

***Experience Pays* - How to make money from your lived experience**



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Introduction

Personal lived experience of mental health difficulties, disability or a significant caring role is often viewed as an impairment or a problem. This is particularly the case in relation to economic participation, where unemployment rates are higher than the general population¹.

This short paper aims to show how, in small ways and large, people can use their lived experience as an asset and earn money from it. People contribute to society in many more ways than merely making money, but it helps. As a homeless man told me nearly fifty years ago, ‘money’s not important unless you have got none.’ Some of the ideas listed here will do no more than provide the price of a cup of tea, but they may form another step on the twin journey of, first, recognising that these experiences can be turned into assets, and second, contributing to the wider community in both economic and other ways.

This paper is not intended to imply that community volunteering roles that provide no more than reimbursement of out-of-pocket expenses are devalued – they can be an excellent way of

contributing to the community, but they are not the focus of this paper. There are sometimes pathways from unpaid volunteering into remunerated activities, and some unpaid roles offer a range of other benefits. Such things might include training, opportunities to travel abroad or meet interesting people, and sometimes a trip that is funded on an expenses-only basis² can be extended without incurring additional cost to allow time to visit an art gallery or meet up with friends.

Nor does this paper imply that people with lived experience of mental health issues or disability *must* use this experience in their work – far from it. Those who do may wish to read '[How to take your lived experience to work](#)', but there are many roles in the workplace where lived experience of mental health issues or disability is no more or less relevant than any other life experience.

For some, personal growth means taking up new, different roles and identities alongside that of carer, disabled person or service user. Indeed, the doors need to be flung wide so that people with lived experience of disability or mental health issues can access any training programme and every job role that is available to anyone else in the community. See, for example, this [Routes into Work](#) guide from NDTi, targeted at school leavers with special educational needs and disabilities.

Like with casual jobs, there are sometimes extraordinary delays between doing the work and receiving the payment. People receiving state benefits or paying taxes are often expected to report any earnings they make, and some will have the devil of a job holding on to what they earn. In order to stay focused on the purpose of this paper, the labyrinthine arrangements of the UK Benefits Agency and Her Majesty's Revenue and Customs are not explored.

Many of the organisations highlighted below avoid creating a contract of employment with the people who occupy the roles listed below. Employment law is complex, and decisions can be challenged through the tribunal system. Nothing in this paper, even when comparisons are made with casual employment or terms like 'job' or 'earning' are used, is meant to imply that there is necessarily a contract of employment in place. Indeed, one way in which some organisations reinforce the point that the people they pay are not employed is to obscure the details of payment.

For example, the Centre for Mental Health has advertised for people with lived experience to become commissioners in their Commission for Equality in Mental Health and [announced](#) that this will '*not be a salaried role... members who are not currently in paid roles will receive payment for their time*', but have not placed any further details of payment levels in the public domain. Such approaches deter people from discussing payment, along with other subtle (or not so subtle) discouragements, such as the delicate announcement that 'not everyone claims.' The final arbiter regarding whether a position is considered employment is not, of course, the organisation itself, but rather government bodies such as the Industrial Tribunal and HMRC.

These roles vary in the range of other skills that are required, as some opportunities offer training while others will be confined to the elite, but even here, lived experience will be a requirement. They also vary in the extent to which support is available, the amount of money that can theoretically be made, the practicality of fitting these roles into reasonable working hours and the relationship between supply and demand – some roles are rare, hard to find and highly competitive.

Examples of making experience pay

Susie's story

I began by volunteering and slowly found that some voluntary roles provided reimbursement of expenses that improved my quality of life – so volunteering for a whole day included a free lunch while mileage expenses helped with car maintenance expenses, thus reducing my living costs.

I gradually discovered volunteering roles that made excellent use of my skills, placed me at the leading edge of innovation in that field and grew my social network. As time went on, I received more and more invitations to be involved in interesting things. Some of these roles had money attached, which at first, I turned down, fearing that it would destabilise my welfare benefit status.

Then came a perfect combination of events, when the benefits people stopped some of my money, two well-paid opportunities came up together, and my living costs went down. It was time to accept the money being offered, cancel my welfare benefits claim and become a self-employed consultant. Nowadays my income is low and fluctuates, but I do make a real contribution to the household budget.

The pathways to earning money that I have found so far are listed below in alphabetical order. Most items listed may be a single example of its category, so further investigation may be needed. For example, NHS Trusts engage people as Non-Executive Directors, but there are many other structures within the NHS that may offer this or a similar role. A few roles are listed while inquiries are underway or that do not specifically seek out people with lived experience, because one might have anticipated that they would have done so, or they might do so in the future.

Actor

Casting services like [Underdog Talent](#) find disabled actors and match them with professional roles in order to meet the industry-wide [Diamond guidelines](#), as adopted by the [BBC](#) and others. See below for adjacent roles, such as film star and simulated patient.

Advocate

[Opening Doors](#) has negotiated with the NHS Trust to enable adults with learning disabilities to visit secure services where they provide non-statutory advocacy. Funding from the NHS trust pays the learning disabled advocates at an hourly rate.

Artist

[Jade French](#) is curating an online exhibition of work by six UK-based learning disabled artists for the 2020 National Advocacy Conference. The artists whose work is picked for the exhibition will receive £65 for displaying their work.

Associate Hospital Manager

In March 2018, Nottinghamshire Healthcare NHS Foundation Trust [advertised](#) for members of the public to sit on the panel that considers whether a patient's continued detention under the Mental Health Act is in the interest of the patient's health or safety or for the protection of other people. They offered £50-£75 per session and asked for three weekdays per month.

Author

Some academic journals, such as the [British Medical Journal](#), welcome papers written by patients but do not pay them. Copyright law entitles authors to gain royalties from their published writing and pictures. Book publishers may pay royalties in proportion to book sales, but, for other royalties (related to photocopying or library loans), it is best to sign up to the [ALCS](#), who, after claiming a small administrative fee, recover all other royalties from published works on behalf of their members and send out an annual payment. The royalty arising from any particular published work is divided between the authors and the editor, so books with a very large list of contributors will deliver only a microscopic fraction to the individual author. A similar organisation called [PLR](#) distributes money to authors in relation to the loan of library books they have authored.

Board member

In May 2018, the [NHS Confederation](#) advertised for service user representatives for the Board of its Mental Health Network. Through this election the Mental Health Network made its Board more reflective of the population served by mental health services. They therefore welcomed candidates from diverse backgrounds and gratefully received all nominations of individuals with protected characteristics. Board members serve for three years and the board meets four times a year. Nominees for the Service user representative positions were sought from any member of the Mental Health Network. Service User representatives provide expert advice, reflect service user views and contribute to the work of the Network on policy and service development, receiving a £200 allowance per meeting, including preparation time, along with reasonable expenses. The Network supports representatives who require the support of an advocate.

In 2018, Public Contributors attended 80 panel and Board meetings at The National Institute of Health Research.

Care and Treatment Review (CTR) Expert Adviser

A [CTR](#) is part of the Transforming Care agenda, helping to reduce the number of people with learning disabilities or mental health issues who are living in hospital rather than in the community. Each panel includes an expert by experience, who is paid £150 per day. See [here](#).

Co-applicant for research funding

The National Institute for Health Research provides advice on how research teams can include an expert by experience as a co-applicant³ for research funding, although they do not provide a straightforward mechanism for funding this role. As a result, aspiring research teams must apply to their local Research Design Service for a small grant (usually no more than £300) to fund all the public consultation that precedes the bid; or utilise core funds held by the university or research organisation. Most commonly, neither of these things are done and there is an expectation that experts by experience will carry out all the duties of a co-applicant on a voluntary basis at the pre-submission stage in the hope that they will receive payments for their subsequent activities should be bid be successful.

Committee chair

The Medical Directorate NHS England Central Midlands and North Midlands advertised in July 2018 for lay people to chair their Performers List Decision Panel. This is on an ad-hoc basis and offers £50 per hour (or part thereof inclusive of VAT). See [more information](#), [job role](#), and [application form](#).

Committee member

The NHS Improvement Quality Committee, which reports directly to the Board, recruited two Patient and Public Voice (PPV) Expert Advisers in spring 2018. PPV Expert Advisers are offered an involvement payment of £150 per full day (for those people not representing or supported by an organisation) for an estimated time commitment of four days per year. Details [here](#). There are many similar committees in the NHS and NIHR, such as Expert Adviser roles with the NHS Strategic Clinical Networks, Clinical Senates and Commissioning Support Units, that pay £150 for a day or £75 for half a day (see the overarching guidance from NHS England [here](#)). Similar rates are offered by the NHS Leadership Academy [here](#).

Consultant

A Community Interest Company called [Experts by Experience](#) engages people with lived experience of mental health issues as Associate Advisers. These advisers are self-employed, but payment rates are not specified on their [website](#).

Consultant learner

Training in Systematic Instruction (TSI) is a structured approach to teaching vocational and independent living skills to people with intellectual disabilities. TSI has an emphasis on errorless learning and encourages decision-making by people with a learning disability enabling them to learn complex tasks. Generally taught over a 3 or 4 day period, the training includes a one-hour observed teaching activity with a consultant learner who has a disability followed by opportunities for the TSI trainees to practice their skills with other Consultant Learners. The consultant learners are paid around £10 for their time and are usually recruited from a local post 16 setting or day service in the local area where the training is being held. In order for the teaching to be authentic, each learner must never have done the task or undertaken the learning before and ideally each dyad of TSI trainee and Consultant Learner will be strangers to one another. Contact [BASE](#) to find out who is teaching TSI.

Consumer Champion

Cochrane UK are appointing some [Consumer Champions](#) to strengthen links with groups of people who use healthcare and pursue a variety of projects. They offer £150 per day.

Doctoral student

Some scholarships are awarded to people who have lived experience of the subject that they are studying, such as the [Rosamund Snow](#) scholarship for patient-led research. It provides one award of

full fees and a stipend of £18,000 per annum full time (up to three years) or £9,000 per annum part time (up to six years). Other scholarships may be available!

Editor

Some academic journals are engaging a 'patient experience editor' to support the production of the journal. In the *British Medical Journal*, this is part of a wider [patient partnership plan](#) through which [three patient editors](#) have been appointed to work with the support of a patient advisory panel and are [paid](#) on a freelance basis. Similarly, one of the two 'editors in chief' at the journal [Research Involvement and Engagement](#) is an expert by experience. Small circulation journals (such as many of those produced by [Emerald](#)) engage interested people in a voluntary editorial group and then offer a small payment to one person to act as the journal editor. This can be a challenging role, such as on the Editorial Board of the [Journal of Patient Experience](#) that is comprised of 13 professionals and one patient. Has an expert by experience ever been appointed to this role and paid?

Film star (!)

The [NHS Leadership Academy](#) invites specific patients and carers to be filmed for presentations in their training events. They pay £25 for an hour or £50 for a two-hour session. They say that the time paid for must include time taken to travel to and from the venue. Advice is available⁴.

Fitness to practice panel member

The [Health and Care Professions Council](#) regulates 17 health and social care professional groups. It's Fitness to Practice panels deal with complaints about qualified practitioners in these professions and will, where necessary, strike them off. Panels pay £202 per day to [panellists](#), which include members of the public, but there is no specific reference to seeking lived experience. After gaining some experience, public panel members can move into the role of panel chair.

Funding Application Reviewer

The National Institute of Health Research engages Public Reviewers to read applications for its research funding and make recommendations. Payments range from £50-£200, working out at about £1 per page of densely written, complex text. Payment details are [here](#) and the application route is explained [here](#). In 2018, public contributors reviewed a total of 567 funding applications. NIHR Involve offers an interactive online training [course](#) to equip people with the skills to become a Funding Application Reviewer.

Independent Expert Adviser – Lived Experience

The Wellcome Trust advertised the role of [Independent Expert Adviser](#) in July 2020. Applicants must be aged 18-24 and have lived experience of anxiety or depression. They are particularly eager to engage people who live in low or middle income countries. Pay is £150 per day.

Inspector

The Care Quality Commission engage [Experts by Experience](#) who have used services in the past five years, or cared for someone who has, as part of their inspection teams to check up on the quality of services. Contracts are managed through [Remploy](#), [Choice Support](#) and [Age UK](#) who pay [£15 per](#)

[hour](#). The arrangements for proper support for the role have been [questioned](#) and contracts are being renegotiated. In 2014, there were about [500](#) Experts by Experience working for the CQC.

Journal Paper Reviewer

When a paper is submitted to an academic journal for publication, the editor must decide whether the paper is suitable for publication, needs amendment or is to be rejected. Peer-reviewed journals seek advice from experts before making this decision, and some (such as [Research Involvement and Engagement](#)) involve people with lived experience in reviewing the submission. In October 2018, the [McPin Foundation](#) offered to train people with mental health issues to undertake such reviews, and [The Lancet Psychiatry](#) pays £75 for a completed review by a trained reviewer. In contrast, the [NIHR Dissemination](#) Centre pays £5 or more for reviews.

Lay Member, Governing Body

NHS Derby and Derbyshire Clinical Commissioning Group advertised a position for a Lay Member of its Governing Body in January 2020, involving five days work per month and paying £15,000 per annum. The role description includes the requirement that the successful candidate is able to 'Contribute a patient/public perspective' but has no further explicit requirements in relation to lived experience.

Lay Specialist Adviser

This is another name for 'Patient and Public Involvement' or a PPI Adviser (see below) who joins the team of a health research project. In a recent [example](#), Advisers were engaged over a two year period to attend either five or ten meetings, and receive expenses plus £15 per hour for reading necessary documents and £20 per hour for attending meetings.

Lay Summary reviewer

When social or healthcare research is completed, the research team often write a 'lay summary' which explains the findings to the general public. Pharmaceutical companies have been known to pay for two hours work at £60 per hour for comments on the lay summary that will make it clear and helpful to the general public⁵.

Lay Visitor

The [Health and Care Professions Council](#) engage service users and carers in the role of [Lay Visitor](#) to visit and assess programmes of education and training delivered by education providers. They ask for 5-10 working days per year and pay £202 per day. Vacancies are advertised [here](#).

Lecturer

The School of Nursing at the University of Nottingham engages people with lived experience to teach some classes and pays them as casual employees at £20 per hour. Some Speaker's Bureaux have specialists who provide after-dinner speakers or inspirational speakers for events and focus on

mental health or other issues – such as [A-Speakers](#), or this [crowdsourced list](#) started by Mark Brown. Local branches of the [human library](#) offer informal (and unpaid) opportunities to people wishing to share their story with others. The [NHS Leadership Academy](#) includes presentations from people with lived experience in its programmes. The Mind head office in London invites [experts by experience](#) to meet staff and tell their story, giving them their travel expenses and £50 to say thank you.

NIHR Evidence Reviewer

The National Institute of Health Research engages with Experts by Experience to read the abstract of a published paper and comment on its significance, thus helping NIHR to decide which papers should be made available as an NIHR Evidence Alert. Reviewing the abstract and answering standard questions is expected to take 20-30 minutes and result in a participation payment of £12.50. More details [here](#).

Non-Executive Director

NEDs in the NHS receive £6,157 per annum. This is a public appointment and does not constitute employment. See [here](#). Sometimes the advert makes it clear that lived experience is an asset – such as this [advert](#) from Norfolk and Suffolk NHS Foundation Trust⁶. Vacancies are advertised [here](#).

Open Employment

All organisations offering job opportunities have a legal obligation to make reasonable adjustments so that disabled people are not subject to discrimination. Some employers carry the [Disability Confident](#) logo and others are [Mindful Employers](#) and so can be expected to provide guaranteed interviews to suitably qualified applicants for all their vacancies. Some also make their own declaration about offering real opportunities to jobseekers with lived experience, such as the [Mental Health Foundation](#) and Nottinghamshire Healthcare NHS Foundation Trust, which declares, ‘*We positively encourage people who have experienced mental health problems to apply for a role within the Trust.*’ A smaller step can be taken, such as in this £27,000 pa job offered by Unlock, where the [advert](#) clearly states that lived experience ‘is not a requirement, but nor is it a bar’.

Some specific posts include lived experience as an essential or desirable characteristic on their person specification, such as vacancies for ex-offenders advertised by the charity [User Voice](#). By sticking at this over time and tracking their success, [NACRO](#), which employs over 900 people to work with ex-offenders, has reached the point where 10% of its entire labour force are people with lived experience.

Particular examples of this are peer mentors (see below), [Peer Support Workers](#) in mental health NHS Trusts (see below), and some researchers⁷. JobCentre Plus have systems to support jobseekers who face additional barriers, while the law insists that reasonable adjustments be made so that people counted as disabled are not subject to discrimination or unfairness.

Patient and Public Voice Expert Advisor

NHS England engages people with lived experience as [PPV Expert Advisors](#) and covers expenses and offers £150 per day / meeting (more than four hours) or £75 per half day (four hours or less), including travel and preparation time.

Peer Mentor

Shelter in Birmingham advertised for a Peer Mentor in March 2018, offering a salary of £15,816-£16,402. Applicants had to have lived experience of two of the following: homelessness, mental health issues, substance misuse and offending behaviour.

Peer Reviewer

The Royal College of Psychiatrists runs the [Quality Network for Forensic Mental Health Services](#) and they pay people currently resident in their services to carry out peer-review visits and family and friends to be involved in quality improvement visits⁸. The tone of these visits and reports is less about judging compliance with a benchmark but rather honest observation and reflection driven by an ambition of service improvement.

Peer Support Worker

NHS Mental Health Trusts and some other organisations are offering Peer Support Worker posts⁹. For example, [Nottinghamshire Healthcare NHS Trust](#) has over 50 such posts and a [training course](#) to equip people with the skills they need to apply¹⁰. In May 2019, East London NHS Foundation Trust advertised for a Peer Support Worker with lived experience as a carer to support other carers, to work 7.5 hours a week in the forensic directorate at salary Band 3, for 6 months initially, with a possibility of extension. Leeds Survivor-Led Crisis Service advertised a post for a Peer Support Worker at a salary of £18,971 where applicants had to have lived experience of bereavement by suicide.

Permitted Work

Some secure residential settings that provide care to people with forensic mental health issues are creating small part-time jobs within the unit that are then taken up by current residents. See an example from Cambian [here](#). Payments meet the national minimum wage and occupy only a few hours a week so that the money falls within the permitted work regulations of the Department of Work and Pensions.

Physical Examination Patient

A PEP teaches physical examination to medical students by allowing the student to practice on the PEPs own body and giving feedback. Specialist roles include Gynaecological Teaching Associates and Urological Teaching Associates (men who do this are sometimes referred to as Male Urological Teaching Associates) while PEPs can also be known as Physical Exam Teaching Associates. [John Hopkins University](#) in the USA pays \$20 per hour, while Texas A&M University Health Science Center pays up to \$75 per hour for this work¹¹. It is not known if these roles are paid in the UK.

Public Involvement lead

Research funded by the National Institute of Health Research and other organisations is conditional on a clear process for involving people with lived experience in the development, design and delivery of the research. As well as payments for committee membership (commonly through a Lived Experience Advisory Group), some projects will pay for a Public Involvement Lead role. This person

brings together the Lived Experience Advisory Group, chairs meetings, writes minutes and liaises with other groups delivering the research. Some Public Involvement leads have lived experience and also serve as Public Co-Applicants on the research funding application. In other teams, this facilitation and support function is carried out by academic research staff. Person specifications sometimes include lived experience as a desirable element, but some do not¹².

PPI adviser

Health research teams sometimes seek out advice from people with lived experience of the condition under scrutiny, and so experts by experience comment on the design, delivery and dissemination of the research project itself. For example, this [study of psychosis](#) recruited ten people with personal experience to form such a group and paid them £100 per meeting. A similar approach is taken in social care research.

Recruitment and Selection panel member

Many NHS organisations are involving experts by experience as panel members when selecting candidates for paid employment positions in their organisation. Guidance on this is available – see [How to involve the public on staff appointment panels](#).

Research participant

In March 2018, a study investigating psychological help for people with psychosis offered £5 to anyone willing to spend half an hour filling in some questionnaires. This example is [here](#). Other research projects offer gift vouchers, like [this one](#) which invited people to undergo a telephone interview or attend a focus group, or [this one](#) which offered a half day of coaching in safe driving and a £30 shopping voucher. The money is sometimes called an ‘inconvenience payment’. Some interventions are invasive, perhaps asking research participants to swallow medicines, and pay participants larger amounts, such as this private pharmaceutical company that are offering [£2,638](#) for two residential stays totalling 16 nights.

Researcher

Some user-led research groups are winning contracts and carrying out user-led research where lived experience is valued both in the researcher and the researched¹³. For example, [SUCRAN](#) engages people with mental health issues, offers a few sessions of training, invites them to register with Unitemps at their local university, and then carries out research projects, paying people around £10 per hour for the opportunities that arise from time to time¹⁴.

Other research teams based at universities or NHS Trusts are employing fully qualified academic researchers who also have lived experience, such as (i) the ENRICH programme based at St George’s which in March 2018 offered a [post](#) at a salary of £25,728 to £31,604; and (ii) the ODESSI study at Middlesex University which offered a 0.6 wte researcher post salaried at Grade 6 (£28,936 to £33,518 pro-rata) in December 2019 that sought a graduate, postgraduate or post-doctoral researcher with lived experience of using mental health services and/or of mental health problems and declared that ‘in other respects, the academic expectations of the role are similar to other Research Assistant posts’.

Service User Adviser

In September 2018, The Royal College of Psychiatrists [advertised](#) for a Service User Adviser with experience in Early Intervention in Psychosis (EIP) services to work on The National Clinical Audit of Psychosis. The role involved providing advice from the perspective of the service user on elements of the audit, including how it responds to the needs of people using EIP services. This includes attending planning meetings and assisting in other matters related to service user experience and involvement. Up to 11 days over two years, at £200 per day plus expenses.

Simulated Patient

Training courses for healthcare professionals sometimes include role plays in which the role of the patient is taken by a manikin dummy or a simulated patient. This person can be an actor, and such individuals can be paid anything between £10 an hour and £300 per day – see [here](#). There is more information about simulation in [How to choose between an actor and an expert by experience](#). Some simulation centres, such as the Trent Simulation Centre in Nottingham rely on volunteers and do not offer remuneration beyond the reimbursement of expenses. An American viewpoint is [here](#).

Trainer

Self-advocacy groups and other networks of experts by experience have developed training programmes and delivered them to a variety of audiences. For example, Advoact is a drama group made up of actors with learning disabilities. One member went for a breast scan but found that the mobile scanning unit was not accessible to patients using a wheelchair. In response, Advoact researched the topic of equal access to health screening for people with learning disabilities and produced a play about it. In the mental health world, every training event delivered in a Recovery College is co-taught by an expert by experience. [REACT](#) in Preston have paid workers with learning disabilities and autism who deliver learning disability awareness sessions to GPs & hospitals commissioned by the NHS.

Translator

Some individuals and groups with lived experience are winning commissions to translate leaflets or reports into appropriate language. The most well-established version of this activity is the production of Easy Read materials by people with learning disabilities. For example, [Opening Doors](#) pay people (at National Minimum Wage levels) for their time and expertise in creating Easy Read materials.

Tribunal member

The [Judicial Appointments Commission](#) appoints a First-Tier Tribunal to make decisions about detention under the Mental Health Act, social entitlement or other matters. Each tribunal has a 'specialist lay member', some of whom have lived experience of mental health issues, disability or are informal carers. For example, the JAC [advertised](#) 115 posts in November 2017, each offering at least 15 days per year at £201.98 per day to disabled people or carers, appointing to help judge appeals on Disability Living Allowance, Personal Independence Payments and Attendance Allowance. Some roles are supported by informal peer organisations, such as the [Mental Health Tribunal Members Association](#).

Where do I find these opportunities listed?

The paragraphs above contain many hyperlinks to relevant websites. In addition, the following might provide some starting points for inquiry:

- Local newsletters, such as [Public Face](#).
- Opportunities to be involved in research may be advertised by the Clinical Research Network.
- [The Centre for Public Appointments](#)
- [People in Research](#) has a list of opportunities to get involved, some of which include remuneration.
- The McPin Foundation has a Directory of service user and carer research groups compiled in 2015 [here](#).
- [Department of Health and Social Care](#) Twitter feed for non-executive vacancies.
- The [Judicial Appointments Commission](#)
- Specific life experience may open doors to particular opportunities, such as those advertised by [Unlock](#) for people with a criminal record.
- The National Institute of Health Research have a dedicated [webpage](#) advertising opportunities.

Roles that do not pay

This section begins a short list of roles which one might have expected to be paid but are not. They include:

- Lay members of a Research Ethics Committee. There are over 1000 members volunteering on more than 80 RECs in England, a third of whom are required to be lay members. However, the guidance document declares that; ‘Our lay members come from a wide range of professional backgrounds. For example, Research administrators at pharmaceutical companies or other clinical research bodies, Lawyers, Hospital Chaplains, administrative staff.’¹⁵, clearly expecting that they will be recognised by a professional regulatory body rather than lived experience, which is not mentioned in the person specification¹⁶ or other guidance materials at all. Moreover, the Health Research Authority generally provides reimbursement of expenses only, although there is a caveat for doctors – ‘If you are self-employed you might be eligible for payment of loss of earnings. For example, locum fees are payable to GP upon submission of receipts from a locum agency or other valid locum provider¹⁷.
- Some organisations (such as [SMA](#)) engage Peer Support Volunteers or give people the title of Peer Support Worker but treat them as unpaid volunteers.

Ten ways in which this might go wrong

There are numerous risks that people have suggested may arise through creating this guide, including:

1. Some roles are meant to be about community contribution, so marketing materials could over-emphasise the importance of payments.
2. It could attract the ‘wrong’ people into these roles – those who are motivated by greed rather than justice or compassion¹⁸.

3. It could draw volunteers away from unfunded positions where they were needed, into roles where money is to be made. Those who stayed might become resentful, and host organisations could be set at odds with one another as their volunteers migrate to roles with better terms and conditions.
4. It could corrupt people who began as warm-hearted volunteers doing as much as they can for love and end preoccupied by the financial benefits of the role, doing as little as they can for the money.
5. It could silence independent critics by demanding compliance in exchange for the payments. Consequently, one group has refused payments because of their commitment to retaining critical independence¹⁹.
6. It could be taken up by the competent and wealthy, thus increasing inequality and further excluding those on state benefits or with few obvious talents. Meanwhile, organisations offering a payment could narrow the range of people they engage and close down all opportunities for people with unusual skillsets or who need additional support to participate.
7. It could draw attention to the fact that public funds are being used in this way, which might attract negative publicity for the organisation that makes the payments or advertises the opportunities.
8. It could shed light on the real values of the organisation, such as the apocryphal story of a pharmaceutical company which made a tokenistic gesture towards involving experts by experience by offering \$4 per hour, or the NHS Trust that pays expert consultants £600-£3000 per day, but caps payments to expert patients at £150 per day and then labels highly competent people with lived experience as 'patients' in order to avoid paying them a higher rate²⁰.
9. It could increase the number of disputes with the Benefits Agency and destabilise people who are already in a precarious financial situation.
10. Simply opening up this discussion may terrify some people who live in fear that they will be assessed as fit to work, driven into an unsuitable job or lose their entire income.

All these risks apply equally to any organisation that is paying staff at all, paying them at different rates or engaging with a mix of salaried staff and unpaid volunteers. It would not be right to keep people in the dark to prevent them having an accident in the light, and so this information is offered in the hope that it will be used wisely.

What is the status of this paper?

Most of the documents we read are finished pieces of work, carefully crafted and edited in private before being shared with anyone else. This is a different kind of paper – it was shared online [here](#) from the first day, when the initial handful of ideas were incomplete, poorly phrased and tactless. The work has been edited many times, and on each occasion a revised version has replaced the earlier material online. This process is still under way, and so this paper may still be lacking crucial concepts, evidence, structure and grammar²¹. As readers continue to provide feedback²², further insights will be used to update it, so please contact peter.bates@ndti.org.uk with your contributions²³.

It is one of a suite of documents available [here](#) that try to open up debate about how in practical terms to empower disabled people and share decision-making in health and social care services – in research, implementation and evaluation.

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

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

¹ See <https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf> page 45, which shows that the employment rate for nondisabled people in Britain in 2015/16 was 79.2% but only 47.6% for disabled people.

² For example, the [Patient Safety Congress 2018](#) offered 30 bursaries covering travel and accommodation. Some organisations offer to book train tickets and hotel rooms on behalf of the person, which ensures that these expenses are reimbursed in their entirety and without delay.

³ Guidance has been provided – see Elliott J, Lodmore M, Minogue V & Wellings A (2019) [Public Co-Applicants in Research – guidance on roles and responsibilities](#) Southampton: INVOLVE. Also NHS R&D Forum (2019) [Involving Service Users and Carers as Co-Applicants, Project Team Members and Co-researchers in Research Guidelines for Sponsors, Research Managers and Governance Leads](#). This is discussed at http://peterbates.org.uk/wp-content/uploads/2017/04/how_to_engage_people_as_research_co_applicants.pdf

⁴ See [How to choose between an actor and an expert by experience](#)

⁵ A discussion about the interface between public involvement in research and the commercial pharmaceutical companies can be seen at <http://peterbates.org.uk/wp-content/uploads/2017/05/How-to-support-effective-public-involvement-in-commercial-projects-1.pdf>

⁶ *'It is down to individual organisations to say if they wish to sign up to the Disability Confident or Mindful Employer Commitments. However, NHS Improvement does encourage applications from underrepresented groups including those who have disabilities in all recruitment documentation. All of our posts ask for individuals to have a commitment to patients. We are about to publish some data on board profiles. We are also looking to meet with other government departments to come up with innovative ways of moving forward on this.'* (Personal communication from Helen Barlow, Non-Executive Appointments Manager, 29/3/2018).

⁷ An example is the [MOAM](#) study that is employing User Voice Peer Researchers.

⁸ CCQI declined the offer of including payment rates in this document (personal correspondence 17/04/18).

⁹ Or you could search for 'Lived Experience Practitioner', like the advert from Oxleas [here](#).

¹⁰ Contact [Scott Pomberth](#) for further information.

¹¹ At Texas A&M University's Health Science Center in May 2019, Gynecological Teaching Associates were paid \$75/Hour for Instruction and OSCEs, Male Urological Teaching Associates received \$75/Hour for providing Instruction, Physical Exam Teaching Associates received \$45/Hour for providing instruction and same-day OSCE grading or \$25/Hour for Grading via video not on the same day. In addition, the Center paid all of these grades for additional training at a rate of \$20/Hour and always pay a minimum of one hour, even if the training was only 20 minutes by phone.

¹² A band 7 role advertised in December 2018 based at Birmingham University made no mention of lived experience (see <http://www.download.bham.ac.uk/vacancies/jd/80618.pdf>).

¹³ [McPin](#) pay their people. Inquiries sent to the following user-led research groups on 24/4/18 – [Suresearch](#), [SUCRAN](#), [Comensus](#), [Shaping our Lives](#), [Service User Research Enterprise](#), [Making Waves](#). This could be augmented by contacting other groups listed [here](#).

¹⁴ Sadly, SUCRAN was obliged to close in autumn 2018, so another example is needed here.

¹⁵ See Health Research Authority (2015) *Information for potential Research Ethics Service Committee members* page 2. This is part of the Standard Application Pack all members (HRA) version 2.0.

¹⁶ Document 1 – Person specification for lay REC member. This is part of the Standard Application Pack all members (HRA) version 2.0.

¹⁷ See Health Research Authority (2015) *Information for potential Research Ethics Service Committee members* op cit page 5.

¹⁸ We might beware of making superficial judgements – one person confided that he claims the money and then quietly donates it to charity. Another took a salary and was then accused of only caring about the money.

¹⁹ Mckeown, Mick; Malihi-shoja, Lisa; Hogarth, Russell; Jones, Fiona; Holt, Keith; Sullivan, Peter; Lunt, John; Vella, Jacqui; Hough, Graham; Rawcliffe, Louise and Mather, Marie (2012) The value of involvement from the perspective of service users and carers engaged in practitioner education: Not just a cash nexus. *Nurse Education Today*, 32 (2). pp. 178-184.

²⁰ Tweet from David Gilbert 17 December 2019.

²¹ As a result, the author assumes no responsibility or liability for any errors or omissions in the content of this paper. The information contained is provided on an “as is” basis with no guarantees of completeness, accuracy, usefulness or timeliness.

²² Contributions and challenges to this discussion have been offered by Shahnaz Aziz, Antony Chuter, Sheena Foster, Amanda Griffiths, Anthony Locke and Dave Waldram.

²³ This document was begun on 15 March 2018. Undated or early versions should be replaced with the most recent, available [here](#).