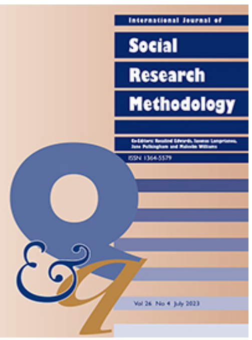

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# Ethical and practical considerations for including marginalised groups in quantitative survey research

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**ABSTRACT**
This paper considers the ethical and practical issues of recruiting for, and administering a quantitative survey with marginalised populations. These issues were identified through a focus group discussion, which consolidated and expanded upon informal conversations held previously by five researchers about their experiences of conducting a face-to-face survey (using predominantly quantitative questions) with people who used amphetamine type substances in North East England, UK. Inductive and deductive thematic analysis of the focus group discussion led to the generation of three key themes: researcher positionality, emotions, and role dilemmas; study design; and ethics in practice. This paper therefore aims to extend literature which explores ethical and practical issues involved in studies with marginalised populations. It makes methodological suggestions for how work across a range of disciplines could make face-to-face survey research, and future studies with marginalised populations, more inclusive for both participants and researchers.

**KEYWORDS**
Study design; reflection; ethics; socially excluded; multiple disadvantage

## Introduction

Despite acknowledgement of the need for and value of more inclusive research practices when working with socially excluded, disadvantaged, stigmatised, minoritised, underheard, underserved, or socially excluded groups (henceforth 'marginalised'), the methods and study designs employed by academics can fail to address the needs of these populations, which may inadvertently result in their voices not being heard (Ojo-Fati et al., 2017; Prinjha et al., 2020). Historically, marginalised groups have been understood as those who are impacted by several complex and intersecting issues such as substance use disorder, sex work, rough sleeping, or institutional care (Fitzpatrick et al., 2011). They have also been defined as being vulnerable, problematic, hard-to-reach, or having multiple complex needs (Asquith & Bartkowiak-Théron, 2021; Revolving Doors, 2021); labels that can be stigmatising and lead to deeper social exclusion (Addison et al., 2022) by placing the 'problem' of lack of engagement on the marginalised populations themselves rather than on existing political systems or broader social issues (Brown & Wincup, 2019).

Within fields of research with populations who have been traditionally marginalised such as people with learning disabilities, inclusive research methods aim to democratise the research

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process and enable such groups to take more integral roles in the process of knowledge production (Nind, 2017). Some have expressed concern that the field of substance use research has been relatively slow to embrace these more inclusive methods and study designs (Cairns & Nicholls, 2018), thereby reproducing persistent power imbalances within the research-researcher-researched dynamic (Shaw et al., 2019). This could be allied to more systemic problems within the ontological and epistemological foundations of academic health research more generally, where positivism occupies a privileged or hegemonic position, with hegemony defined as holding a position of dominance, or influence, at the exclusion of others (Kontos & Grigorovich, 2018). While creative methods have been employed, for example, to engage women who use drugs (Grace et al., 2022), this focus on a positivist paradigm can lead to certain research and scholars also being marginalised (Hale et al., 2007). Broadly speaking, quantitative research, and more specifically experimental study designs, are frequently held up as the 'gold standard' of knowledge generation, based on a positivist epistemology that high-quality research equates to that which is objective, generalisable, and value free (Porta & Keating, 2008).

Within the field of substance use, a positivist epistemology can lead to assumptions that drug use is a medical 'problem' requiring assessment, treatment, and legal responses (McNeil, 2021). This can lead to the collection of data with a focus on statistical associations between exposures and outcomes (Cooper & Tempalski, 2014), which in turn forms the basis of reports around drug use prevalence, and links to crime (e.g. ONS, 2020). This approach has value and can provide evidence that might, for example, inform recommendations for policy and healthcare practices. However, such data is unable to encapsulate the wider context behind people's substance use, which might be better captured through qualitative research methods (Martin, 2023). Qualitative research often (though not always) starts from a constructivist epistemological position, and explores the social context of substance use from the standpoint of there being no single truth, but multiple realities (Rhodes & Coomber, 2010). It encapsulates social determinants, such as poverty or access to services, into the concept of substance use as a response to context and environment (van der Linden, 2015). However, while qualitative methods are often considered more appropriate than quantitative in facilitating understanding of the meaning attributed to certain practices by marginalised groups, alternative approaches may be required to respond to different research questions, contexts, and research funding requirements (Skivington et al., 2021). For example, cross-sectional surveys can help to determine the prevalence of, and factors contributing to specific issues or conditions in socially disadvantaged populations (Bonevski et al., 2014).

Questioning our approaches to study design, our perspectives, and assumptions about the knowledge that we hold as researchers is built into the field of reflexivity (Bourdieu, 2004), and in the substance use field, as in other research areas, there exist numerous examples of reflexive accounts of researchers' experiences of working with marginalised populations. However, these are predominantly based on conducting qualitative studies (Morina, 2021), with this lack of reflexivity in alternative research paradigms possibly attributed to researcher emotions not being considered as part of or relevant to quantitative approaches (Bluvstein et al., 2021; Jamieson et al., 2023). Indeed, reflecting on the emotional experiences of using quantitative methods remains a relatively novel field, with a paucity of literature on the topic (Lazard & McAvoy, 2017).

Without allocating time to reflect on learning from quantitative research conducted with marginalised populations, there is the risk that repeating previously hegemonic study designs will continue to disadvantage these groups (Hussain-Gambles et al., 2004). As a tool to address this, reflexivity allows researchers to 'stand in a self-critical position and reflect on how knowledge is produced' (Souleymanov & Allman, 2016, p. 1440). It also calls for an awareness of power relations and positionality: how our own privilege and identity as academic researchers impact upon our interactions with participants (Poland et al., 2006; Schmitz & Hamann, 2022). While discussions about positionality are an integral part of qualitative research, they can also be of benefit within quantitative studies, helping to define boundaries and clarify the researchers' influence on the study (Jafar, 2018; Schmitz & Hamann, 2022).

The current study was born out of informal conversations held between the five researchers who had all been involved in the data collection for the quantitative survey phase of a wider mixed-methods research project, described in brief below, with further detail available in the published protocol (Rosenkranz et al., 2019). During these initial conversations, the researchers, who had experience of using both qualitative and quantitative research methods in a range of settings, identified similar ethical and practical challenges encountered in conducting the survey and discussed the potential benefits of recording these experiences via a facilitated focus group. In doing so, we aim to contribute to the emerging literature which explores ethical and practical issues involved in studies with marginalised populations and to make methodological suggestions for how work across a range of disciplines could make studies with these groups more inclusive for both participants and researchers. In the following section, we describe the methods employed in this reflexive piece of research, including a brief overview of the wider study around which our discussions were based. We then explore the key themes identified in focus group discussions relating to ethical and practical concerns encountered during survey fieldwork, before concluding with consideration of the implications for future research methods.

## Methods

The focus group method was selected as it was perceived that it would enable the researchers to explore their own thoughts and reflections while also interacting with each other's experiences; taking an interpretive approach that prioritised their meanings and experiences (Merton et al., 1987; Morgan, 2019).

### *Participants*

Five researchers who were involved in the collection of quantitative data for the third phase of a previous mixed-methods research study participated in the focus group. They included one project manager, three researchers employed by two universities, and one 'insider researcher' who volunteered with a local community organisation. Researcher 1 (female) had over 15 years of research experience with vulnerable groups; Researcher 2 (female) had 12 years of practitioner experience working with individuals experiencing mental ill health and substance use disorders, and 11 years of applied research experience; Researcher 3 (male) was a frontline worker with over 30 years of experience working with marginalised populations, and was a volunteer researcher; Researcher 4 (male) had 15 years of experience of frontline work with marginalised groups, and 10 years of applied research experience; Researcher 5 (male) had 7 years of research experience, and prior experience working with children and young people. All researchers involved in this paper were from a white British background. In addition to the field researchers involved in the focus group, two additional authors collaborated on the writing of this paper: the Principal Investigator for the UK arm of the wider study, and a researcher employed by Newcastle University who also facilitated the focus group.

### *Wider study context*

The focus group discussions explored the researchers' experiences of working on a mixed-methods cross-European study (ATTUNE, referred to hereafter as 'the wider study') that aimed to understand which factors shape use of amphetamine type substances (ATS) over the life course. Data collection for the wider study spanned three phases. First, a systematic review and synthesis of international qualitative literature highlighted the heterogeneity of ATS users and the complex interplay of individual, social, and environmental factors shaping ATS initiation and trajectories (O'Donnell et al., 2019). Second, and informed by the review findings, qualitative interviews with ATS users and non-users explored perceived critical turning points into and out of stimulant use, with UK data suggesting that mental and physical health, and adverse life events, influenced individual drug use pathways (Addison et al., 2020).

The third, quantitative phase of the wider study formed the basis of the later focus group discussions that are explored in this paper. A cross-sectional computer-assisted personal interview (CAPI) survey of current, former, and non-ATS users was conducted to validate and enhance the generalisability of the qualitative interview findings (Rosenkranz et al., 2019). Surveys took about 45–60 minutes to administer, and participants were given a voucher as remuneration for their time (around €20). Survey questions were developed in collaboration with European study partners, people with lived experience of substance use, and some of the researchers involved in this paper. The review of qualitative literature and semi-structured qualitative interviews that preceded the survey questionnaire also informed decisions around which questions to include or exclude. The survey was then piloted with ATS users, and as a result was reduced in length prior to wider delivery.

In the survey, sociodemographic data were collected with standard questions on gender, age, and ethnicity, alongside educational status, income and employment, and relationship status. Standardized screening tools and questionnaires were used to assess current and prior substance use. Data were also collected about injecting drug use and treatment experiences, the usual setting of ATS use, user motives and (self-imposed) consumption rules. Additional questions related to self-reported factors contributing to participants' biographical burden (e.g. number of stressful life events such as physical/sexual violence, homelessness, or imprisonment). Self-reported diagnoses of selected mental disorders were collected, and participants self-rated their physical and mental health.

The survey was administered via a digital tablet, onto which interviewers entered participant responses. In addition, printed show cards were provided with the research materials to assist participants in understanding some of the questions, for example study definitions of terms such as 'amphetamine-type substances'. During the wider study, relationships were developed with a range of statutory and community groups to assist with recruitment and engagement, and quantitative fieldwork took place between September 2016 and August 2019. Details on the wider study are described in full in the published protocol (Rosenkranz et al., 2019), with findings reported elsewhere (Adams et al., 2022).

### Focus group data collection

For the focus group discussions which form the basis of the current paper, the lead author devised a topic guide which built upon the informal initial conversations described previously. This was emailed to attendees before the focus group (Supplementary Material 1). A critical reflection approach was used (Beres & Fook, 2019; Schön, 1992) in order to explore personal practice and elements of study design that may have facilitated or hindered access to, and engagement with, the populations they had sought to reach; and to identify potential improvements for future study designs. The focus group was held virtually via videoconference for practical reasons, including lower financial and time investments (Lobe & Morgan, 2020), and Covid-related concerns about in-person meetings. The focus group took place in October 2021 and was facilitated by a colleague (an academic researcher with a social science background) who was known to all five researchers, but who had not been involved in the survey delivery. The focus group was audio-recorded and transcribed verbatim.

### Analysis

The researchers' informal discussions about their experiences of carrying out the survey informed the decision to run the focus group, the topic guide issues to be covered, and also meant that the process of analysis began with experiential ideas about what might be important to explore, such as emotional responses to the study and ethical and practical challenges. However, they still endeavoured to generate an interpretation that was predominantly based on the data generated through the focus group. As such, in the first stage of coding, the first author (MA) familiarised themselves with the focus group transcript, and inductively developed an initial coding framework. Next, three further researchers (HA, KJ, LS) who also attended the focus group independently reviewed the focus group transcript. An analysis meeting was then held to discuss and refine the initial framework, an iterative process that focused on a semantic level of analysis. A subsequent meeting took place in which the first author presented their interpretation; this was modified and agreed by all co-authors to provide the interpretation presented in this paper. Microsoft Word and NVivo version 1.6 (QSR International Pty Ltd, 2021) were used to store the transcript and support coding. The following three descriptive themes were generated: researcher positionality, emotions, and role dilemmas; study design; and ethics in practice.

### Ethical approval

Ethical approval for the focus group was granted by Newcastle University Ethics Committee (14249/2020) on 1 September 2021.

## Ethical and practical concerns encountered during fieldwork

### Researcher positionality, emotions, and role dilemmas

The survey in the wider study used standardized screening tools and questionnaires for measuring substance use, mental health, and several other sensitive topics. It was delivered to individuals who had experienced: homelessness; mental ill health; childhood sexual abuse; a history of violence; growing up in institutional care; and multiple and/or extended prison sentences, and had the potential to raise powerful or deep-seated emotions in some participants. Various types of survey responses were elicited, including closed questions and Likert scales with multiple options. The researchers in the focus group all shared their emotional discomfort, as illustrated by these quotes in which they identified dissonance in specific areas. Researcher 5 struggled to reconcile asking in-depth questions about sensitive topics such as adverse childhood experiences with the study's focus:

> (I) possibly feel a little bit uncomfortable about some of the things that we were asking . . . knowing what we actually needed from the data . . . Why were we asking them?

Other scholars have noted the need for such emotional reflexivity, and for making space for emotion during fieldwork (Scott, 2022) which was demonstrated by Researcher 3. Reflecting on how the interviews were progressing, they had considered the impact of physical setting upon people's lived experience and made adjustments accordingly:

> I actually felt . . . really uncomfortable delivering that questionnaire as was . . . I did a sort of reflective piece on my own, looked at what was going on for me and I completely redesigned the setting. So I moved it to the upstairs of the building and the upstairs offices . . . where clients normally don't go, so it's quieter . . . [While] Adverse Childhood Experiences and their links to substance use are really important, I think if we're going to ask those questions, I think more consideration must be given to both the researcher and the participants, in terms of their safety.

This emotional dissonance was also evident in the role conflict identified by several participants between the demands of conducting the survey, and their previous practitioner experience and practices within health and social care fields. This conflict operated at multiple levels. Tension existed between asking questions in a therapeutic, empathic, active listening style as opposed to focused and time-limited data collection, while at a methodological level the appropriateness of a quantitative approach when discussing sensitive topics with this population was called into question. Finally, researchers felt that the survey method curtailed opportunities for further discussion of issues important to participants, illustrated by the following quote:

> There was some phenomenally good discussions and qual stuff missed [qualitative information shared by participants that wasn't captured in the survey]. Some absolute gems . . . (Researcher 3)

There was also discussion in the focus group about the support and supervision that was available to them during the study. Researcher 4 highlighted the contrast between the different expectations of support for researchers and for practitioners outside of academic settings, stating that when working with 'violent men and men who battered women' they used to have clinical supervision every 3 weeks. This point resonates with other settings in which researchers have described feeling differently about asking for support within academic roles compared to clinical roles, for example when working with people who had experienced trauma (Nikischer, 2018).

## Study design

### Cultural sensitivity

Research that is culturally sensitive incorporates factors such as ethnic or cultural experiences, norms, values, beliefs, or behavioural patterns into its design (Barrera et al., 2013). Studies with marginalised groups have highlighted the importance of using culturally inclusive language that is worded at the correct literacy level for participants (Bonevski et al., 2014, p. 160), and there was discussion in the focus group around how hegemonic methods that might seem innocuous at the design stage could be culturally insensitive 'in the field'. For example, the researchers discussed that the use of matrix-style questionnaires with multiple-choice responses such as 'impossible, difficult, neither easy nor difficult, rather easy, easy' were found to be problematic for some participants, illustrated by the following commentby Researcher 3:

> Matrix-style [survey response options] . . . were really not helpful for people with cognitive issues, literacy issues, or substance misuse issues . . . [and] scales that ask about work colleagues and home ownership . . . can be really alienating for . . . homeless people, or people who've never worked.

Additionally, researchers commented that the cue cards provided with the research materials, that were designed to aid understanding of some of the questions, resulted in some emotional discomfort for those survey participants with literacy issues who were unable to read them. The length of the survey was also discussed: surveys took approximately 45–60 minutes to complete, and in some circumstances extended to 90–120 minutes, which proved a challenge for both participants and researchers:

> People did get a bit fidgety and restless, which was totally understandable, because some of the surveys did go on for quite a long time . . . . it was difficult as a researcher, so I can only imagine that it was exhausting as well, for a participant (Researcher 4).

These comments are aligned with Braun and colleagues' experiences (Braun et al., 2020) that longer surveys have a greater potential for participant disengagement or fatigue.

### Excluded within excluded

One of the research objectives of the wider study was 'targeted recruitment of different ATS user groups with regard to frequency, dependency, former or current use' (Rosenkranz et al., 2019, p. 2), and a conscious focus of the UK recruitment strategy was to access people who might not traditionally engage with research. While Duvnjak and Fraser (2013, p. 178) report that 'the hard to reach [sic] usually fall into the very lowest levels of the social hierarchy', this is not always the case.

In this study, researchers found that people in drug treatment, who in other respects might be viewed as a socially excluded group, were often easiest to access. The groups that researchers found hardest to access were infrequent users, those from more socio-economically advantaged backgrounds, and non-ATS users. Researcher 4 stated: 'I interviewed a few professionals as well … social workers, who were vulnerable in a different type of way'. Although researchers had identified groups who might not traditionally engage with research, there was the subsequent challenge of accessing them, with the existing recruitment sites and strategies found to be either inappropriate or ineffective. In addition, Researcher 2 questioned who else might have been inadvertently excluded:

> Were there people who were just hidden from us as researchers because they weren't accessing networks? Or they were isolated? I think those omissions are important to recognise because they speak to policy and practice as well; so if they're not accessible or known to us through research networks or service provision, then are they known to anyone?

Overall, researchers reflected on the importance of keeping an open mind to diversity among research populations, and challenging their own assumptions about whose voices might be seldom heard within an identified population.

### *Benefits of the study design*

Researchers mentioned that the design of the study had specifically allowed them time to become embedded into services and to become a regular 'face'. By doing so it had facilitated their access to and engagement with populations who otherwise may have been inadvertently excluded from the Europe-wide research project:

> The other thing for me was actually having the capacity or the opportunity to stick within services and just hang out and be available in waiting rooms… sometimes I would approach somebody, and they may decline on that first opportunity but when I was there a few days later, they were like: 'oh, are you still doing it?' And then they were more happy [for the research] to take place because I'd become a familiar face… (Researcher 2)

Researchers discussed how their pre-existing relationships with public and professional stakeholders, established and maintained over time, were essential to their ability to access certain groups. Researcher 1, who was involved in the project's management, shared how this approach had been built into the study's design:

> Right from the outset, we did a framework where we were supposed to be using "seeds", to try and reach the people who are furthest away on the network… we then had to adapt our sampling framework to make it more purposive and because we did that… it meant that we drew more on social capital within the project team itself.

The use of vouchers was noted as another positive factor in recruitment, as a remuneration for, and acknowledgment of people's time, especially given the length and in-depth nature of the survey. A secondary benefit of the vouchers was identified by Researcher 3, who noted that potential study participants who were interested in completing the survey were able to tell peers that they were only taking part in the study for the voucher, which could be seen to enable a 'cover story' for taking part.

> So they would say, 'oh yes, for the money, for the money' and yes, that was a part of it but it was also that… word spread about the nature of the conversation and the kind of things we were talking about.

In addition, the digital tablet used to collect questionnaire data was felt to be a more interactive and inclusive approach to data collection, creating less of a barrier between researchers and survey participants than a traditional paper survey and clipboard. Researchers also highlighted personal learning, with Researcher 4 having to 'reflect quite a lot on my own sort of assumptions and understanding about different populations', while Researcher 1 considered her role and position:

> I was very mindful of being seen in a particular way, going in certain spaces and around certain people … I was mindful of the privilege and the power that I'd brought to the situation.

The study's broad eligibility criteria encouraged recruitment from diverse populations, and the conscious efforts to access people that might traditionally not engage with research were lauded:

> I think one of the important things about the study was that we made a really conscious effort to try and access people that might traditionally not engage with research … that was one of the things that we felt was important all the way through (Researcher 5).

This supports positions held by those such as Logie (2021) that challenge assumptions around populations being hard to reach or engage, instead suggesting that it is the responsibility of researchers to take additional steps to move towards these groups, and to make their studies more accessible.

## *Ethics in practice*

A central topic of discussion within the focus group was how the formal process of ethical approval did not always take into account real-world dilemmas. One such situation was discussed in which Researcher 1, following from discussions held with a police officer with whom she had previous connections, had spent the morning on an allotment conducting surveys with a group of men who had previously been involved in the criminal justice system. Taken out of context, if the situation of a lone female researcher undertaking an interview at a remote allotment with this group had been presented to an ethics committee, it may well have been rejected on the grounds of risk to researcher safety. Guillemin and Gillam (2016, p. 269) discuss this gulf between procedural ethics and 'ethics in practice'. Researchers working with marginalised populations may have to make such 'on the spot' decisions in which they have to balance their own, and participants' risk, against the importance of providing an opportunity for an eligible participant to take part in data collection (Jackson, 2021).

Another area discussed was the process of securing informed consent: a central aspect of research ethics that seeks to counteract the potential danger of participants being coerced to take part in research and to ensure that they fully understand its purpose, including how their data will be used (Corrigan, 2003). Researchers discussed the challenges posed by the expectation from ethics boards of a period of delay between introducing a study and conducting research, illustrated here by Researcher 2:

> This research … but any research that's trying to get [to] a vulnerable population, is allowing them time to consider and think whether they want to take part in the research, but not giving them long enough so that you lose them and … what is the correct timeframe to allow for that, and how do you facilitate that in research with this population group?

Researcher 3 highlighted how this requirement of delay was misaligned with the setting in which he had conducted surveys: a community kitchen serving food and clothing to people who experienced social exclusion. Although he had sat with potential participants while they ate and was able to answer their questions about the study, the service was noisy and fast-paced, with frequent disturbances in the building:

> If you're dealing with a transient population and certainly in the [local service] that I was working with, it's … you know, in and out, in and out, there's fights going on, there's kick-offs [noisy arguments], there's a whole lot going on.

This setting was therefore not conducive to potential participants' contemplation of the possible consequences of engagement in research. In addition, people who were rough sleeping, or who were current users of amphetamines, seldom had time or inclination to consider their participation, and instead asked to be interviewed immediately. These observations were congruent with K. Pollock

(2012, p. 9) who suggested that the ‘complex and shifting nature of real-world settings’ can conflict with the bioethical framework underpinning current ethical regulation.

## Discussion

This paper contributes to literature on the ethical, practical, and methodological considerations of survey research with marginalised populations. It provides unique insights into one research team’s experiences of administering a quantitative survey with a marginalised population in a health research study. In this section, we explore implications for future research teams carrying out quantitative survey research with marginalised groups in any discipline.

### *Matching paradigm to population*

Researchers felt hampered by the positivist research design, its expectations of delivering the survey in a neutral and impartial manner (Creswell & Clark, 2018; Rapley, 2012), and the loss of valuable contextual qualitative data that emerged during conversations with participants. Social constructivism highlights the value of this contextual data and the knowledge rising from social interactions (Berger, 1967; Creswell & Clark, 2018), and many of the researchers’ conflicts appeared to link to epistemological paradigms. They were aware of the need to try to maintain a level of neutrality when conducting the survey, as it was being conducted within a post-positivist paradigm that values knowledge construction that is framed as ‘neutral’. However, to build rapport and feel they were supporting participants, they had to engage at a relational level tailored to each participant. Notably, most of the researchers had been part of the earlier qualitative arm of the study, conducted with the same population, which was carried out within a more constructivist paradigm that values researcher involvement in the exchange that happens during data collection (Denzin & Lincoln, 2008). The perceived role of people being researched also comes to play in this epistemological debate, with the positivist approach viewing them as items of study, as opposed to the constructivist view of them as research participants (Tubey et al., 2015). For both paradigms, methodology plays a central role in the direction of conversation. Rapley (2012) highlights the work that goes into this exchange, be it the interactional dynamics of qualitative approaches, or the maintaining of interviewer neutrality that is ‘not only good but also necessary practice’ (p. 541).

Future studies with marginalised groups should therefore consider in advance whether surveys of such an in-depth nature are appropriate for the context in which they are to be delivered, and if so, how they can be structured in such a way as to minimise harm and maximise cultural sensitivity to participants. For example, when conducting a survey with preliterate adults, Lee et al. (2015) developed specifically adapted researcher-assisted self-completion questionnaires that used images and verbal guidance. This allowed researchers to provide the assistances needed to reduce the cognitive burden on participants that has been identified as a potential hindrance to data quality (Hassenstein & Vanella, 2022). Despite the wealth of such research in the social sciences on methods of delivering surveys, and with other areas of health education more responsive to adapting their methods accordingly (Han et al., 2022), researchers in the current study felt that greater consideration had yet to be accorded to these issues when working with marginalised populations who are less represented within research.

One of the key messages that resonated from the current study was the importance of piloting tools for cultural sensitivity or relevance; an issue that has been previously identified in studies with marginalised populations (e.g. M. Anderson et al., 2009). Of consideration however was the additional challenge of the wider study being a multi-partner international project; cultural interpretations of stigma or sensitivity were at play, and much compromise was required between partners about the content and design of the survey instrument. There were nuances of language and cultural significance, with some of the questions that the UK team found sensitive or stigmatising not seen as such by colleagues outside the country. However, researchers’ experiences of delivering the survey were aligned with this commentfrom Gatlin and Johnson (2017, p. 160) who suggested that ‘most widely used instruments have only been normed with a dominant cultural group’. Responsive approaches to quantitative data collection could be used. For example, the scale adapted by Adley et al. (2022) for use with a marginalised population (see Supplemental Material 1) replaced culturally insensitive terms such as those relating to work colleagues or home ownership, and was delivered in the form of a printed grid to aid those with cognitive and literacy issues. In addition to adapting materials, it may also be possible to make additional use of the tablet as delivery method, with Hassler et al. (2018) finding that confusing or difficult questions may be answered more frequently by using tablets to focus on a single question at a time.

Including a person with lived experience on the wider study’s advisory panel was an innovative approach adopted by the UK arm’s research team that should be widely adopted. Increased involvement of people from the target populations in the project design may have further helped to address issues of cultural sensitivity, with Jones et al. (2006, p. 268) claiming that ‘without careful consideration to culture, our research paradigms, data collection methods, and interpretation of findings will continue to be significantly flawed’. Peter and Friedland (2017) called for closer relationships to be formed between researchers, ethics committees, and participants to gain greater understanding of participant vulnerability and risk, for example the academic-community partnerships found in Community Advisory Boards (Price et al., 2020). Our findings were aligned with the stance held by some of the researchers, already working within this paradigm, that implementing participatory research methods in future studies might integrate meaningful involvement of people from marginalised populations into the co-construction of research between researchers and the people affected by the issues under study (Jagosh et al., 2012). This may however require a shift in consideration of ‘what counts as’ knowledge and how research is funded, with some institutional structures within public health and medical schools hesitant to fund participatory action research in favour of more dominant knowledge production processes (Haarmans et al., 2022; Koch, 2015).

### Researcher backgrounds and experience

There were many advantages of using an experienced research team for this project. However, while this experience may have brought benefits in terms of recruitment and engagement, Gillies (2004) cautions that this resource is often restricted to specific researchers and cannot be passed on to others. This poses challenges for early career researchers who may wish to develop the necessary skills to conduct research with marginalised populations. Within the focus group, researchers shared concerns that novice or early career researchers, who may not have had their experience working alongside these groups, might have been placed in a vulnerable, or unsafe position had they been asked to conduct this study. Recommendations to address these issues have been made, including that early career researchers gain prior work experience with marginalised populations (Ensign, 2003), access support from experienced researchers to anticipate ethical issues (Jackson, 2021), or take part in a structured mentoring programme (Dickson-Swift et al., 2008).

Ethical literacy is a term used to describe a live, pragmatic, and flexible approach to the assessment and application of risks and ethical issues as they emerge during research projects (Wiles, 2012). Despite the formal approach to receiving University ethical approval, there are calls for researchers to be given more autonomy to respond to ethical dilemmas that they may encounter ‘in the field’, without compromising participants’ or their own welfare (Guillemin & Gillam, 2016). Researchers highlighted the importance of ethical literacy when working with marginalised populations, which in many cases they appeared to have developed as part of their practitioner roles. They commented that this flexibility should be highlighted as good practice, with the concept of ethical literacy passed down to novice or early career researchers who might otherwise feel obliged to adhere rigidly to processes approved by ethics boards.

While some researchers in the focus group commented on the lengthy process of receiving ethical approval and the ‘lag’ in making subsequent ethical amendments, one of the researchers, who had led his department's ethics board, noted that it can take as little as 10 minutes to make an amendment and that delays to ethical amendments are institute-specific. There was however consensus within the focus group that there would be overall benefits in ongoing ethical discussions taking place as required throughout the study, rather than being a static process at the start of a project. Without having this focus at various points in the project to reflect on issues that had arisen, opportunities for learning were being lost. This resulted in the perpetuation of individual researchers holding on to the knowledge and skills required to manage complex ethical dilemmas, and this knowledge then failing to be passed on to institutes in an embodied and objectified form.

There was demand for supervision from researchers, and while this had been available, it wasn't always accessed. Ongoing supervision for staff is embedded into working practices for other healthcare professionals, and widely considered an integral part of good professional practice (A. Pollock et al., 2017). While D. G. Anderson and Hatton (2000) note the importance of researchers debriefing with colleagues and being caring of themselves, there are perhaps cultural factors why this may not take place within academia. Borgstrom and Ellis (2020, p. 591) suggest that 'often researchers are expected to conceal, deny, or demonstrate how they will minimise their vulnerability', while others point to the predominance of the positivist paradigm within research whose stance is that the researcher's 'value-free' and objective position should therefore mitigate against any personal and relational nature of the research process (Williamson et al., 2020). The researcher is aware of being labelled unprofessional when displaying emotions, that raising their concerns could reflect some sort of weakness, and therefore these emotional responses remain unspoken (Attuyer et al., 2018; Hubbard et al., 2001). Given the pressure on project leaders to also provide supervision (Kyvik, 2012), alternative approaches could also be explored, for example development of a peer support network or the implementation of action learning sets (Hopkins et al., 2021; Nordentoft & Kappel, 2011), daily debriefs, external supervision, or an allocated 'on call' peer support worker.

## Conclusion

This paper acknowledges the often-complex ethical and practical dilemmas that researchers may experience when working within quantitative survey research with marginalised populations. The authors suggest that early career researchers should be prepared for such situations, and that they are not only introduced to the concept of emotional literacy and supported to develop these skills before entering this area of work but are also fully supported by experienced colleagues when in the field. Ongoing ethical discussions, both mid- and post-study might improve the protection and safety of participants and researchers and also, by expanding NHS and university ethics committees' understanding of 'real-world' issues, make future studies more accessible and inclusive.

In addition, the adoption of more responsive approaches by funders, research teams, and ethics boards specifically to integrate marginalised populations in research design and implementation is needed. Research teams across other disciplines might look to the voluntary and community sectors, in which organisations have adapted their working practices to meet the varying needs of these groups; offering flexible, person-centred services that focus on the quality of relationships between staff and service users, or are delivered in outreach or other culturally safe settings.

Population surveys are used extensively within the substance use field to attempt to answer some complex issues that may present within marginalised populations. While such surveys have value, the authors of this paper agree with existing social sciences literature that careful attention should be paid to how, when, and what is asked of these participants. Another issue of consideration is where the nexus of power is located, in terms of the methods used to collect data. While research within the field of public health has been more responsive to changes in study methods, within the UK and many other countries drug use is framed as a criminal justice issue. Data may therefore be collected with the intent of serving government policies around reduction of criminal behaviour, rather than reducing individual harm, and data collection methods within this framework may therefore be less responsive to the needs of individuals who are the subject of the research.

Broader consideration of these issues across multiple disciplines would also highlight the importance of further consideration of the impact of study design on marginalised groups. Although extensive piloting with diverse population groups could lead to the development and validation of tools that are sensitive to multiple cultures, this is seldom practical due to financial and time constraints. While compromises are inevitable, our findings would however suggest greater consideration of cultural sensitivity during the study design process. The authors recommend the meaningful involvement of those populations who are the subject of the research topic in the study design process, and the implementation of participatory research design methods in future studies with marginalised populations.

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