

# PPI payments and asylum seekers in UK health research



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## 1. Abstract

This paper explores eligibility and practical challenges of offering Patient and Public Involvement (PPI) payments to asylum seekers in UK health research. While PPI payments are intended to recognise the contributions of individuals with lived experience, asylum seekers face unique barriers—including legal ambiguity, fear of repercussions, and systemic exclusion. Drawing on published studies, policy guidance, and correspondence with

researchers and refugee support organisations, this paper outlines the current landscape and calls for clearer frameworks to ensure equitable participation.

## 2. Introduction

Health research in the United Kingdom should be coproduced with people who have lived experience and nonsalaried Public Contributors should be offered a payment in recognition of their contribution<sup>1</sup>. The offer of funds is known as a Patient and Public Involvement (PPI) payment<sup>2</sup>. However, asylum seekers may be unable to receive a payment due to legal<sup>3</sup>, institutional, and cultural barriers. One impediment is that PPI is sometimes misunderstood as work<sup>4</sup>, and, since asylum seekers cannot be employed, they are informally prohibited from receiving PPI payments. This paper examines whether this impediment is based on fact or whether PPI payments might be ethically and practically offered to asylum seekers. A parallel paper has already been produced addressing the eligibility for PPI payments of serving prisoners in the UK<sup>5</sup>. Further groups (e.g. children and young people) may be added to the series as this exploration continues.

There are many other challenges in conducting research with this group<sup>6</sup>, who may have difficulties in accessing the usual advertising<sup>7</sup>, live in such straitened circumstances that their ability to give free and informed consent may be doubted<sup>8</sup>, require interpreters, and who may be surrounded by staff who discourage payment. Indeed, James<sup>9</sup> lost one asylum seeker co-researcher from her team when that person was relocated to another part of the country by the Home Office at 24 hours' notice.

Asylum seekers live in fear of physical violence, detention and deportation, so even positive activities, such as helping to design, manage and deliver health research, are subject to scrutiny in case they lead to unwanted consequences. Obscure, conflicting policies and language barriers exacerbate these difficulties. This paper focuses narrowly on the practice of making PPI payments for coproducing research and is one of a suite of resource guides<sup>10</sup> that consider niche topics in coproduction of research.

Public Contributors are not employed and PPI payments are not wages, but officials may misinterpret their situation and decide that they have broken a rule, thus jeopardising their asylum claim. This paper attempts to enter this contested space and suggest relevant policies, practices and precedents which will enable people with lived and living experience to enrich health research.

## 3. Defining roles and eligibility

We distinguish five roles in research: researchers, PPI coordinators, third-sector representatives, study respondents, and public contributors. Each role carries different expectations, qualifications, and payment structures. The table below clarifies which roles asylum seekers can legally occupy and where ambiguity remains.

### 3.1 Categories of persons

The term 'asylum seeker' overlaps with other categories, including refugee, forced migrant, undocumented migrant, person seeking sanctuary, failed asylum seeker, refused asylum seeker and person without recourse to public funds. The following discussion will treat all these categories as

one until a reason is found to separate them. When considering the role of lived experience in health research, things do not get much easier. Here are some working definitions along with a commentary.

Table #1: Categories of persons

Persons engaged in the study	Typically...
Researcher	This person holds at least a Master’s level qualification in research methods. They are employed by the university or a similar research institution. They may have lived experience of the topic under examination and those who do may choose to share that fact and become known as a ‘survivor researcher’ or perhaps ‘convict criminologist’. The team of researchers includes the Principal Investigator and academics who work elsewhere and sit on the Advisory Board or Data Management and Ethics Committee for this study. The equalities agenda seeks to lower unnecessary barriers to these qualifications and job roles by making reasonable adjustments to training, recruitment, supervision and promotion so that researchers with lived experience are included. People currently seeking asylum are prohibited from working in the UK, so cannot be employed as a researcher.
PPI Coordinator	This person is employed as a staff member or contractor to coordinate Patient and Public Involvement in respect of this study. They may have lived experience of the topic under examination or of using healthcare, as well as generic experience in community engagement, facilitation and coproduction. They may not have the research qualifications listed above. People currently seeking asylum cannot be a contractor or employee.
Third sector Representative	Where the topic being researched has stimulated the development of charitable and community interest groups, representatives of these groups may join an advisory group for the study and assist with recruiting PPI members or study respondents. The charity may receive a block payment from the research institution in recognition of their contribution to the study, but the representative then engages with the study as part of their role within the charity. They do not receive any financial benefit as individuals from the study budget, although the block payment may indirectly secure their position within the third sector organisation.
Study Respondent	The study respondent, sometimes called the research ‘subject’ must be provided with a Patient Information Sheet and give their informed consent before they contribute data for analysis. Their identity is routinely obscured by data anonymisation and reporting restrictions. Their safety is the prime focus of the Research Ethics Committee. They may receive a gratuity as a thank you. Confusion sometimes arises when this person is referred to as a study <i>participant</i> and the Public Contributor is offered a ‘ <i>participation</i> ’ payment. Study Respondents can be viewed as passive objects from whom data may be mined for the study, or active, thoughtful and ethical individuals who share in a wide range of tasks, from managing their own healthcare to taking an interest in research – but this active ‘partner’ role does not make them Public Contributors. People currently seeking asylum can be Study Respondents.

Persons engaged in the study	Typically...
Public Contributor	The Public Contributor is involved in Patient and Public Involvement or PPI. Their specific contribution rests of their identity as a person who has lived through or is living through the experience under scrutiny, as an informal carer of someone who has done so, or as a member of the public who stands outside the academic setting. They provide informal advice and support at every stage of research production from priority setting to publication. They are engaged in the development, design and delivery of the research. The research institution holds a general duty of care towards them, but, as they are not a Study Respondent, they do not require specific ethical approval, a Patient Information Sheet or formal consent processes before joining the team. They are not employed by the research institution and will be offered a PPI payment as a thank you. Since PPI payments are not wages, there is no reason why people currently seeking asylum should be excluded.

An individual study may blend some of these roles or flex some of these arrangements. For example, when Participatory Action Research approaches are used, as in the PhotoVoice example by James<sup>11</sup> described below, the study respondents are themselves co-researchers. That is, they collect and interpret the data about themselves alongside the academic researchers, collapsing the traditional separation of study respondent and researcher into one.

In other examples, the PPI budget may be used to reimburse expenses for PPI activities, fund participation payments to Public Contributors and pay the salary of the PPI Facilitator. Sometimes both researchers with lived experience and Public Contributors become study respondents in addition to their main role on the study team. While blending these roles can be a carefully considered and justified decision based on a legitimate epistemology, there can also be situations where roles are confused and inappropriately merged. This can happen when adverts seeking to recruit Study Participants appear on a website that is intended to recruit Public Contributors.

### 3.2 What Counts as Lived Experience?

Most funding bodies expect the health research team to include Public Contributors in their study whilst embracing the widest possible definition of who would be eligible. This is illustrated by Robinson and colleagues<sup>12</sup> who conducted a study of people subject to forced migration. They worked hard to consult with a wide range of stakeholders and used a splendid range of approaches in their efforts to listen to the study participants, including the offer of a shopping voucher for those who shared their experiences. The paper describing this in detail is not yet published, but an earlier publication from the team hints at the possibilities set out in Table #2 below.

Table #2: Relationships with lived experience

Some or all members of this group are	Researchers	Coordinator PPI	Third sector representatives	Study Respondents	Public Contributors
Currently seeking asylum				✓	✓
People with prior lived experience of seeking asylum	✓		✓	✓	

Some or all members of this group are	Researchers	Coordinator PPI	Third sector representatives	Study Respondents	Public Contributors
People with prior experience and skills in PPI		✓			
Qualified in research methods	✓				
Contractors or employees	✓	✓			
Offered PPI payments <sup>13</sup>					✓
Offered a gratuity or incentive in compensation				✓	

In this study, the PPI Facilitator did not have lived experience of the asylum system but engaged Public Contributors who did. Vouchers were offered, but it is not yet clear what they were worth or whether they were for Study Respondents, Public Contributors or both. The team's forthcoming publication explaining exactly what they did in relation to PPI is awaited with interest.

Elsewhere, the category 'third sector representatives' might specifically include Community Researchers who have prior lived experience of seeking asylum, are well connected to others who are currently seeking asylum, who have no more than minimal awareness training on research methods and who are contracted to support the recruitment of study respondents as well as assisting in the tasks of gathering and interpreting data. For example, Betancourt and colleagues<sup>14</sup> included refugees as waged Community Research Assistants, staff who delivered the intervention under scrutiny and as Community Advisory Board members, but not as nonsalaried Public Contributors who were offered a PPI payment. This shows that the table is not intended to describe categories which are mutually exclusive and collectively exhaustive, but rather, to start a dialogue about the distinctive arrangements for individual studies and the common ground between them.

### 3.3 What counts as PPI?

Ideally, PPI means coproduction of the research, so Public Contributors would be involved throughout the research process from the initial conception, funding application, ethical approval and shaping the detail of the study design through to data collection, analysis, reporting<sup>15</sup> and dissemination. Whilst coproducing research with asylum seekers has a long history<sup>16</sup>, not all studies realise this aspiration, and PPI can sometimes shrink to a single conversation. The lead researcher may seek advice from an established PPI group that meets periodically for other purposes; such a group may or may not have members with lived experience relevant to the study topic. In Carter's study<sup>17</sup>, for example, the protocol was discussed on a single occasion, and no other involvement was reported, while Humphrey<sup>18</sup> sought advice about her study during a single meeting of a 'borrowed' group. In these situations, there may be no charge levied on the study, and members of the group may or may not receive a PPI payment from the convenor.

Boshari and colleagues<sup>19</sup> explored the feasibility of establishing a Community Advisory Board to collaborate in the coproduction of health research in respect of asylum seekers and refugees and recommended investment as a key success factor. Meanwhile, Hargreaves has "a migrant health community research network, about 70 migrant community leaders and people with lived experience of migration from many different countries—and they support all our research at all

different stages of the research cycle”<sup>20</sup> – although it is not clear if this includes people currently seeking asylum or if they are offered PPI payments. Whilst a standing group of this kind can provide a rich resource, careful reporting is required to ensure that the relevance, depth and spread of involvement is made clear.

#### 4. PPI payments for asylum seekers?

Michelle James engaged two asylum seekers and one refugee as co-researchers in her study, where they advised on many aspects of the research design and conducted data collection interviews with study respondents. Co-researchers were offered a single £20 Amazon voucher, a university certificate of participation for their personal files and citizenship or job interviews, and bus fares, hot drinks and biscuits for the interviews. Study respondents received a £5 supermarket voucher as a thank you for their involvement.

In looking for examples of PPI payments being made to asylum seekers it rapidly becomes clear that there is a broad terminology in use and many terms may be used. Some refer to PPI payments, others to payments for research participants, and some terms are used appropriately while others are not. This means that the following search terms are likely to locate content in a paper which may be relevant to this exploration: compensate, employ, incentive, involvement, pay, £, \$, PPI, reward, salary, thank, voucher and wage.

Maddy Power works with an Experts by Experience panel which includes asylum seekers and where everyone is offered a PPI payment for their time as they contribute to the Safety Nets study of social security<sup>21</sup> funded by the Nuffield Foundation. Payment levels match NIHR rates, all members of the panel are made the same offer irrespective of immigration status, and it is provided as cash or a bank transfer rather than in the form of a shopping voucher<sup>22</sup>.

Jessica Carter<sup>23</sup> formed a PPI project advisory board for a study of catch-up vaccinations for migrants and compensated them for their time and contributions, but it is not known if this included people currently seeking asylum.

Nanakali and colleagues<sup>24</sup> formed a PPI group to support their development of an interview topic guide and assist in recruiting study respondents. They offered a £20 voucher to study participants, but we do not know if the PPI group included people concurrently seeking asylum or if they were offered PPI payments.

#### 5. Neighbouring practices

While we focus on payments for research participation, it is helpful to also consider neighbouring practices, such as incentive/compensation payments offered to study respondents and practices that have arisen in participatory action research. These areas can shed light on the issues that must be addressed in respect of PPI payments.

### 5.1 Examples from other countries

Lampa and colleagues<sup>25</sup> engaged four refugee parents as public contributors in Sweden and paid them an hourly rate equivalent to that of a research assistant. Baird and colleagues<sup>26</sup> worked with refugee women from South Sudan who were relocating to the United States and offered a \$25 shopping voucher to those who participated in focus group discussions as study respondents.

### 5.2 Incentives for study respondents

Several studies have offered incentives to asylum seekers who become study respondents. Practices vary widely with little consistency or transparency. The lack of clarity around whether these payments are permissible poses risks to participants.

All research studies that are examining the health of the UK population should include a few asylum seekers amongst their cohort of respondents or be able to explain why they have been excluded. When the cohort includes all kinds of people, asylum seekers may be offered an incentive to participate as part of the normal offer made to all. As we have seen, this is distinct from, but adjacent to our topic which is payments for research coproduction. Only the most diligent and pedantic team would stratify the cohort according to immigration status, assign different mechanisms of recognition to each subgroup, and in consequence, generate perceptions of inequality. More common would be the practice adopted by Cumming and Symon (2025)<sup>27</sup> in their study of the experience of being pregnant and homeless in the UK, where nine of the fourteen mothers happened to be seeking asylum and all fourteen were offered a shopping voucher in recognition of their data contribution.

Circumstances are different when the whole cohort are asylum seekers and the study team must decide on incentive mechanisms for all study respondents in the light of their immigration status.

Two research projects<sup>28</sup> have offered cash to asylum seekers as a thank you for participating as a study respondent, including reimbursement for travel expenses and a small sum for a meal. Most study teams prefer to offer asylum seekers a shopping voucher rather than cash to recognise that they have provided data for analysis<sup>29</sup>. This may be because asylum seekers have difficulties in opening a bank account<sup>30</sup> and research institutions are sometimes reluctant to make payments in cash<sup>31</sup>. Both the taxation and welfare benefits system can regard vouchers as if they were cash and the Border Force may deem receipt an indication that the person has broken a rule governing immigration. This means that providing any kind of financial incentive may trigger unwanted action by these agencies.

Research teams varied in the value of the voucher they offered to asylum seekers. This might be £10<sup>32</sup>, £20<sup>33</sup>, £25<sup>34</sup>, £30<sup>35</sup> or an unspecified sum<sup>36</sup>. In other examples, the format was not given - cash, a bank transfer or a shopping voucher - but the value was stated as £10<sup>37</sup> or £20<sup>38</sup>.

Payment rates for study respondents are sometimes borrowed from guidance designed to guide payments for coproduction. For example, in the study reported by Deal et al<sup>39</sup>, asylum seekers who became study participants were offered a shopping voucher worth £37 for a 90 minute interview. This sum is approximately a quarter of the £150 day rate which NIHR INVOLVE offered to Public Contributors who were actively involved with coproducing outputs. On other occasions, the adoption is explicit, as where Humphrey<sup>40</sup> cites NIHR policy guidance on PPI payment rates as a justification for the payment rate she offered to research participants. In the absence of more direct guidance<sup>41</sup>, this seems an entirely reasonable approach.

In a study<sup>42</sup> using PhotoVoice<sup>43</sup>, James gave each photographer (study respondent) who took part a £5 supermarket voucher so that they could buy themselves some dinner after the workshop, since it was Ramadan and they did not eat until after nightfall. Payment rates did not vary with immigration status. Each photographer also received a printed copy of the photographs they had taken, attended the professional exhibition the photographers had put on together and were then taken out for a celebratory meal afterwards. Elsewhere, a Research Ethics Committee has advised against providing compensation to asylum seeking study respondents<sup>44</sup> but the reason is unknown<sup>45</sup>.

### 5.3 Participatory research models

The initial international trawl by Filler et al<sup>46</sup> found 4,125 studies of refugee healthcare that used Community Based Participatory Research methods, but only two mentioned compensation for people involved in coproduction.

In a study reported by Lovell-Kennedy et al<sup>47</sup>, academics worked in partnership with a birth-companion charity to explore the experiences of mothers with babies in the UK asylum system. The charity recruited, trained<sup>48</sup> and paid five community researchers who in turn recruited respondents from within their own language community as interviewees and focus group members, as well as contributing from their own lived experience of the asylum system. The community researchers had previously been asylum seekers but had been granted permission to work and so were employed by the charity on short-term contracts.

This research team were advised against providing cash or cash-like equivalents (e.g. shopping vouchers) for research participants<sup>49</sup>, so they enabled the charity to provide reimbursement for transport expenses and lunch for participants and their children attending the charity's premises for research purposes. The charity also held a supply of packaged food, toiletries, baby items etc. that were given as donations to participants who wanted them. It is not clear whether PPI payments were offered.

Shankley and colleagues<sup>50</sup> engaged 11 asylum seekers aged 16-25 as peer researchers who "assisted with each stage of the research, including determining the research questions and methods, applying for ethics approval, designing project-specific documents, and as research participants, interviewers, interpreters, data analysts and disseminators." We do not know whether they were offered PPI payments.

Crawshaw and team<sup>51</sup> used their PPI funds to provide vouchers to study participants, make payments to members of a coalition that helped to design their Community-Based Participative Research, reimburse expenses, make grants to support the running of two third sector organisations and host a celebratory event for all at the end of the study. People seeking asylum were included as study participants and invited to the celebration, whilst former asylum seekers were found in many roles across the study.

Stevenson and colleagues<sup>52</sup> appointed a Lead Patient Advisor to coordinate a patient advisory panel for their research which was made up of 18 asylum-seeking, refugee, undocumented, or low-income mothers. The women were involved in conceptualisation, analysis, and dissemination of the project. Patient advisor's time, childcare, and travel were reimbursed. The panel met with academic colleagues four times per year and some patient advisors were involved in systematic review screening and qualitative interviewing, for which they were given research training.

Doctors of the World<sup>53</sup> use co-productive methods when undertaking research and engage people with relevant lived experience as National Health Advisors, using NIHR recommended PPI payments.

#### 5.4 Coproducing service delivery

Some organisations that support migrants, such as Migrant Help<sup>54</sup>, are working towards the involvement of people with lived experience in service development, delivery and evaluation. This shows that the voice of refugees and asylum seekers is valued.

## 6. Legal, policy and practice considerations

This section examines UK government guidance for asylum seekers in respect of healthcare, employment, volunteering, and those deemed to have no recourse to public funds. The topic of PPI payments for asylum seekers is not addressed in any policy document that has yet been found, whether relating to healthcare, immigration, research, welfare benefits or taxation. Such guidance as can be considered relevant is contradictory and confused<sup>55</sup>, placing PPI payments in a liminal space where misinterpretation by officials could jeopardise asylum claims, even if payments are lawful.

The uncertainty and fear that surrounds this topic is palpable. Public Contributors are afraid that accepting a payment will adversely affect their asylum claim, while researchers fear that they will precipitate the deportation of people who were trying to help them. Everyone fears media attention and vigilante attacks. Even writing about this topic is viewed with suspicion, since drawing attention to the possibility of PPI payments being made to asylum seekers may trigger politically motivated prohibition. It may be the reason why so many research teams cited in this report have not responded to a request for more details about their practice. The best way forward may be to withdraw this paper or retain it as an ‘underground’ resource, helping researchers to learn from one another without acting as a lightning rod for adverse publicity. It is a sad indication of the contemporary climate where scholarly curiosity and openness have been swept away by fear and replaced with secrecy.

### 6.1 Healthcare

Asylum seekers may access free NHS services<sup>56</sup>. Refused asylum seekers are entitled to free primary care, accident, emergency and non-emergency advice (the 111 service) as well as free treatment for specific infectious diseases, sexually transmitted diseases and conditions caused by torture, female genital mutilation, domestic or sexual violence and free access to family planning, health visitors, school nursing, family planning and end of life care services. Other healthcare services, including pregnancy services, may levy a charge<sup>57</sup>. The United Nations Global Compact on Refugees expects the UK to “expand and enhance the quality of national health systems to facilitate access by refugees and host communities”.<sup>58</sup> Enhancing healthcare requires research so there is no justification to be found here for excluding asylum seekers from the usual mechanisms, including PPI payments.

## 6.2 Employment

Unlike many other countries, the UK does not permit asylum seekers to work<sup>59</sup>. The National Institute for Health and Care Research has explained that PPI activity is not considered to be work when they assert that: *'Involvement in research activities should not be mistaken as capacity for work, and recruitment for service user involvement should not be confused with recruitment for employment'*<sup>60</sup>. Expenses paid in relation to PPI activities are ignored in means assessments conducted by the Department of Work and Pensions<sup>61</sup>, work-related entitlements such as holiday pay do not apply, and, unlike employees and their wages, Public Contributors may reject the offer of a PPI payment without impacting their entitlement to welfare benefits. In seeming contradiction, PPI payments are referred to as 'earned income'<sup>62</sup>.

If this ambiguity was resolved by declaring that asylum seekers are to be denied PPI payments because PPI counts as employment and they must not generally work, then this would impact all Public Contributors, whether asylum seekers or citizens<sup>63</sup>. Indeed, reframing PPI activity as work would bring in a host of contractual obligations and entitlements, vastly inflating the procedural and financial costs for research institutions, as well as silencing some significant voices and weakening research.

## 6.3 Volunteering

The UK government encourages asylum seekers to volunteer and may insist on it in the future<sup>64</sup>. Guidance defines volunteering as for community benefit but not taking the place of a paid role, conferring no payment other than reimbursement of expenses, and providing no contractual obligations or entitlements<sup>65</sup>. PPI activities satisfy all these expectations apart from the payment item, so this suggests that PPI activity is not usually considered to be volunteering.

If the ambiguity was resolved by declaring that asylum seekers are to be denied PPI payments because PPI must conform to this definition of volunteering, then all Public Contributors would be likewise refused PPI payments. So, in summary, research teams should offer PPI opportunities to asylum seekers, but fears around immigration restrictions prevent asylum seekers from taking them up. This is the 'double bind' described by Mäkelä and colleagues<sup>66</sup>. Khanom and colleagues<sup>67</sup> responded to this dilemma by recruiting eight people who were seeking sanctuary, who were trained as peer researchers and then played a vital role in recruiting study participants, supporting respondents to complete questionnaires and facilitating focus groups – but who were described as 'legitimate volunteers' and so were unpaid.

## 6.4 No recourse to public funds

The Immigration and Asylum Act 1999 removed asylum seekers' right to work, created the concept of 'no recourse to public funds', denied all claims for welfare benefits and set asylum support at 70% of standard benefit levels<sup>68</sup>. UK government guidance on what is included in the 'no recourse to public funds' list does not mention research<sup>69</sup>, so there appears to be no justification here for refusing to offer PPI payments to people categorised in this way. Since this group are subject to the harshest restrictions, there can be no justification from this position for denying others in the asylum system the offer of PPI activities and payments.

## 6.5 Duty of care

One research team concluded that they had an ethical duty to offer PPI payments to asylum seekers who were helping them improve the quality of their research, as well as making the three payment modes available – cash, shopping voucher or bank transfer. Alongside this, they had a clear duty to explain the risks that receiving such payments may pose, with the help of interpreters as necessary. All Public Contributors would then be offered a PPI payment and make their own mind up about whether to accept it or not and their preferred mode of receipt.

## 7. Conclusion

In the absence of explicit guidance, both researchers and asylum seekers may avoid PPI payments out of fear of jeopardising asylum claims. This perpetuates exclusion and undermines the goals of inclusive research. Resolving the uncertainty by reframing PPI as either work or volunteering would dismantle the PPI edifice for all health research. Making a special case of asylum seekers by denying them payments for research participation and research coproduction may suit the hostility narrative but it would be unjust, weaken research and damage ensuing policy. The only fair response to the present uncertainty would be to clearly state that asylum seekers are eligible for incentive payments for research participation and PPI payments for coproduction.

To date, very few studies have been found where PPI payments were offered to asylum seekers<sup>70</sup>, and most research papers are hazy on detail<sup>71</sup>, but several examples of innovative practice suggest possibilities. Some may worry that drawing attention to this issue will trigger punitive action and cause the limited opportunities available at present to be closed down.

## 8. How this paper is being written

The investigation that generated this paper is driven by simple curiosity. The work is unfunded and is conducted as a piece of citizen science rather than under the control of any organisation. Accountability is achieved by following the *Writing in Public* framework<sup>72</sup>. Some people have been approached for advice<sup>73</sup>, and am grateful to the people<sup>74</sup> who have contributed to this evolving resource<sup>75</sup>. Please send me your suggestions for further improvements.

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<sup>1</sup> [Payment guidance for researchers and professionals | NIHR](#)

<sup>2</sup> See [Payment-guidance-for-members-of-the-public-considering-involvement-in-research.pdf](#). Also [https://peterbates.org.uk/wp-content/uploads/2017/04/how\\_to\\_make\\_sense\\_of\\_our\\_payments\\_offer.pdf](https://peterbates.org.uk/wp-content/uploads/2017/04/how_to_make_sense_of_our_payments_offer.pdf)

<sup>3</sup> From a political/legal perspective, asylum seekers are not deemed to be citizens and are therefore disenfranchised and silenced, while in contrast, the ethos of coproduction grants them a voice and a role in improving the public services they receive. This contradiction may underpin many of the tensions in this field, generating antipathy to coproduction since it is viewed by some as ‘encouraging them to stay’. Strokosch K & Osborne SP (2016) Asylum seekers and the co-production of public services: Understanding the implications for social inclusion and citizenship. *Journal of Social Policy*, 45(4), 673–690. <https://doi.org/10.1017/S0047279416000258>

<sup>4</sup> One experienced researcher commented, “Unfortunately, we cannot pay asylum seekers as they are not entitled to work, we can only give out of pocket expenses in the form of a shopping voucher. This is widely practiced in the refugee and asylum seekers research networks.” The author would question both the relevance of a prohibition on working to offering a PPI payment, and the practicality of providing an exact reimbursement of expenses through a voucher.

<sup>5</sup> <https://peterbates.org.uk/wp-content/uploads/2025/10/PPI-payments-and-prisoners.pdf>. Also Bates P, Phillips J & Honeywell D (submitted) Paying prisoners to coproduce research: the case for reform.

<sup>6</sup> Radley C, Greenfields M, Coker S, Pola YM & Searl G (2024) Building a Pathway to Participation: understanding the barriers to health research participation for refugees and asylum seekers - a project report. Anglia Ruskin Research Online (ARRO). Report. <https://doi.org/10.25411/aru.25724301.v2>.

<sup>7</sup> [Home - People in Research](#). For an evaluation of the adverts found on this site, see <https://peterbates.org.uk/wp-content/uploads/2024/12/Going-cheap-on-expenses.pdf>.

<sup>8</sup> Mackenzie C, McDowell C & Pittaway E (2007) Beyond ‘do no harm’: The challenge of constructing ethical relationships in refugee research. *Journal of Refugee Studies*, 20(2), 299–319. <https://doi.org/10.1093/jrs/fem008>

<sup>9</sup> James M (2024) *A Human-Centred Investigation into the Impact of Social Protection on the Wellbeing of UK Asylum Seekers* (Alternative Format Thesis). Downloaded from [323698476\\_Redacted.pdf](#).

<sup>10</sup> See [How To Guides – Peter Bates](#)

<sup>11</sup> James ML (2023) Ethical dilemmas, rewards, and lessons for the future: Conducting participatory photographic research with asylum seekers. *International Journal of Qualitative Methods*. Sep 27;22:16094069231205177.

<sup>12</sup> Robinson AR, Khan ZR, Broadhurst KA, Nellums LB, Renolds G, Faiq B, Smith A. Mechanisms and attitudes in responsive healthcare for forced migrant communities: a qualitative study of transnational practice. *BMJ open*. 2025 Feb 1;15(2):e090211.

<sup>13</sup> The PPI budget may be used both for funding a PPI Facilitator who is engaged as a contractor or employee and for PPI payments made to Public Contributors who are not otherwise paid or contracted to deliver their role.

<sup>14</sup> Betancourt TS, Berent JM, Freeman J, Frounfelker RL, Brennan RT, Abdi S, et al. (2019) Family-Based Mental Health Promotion for Somali Bantu and Bhutanese Refugees: Feasibility and Acceptability Trial. *Journal of Adolescent Health*. 66(3):336–44. <https://doi.org/10.1016/j.jadohealth.2019.08.023>.

<sup>15</sup> It is noteworthy that government policy in the USA has banned some co-authorship of scholarly publications with foreign nationals. “Effective immediately, all United States Department of Agriculture (USDA) employees and affiliates are prohibited from... authoring or co-authoring a scholarly publication, in their official capacity, along with a foreign national without a USDA-approved arrangement in place prior to the initial drafting or editing of any manuscript.” [America First Memorandum for USDA Arrangements and Research Security](#). At present, the USA National Institute for Health has no such restriction on authors – see [Requirements for Disclosure of Other Support, Foreign Components and Conflicts of Interest | Grants & Funding](#).

<sup>16</sup> For example, five asylum seekers were trained and then facilitated focus groups in Glasgow in 2004. See O'Donnell CA, Higgins M, Chauhan R, Mullen K (2007) " They think we're OK and we know we're not". A qualitative study of asylum seekers' access, knowledge and views to health care in the UK. *BMC Health Services Research*. May 30;7(1):75.

<sup>17</sup> Carter J, Knights F, Deal A, Crawshaw AF, Hayward SE, Hall R, Matthews P, Seedat F, Ciftci Y, Zenner D, Wurie F. Multi-infection screening for migrant patients in UK primary care: Challenges and opportunities. *Journal of Migration and Health*. 2024 Jan 1;9:100203.

- <sup>18</sup> Humphrey A (2023) [Remote primary healthcare in the UK: How does marginalisation shape experiences of healthcare?](#) PhD thesis, London School of Hygiene & Tropical Medicine.
- <sup>19</sup> Boshari T, Johnson E, de Zoete E, Billett J, Ciftci Y, Carter J, Hargreaves S & Weil L (2024) Co-producing a model of asylum seeker and refugee collaboration in regional health policy and practice: a qualitative applied research methodology. *The Lancet*. Nov 1;404:S90.
- <sup>20</sup> Prasad A (2025) Sally Hargreaves: co-producing solutions for migrant health. *The Lancet*. Sep 13;406(10508):1078.
- <sup>21</sup> [Safety nets — Social security for families in a devolved UK](#).
- <sup>22</sup> Personal communication, November 2025.
- <sup>23</sup> Carter J, Goldsmith LP, Knights F *et al.* (2024) Health Catch-UP!: a realist evaluation of an innovative multi-disease screening and vaccination tool in UK primary care for at-risk migrant patients. *BMC Med* **22**, 497. <https://doi.org/10.1186/s12916-024-03713-4>.
- <sup>24</sup> Nanakali SS, Hassan O, Silva L, Al-Oraibi A, Chaloner J, Gogoi M, Qureshi I, Sahare P, Pareek M, Chattopadhyay K & Nellums LB (2023) Migrants' living conditions, perceived health needs and implications for the use of antibiotics and antimicrobial resistance in the United Kingdom: A qualitative study. *Health Science Reports*. Oct;6(10):e1655.
- <sup>25</sup> Lampa E, Sarkadi A, Osman F, Kihlbom U & Warner G (2022) Tracking involvement over time: a longitudinal study of experiences among refugee parents involved as public contributors in health research. *International Journal of Qualitative Studies on Health and Well-Being*, 17(1). <https://doi.org/10.1080/17482631.2022.2103137>. Also Warner G, Baghdasaryan Z, Osman F, Lampa E, Sarkadi A (2019) 'I felt like a human being'-An exploratory, multi-method study of refugee involvement in the development of mental health intervention research. *Health Expectations*. 24(S1):30–39.
- <sup>26</sup> Baird MB, Domian EW, Mulcahy ER, Mabior R, Jemutai-Tanui G & Filippi MK (2015) Creating a Bridge of Understanding between Two Worlds: Community-Based Collaborative-Action Research with Sudanese Refugee Women. *Public Health Nursing*. 32(5):388–96. <https://doi.org/10.1111/phn.12172>.
- <sup>27</sup> Cumming S & Symon A (2025) Pregnant and Homeless in the UK: A Qualitative Analysis of Maternal Experiences in Temporary Accommodation. *Birth*. Apr 4.
- <sup>28</sup> Personal correspondence, November 2025 and January 2026. In both cases, the researcher wished to remain anonymous.
- <sup>29</sup> For example, see Robinson A, Musotsi P, Khan ZR, Khan Z, Nellums L, Faiq B, Broadhurst K, Renolds G, Pritchard M & Smith A (2025) Opportunities and practices supporting responsive health care for forced migrants: lessons from transnational practice and a mixed-methods systematic review. *Health and social care delivery research*. May 1;13(13):1-82.
- <sup>30</sup> Asylum seekers in the UK will find it difficult but not necessarily impossible to open a bank account. See [Refugees and asylum seekers: how to get a bank account - Positive Action in Housing](#).
- <sup>31</sup> Cash is less traceable than vouchers and may involve small denominations, multiplying the time and trouble involved in managing and recording the transactions. Staff who handle cash may be more anxious about proving their integrity in this role.
- <sup>32</sup> Spira J, Wright H, Komolafe K & Kushnir C (2025) The impact of hotel accommodation on asylum seekers' mental health: a mixed methods study. *The International Journal of Human Rights*, 1–27. <https://doi.org/10.1080/13642987.2025.2520836>. Research participants were offered a £10 voucher (personal communication, Oct 2025).
- <sup>33</sup> Albanese A [Exploring the mental health and psychosocial experiences of asylum seekers, refugees and undocumented migrants in the post-migration context](#) (Doctoral dissertation, University of Glasgow).

<sup>34</sup> Humphrey A (2023) op cit.

<sup>35</sup> Power M & Baxter M (2025) "I think they are actually a bit racist in not giving us everything that we need in terms of medication": Racialised governance and asylum seeker access to healthcare in England. *Social Science & Medicine*. 2025 1;365:117558. See also Power, M., & Baxter, M. (2024). Lived experiences of food insecurity and food charity among asylum seekers in England: racialized governance and a "culture of suspicion." *Ethnic and Racial Studies*, 1–23. <https://doi.org/10.1080/01419870.2024.2399726>.

<sup>36</sup> Mulcaire J. *Kafkaesque Systems and Draconian Treatment: The Impact of Statelessness and Seeking Asylum on Mental Health*. Doctoral dissertation, University College London.

<sup>37</sup> Wendelboe-Nelson C, Fisher JC, Straka TM, Sousa-Silva R, Menzel C, Alejandre JC, de Bell S, Oh RR, Bonn A & Marselle MR (2025) Outdoor health intervention for refugees, migrants, and asylum-seekers: A mixed-methods pilot study. *Health & Place*. Jan 1;91:103387.

<sup>38</sup> Whitehead J, Fokaf O, Deinekhovska T, Egan M & Seguin M (2025) Stressors faced by forcibly displaced Ukrainians in England within 6 months of arrival: A qualitative study. *Social Science & Medicine*. Apr 1;371:117909. **Also** Clarke TJ (2025) Exploring the mental health and acculturation needs of sexual and/or gender minority forced migrants. Available at [CLA20502155 thesis library copy.pdf](https://doi.org/10.1080/01419870.2024.2399726).

<sup>39</sup> Deal A, Salloum M, Hayward SE, Crawshaw AF, Knights F, Carter J, Al-Sharabi I, Yahia R, Fisher S, Morais B & Bouaddi O (2025) Precarity, agency and trust: Vaccination decision-making in the context of the UK asylum system. *SSM-Qualitative Research in Health*. Jun 1;7:100515. This research is also described in Deal A, Crawshaw AF, Salloum M, Hayward SE, Carter J, Knights F, Seedat F, Bouaddi O, Sanchez-Clemente N, Lutumba LM, Kitoko LM. Understanding the views of adult migrants around catch-up vaccination for missed routine immunisations to define strategies to improve coverage: a UK in-depth interview study. *Vaccine*. 2024 May 10;42(13):3206-14.

<sup>40</sup> Humphrey A (2023) op cit.

<sup>41</sup> For a review of the confusion surrounding payments for research participation, see <https://peterbates.org.uk/wp-content/uploads/2022/08/How-to-set-payment-levels-for-research-participants.pdf>.

<sup>42</sup> James ML. 2023, op cit.

<sup>43</sup> Study respondents select a topic of significance to their lives and then are given cameras. They take photographs, add captions and discuss their meaning with researchers. See [PhotoVoice - Projects, Training, Photography for Social Change](https://peterbates.org.uk/wp-content/uploads/2022/08/How-to-set-payment-levels-for-research-participants.pdf).

<sup>44</sup> "As per the stipulations of the ethics committee, participants will not be provided any compensation for their involvement in the study." Beuthin O, Shahid S, Yu LM & Bhui K (2024) Feasibility and Acceptability Study of a Culturally Adapted Web-Based Intervention to Reduce Suicidal Ideation for Syrian Asylum Seekers and Refugees in the United Kingdom: Protocol for a Mixed Methods Study. *JMIR Research Protocols*. Sep 2;13(1):e56957.

<sup>45</sup> Inquiry sent 04 Nov 2025.

<sup>46</sup> Filler T, Benipal PK, Torabi N & Minhas RS (2021) A chair at the table: A scoping review of the participation of refugees in community-based participatory research in healthcare. *Globalization and Health*, 17(1), 103. <https://doi.org/10.1186/s12992-021-00756-7>. Inquiry sent 18/11/25 asking for details of the two papers that did specify compensation arrangements. No response as yet.

<sup>47</sup> Lovell-Kennedy S, Grieve LM, Shemery S, Mufara V, Lerkins T, Umanhonlen B, Tamami S, Abdilahi F, Purdie A & Ball HL (2025) 'We don't ask for a luxury life, just basic things': the experiences of mothers with babies in the UK asylum system. *Wellbeing, Space and Society*. Jun 1;8:100264.

<sup>48</sup> The university holding the research contract agreed to pay the charity to enable it to hire the community researchers. They received a basic introduction to research methods, ethics, recruitment, data protection etc., although the community researchers had a range of levels of prior education in relation to research methods.

Language skills and lived experience were the key recruitment criteria to maximise the diversity of participant recruitment in the project. Some are now employed on permanent contracts with the charity.

<sup>49</sup> The study team are to be commended for their pioneering work in this study. Only the most persistent analyst would wonder where the advice came from and whether it was based on fear or knowledge.

<sup>50</sup> Shankley W, Stalford H, Chase E, Iusmen I & Kreppner J (2023) What does it mean to adopt a trauma-informed approach to research?: Reflections on a participatory project with young people seeking asylum in the UK. *International Journal of Qualitative Methods*, 22. <https://doi.org/10.1177/16094069231183605>.

<sup>51</sup> Crawshaw AF, Kitoko LM, Nkembi SL, Lutumba LM, Hickey C, Deal A, Carter J, Knights F, Vandrevale T, Forster AS, Hargreaves S. Co-designing a theory-informed, multicomponent intervention to increase vaccine uptake with Congolese migrants: A qualitative, community-based participatory research study (LISOLO MALAMU). *Health Expectations*. 2024 Feb;27(1):e13884.

<sup>52</sup> Stevenson K, Ogunlana K, Alomari M, Agoropopoola R, Stevenson F, Knight M & Aldridge R (2023) Lessons learned from co-production in public health research: the MAMAH case study involving underserved migrant mothers in the UK. *The Lancet*. Nov 1;402:S87.

<sup>53</sup> [National Health Advisors - Doctors of the World](#).

<sup>54</sup> [Co-production | Migrant Help](#). Arjun Malhotra, Head of Client Voice at Migrant Help is in discussion with the Home Office about the topic of this paper and hoped to obtain some guidance from the Home Office by August 2026. Migrant Help, 128 City Road, London EC1V 2NX, Tel: 01304 796670.

<sup>55</sup> One charity has commented that the Home Office do not have a policy setting out the eligibility of people without immigration status for thankyou payments in connection with either research coproduction or study participation. As a result, some publicly funded studies offer payment to all, regardless of immigration status, while others will only reimburse travel costs. The charity has asked the Home Office for clarification (personal communication Nov 2025).

<sup>56</sup> [NHS entitlements: migrant health guide - GOV.UK](#).

<sup>57</sup> Jones L (2023) Eligibility for free healthcare. *InnovAiT*. Oct;16(10):516-20..

<sup>58</sup> [Global Compact on Refugees – booklet | UNHCR](#)

<sup>59</sup> Gower M, McKinney CJ & Oxley G (2024) [Asylum seekers: the permission to work policy](#) House of Commons Library.

<sup>60</sup> [Liaison with Jobcentre Plus | NIHR](#)

<sup>61</sup> Advice for Decision Makers Chapter H3: paragraph 3161. [ADM Chapter H3: Earned income - employed earnings](#)

<sup>62</sup> Advice for Decision Makers Chapter H3: paragraph 3164. [ADM Chapter H3: Earned income - employed earnings](#)

<sup>63</sup> This field is labyrinthine in its complexity and rules may have changed. Please lead me to a better understanding.

<sup>64</sup> HM Government is consulting on adopting an approach called Earned Settlement, in which volunteering would reduce the delay before people were granted full citizenship. See [Earned settlement - GOV.UK](#).

<sup>65</sup> [Permission to work and volunteering for asylum seekers \(accessible\) - GOV.UK](#)

<sup>66</sup> Mäkelä P, Given-Wilson Z, Al Berkdar K, Aljumma Z, Mostafanejad R (2024) Coproducing a film resource for asylum seekers in the UK—A field reflection, *Journal of Refugee Studies*, Volume 37, Issue 2, June. Pages 569–578, <https://doi.org/10.1093/jrs/feae002>

<sup>67</sup> Khanom A, Alanazy W, Ellis L, et al (2019) [The Health Experiences of Asylum Seekers and Refugees in Wales: Technical Report of the HEAR Study](#) Cardiff: Public Health Wales NHS Trust and Swansea University.

<sup>68</sup> Ramachandran N (2024) The Enforced Destitution of Asylum Seekers in the UK. *Journal of Human Rights and Social Work*. Mar;9(1):139-53.

<sup>69</sup> [Public funds](#)

<sup>70</sup> One senior academic commented that “In 26 years of research with asylum seekers I have never heard of their engagement [in coproducing research]”. Personal correspondence, October 2025.

<sup>71</sup> While most papers simply fail to mention the possibility of PPI payments, Gordon et al are to be commended for at least attempting to make their position clear; “Funding constraints meant participants were unable to be offered financial incentives.” This is somewhat disingenuous, as responsibility lies with those who drafted the funding application, and this statement said nothing about coproduction of the research. See Gordon AC, Crenstil C & Mamluk L (2023) Attitudes and experiences of asylum seekers and refugees to the COVID-19 vaccination: a qualitative study. *BJGP open*. Jun 1;7(2).

<sup>72</sup> Bates P (2024) [How-to-write-in-public.pdf \(peterbates.org.uk\)](#).

<sup>73</sup> Inquiries were sent to 61 UK refugee support voluntary organisations and 40 researchers. Only two refugee support organisations responded by engaging with the issues. Most either did not respond at all or sent a standard message saying that due to capacity issues, they cannot help with research.

<sup>74</sup> Comments and advice have been gratefully received from Helen Ball, Tianne Haggard, Michelle James, Anna Miller, Jenny Phillimore, Sam Reid, Anthony Uwandu-Uzoma and Hannah Wright, as well as others who asked for anonymity.

<sup>75</sup> All errors and omissions are the sole responsibility of the author. The information is provided in good faith, and so readers engage with the contents at their own risk and undertake not to hold the author liable for any injury, loss, or damage arising through reading or acting on its contents.