



Reaching the Right People: Reflexive Practice to Support Effective Recruitment, Participation, and Engagement in Research With Communities Affected by Stigma

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Abstract

Recruiting participants to qualitative studies is often a challenge—reaching the right people, and the right people choosing to participate, is a primary consideration for researchers. For research on HIV, as a condition which continues to be stigmatized, this can be magnified. However, being part of the HIV voluntary sector and occupying a role of “HIV advocate” can provide routes to overcome this challenge. Using the example of the researcher’s transition from voluntary sector worker to academic PhD researcher, this article explores how recruitment can be facilitated by utilizing personal and professional networks and how, in turn, this can present new challenges in reaching participants who are not “research regulars,” who are experienced in participating in qualitative research. It further explores reflexive methodologies as applied to participatory research on HIV and aging as it affects women in the UK and asks how the roles of “advocate” and “researcher” complement and challenge one another. Reflexive practice and an analysis of the researcher’s motives and how this impacts on recruitment, participation, and dissemination are considered. A three-part approach to reflexively engaging with participants’ questions is put forward. This provides a new perspective on participatory approaches in relation to research recruitment specifically.

Keywords

participatory research, reflexivity, recruitment, gender, HIV, stigma

What Is Already Known?

Recruitment can be challenging in any qualitative research, and potential participants are likely to have questions about the research, including the motivation and qualifications of the researcher and the aims and purpose of the research. Where the research topic or participants are stigmatized or marginalized, these questions can be amplified by concerns about the impact of taking part in research or mistrust of research or researchers in general.

What This Paper Adds?

This article adds a three-part approach to applying reflexivity to research recruitment, applying the question “why are you doing this research?” to consider the motives behind the research, the qualifications, experience and motivations of the researcher, and the justification for the research itself including planned impact. This model supports effective recruitment by engaging with the questions and concerns participants are

likely to have. The application and utility of the model is explored through the experiences of the lead author’s PhD research with women aged over 50 living with HIV.

Introduction

“I hope she’s grateful to us for doing this.” Words I overheard from one participant to another, as they chatted in a waiting room before taking part in a workshop as part of my PhD research. A reasonable expectation, from participants who were giving their time, stories, and input to support my study. In designing research and selecting methods, recruitment is a

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central priority. Participant safety, ethical research practice, incentives, and advertising are all part of this consideration. So too is thinking about how to reach the “right” participants, which might involve reaching people who are not frequently engaged in research, or reaching the diversity of the population or community that is being researched. It is also critical, I would suggest, to consider what participants’ interests are in taking part and ensure that these are addressed. Beyond confidentiality and incentives, participants want to know that the research is worthwhile, that the researcher appreciates their input, and to understand the motives and aims of the researcher.

In this article, I discuss how reflexive practice and embedding research in a context of advocacy and social justice supports effective recruitment, particularly within communities affected by stigma. This draws on my experiences of researching the experiences of older women living with HIV in London, as part of my doctoral research (“I” referring to the first author of this article). I outline an approach to interrogating your own motivations and intentions as a researcher and, using this to situate research into advocacy, to commit to using research as a tool toward achieving change.

Broadly, reflexive practice requires the researcher to explicitly position themselves within their research and to acknowledge the influences of their own views, context, experiences, and role in shaping all aspects of the research (Green & Thorogood, 2014). This is increasingly prioritized in conducting qualitative research but is less often applied to the process of recruiting to research, instead being more frequently associated with the analysis and presentation of findings. In this article, I make a case for engaging reflexively with your research design and expected impact at the outset of a study, in order to be able to respond effectively to potential or actual questions from participants and ensure recruitment materials and processes are effective for diverse participants (diverse being relative to the study being conducted and the sample sought).

Participatory research approaches create space for participants to contribute to the research design and process beyond the traditional role of “research subject.” In combining participatory and reflexive research approaches, space is created to consider the role and motivations of both the researcher and the research participant, and through this I suggest that more effective, diverse, and representative recruitment and participation can be supported. I propose a model for researchers to critically and reflexively engage with during the recruitment stage of their research, to support more effective recruitment processes. This is a three-part question, which I present in detail in this article.

The consideration of aims, outcomes, and value for participants is perhaps especially relevant in the context of PhD research. Necessarily individual, a focus on receiving the PhD as the primary outcome of the research project could risk excluding the motivations and priorities of the participants who, after all, cannot really be expected to care whether or not I get a new title and a qualification. How many people read a PhD thesis? I can confidently expect my supervisors, examiners, and perhaps my mum to pick it up and read it in full. Other

researchers will access it and reference it. But to have impact, more work is needed to take the research beyond the academic library shelf.

I argue that in order to overcome challenges in recruiting participants, especially in a subject area such as HIV where stigma persists, and to ensure participants feels their contributions are valued and meaningful, it is effective to situate the research within wider social justice advocacy and the research itself as a form of advocacy. This entails ensuring your study is constructed with impact integrated into the approach, from recruitment through to dissemination.

Where stigma is a potential barrier for participants, this can pose a methodological challenge for researchers in that the diversity of the population or community being researched may not be reflected in participants who are willing to take part. Ensuring that my study reached participants who did not habitually take part in research was a priority, a challenge which is likely to affect other researchers in similar topic areas. I propose a three-part model for researchers to reflexively engage with the recruitment of potential participants, to support overcoming this challenge.

Recruitment Challenges in HIV-Related Research

Recruitment to qualitative research can be challenging in general: reaching potential participants; providing the support, resources, and encouragement necessary to persuade them to participate; and ensuring diversity and representation in the final sample. HIV stigma adds an additional set of challenges to recruiting to HIV-related qualitative research.

Over 30 years into the HIV epidemic, with effective treatment available and a thorough understanding of how HIV is and is not transmitted, stigma nevertheless persists, impacting directly and indirectly on the lives of people living with HIV. Understanding this context is critical to effective recruitment to HIV-related research. According to a national survey of people living with HIV in the UK that measures perceptions and experiences of stigma and discrimination and the impact this has, 30% of respondents worried about being treated differently by employers or colleagues, 52% had avoided progressing a relationship, 23% avoided social gatherings arranged by friends, and 28% had been rejected by a sexual partner (The People Living With HIV Stigma Survey UK, 2015).

Participating in HIV-specific research necessitates sharing that you are living with HIV, often with a stranger, which can be a significant barrier in this context of stigma and discrimination. Qualitative research further requires discussing HIV and the impact it has had, and so concerns about confidentiality, anonymity, and the potential risks associated with both the personal interaction of the research and the subsequent publication and dissemination of findings can be significant.

While this may prevent many people from participating, it is also the case that there are “research active” participants: people who regularly take part in research. For this group, and particularly those who are actively connected with bodies and

networks like the UK Community Advisory Board or HIV service providers, the problem for recruitment can be research fatigue, that is, constant invites, and often for similar types or topics of research, as research (and research funding) moves in trends and cycles. For example, in my role as head of policy and research at a national HIV charity a few years ago, almost every piece of academic research (often from BA or MA students) I was approached to support recruitment through our networks was for African women to talk about their experiences of “disclosure” (a term which is itself controversial for many advocates, as it has negative and legal overtones). Potential participants who I might share the invitation with soon became fatigued of this topic, as indeed did I, so I reached the stage of no longer supporting recruitment to studies with that focus.

For both experienced research participants and those who might participate for the first time or have done so very few times before, mistrust of research and researchers is a further challenge. This is particularly the case in the context of HIV, as a stigmatized condition and one with a complex research history. This can include a mistrust of pharmaceutical companies and taking part in clinical research due to historical challenges. More broadly, there might be a sense of research “done to” the community rather than with or for, compounded by a lack of clarity around motives, benefits, and outcomes. Poor dissemination of findings and lack of feedback of research outcomes to participants are also cited by past research participants as causes of negative views of research participation (Sophia Forum and Terrence Higgins Trust, 2018). Understanding the impact research has had is key to a positive view of having contributed. For example, the Invisible No Longer study of the experiences of women living with HIV in the UK asked participants their views on research participation and found that women had interest in taking part in research but were discouraged by concerns over confidentiality, time involved, and a lack of follow-up after participation to know what impact the research had.

All these issues apply to HIV research recruitment across the board, but there are particular additional challenges in terms of recruiting women, who are often underrepresented in HIV research both in the UK and at the global level. In the UK, almost a third of people living with HIV are women (Kirwan, Chau, Brown, Gill, & Delpech, 2016). At a conference of the British HIV Association held in April 2016, one clinician and researcher with a particular interest in women reviewed research presented as posters at the conference and calculated that studies that were open to both men and women participants had an average of 19% of women participating, with some having no women take part (personal communication, tweeted after the conference). In clinical research, a recent systematic review of patients starting antiretroviral treatment for HIV through randomized controlled trials concluded that women were underrepresented among participants (Smith et al., 2016). At the global level, a systematic review of clinical research found women were just 19% of participants in treatment studies, 38% in vaccine trials, and 11% in HIV cure

research, despite being just over half of the global total of people living with HIV (Curno et al., 2016).

A study conducted in Ontario, Canada, involving staff tasked with recruiting 490 women living with HIV to a study explored their perceptions of barriers to recruitment for women living with HIV (Loutfy et al., 2014, p. 58): “The highest ranked recruitment barriers identified were: sensitivity of the research topic (59%), time/availability constraints (59%), language barriers (53%), HIV disclosure/stigma issues (47%), lack of trust of research personnel (41%), fear of research (41%) and inaccessibility to child care and transportation (41%).” Barriers to recruiting women living with HIV in particular are acknowledged by Loutfy et al. as a long-standing issue that requires focused attention and further research.

Many of these barriers are practical and should be addressed in the design of any research study, such as providing transport reimbursement or childcare. Others are likely present in other research areas but may be particularly impactful and persistent in HIV, due to stigma. Disclosure and stigma issues, fear of research, and lack of trust of researchers are critical issues that have also been found in recent studies of women living with HIV in the UK (Sophia Forum and Terrence Higgins Trust, 2018). Adopting a reflexive approach allows the researcher to consider their own position in these issues, to anticipate and prepare to respond to questions, and to understand their positionality as a researcher who may face mistrust and need to address and overcome it effectively.

Aging is a growing focus of HIV research, in the UK and globally, as effective treatment leads to more people reaching older age with HIV. Studies in the UK exploring the experiences of people aging with HIV have included women, but not focused exclusively on women, and some have struggled to recruit women to mixed gender research. The population of older women living with HIV is diverse, in terms of ethnicity, age, length of time living with HIV, sexuality, gender identity, and other factors, which are not well-explored in the existing literature. There have been three major national qualitative studies on aging and HIV in the UK. The first, 50 Plus, conducted by the Terrence Higgins Trust in 2010, recruited a proportionate sample of women, but presented its analysis disaggregated by gay/bisexual men, Black African women, and White heterosexuals (including women and men), which masks the specific experiences of women (Power, Bell, & Freemantle, 2010). The HIV and Later Life study similarly recruited representative numbers of women and disaggregates its analysis by mixed gender Black African and White heterosexual groups (Rosenfeld et al., 2015). The most recent, a further study by Terrence Higgins Trust (2017), included a representative number of women participants and did disaggregate results for women as a group in a specific section of the final report. However, this did not explore the differences in experiences for women within this group.

As I started planning my thesis project, in early 2015, I sought to ensure I recruited a diverse group of participants to respond to the gaps in the existing evidence base in exploring how differing identities and experiences might impact on the

experience of aging with HIV. Achieving this involved ensuring the research was accessible and appropriate to a wide range of women, including women who had not necessarily participated in research before, and may experience additional concerns about taking part or barriers to doing so.

Building on existing evidence on the underrepresentation of women living with HIV in research and barriers to recruitment, I sought to engage with recruitment reflexively to address methodological challenges due to under-recruitment or lack of diversity in recruited participants. Exploring participants' motivations for participating and barriers to participating, the intention of the researcher and the research emerged as an important consideration to address in recruitment processes.

Method

As I was seeking to recruit a diverse range of women, including women who had not previously or frequently participated in research, and in an under-researched area where much foundational work in defining the group being studied had not yet been done, I structured my project with different methods of data collection to facilitate different forms of engagement. My study consisted of six phases, five of which included the participation of women living with HIV. As this article focuses on methods rather than findings, I do not share the outcome of these different phases of research but share the overall research design to give an indication of what participants were recruited for.

1. Documentary analysis of existing literature, including a systematically approached review of social science research on aging, women, and HIV; a conceptual review of community and participation in the context of HIV; and a narrative review of the clinical literature on aging, HIV, and women.
2. A participatory literature review, involving two older women living with HIV with some prior research experience, who reviewed a summary of findings from the social science literature review and shared their interpretation of meaning, gaps, and potential research questions emerging from the review.
3. Participatory and creative workshops with 18 women living with HIV, aged 50 and over, including semistructured discussion and a creative activity.
4. Policy review and 10 key stakeholder interviews, with clinicians, service providers, researchers, advocates, and other relevant experts, including two women living with HIV.
5. Life story interviews, with 14 women living with HIV, aged 50 and over.
6. Participatory analysis workshop with four women living with HIV to collaboratively analyze findings from the life story interviews.

The research was conducted as part of a PhD project at the University of Greenwich, in the department of Family Care and Mental Health. It was carried out within this department under

supervision and was reviewed and approved by the University Research Ethics Committee.

Each of the five methods that included women living with HIV as participants involved recruitment, and while each was different, I developed a framework that guided my approach throughout.

This framework enabled me to recruit diverse participants to my study, including many women who had not participated in research before. Participants described making their decision to participate based on their assessment of the value and purpose of the research and their knowledge of me as a researcher, in addition to their own sense that research on aging as women living with HIV was necessary and valuable.

In the life story interviews, for example, I recruited 14 participants, in a sample that was more diverse than in other similar studies on aging and HIV (Power et al., 2010; Rosenfeld et al., 2015; THT, 2017). This included two bisexual women, one transwoman, and diversity in terms of ethnicity (five White British, one White Other, one Black British, and seven Black African) and in length of time since HIV diagnosis. Some participants were already known to me through my advocacy networks, but the majority were recruited through contact with third sector organizations, including one which invited me to give a presentation on my research to their service users to help with recruitment. This was a good example of utilizing my network to reach people I did not already know and demonstrates the value in building good relationships with organization as well as individuals.

It also required additional reflexive consideration of the dual roles I simultaneously occupied in conducting this study: "advocate" and "researcher" and where these overlapped or potentially conflicted. I introduced myself to each participant or potential participant, defining my role as a PhD student, how I was supported, the details of the study, and where the participant knew me in other contexts, clearly delineated this work from other roles. I developed a participant summary sheet that explained clearly what impact the study would potentially have and how findings would be shared and the timeline for this. As an advocate, I reflected on my own priorities and preferences, for example, for swift dissemination of results to enable evidence-informed advocacy around issues I found in my research and potential conflict with the priorities of a PhD and academic research, such as peer-reviewed journal publications. I managed this by adopting two strategies. Firstly, I developed and self-published an online summary of early findings, to ensure these were placed in the hands of advocates in a timely way, while also protecting the ability to seek peer-reviewed publication of full findings after analysis was completed in full. I also pursued multiple opportunities to present findings in conferences, workshops, and other settings.

A Reflexive Approach to Recruitment: Why Are You Doing This Research?

In my research, I adopt a feminist and reflexive approach. My own role as a PhD student doing this study is part of my wider roles and participation in the HIV community, including 9 years

work experience in the HIV voluntary sector, both in the UK and globally, and ongoing professional and voluntary roles with UK and international charities. Many of the people participating in my research, or supporting recruitment to it or engaging in other ways, are people with whom I have other previous professional or personal connections, which have proven to be important and beneficial as I conduct this study.

In terms of research specifically, I have experience of both supporting recruitment for academic and other studies through organizations I worked for, as well as carrying out research myself. This former experience provided invaluable insights, which may not always be available to PhD students, for example, into the issue of research fatigue when a topic is over-researched, either overall or for one specific group or community (no one ever approached me to support recruitment to a study for African men about experiences of disclosure). I also learned that voluntary sector staff, as well as acting as gatekeepers to potential research participants, also act as research critics, determining whether a study is worth supporting based on topic, level of knowledge of the topic or community displayed, and likely impact. For example, I am a trustee for an organization working on women and HIV, and we are sometimes approached to support research through dissemination of recruitment materials to our network. One request was for a study on the experiences of “illegal immigrants,” inaccurate and stigmatizing terminology that ensured we did not circulate the materials.

I also learned that for research in the context of a stigmatized condition, where research fatigue is a risk, and where there is a sense of ensuring potential participants are safe and respected, recruitment is greatly supported by personal networks. Being known and being trusted are huge assets. Staff in the voluntary sector are busy and overstretched and lack the time and resources to support everything, but if you can gain their support, it is invaluable. In the HIV sector, people often have very close, trusting bonds with service provider staff, whether that be a peer counselor, outreach worker, or other service provider. The difference between an invitation to participate in a research study that is received “blind” as an e-mail or newsletter item from an unknown researcher, and a direct contact from one of these trusted people, who says this research and this researcher are worth participating with, is immense. Although it is of course critical to ensure that participants are not influenced or pressured to take part, reassurance from a trusted contact is invaluable.

Reflecting on this, and the questions that I would ask of potential researchers as well as questions asked of me by individuals or organizations I approached for initial help in recruitment, I identified a key guiding question, which is really three questions: *Why are you doing this research?* That is,

1. What is the purpose of doing this study?
2. Why are you the right person to do it, and what is motivating you?
3. Why this topic, with these methods in this community, at this time?

Recruiting effectively means being able to answer all three questions when asked by potential participants or those who might support recruitment or engage in or disseminate the research. For me, the answer to this key question, as well as the route to effective recruitment, is bound up in my past experiences and in my roles and identities as I do this research, as a researcher pursuing a qualification and seeking to produce new knowledge, as an advocate committed to promoting the rights of women living with HIV, and as an ally and participant in a wider HIV community of practice and activism.

Through these roles and experiences, I came in to my PhD research with preexisting networks across the HIV voluntary sector, and with activists and other researchers, which combine to support me as a “known quantity.” Particularly in a stigmatized context, this is vital, recruitment doors are opened up by trust, and a sense that “this one is ok.” In fact, I was introduced in exactly that way at a recent conference by a leading advocate and woman living with HIV, as “ok for a woman who isn’t HIV positive.” Understanding your commitment, motivations, and purpose is an important part of opening doors to networks and individuals where mistrust has to be overcome. In fact, the context of stigma and mistrust of research in relation to HIV demands this reflexive approach in some respects, as you will be questioned on your motives and intentions so you have to engage in considering them.

The First Question: Why Are You Doing This Research?

Participation is a choice made by individuals, based on a range of factors, including the purpose of the research itself and what the experience of participating will be like. How the findings will be used and who will benefit from the outcomes of the research are frequent questions, from potential participants themselves and from those who might support in other ways. In addition to consideration of factors such as incentive or reimbursement for time and travel, the experience of taking part itself is important to understand from the participant perspective. In qualitative research, the opportunity to tell your story and share your experiences with an active and interested listener can be a benefit for participants. This should be understood in the specific context of each study and participant, however, as for example in my study, where telling their “HIV story” may be something participants actually do frequently and in contexts that are challenging. They may have to describe their challenges, health problems, and experiences to HIV clinicians, primary care health workers, Border Agency staff and others in the migration process, job center staff, housing support officers, the local council, benefits assessors, and others. Telling your story can be exhausting and depleting when it is a currency so often demanded. This in part led me to the participatory methods I’m using in my study, wherein the purpose, what is shared, and how the story is told are not down to me as the researcher and preexisting structured questions but are led and shaped by the participants. In this way, the story can be recreated and retold according to what the participant prefers and chooses in the research encounter. This also allows a focus

on coping, adapting, and thriving as well as struggles and problems.

Participatory approaches also support explaining the purpose and motivation of the study, by centering the participants in the process. Beyond this, it is critical to be able to answer the question that in my experience as a researcher, many participants will ask: “what difference will it make?” Research for its own sake is not enough, particularly perhaps in academic research toward a qualification where there may be specific concerns about the research being directed toward this goal and not making an external impact. It is critical, of course, not to overpromise and to manage expectations of what a single qualitative study can achieve. However, committing to dissemination designed for impact, such as a short report with clear recommendations to share with voluntary sector organizations and advocates to support advocacy activities, the use of social media and blogs to share findings with a wide audience, engaging with media outlets to disseminate research findings, and other activities can also help to put evidence from research where it can be used and is most visible. Effective advocacy is evidence-based, and as a researcher and an advocate, I understand the power of well-constructed, ethically approved, academic research to influence change when placed in the hands of advocates. Defining research as mutually supportive of and intertwined with advocacy also supports recruitment, where both potential participants and recruitment gatekeepers are more likely to see value in supporting a study that is led by a researcher who is active in promoting social justice and can answer the question “why” with a commitment to research impact.

The participant information sheet I circulated to potential participants clearly outlined why the study was being undertaken and who might potentially benefit and in calls or face-to-face conversations to recruit participants I explained my background, motivation for conducting the study, and dissemination plans. Doing this clearly, in accessible language and with a focus on impact, helped to reassure participants about the motivations driving the research.

The Second Question: Why Are You Doing This Research?

Adopting a reflexive approach also supports effectively responding to the second question. In stigmatized communities, your name and academic institution are not enough of an introduction. Very often, you will be asked to define your personal interest and motivation, what led you to this work, and why you are invested in it. As someone who is not living with HIV and does not belong to the communities most affected or disproportionately impacted by HIV in the UK (gay and bisexual men, Black African migrants, and transcommunities), I have often been asked why I work on HIV. My values, my identity as a feminist and women’s rights advocate, and my career journey are all important parts of giving a convincing response to this question. Beyond this, demonstrating an ongoing commitment and wider investment than my professional role, such as

volunteering as a trustee and working on and supporting different campaigns, help to embed me in the community working on HIV in the UK. The value in participating, networking, and being known is really significant, especially in a stigmatized context such as HIV.

As an example, the organization for which I am a trustee was recently approached by an academic, who was researching a key issue on our agenda, and one that many of our trustees work on in research and service roles. None of us had ever heard of or come across this researcher, whose biography on his university website nevertheless described him as a leading figure in this field. Our discussion on supporting recruitment to his research was therefore shaped by our sense of confusion at how it could be that we had no knowledge of him or his work and had not had any previous contact with him, which in turn shaped our decision to provide only minimal support.

Finally, it’s vital to be honest about motives and personal gains. I am in part doing this research because I want a PhD, because of the personal benefits that brings. I was also funded for the first 3 years of my study and acknowledging that is also important. Research can sometimes be framed as an altruistic endeavor “giving people a voice” but that is not the complete picture and participants know this. I am often asked whether and how I am funded and what I am being paid. Answering this honestly can actually reassure potential participants and help to support recruitment. As indicated in the quote that opened this article, participants were open about their interest in my motivations and what benefits I would get from the research, so it is important to be upfront about this. Initially, I found this point of view challenging, as it felt like a criticism, but engaging with participants in conversation about the issue revealed that no criticism was intended, but there was a general awareness that research was also beneficial to the researcher. Acknowledging this and talking to participants about it opens up an honest and open dynamic.

The Third Question: Why Are You Doing This Research?

The third question within the question is why this specific research: this topic, at this time, with these people, in this place. In my experiences recruiting through the voluntary sector, social media, and networks (formal and informal) of people living with HIV, it has been critical to be able to make a convincing case that the research is responding to a lack of evidence or an unmet need and engaging an under- or unrepresented group. Moreover, constructing a research project and questions which responds to or resonates with potential participants’ or supporters’ own sense of gaps or areas of need has been vital for effective recruitment. Involving women living with HIV in the literature review greatly supported this process, by ensuring that the research questions and approach were informed by the lived experiences of older women living with HIV, which in turn helped to ensure that the research itself would be of interest to other older women with HIV.

Making the case for your research is an important skill that PhD students hone over supervisions, upgrade processes,

conferences, and the viva. It is also important for engaging with participants and other stakeholders and gatekeepers. A wide, informed, and critical understanding of the evidence base and other ongoing research and other projects is important. So too is the ability to describe and defend what you are not doing. My study focuses on the experiences of women living with HIV, aged over 50 and living in London. It does not include the experiences of men, or women outside London, or women under 50 or people with other long-term health conditions. At various times, I have been questioned on all these things and asked to explain my choices. Reflecting on and understanding what you are not doing is important too.

In the context of HIV, or more generally research with participants who may in some cases experience stigma, discrimination, marginalization, or vulnerability, it is possible to frame research in ways that are disempowering or reducing of participants. From my own experience, I have frequently been contacted by students and other researchers or individuals seeking professional roles or internships, who justify their interest in HIV by a desire to “help people.” This constructs people living with HIV as victims, suffering and struggling and awaiting rescue. Such a response will almost certainly result in a lack of support and engagement for whatever is sought and is easily discerned by individuals who would reject such a patronizing approach.

Conclusions

Research that involves participants involves a type of exchange. The participants give their time, support, stories, and experiences. As the researcher, it is vital to reflect on and understand what you are giving to the participant in return. Beyond the foundational imperatives of ethical practice, confidentiality, respect, and material offers such as expenses, participants also look for reassurance that research is done for a purpose, is done by a researcher who has the right experience and motivations, and is relevant and will have impact. The three questions outlined in this article are designed to support reflexive practice to engage with these issues and will support engaging with participants and other stakeholders.

In addition, they provide a framework for embedding impact within research from the outset, by reflecting on what change is sought and how the research can contribute toward it. While it is essential to ensure that participants understand that their taking part in the research will not accrue personal benefit to them directly, where this is not the case, it is worthwhile to consider how dissemination and engagement can ensure that research is shared to inform and influence beyond the confines of academia and support advocacy in the real world.

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