of vouchers to this group to reduce risk to individuals, this is not good practice in the eyes of the Health Research Authority⁴⁸, who suggest that adults who misuse substances should not be treated differently to other participants. However, it is advisable for organisations engaging with any population to be aware of the signs of financial exploitation and risk assess each situation individually.

Inequalities in recruitment from black and minority ethnic groups

People from black and minority ethnic groups in the UK continue to be routinely under-represented in research⁴⁹. In addition, black and minority ethnic group service user participation across co-production services in health and social care has decreased in recent years in the UK⁵⁰. There is limited evidence about the experience of paying for participation for black and minority ethnic groups. However, best practice guidelines are available to increase participation in research⁵¹ in black and minority ethnic groups.

Case studies

As we have seen above, the regulatory and ethical frameworks guiding practice around payment for participation are still emerging. The case studies below demonstrate a range of approaches being taken across Scotland and the rest of the UK, by organisations determined to recognise and resource the time and expertise shared by people with lived experience of the issues they work across. Organisations are finding a variety of ways to navigate some of the complexities outlined above, and this research shows there is a clear need for more comprehensive guidance, to enable more organisations and decision makers to meaningfully resource and support the participation of people with lived experience, as a core part of a Human Rights Based Approach.

All Case Studies have been anonymised.

Case Study 1

This case study explores the role of paid participation in market research and public consultation work.

About the organisation

This organisation is a private limited company that works with a range of statutory partners in the UK. Their mission is to help their partners understand the public and their views to better inform policy.

Target population and known barriers to paid participation

The organisation engages with a wide range of people who make up the public, but often makes a concerted effort to over-sample marginalised groups in their work in order to amplify these voices. They undertake a range of work, from surveys to in-depth deliberative work. Often, projects centre on asking the public to review or re-design services based on their experiences or the experiences of others presented through case studies, while weighing up trade-offs.

Because this market research organisation engages with such a wide range of stakeholders, there are multiple barriers to receiving payment. However, the most commonly reported barrier is the potential impact on benefits. The organisation notes that participants are more likely to disclose their barriers to payment in longer-term work, rather than during one-off consultation.

Approach to paid participation

This market research company offers payment as standard across all of their work, and they frame it as both an 'incentive' to involvement for lighter-touch work, as well as a recognition of labour and time spent for longer-term projects.

Rates of payment are internally benchmarked and paid at half day or full day rates. However, staff also make an effort to recognise additional costs associated with participation, including the emotional labour of participation or any preparatory time involved. Payment is generally offered at a single rate and is expected to cover both time spent on the work and the costs of attendance (such as transport and childcare), although in some cases supplementary funding is available to help people who face additional barriers to attend. For each project, teams will meet to discuss the best approach to payment and explore any barriers to payment.

Rates of payment are internally benchmarked and paid at half day or full day rates. However, staff also make an effort to recognise additional costs associated with participation, including the emotional labour of participation or any preparatory time involved.

Payment is administered in a variety of ways. For larger-scale research such as surveys, vouchers are offered to participants in some instances. This is a reflection, in part, of the administrative burden of administering payment for hundreds of participants at once. For engagement events done in person, cash is available. In longer-term deliberative or co-production projects, a blend of cash or BACS payments and vouchers are both made available. There is more scope within this longer-term work for staff to be flexible to individual needs and responsive to challenges raised by participants. For example, they can stagger payments across longer time periods to help individuals manage their payment in relation to Universal Credit.

The offer of payment to participants is always made upfront. This allows people to make an informed choice about their commitment to the work. Standardised wording is used to outline the offer of payment and the responsibility of participants in exploring how it may impact on their tax and benefits. Participants of longer-term projects are also given the opportunity to contact the project team to discuss any concerns. The organisation signposts

participants to services who can support them to find out more about the impact of payment, such as the Citizens' Advice Bureau.

Learning from the process of paid participation

The attitude to managing risk varies across teams in the organisation and risks for paid participants are considered differently in different contexts. Because payment is seen as a standard offer and the background of participants varies so significantly, the resource implications of carefully considering the impact of payment for each individual participant would be untenable. However, there is movement towards thinking more carefully about risk and payment in all projects, rather than just those that focus on marginalised groups with known barriers to paid participation.

Case Study 2

This case study explores paid participation in the context of a long term co-production project engaging care-experienced young people.

About the organisation

This three-year co-production project is funded by a charitable trust and aims to develop the capacity of care-experienced young people to lead on issues that affect their lives. The project uses a blend of workshops and peer research to engage care-experienced young people from a range of backgrounds.

Target population and known barriers to paid participation

The people with lived experience engaged in this work face a range of barriers to participation. Some participants receive benefits, others work or are in full time education and some are self-employed. Some participants are students who receive loans or grants. There are lots of complex individual financial circumstances, but the long term relational aspect of the work means that the project lead is aware of these circumstances.

Approach to paid participation

The offer of payment to participants from a care-experienced background is made as standard in this project. Many professionals engaged with the project are participating as part of paid posts, so are not offered payments. This payment is framed as a recognition of the time and emotional labour that goes into participation in this work. Payment is benchmarked against similar co-production services and paid following each workshop. Participants' travel costs are also paid upfront and support is given to book travel to workshops.

Because of the long term commitment of this work, participants are asked to register as self-employed and submit invoices following workshops. This has been a learning curve for many participants who have limited experience of managing their personal finances and some of whom have no experience of self-employment. To respond to these issues, the project has offered three coaching sessions through the course of the project to learn more about self-employment and invoicing. The project has also created a pro-forma invoice that can be completed by participants with support. Despite this support, some participants still struggle to manage the invoicing and self-employment element of participation.

This self-employment approach to payment can be a challenge for participants, particularly those who are in receipt of benefits or concerned about tax thresholds. The project lead notes that they can stagger payment to better align with tax years and ensure that participants do not go over tax thresholds.

Participants in receipt of benefits are advised to speak to benefits advisors and job coaches about what payments mean for them. The project lead notes that they are more limited in their ability to support people to navigate barriers related to benefits due to the complexity of benefits entitlement and lack of freely available guidance.

Registering as self-employed and submitting invoices was a learning curve for participants with limited experience of managing personal finances. Three coaching sessions were offered alongside pro-forma invoices – but some participants still struggled to manage this.

Learning from the process of paid participation

The communication of payment in this project was made upfront and was important for establishing the values of shared power and recognition of lived experience. This was particularly important given that the professionals engaged with the work are paid to participate. However, the project lead noted that it is important to set expectations around the mechanisms of payment at the outset of the project. The project lead recounts incidents where invoices were submitted past the deadline, and participants were impatient that they weren't able to be paid quickly following a late submission.

It is likely that in the future, the co-production team will administer one-off payments to people participating in the peer research element of this work. This team will have to consider best options for administering this payment, including issuing vouchers. The project lead believes that this process may help participants to understand the complexity of paid participation from a different perspective.

Case Study 3

This case study explores payment in the context of citizen participation processes in Scotland.

About the organisation

This organisation is an arm's-length organisation (ALO) which is publically funded to design and deliver citizen deliberative exercises in Scotland with the aim of supporting democratic processes in Government. Whilst their remit is set by government or legislators, the organisation operates at arm's length to ensure an independent and unbiased approach in its engagement with contributors. The organisation is subject to public funding regulations and government procurement and employment procedures.

Target population and known barriers to paid participation

The organisation's public participation processes are designed to be a representative sample of citizens in Scotland, and as such, groups of participants are recruited according to the demographic factors relevant to a particular project (e.g. ethnicity, gender, age, geography, income level, political affiliation, attitudes to a particular issue). Working with such a broad range of participants means that the organisation regularly encounters the many and varied barriers that individuals encounter when engaging in paid participation. These barriers include:

- Potential tax liabilities
- Potential detrimental impact on benefits
- Lack of access to a bank account
- Having no fixed address

Approach to paid participation

The organisation offers payment as standard across its public participation work. It frames payments to participants as 'a gift of thanks,' to reflect the organisation's values and the importance it places on the contributions of participants. The organisation also positions payments in this way with the intention of easing concerns about potential impacts on benefits. Depending on the needs of individual projects, the organisation may take on responsibility for administering these payments themselves, or may contract a third party organisation to do so.

In terms of recruiting participants, the organisation has found payment to be

instrumental, especially in enabling participation from seldom-heard groups. Participants working with the organisation sometimes reflect that they first joined the process for the money but continued participating because it was fulfilling and interesting. The organisation is concerned that without a financial incentive, they would be less successful in engaging with hard-to-reach individuals and would end up working with a collection of 'usual suspects'. The organisation reflects that these 'thank you gifts' also lead to higher retention rates over the course of longer projects.

At the outset of any new process, organisers discuss how to calculate the 'gift of thanks' for participants, taking into account the time and emotional commitments required of those taking part in what are often long-term projects. Individual projects are supported by an advisory board who can inform best practice and help find the balance between the best use of public funds and the importance of recognising contribution. For processes such as [Citizens' Assemblies](#), the organisation pays participants a standard amount of £200 per weekend. The process was planned across 6 weekends, with an optional 7th weekend subject to members' decision making. In its response to COVID-19, the organisation has adapted its payment amounts to reflect the differing commitments associated with online involvement.

When the organisation is responsible for administering payments, payments are made by BACS on receipt of a short form from each participant, which they complete at the end of a weekend. Participants can request vouchers as an alternative to BACS payments. In addition to the payment which recognises their contribution, participants are also offered accommodation and food for the weekend, and transport costs are reimbursed. Where engagement is online, organisers offer use of IT equipment and pre-paid internet access. To remove additional barriers to participation, organisers will reimburse childcare and caring costs, including paying for participants to bring those for whom they have caring responsibilities along for the weekend, where appropriate. The organisation noted a challenge in reimbursing costs for informal childcare

In terms of recruiting participants, the organisation has found payment to be instrumental, especially in enabling participation from seldom-heard groups.

where the participant does not provide an invoice. Based on advice from their finance team, reimbursement for informal childcare is capped at £5 per hour. The organisation also provides opportunities for mental health support required by participants as a result of issues that arise during the

engagement process.

Learning from the process of paid participation

Through their experience of organising citizens' participation processes, the organisation has developed ways of managing unforeseen challenges in paid participation. For example, participants with no fixed address are not stopped from registering for processes, and there are options for payment via vouchers. In order to ensure its staff were familiar with, and able to manage, the risks of financial exploitation, the organisation invested in safeguarding training and developed a safeguarding policy specifically around financial exploitation.

One aspect of administering paid participation noted by the organisation was the importance of managing expectations for payment, particularly in respect of timelines, with an unexpectedly high amount of administrative resources required to respond to questions about when payments would be made. Organisers learned that outlining payment timelines and other relevant details at the outset of a project can save a great deal of staff time and allay stress in participants later in a project. For a recent piece of work, the organisation engaged a third party provider to take on the management and administration of payments. Organisers reported that whilst this reduced the administrative burden on them. They had less contextual understanding of individuals' personal circumstances, and less opportunities to connect with participants.

The organisation feels that, particularly for large-scale citizen participation processes, it is essential that precise guidance was available to participants about their responsibilities in respect of understanding potential tax liabilities and benefits impacts. Potential participants are made aware of the offer of payment early in the recruitment process, and then have the option to find out more about how payments can be made and the risks and liabilities attached. The organisation provides participants with its own standardised guidance in writing, via telephone, and during door-to-door recruitment (when used). While organisers had hoped to be able to provide a definitive policy delineating the impact of payment on individual benefit entitlements, they found this to be unachievable due to the lack of clear advice from the Department of Work and Pensions despite a formal request for guidance. The organisation does feel confident to advise participants that a 'payment of thanks' should not impact on benefits, but asks for participants to verify this independently.

When weighing up the risks and benefits of paid participation, the organisation

is emphatic that potential negative impacts of payment need to be carefully considered in advance of a project, and teams must be equipped to respond to issues as they emerge. Citing an example of a participant who was so afraid of the impact on their benefits that they withdrew from a project, the organisation is well aware that people in receipt of benefits are justifiably fearful of the sanctions and loss of income which could result from paid participation being mishandled. As such, the organisation recognises that support for individuals is essential to overcome this deterrent to participation. However, the organisation operates on the basis that ultimately, responsibility resides with individual citizens to make an informed choice about whether to accept payment and the liabilities that may accompany it.

Case Study 4

This case study explores the development of a ‘thank you’ policy in a charity that seeks to address poverty in the UK.

About the organisation

This organisation is an incorporated charity governed by a board of trustees. They are committed to ending poverty in the UK, and have a dedicated participation team to include the voices of lived experience in the organisation’s work.

Target population and known barriers to paid participation

This organisation works closely with people currently living in poverty or with experience of living in poverty. Due to the nature of poverty in the UK, many of the people engaged with the charity have long term conditions, are disabled or are carers. The charity works closely with pre-formed community groups, which includes groups for asylum seekers.

The populations this charity serves face numerous barriers to paid participation, including:

- Potential tax liabilities
- Potential detrimental impact on benefits
- Employment law complexities
- Having no fixed address
- Limited digital access

The charity recognises that the benefits system is a particular barrier to participants, some of whom have deep mistrust in the system.

Approach to paid participation

The organisation offers payment or a ‘thank you’ acknowledgement to participants across a range of projects. This payment is offered as a recognition of the contribution of lived experience in all of their work. People with lived experience can have their contribution recognised through either ‘thank you vouchers’ or BACS payments. However, participants who wish to receive BACS payments must operate as freelance self-employed consultants and are expected to take on responsibility for managing their own tax liabilities. The organisation signposts to support agencies to help people set this up if it is a route that people want to go down and also connects them with

other people they are working with who are set up as self employed in similar types of activity.

The charity developed their payment rates based on a benchmarking exercise of comparable work. They have a standard rate based on activity type and time contribution (for example, a standardised rate for a ½ day workshop). However, the organisation notes that they do not offer a standard hourly rate for work completed because this may be construed as constituting an employment relationship. For work including people seeking asylum in the UK, the organisation is clear that participation is not a work replacement, and are more likely to recommend vouchers for payment. The organisation also includes costing for any necessary preparation for workshops. They note that some work is particularly emotionally challenging, and try to acknowledge this when setting their rates of payment. This charity can also offer additional resources to enable participation, including the payment of travel expenses, food and childcare (the charity's policy only allows for the reimbursement of formal childcare arrangements currently, which can be a challenge for individuals who rely on informal childcare for attendance). They have also provided data passes to enable online access for digitally excluded participants.

When embarking on work with people with lived experience, the organisation clearly outlines their offer of recognition in their payment and 'thank you' policy which was developed with support from an employment law consultant and with the input of people with lived experience engaged with the organisation. This policy discusses potential risks of payment and advises participants where they can seek guidance (ie. Citizens' Advice Bureau). This ensures that people can take a fully informed decision.

During their interview, the charity reflected on the challenges of developing this policy. They had hoped to offer more comprehensive advice about how payment and 'thank you vouchers' may impact on benefits entitlement. However, the complexity of the benefits system and lack of transparency in guidance makes this challenging. In addition, the introduction of Universal Credit means participants are less likely to know their specific benefits entitlements and so cannot make judgements based on this information. The charity's policy aims to provide clear information and signpost people to

Ultimately, this organisation feels it is important for people to have the information about potential impacts on tax and benefits to make an informed choice about what works best for them.

robust support. But the organisation notes that it cannot offer individual advice and that participants are responsible for making an informed choice about payment. The organisation is committed to ongoing development of this policy, and regularly reflects on their 'payment and thank you' policy with the people they are currently working with.

From a values perspective, the organisation wants to take an enabling approach through encouraging people with lived experience to take fully informed and independent decisions with guidance from those best placed to offer it. Using transactional analysis as a framework, the organisation describes this process as enabling an adult to adult transaction (where both parties have responsibility and agency). This ensures that the organisation does not contribute to dynamics of control and disempowerment through their work with people with lived experience.

Learning from the process of paid participation

The charity's partnership work can impact their approach to payment. Despite having their own clear payment policy, they note that when working with smaller, grass-roots organisations, the charity may take cues from their partners. They also need to recognise that they cannot raise expectations of payment that partner organisations cannot afford to sustain after the project ends.

During their interview, the organisation described the risks of a paternalistic attitude in the charity sector towards people with lived experience and felt strongly that people with lived experience should still have choice and agency.

The organisation believes that people have the right to decide themselves if they wish to be paid in cash or receive 'thank you' vouchers. The charity reflects that there are often assumptions that people with lived experience would never want to receive vouchers. But they reject this assumption as in their experience, some participants feel safer using this option. Ultimately, the organisation feels it is important for people to have the information about potential impacts on tax and benefits to make an informed choice about what works best for them. The charity also emphasised that it is valuable to explore policies of paid participation with people with lived experience, who may offer a different perspective.

Case Study 5

This case study explores paid participation in the work of a co-production centre based within a University.

About the organisation

Based within a UK University, this co-production centre brings together a community of people with lived experience, researchers, practitioners and students. The centre works with a range of organisations including academic institutions, statutory organisations, local grassroots community groups and charities.

The centre is partially funded by an academic grant and partially via income generation. It is subject to financial reporting through University finance departments. This centre aims to involve a diverse range of voices and lived experience in research, service and policy development design through co-production, they have a focus on health and beyond. Co-production activities include being built into grant proposals to support research teams to co-produce, consultancy work for external organisations, delivery of co-production training and partnering with other organisations to deliver events or similar. They have a two-year strategy to design, sustain and fund the long-term sustainability of the centre.

Target population and known barriers to paid participation

The centre works with a wide range of stakeholders with lived experience and works to ensure its engagement network includes voices marginalised by society, including people in prison and homeless people. The organisation's focus on health research means that many participants have long term conditions. Barriers to paid participation for members of the centre may include:

- ◆ Potential tax liabilities
- ◆ Potential detrimental impact on benefits
- ◆ Right to work checks for those entering into temporary contracts
- ◆ People having no fixed address
- ◆ Reticence (for personal reasons) to share personal financial details or submit to a right to work check

Approach to paid participation

The centre offers payment to participants as standard making sure that they know it is fine to say no if they don't want to be paid for whatever reason. This has been an important value statement of their work from the outset. The centre administers these payments themselves, with the exception of projects where they worked with people without a fixed address, in this case then a partner organisation is sought as they are better equipped to understand and manage barriers associated with payment for this group. Occasionally, people refuse payment for participation and ask for a donation to be made to a charity on their behalf. The payment rate is currently benchmarked against the National Institute for Health Research (NIHR)⁵² day rates, although the centre notes this is under review. The centre offers a range of options for payment based on their understanding of best-practice guidelines. These include:

1. Temporary employment managed through a third party organisation for temporary workers at the University (paid after submission of a timesheet)
2. Payment of cash following the completion of an expense form
3. 'Thank you' voucher

The centre reflects that some members are reticent to submit to right to work checks to gain temporary employment. Right to work checks before COVID-19 required the participant to travel to the University, which was sometimes a challenge due to distance and accessibility concerns. In addition, other participants prefer cash or voucher over a BACS transfer because they do not feel comfortable sharing their bank details.

In addition to payment for participation, the centre can offer support with travel and internet access costs and is developing a policy with explicit offers of support for people with caring responsibilities. These have always been available, but the centre feels they could have been more explicit outlining what was available and how to access it. The centre also offers opportunities for development including access to a large network of people, training and a co-production resource bank. They see this as part of the wider benefit of participation.

The centre is now in the process of co-producing a payment policy that outlines the offer of payment, options for administering payment and the liabilities involved in accepting payment. While they hope to build their capacity to respond to concerns about payment and or any impacts on benefits, they are clear that they must recognise that they are not the experts.

They currently signpost participants to third party organisations for specific advice if it is required.

Learning from the process of paid participation

The centre is using a co-production process to develop a payment policy for their work. The policy draws on guidance from HMRC, the DWP and the University finance department as well as the expertise of people with lived experience. Through this process, they hope to navigate the challenges of shared responsibility in paid participation processes. The centre hopes to forge new approaches to paid participation that may challenge barriers and assumptions within the University and beyond. They believe that their choice to publicly co-produce a payment policy demonstrates their commitment to the values of co-production. Their belief is that this process may be 'messy', but that the end policy will be a much better product as a result of this collaboration and transparency.

Case Study 6

This case study explores paid participation at a limited company with a social purpose

About the organisation

This organisation is a limited company with a social purpose. The organisation aims to build [social capital](#) and promote democratic processes that move beyond vote and protest. They are commissioned by a range of statutory partners to offer insight to decision makers about how the public views policy issues. The organisation delivers a range of social engagement activities including World Cafes, co-production processes, Citizens' Assemblies and participatory budgeting sessions.

Target population and known barriers to paid participation

The organisation works with a very broad population, and individual projects often have different demographic requirements. They work with marginalised populations, including people living in poverty, people involved in crime, people who are unregistered with the NHS or unknown to services. They also work with black and minority ethnic communities. The organisation is interested in intergenerational work that engages young people and working people in their 30s in deliberative processes. Some projects purposely sample from certain demographics, while other activities have an open-door policy and do not collect demographic information until after the event.

Because of the wide range of backgrounds of participants, the organisation notes a range of barriers to paid participation, including:

- ◆ Right to work as an asylum seeker
- ◆ Potential tax liabilities
- ◆ Potential detrimental impact on benefits
- ◆ People with historic distrust of institutions/those in a position of authority

Approach to paid participation

The organisation offers payment as standard across its public participation work with the exception of commissioned work where paid participation is not funded. Payment is framed as a 'gesture of good will' rather than payment of work or volunteering, and is a key incentive for involvement in engagement work.

Payment rates are set using the National Living Wage as a minimum.

However, recent guidelines from Citizens' Assemblies have established a day rate of £75 as good practice, and the organisation now uses this rate as a benchmark. For longer term work, this can add up to more significant amounts. In a recent co-production project, residents were asked to attend 13 three-hour meetings paid at £10 an hour for a total payment of £390 for their involvement.

Cash is the preferred method for administering payment within this organisation, as some participants dislike sharing the personal information required for BACS payments. Due to the shift to online engagement during COVID-19, the organisation has transitioned to offering e-vouchers for participation. The organisation notes that buying and administering these vouchers has been an additional administrative burden and they do not offer participants the same flexibility as cash payments.

For longer projects, the organisation states that they advise people of their responsibilities in respect to tax and potential impact of benefits. However, they note that outlining these complexities at the outset of a project can be a deterrent to participation.

Where possible, cash incentives are offered in place of refunding expenses, which can be a complex process requiring additional administration. Payment for childcare is also not offered as standard, but the organisation can sometimes offer an additional £10 per hour for participants who say that lack of childcare is a barrier to participation. In the past, the organisation has had to develop alternatives to paid participation when commissioned by partners who cannot offer cash payment. These include:

- ◆ Offering young people a month's gym membership to a local gym
- ◆ Hiring a photographer to take family portraits at a planning event for the Bangladeshi community

For the latter example, the organisation notes that the resource that went towards the photographer, development of photos and managing sending out prints to families who attended cost far more than a ½ day rate for participants.

Learning from the process of paid participation

This organisation is commissioned by partners who may have a more risk-averse view of payment than they do. They recognise that they may operate with more flexibility because they are a private limited company. However,

the organisation feels confident in their approach to payment and offers to speak to anyone concerned about the risks, including local media, about their rationale for payment. The organisation also recognises the need for internal sense-checking of payment procedures, and notes the importance of working with their accountant and wider staff teams to carefully consider risks.

Ultimately, the organisation reflects that payment is an incentive for involvement and can widen participation. However, they also recognise that payment does not guarantee a positive engagement experience. They state that other organisations need to make sure what they're offering people is more than a PowerPoint session. Their philosophy is that engagement must be led by people and communities and sit within the spirit of co-production.

Finally, the organisation reflects that many of the people who have been involved in long term co-production projects with them have said at the end of a process "I would have done this without payment". However, the organisation believes that without that initial financial incentive, they would not have attended and had the positive experience. In their view, this is the route to building social capital and more engaged communities.

Ultimately, the organisation reflects that payment is an incentive for involvement and can widen participation. However, they also recognise that payment does not guarantee a positive engagement experience. They state that other organisations need to make sure what they're offering people is more than a PowerPoint session. Their philosophy is that engagement must be led by people and communities and sit within the spirit of co-production.

Case Study 7

This case study explores paid participation at a public participation charity.

About the organisation

This organisation is a charity with a remit for embedding democratic public deliberation across the UK. The charity supports processes that enable members of the public to make decisions about issues that affect their own lives. The charity delivers its mission with a range of partnerships and long term project-work.

Target population and known barriers to paid participation

The organisation works with people from a wide range of backgrounds. Larger projects aim to recruit groups that are 'broadly representative' of the public and use methods such as sortition to do so. Other projects seek to engage groups with shared lived experience of a particular issue. Due to the numbers of people engaged and the diversity in participant demographics, the organisation notes that they cannot be fully aware of each individual's financial circumstances, but advised that the most frequently encountered barrier to paid participation is detrimental impact on benefits.

The organisation also notes that discussions about money and payment can be sensitive for participants.

Approach to paid participation

The organisation offers payment as standard across its public participation work. It frames this payment as a 'thank you gift', or an honorarium for time spent contributing to the organisation's work. Payment is seen as a tool to address barriers to participation, particularly for populations who may be sacrificing paid work to attend.

Rates are usually paid on a ½ day or full day basis and are benchmarked against other projects within the organisation. The process for deciding on rates is iterative, and reflects best practice within the sector as well as consideration of specific project circumstances. This organisation can administer payment in a range of ways, including:

- ◆ BACS payment directly into a bank account
- ◆ Vouchers⁵³
- ◆ Cash has been available for past projects

The organisation has used cash thank you gifts when appropriate, but prefers to use BACS payments where possible particularly in larger group workshops where there is difficulty handling large cash sums. BACS payments and vouchers also offer a clearer audit trail for the charity. They also received guidance that payments are considered capital, and as such can put individuals over thresholds for tax and benefits.

In addition, payment for expenses to cover things like travel and subsistence is something they can offer upfront. Recent guidance shared by a strategic partner organisation has reassured this charity that while no payment can be offered with the guarantee it won't impact on tax and benefits, their approach does offer some flexibility to participants.

In addition to these honorariums, the organisation is sometimes able to offer funding for childcare when it is available. They have also invested in Chromebooks and wifi dongles for digitally excluded participants, which are loaned for free at the outset of the project. At the end of the project, participants can choose to buy these at a significantly decreased cost. However, the charity reflects that the shift to online engagement is not necessarily cheaper, as there is significant resource dedicated to supporting people to learn IT skills and build the confidence needed for successful engagement in online participatory processes.

The offer of a thank you payment is communicated at the outset of any work and is outlined in writing. The organisation makes clear to participants that payment may impact on benefits and tax, and they can't advise on whether it will for each individual. They also make options for payments clear, making clear that vouchers still may impact on benefits. They note that it is important to make no assumptions about individual circumstances when sharing this information.

Learning from the process of paid participation

The charity is clear that while they have extensive experience of offering payment for participation, they still operate with the same degree of uncertainty as the rest of the sector. The organisation's policies towards payment outline what issues they are aware of, but they say they must also be

The charity reflects that the shift to online engagement is not necessarily cheaper, as there is significant resource dedicated to supporting people to learn IT skills and build the confidence needed for successful engagement in online participatory processes.

clear about what the organisation does not know and cannot advise on. The organisation does not have the expertise to offer individualised advice on the tax and benefits systems and is not legally empowered to do so.

The organisation believes it would be beneficial if there were clearer guidance from HMRC and DWP on this area. They note that there is huge variability in practice and it can be challenging for both charities and individuals to successfully navigate payment.

A key piece of learning for this organisation is the importance of offering additional support for participants to understand and engage in any materials produced regarding payment. The charity reflects that by making assumptions about literacy and financial confidence of participants, people could be at risk of agreeing to things that they do not fully understand. Using accessible language and taking the time to explain concepts like 'liability' can mean participants get the opportunity to make an informed choice, and feel comfortable seeking support and advice in the future.

Case study 8

This case study explores paid participation for victim-survivors of human rights violations.

Alex specialises in strategic litigation, community organisation and promoting awareness, respect and understanding of human rights. Alex's work focuses on restorative justice and community empowerment; she has a career of over 20 years working with a number of non-governmental organisations, and her interview reflected her experience across these organisations. Alex works with marginalised populations, including those affected by genocide, and indigenous peoples who are victim-survivors of human rights violations.

Barriers to participation in Alex's work for these populations include:

- ◆ Extreme poverty
- ◆ Structural victimisation and the threat of retribution
- ◆ The emotional strain of involvement and the risk of retraumatization
- ◆ Childcare requirements
- ◆ Language difficulties
- ◆ Cultural backlash (particularly for women taking part)
- ◆ Lost income due to taking time away from work

Neither standard nor ad-hoc payments are offered to participants in Alex's work, but other offers to enable participation are made (e.g. travel, training, food, lodging and mental health support). A key aspect of the work for participants is the accompaniment and protection for those involved by non-governmental organisations. Furthermore, the work itself attracts the attention of the international human rights community, which may afford potentially vulnerable participants additional safety and communicate their struggle for justice to a global audience.

Alex explains three key reasons why monetary payment is not offered to participants in exchange for their participation: the principles of the work, community cohesion and resource implications.

The underlying principle of the work is to build the capacity of communities to respond to human rights violations and to enable those communities to give testimony about their experiences. Alex believes that introducing paid participation to communities undermines the core drive of the work: justice

and a guarantee of no-repetition. It also poses the risk of coercion, which is of particular concern in communities where participation in such work may put lives at risk.

Alex describes community cohesion and organisation as a core goal which she views as incompatible with payment. Her work seeks to strengthen and organise support networks that will last for decades beyond the initial support offered by non-governmental organisations. A key long-term outcome sought by Alex in her work is to enable participants to become natural leaders within their communities.

The scope of these projects entail significant resource implications for communities with complex social and economic divides. For many of the individuals involved, the unique personal sacrifices required, and the risks associated with being part of such work, make putting a price on such a contribution impossible for Alex.

In Alex's experience of participation, it is fundamental to be upfront with the communities that the organisation is attempting to engage, and ensure that they are supported. Alex recounted the experience of commencing a victim-survivor litigation process with a particular community, working with community members to be clear about what resources were available to the movement and why these were limited. Later, when this same community organised their own justice and reconciliation movement, informed by their work with Alex and partner organisations, they went through the same process of outlining to their community what resources they could and could not offer. In doing so, the new movement shared the same frustrations as Alex and their team did, in seeing that poverty is a serious barrier to genuine participation. This obstacle is not something that can be overcome by temporarily inducing individuals to take part through using up meagre resources on financial incentives, which risk creating a transactional relationship rather than a genuine commitment to the causes of justice and reconciliation

Alex describes community cohesion and organisation as a core goal which she views as incompatible with payment. Her work seeks to strengthen and organise support networks that will last for decades beyond the initial support offered by non-governmental organisations.

Case study 9

This case study explores the challenges of paid participation in community-based participatory research.

Rachel is an experienced community based action researcher with a special interest in supporting communities affected by violence who are seeking justice and redress. Rachel is a professor at a University, and her work is funded through a variety of grants from academic funders and charitable trusts. Rachel's work focuses on victims of political conflict and institutional child abuse.

Participants in Rachel's research face complex barriers to participation, including:

- ◆ Poverty
- ◆ The emotional strain of involvement and the risk of retraumatization
- ◆ The long-term impact of institutional abuse and violence leading to a mistrust in authority
- ◆ Fractured community and interpersonal relationships

Neither standard nor ad-hoc payments are offered to participants in Rachel's research. However, her research offers the opportunity to organise and legitimise the community justice movement by collecting testimony and writing reports. Rachel is also able to offer meeting spaces, as well as introduce communities to statutory and third sector organisations who can support them. Rachel reflects that in the past, her work has united divided survivor communities and facilitated more coherent approaches to justice and redress which have directly led to positive outcomes for survivors.

In her interview, Rachel raises ethical questions about payment in the context of participatory community-led research. She describes the risks of financial coercion for communities living in poverty, who may be motivated to share deeply personal testimony due to financial insecurity. Rachel also notes that for victim movements seeking justice, the source of payment may pose an additional barrier. In Rachel's view, accepting payment from those same institutions that perpetrated harm may amount to 'blood money', and could inhibit the movement's ability to be separate from and critical of these institutions.

Rachel does acknowledge that money is a 'silent undercurrent' in some

of her work and is discussed amongst participants. However, Rachel frames this as a more strategic issue and notes that the underfunding of community, grassroots organisations needs wider investment than a single researcher could offer. In the past, Rachel has used her position to raise concerns about funding and introduce communities to other organisations who can support them i.e. by subsidising travel.

When participants share barriers to participation, Rachel is proactive in seeking to remove those barriers (for example, travelling long distances to reduce travel costs, or interviewing participants at home so they do not need to secure childcare). Rachel reflects that bridging these divides is an important part of her role as not just a researcher but an advocate and ally. It is an important part of how she connects with communities and can offer her own personal time to support inclusion.

Ultimately, Rachel reflects that most survivors involved in her work are driven by the hope for personal resolution, as well as the drive to advocate and seek justice for other survivors. For Rachel, the question of payment is a question of agency. She reflects that some research, such as surveys with a large sample population, may need to offer financial incentives. However, for participatory researchers who are responding to community movements and are embedded in issues of justice and redress, the drive for involvement must come from the community itself. Rachel's work is fundamentally relational, which she feels sits in tension with the transactional and commercial nature of payment.

Rachel raises ethical questions about payment in the context of participatory community-led research. She describes the risks of financial coercion for communities living in poverty, who may be motivated to share deeply personal testimony due to financial insecurity

Additional cases of note

The below examples were seen as potential models of interest, but insufficient information was available to present as a fully considered case study.

1. A Trust for London review⁵⁴ of 20 organisations summarised arguments for best practice payment in the youth sector. The findings from this review saw that vouchers were the preferred method for payment, but specified constraints relating to young peoples' payment potentially influencing the wider benefit entitlements for their household, affecting their parents and siblings.
2. INVOLVE supports participants through a formalised link with the Citizens Advice Bureau, which allows individuals to access confidential, specialised detailed advice on their personal situation, without making themselves known to their Jobcentre work coach⁵⁵.
3. Inspiring Change Manchester's GROW – Getting Real Opportunities of Work⁵⁶ the project offers traineeships to people who face multiple barriers to employment including homelessness. Each GROW trainee receives a personal development budget of £1500 for their participation, which they can use for training, conferences, equipment or therapy.

Evaluating different approaches to payment

Why offer payment?

Across the case studies, organisations framed paid participation in different ways. These include as an incentive for participation, a recognition of time and expertise or as a ‘thank you’ for contribution. The values underpinning the choice to pay people with lived experience for their contribution are an important factor for any organisation to consider when developing a payment policy. Many of the organisations interviewed noted the fundamental benefits of paid participation on the work itself, ie. better retention of participants on longer term projects, and wider engagement from seldom-heard groups. It is important to acknowledge that offering paid participation can be of mutual benefit.

It is of note that several organisations felt that deliberate wording in relation to participant payments (notably “gifts of thanks” and “honorariums”) would negate potential tax liabilities or impacts upon benefits. This interpretation does not accord with the guidance available from the relevant Government departments that was considered by the researcher, but it is acknowledged that at least one organisation had sought advice on the matter from a Government department and used this to inform their policy. It is relevant to highlight here that advice from such departments is both difficult to obtain and seemingly inconsistent. Payment in vouchers can be treated as a gift but this must be specifically ruled on by the organisation’s local tax office.

Why not offer payment?

Case studies 8 and 9 offered examples of scenarios where payment for participants was deemed inappropriate by the organisations concerned, due to:

- ◆ Scarcity of resources in the face of a very large scale and long-term projects
- ◆ Potential to encourage participants to put themselves at real risk of physical harm for financial gain due to the culturally contentious nature of the work
- ◆ A view that payment minimises the gravity of the work being undertaken to

the point of being offensive to those involved, or makes a potentially re-traumatising process transactional

- ◆ Discouraging or distracting potential participants from genuine engagement in a process which is intended to have a far-reaching and long-term reparative community impact, from which many will benefit, for the sake of a relatively insignificant financial incentive

It is important to note that whilst these two case studies did not pay participants, they did ensure participants were enabled to overcome barriers to participation, through flexible research design or the reimbursement of expenses. While this learning may not be immediately relevant for the work that the Commission seeks to undertake, it is important to consider the ethical implications of paid participation in the context of human rights movements and particularly survivor dynamics. It may also help the Commission to understand why participants may choose not to receive payment for their contribution, and to sensitively navigate these dynamics within groups with different individual circumstances and motivations.

Understanding the barriers to payment

Both the case studies and reading of relevant legislation and guidance confirmed a number of barriers identified in the scoping of this research including:

- ◆ Welfare benefits entitlement
- ◆ Tax implications
- ◆ Employment law

An additional barrier noted by some organisations which was not considered in the scoping document for this report was institutional mistrust. This may be particularly relevant for individuals with lived experience of poverty. For these individuals, the case study organisations found that making available different options for payment including vouchers was particularly important.

One particularly challenging matter to navigate is payment to participants who may be at risk of financial exploitation. One organisation addressed this complex matter with specific safeguarding training for their team, resulting in increased confidence of staff to recognise potential signs of exploitation. Some organisations acknowledged that there were gaps in their knowledge about barriers to payment, particularly for shorter-term engagement. Across

some case studies, there was discomfort around discussions about money with participants and concerns as to how appropriate it was to ask about individual circumstances, although more information meant better quality support. Enquiries about individual financial circumstances must be handled delicately and with due attention to confidentiality and GDPR.

Calculating payment amounts

Not all organisations who participated were able to share the rates paid for participation. But for those who did, there was wide variation in payment amounts across organisations, which included:

- ◆ Basing payment on the UK Living Wage
- ◆ £20 for a 1.5 hour commitment
- ◆ £200 for a full weekend of engagement

Calculating fair compensation was dependent on a variety of factors, but most commonly reported were:

- ◆ The use of national standards (e.g. the UK Living Wage)
- ◆ Whether the payment was intended to cover additional expenses (ie. was payment in place of expenses or were expenses compensated in addition)
- ◆ Benchmarking against comparable work
- ◆ Time spent contributing (including travel time and preparation time)

Several case study organisations based their policies on those of INVOLVE, an engagement and public participation charity who have been developing policies for paid participation since 2002. The majority of the case study organisations were principally concerned with ensuring participants were paid an amount that fairly reflected the value of their contribution, as opposed to being hyper-vigilant of being seen to over-pay people, though two organisations did note the impact of press scrutiny on determining rates of payment. Some organisations noted the importance of acknowledging the emotional labour involved in sharing lived experience, and factored this into payment amounts. Most organisations noted that payment amounts were frequently revisited to ensure they reflected the expectations of the work as well as emerging best practice.

Most organisations paid based on full day or ½ day contributions, regardless of how long that full or half day was, rather than break this down into an hourly rate. Use of an hourly rate may be more likely to indicate the existence of an

employment relationship.

Good practice guidelines

The case study organisations listed the following sources when asked how they informed their paid participation policies:

- ◆ Her Majesty's Revenue & Customs website (HMRC)
- ◆ Citizens' Advice Bureau (CAB)/Citizens Advice Scotland (CAS)
- ◆ JobCentre Plus
- ◆ Department for Work and Pensions (DWP)
- ◆ Home Office website
- ◆ Social Care Institute for Excellence (SCIE)
- ◆ Department of Health and Social Care (DHSC)
- ◆ Employment law specialists
- ◆ Internal finance, HR, and procurement teams
- ◆ Social media
- ◆ Wider professional networks
- ◆ Partnership organisations
- ◆ Involvement and engagement organisations

In addition, some organisations noted the importance of working with people with lived experience to develop solutions to individual barriers to paid participation

Almost all of the organisations interviewed expressed frustration at the lack of clear, formal guidance from the relevant Government departments, particularly from the DWP, mirroring learning from the desk-based research part of this report. Most organisations had used online resources, or asked local benefits advisors but information was limited and inconsistent. One organisation had written formally to the DWP for guidance and had not received a response.

Most organisations discussed benchmarking best practice with other projects or seeking advice from organisations with more experience in paid participation. It is important to note, however, that there is a wide variation between practice across the case studies and very different interpretations of regulatory and legal constraints. It is clear that organisations often based their policies on the models of others, sometimes without seeking relevant and qualified guidance. It is important not to underestimate the risk (both to

an organisation and its participants) of relying upon another organisation's potentially subjective interpretation of the limited information available. There is perhaps an ongoing engagement opportunity for the Commission to lead a discussion on best practice approaches and formalise these learning networks.

Informing people of their payment and related responsibilities

There was a significant variation in how people with lived experience were informed of the risks and benefits of payment across these projects. Some organisations do not offer written guidance (particularly for one-off engagement events), whilst others use more formal policies for all interactions that include payment. None of the organisations interviewed had made their information available in accessible formats such as easy read, or had translated them into another language. One case study explicitly mentions the importance of guiding people with lived experience to understand policies surrounding payment, and not assuming that signing a receipt is sufficient evidence of informed choice. In contrast, another organisation was clear that navigating the risks of payment was the responsibility of participants and that the charity sector's paternalistic attitudes were at risk of infantilising people with lived experience. The harshness of sanctions in the UK benefits systems means that even minor errors or omissions on the part of a participant can have a catastrophic impact on their ability to meet basic living costs. As such, although attitudes to individual's responsibilities differed across the case studies, it is important to recognise that paid participation, if mishandled, presents a very real threat to the wellbeing of those who rely on benefits payments.

For organisations with written policies, these policies detailed:

- ◆ Payment amount offered
- ◆ Additional expenses offered
- ◆ Statements of shared or individual responsibility towards navigating potential risks

Some policies also signposted people with lived experience to sources of guidance (e.g. Citizens' Advice Bureau). Some organisations offered more than signposting, with opportunities for participants' skills development such as

workshops on self-employment skills.

Many organisations interviewed were clear about their own limitations in providing advice and guidance on tax liabilities and potential benefits impacts and were anxious about their perceived roles as ‘experts’. Most organisations acknowledged that they were operating in a space of uncertainty and felt that it was important for participants to understand this.

Administering payment

Two organisations interviewed were contracted to administer payments for partner organisations. One organisation had chosen to contract a third party organisation to administer payment for one of their larger projects. The benefits included

- ◆ Reduced administrative resource for the contracting organisation
- ◆ The intermediary has more experience of navigating barriers to payment

The contracting organisation interviewed noted that using an intermediary to administer payment meant they were less aware of the individual circumstances and challenges faced by their participants.

Dependence on payment

A dependence on paid participation, particularly for people with lived experience of poverty, was a concern for some organisations during long-term projects. It was important for organisations engaged in long-term projects to outline the expectations and duration of engagement to participants. Particularly in long-term projects, consideration should be given to whether an employment relationship exists with participants.

Audit trails

All organisations were able to identify the ways in which paid participation was accounted for in their financial reporting. Some organisations were held to more strict standards by funders, finance teams or public spending requirements. One organisation highlighted the importance of GDPR. Some organisations felt that BACS payments were easiest from an audit trail perspective. While these may be more convenient from an organisational

perspective, other organisations noted that the flexibility offered by cash payments or vouchers may be preferred by participants.

Responses to COVID-19

The transition to online engagement has meant a significant change in approaches to payment across the organisations interviewed. This demonstrates the need for a flexible approach to paid participation, and a commitment to navigating challenges as they emerge. COVID-19 has also highlighted barriers relating to digital exclusion that may not have been previously explored.

Overcoming additional barriers

Some organisations described instances where payment policies were not fit for purpose for an individual's circumstances. Most organisations were able to outline how they overcame such issues with common sense solutions. Notably, none of the case studies reported any instances where such issues had led to harm.

Final recommendations to the Commission

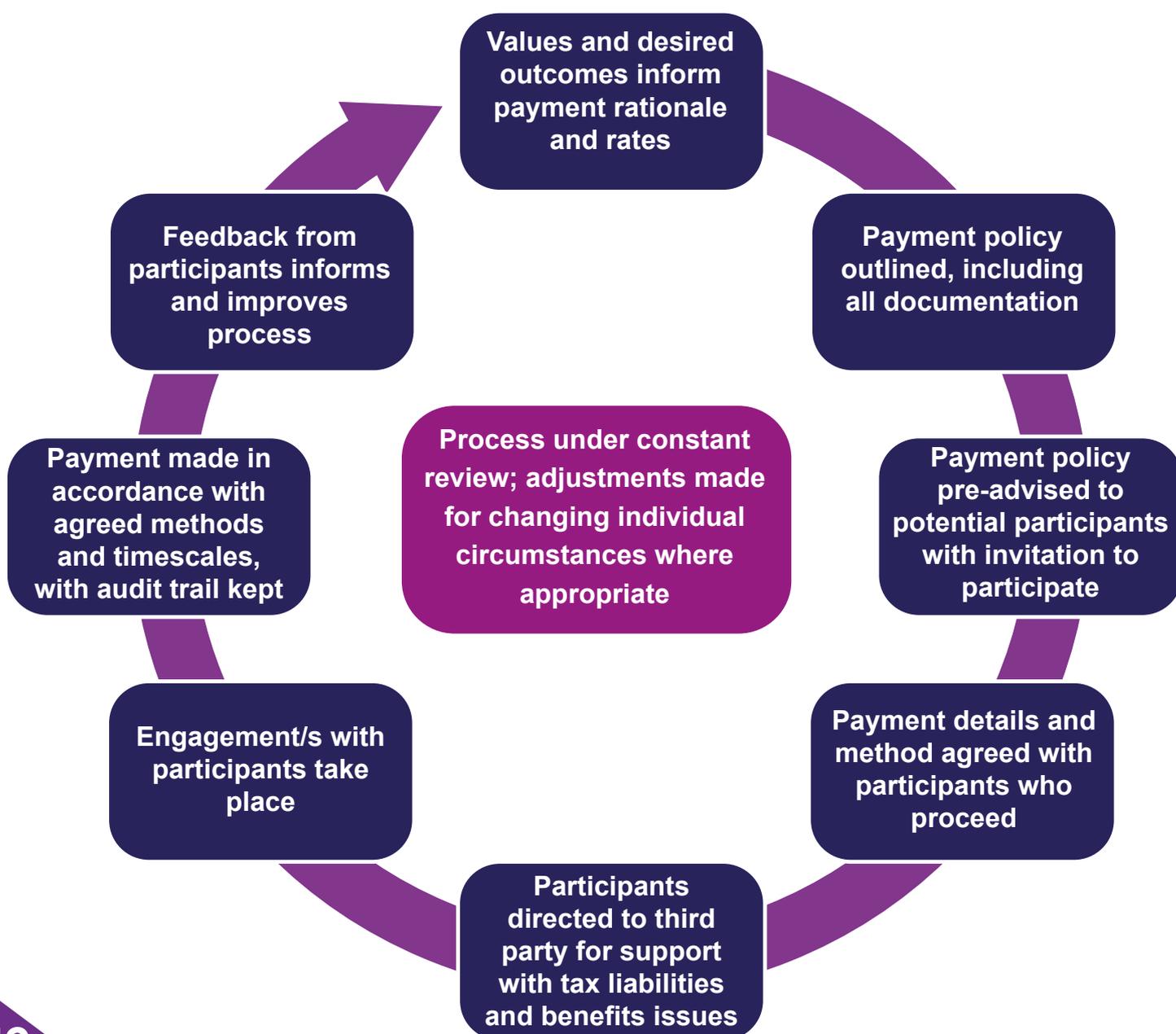
Based on the findings of this report, it is proposed that the Commission should:

1. Develop a values-based statement on paid participation that outlines why payment is under consideration, and what benefits payment offers for both potential participants and the Commission itself. This document should serve as the foundation of the development of a payment policy setting clear guidelines as to when, how and in what circumstances participation payments will be offered. The Commission may wish to explore the option to co-produce this statement, and the subsequent policy, with people with lived experience.
2. Establish payment rates benchmarked against industry standards. These rates should be clearly and logically reached, with the reasoning readily available; amounts should also be indexed against living costs.
3. Create a clear policy for paid participation, detailing all stages and necessary documentation, that can be shared with participants and partner organisations. This policy should be available in a range of formats that respond to any accessibility needs. The policy should detail all relevant processes and the documentation required to produce a robust audit trail.
4. Ensure any policy makes clear that reimbursement of expenses and payments for participation are separate, and are documented as such.
5. Make offers of payment available in a variety of formats (ie. BACS payments, cash, vouchers) in order to ensure the broadest possible engagement.
6. Seek advice from an employment law specialist if there is any dubiety in respect of whether a participant should be engaged as an employee. This is particularly pertinent for those involved in long term and regular project work.
7. Support participants to manage risks associated with payments by establishing a well-informed independent source to offer individualised guidance and support to participants where needed, such as the

partnership model developed with Citizens Advice Bureau. Alternatively, consider contracting payment to a third party organisation; or developing a payment policy with a third party organisation with extensive experience of delivering such work.

8. Deliver safeguarding training to staff to inform their confidence and competence to recognise potential instances of financial coercion.
9. Continue to review payment policy at key points including: at the outset of any new project, when informed of any individual circumstances that require action, and in the evaluation of any project.

Drawing on the findings of this report, here is a proposed model for the development and ongoing delivery and refinement of a paid participation process for the Commission:



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Please note that throughout this report, legislative, regulatory and best practice guidance is referenced using direct URLs as these documents are under continuous review.

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Appendix A - Semi Structured Interview Guide

Name of organisation

Do you wish to remain anonymous in the final report? Yes/No

Discuss options for anonymisation and outline withdrawal timelines

What type of organisation are you, and how are you structured and governed?

What is your core work/mission?

What is the background of people with lived experience who engage with your organisation?

What work do you do that involves people with lived experience? (ie. research, steering group, project-based work)

Do you offer payment to people with lived experience who support your work? (and is this universally offered or on a case by case basis?)

Do you have a standard rate you offer to people with lived experience? (and if so, can you share how you decided on this rate?)

How do you communicate the offer of payment for participation? What support do you offer to understand the benefit/potential risks of payment?

What are some barriers that your population faces to paid participation? (ie. benefits, right to work, employment, personal risk)

How does your approach to payment recognise these barriers?

Where do you find good quality information and up to date guidance on barriers to payment? (ie. contract law, tax liability, benefits entitlement)

Do you work with any partner organisations to support participation/manage issues in involvement?

Do you offer support to navigate systems related to paid participation? (ie. welfare rights/tax)

Have there been any individual cases where your payment model hasn't worked? Can you share the stories of any individuals whose circumstances were incompatible with your payment model?

Do you offer any alternative to paid participation for those who choose not to or cannot receive payment? (ie. training, childcare etc)

What are your organisation's financial reporting requirements (both internal and statutory, if relevant), and how are payments to people with lived experience accounted for?

Do you have any specific reporting requirements (financial or non-financial) for remuneration of people with lived experience?

How does your organisation view/handle its responsibility to paid participants who may be adversely impacted by receipt of a payment?

Is there any key learning from your experience you want to pass on to this work?

