



BEST PRACTICE GUIDELINES FOR RESEARCH AROUND DRUGS ISSUES

ABOUT THE RESEARCH

Research into the social and economic consequences of illegal drug use needs to integrate the different voices affected by drugs and drug policy. Conducting research with these populations can advance knowledge about what underlies participation in illegal drug markets and the impacts of drug policies on marginalised groups, while contributing to the development of interventions and policy that can minimise harm.

This guidance has been drawn up as a result of a University of Bristol Brigstow Institute project in coordination with Transform Drug Policy Foundation (2023).¹ Fear of legal consequences, stigma and prejudice associated with drugs and populations producing, selling and using illegal drugs present a serious obstacle for researchers wishing to work on drug issues due to perceived increased risk of harm to participants and/or the researcher.² Research Ethics Committees (RECs) are not immune from replicating bias, prejudice and moralising judgements, whether consciously or unconsciously, which affects the scope, processes and potential impact of research on illegal drugs, people who use drugs, drug markets, and drug policy - particularly drug policy reform. Although experiences vary, researchers are frequently required to provide “additional safeguards” to ethics applications which can be timely, expensive, unduly burdensome and often prohibitive for researchers, RECs, and research participants. Research on the health and safety of marginalised populations affected by drugs in different ways is needed, and ultimately such challenges risk stifling knowledge production in this area, and in turn, can hinder positive policy developments that improve outcomes for these populations.

The recommendations presented below are intended to guide researchers and academics working on these issues across different disciplines when they are submitting university ethics applications and for RECs to have a standardised, cross-disciplinary approach to assess and advise research on psychoactive substances. Though carried out in Bristol, the findings will be applicable in other research organisations and are intended to facilitate future ethical research on drugs issues and destigmatise potential research participants.

THE POWER OF STORYTELLING

Storytelling is a proven effective strategy to break down the stigma around drug use and the groups involved in the illegal drugs market in the UK.³ Storytelling enables people to challenge the preconceptions and assumptions that surround the drugs debate. Though emotional narratives, wide audiences can be engaged in difficult issues in new ways. It encourages broader discussion of the policy implications for the populations upon whom they impact most,

but who are routinely marginalised from public discourse. Additionally, it offers a platform for voices to be heard in a way that is meaningful for participants, many of whom have had their experiences denied, rejected and silenced by prohibitionist narratives which conspire to keep the status quo.

As in other fields of research, there is a need to balance the safety and security offered by anonymity with the power and authenticity of showcasing human narratives, faces and names. Experience from the drug policy reform movement teaches the value in not anonymising all data. Anyone's Child, a Transform Drugs campaign, is a network of family members affected by prohibitionist drug policy, who share their first-hand experiences of bereavement, criminalisation and stigma. The campaign draws on storytelling using human faces and voices to evoke empathy and support, and to make conversations about drug policy accessible and relatable. The families involved in Anyone's Child have described feeling empowered after sharing their stories with researchers, politicians, the media and the public. It enables them to dignify their loved ones and to regain control over the narratives of their experience, which, in some cases, have been silenced or denied for years, out of fear and stigmatisation.⁴

Although researchers should take great care to protect the privacy of participants and the confidentiality of all sensitive information that they provide, anonymity should not be a prerequisite of drugs research as this promotes a subconscious narrative shame. Rather, it should be decided on a case-by-case basis and guided by the desires of the participant.

VULNERABILITY AND SENSITIVE TOPICS

Researchers working with vulnerable populations have ethical and legal obligations to protect the identity of their participants as well as any sensitive information they uncover during their study. The inclusion of people involved in illegal drug markets, often considered a vulnerable population, as participants in research presents several perceived increased risks that must be addressed in ethics applications. This often comes from well-founded concerns about the potential vulnerability of participants, and efforts to protect their safety and well-being.

However, evidence shows that the assumption that all people who produce⁵, sell⁶ and use drugs are vulnerable is mistaken.⁷ Moreover, treating people who use or sell drugs in homogeneous categories, fails to consider important potential differences in people's experiences. The question of whether research on the lives of people involved in illegal drug markets is ethical may depend more on the demands placed on participants, whether the level of drug consumption of an individual could have a negative impact on their comprehension and performance as research participants, and the risks that they may be exposed to, or benefits received, because of their participation. Furthermore, exaggerated perceived risks informed by media and prohibitionist laws may distort judgement of actual risks⁸

When research does involve sensitive issues, protecting the mental health and wellbeing of the researcher, as well as the participant, is paramount. The stigma surrounding drug issues can make talking to friends and family difficult which adds additional strains for the researcher. Individuals need to have appropriate and regular supervision set up in advance of doing research and we recommend setting up peer support groups to talk about these issues.⁹

Research on drug issues can draw on existing relevant literature and guidance on the ethics of working with vulnerable people¹⁰, in fragile or conflict zones.¹¹ Researchers conducting participatory projects with populations involved with illegal drugs should take great care to build trusting relationships with participants to allay fears of legal jeopardy and other forms of stigma, violence and exploitation. Generally, long term engagement in a research community and implementing collaborative and creative methods should be encouraged.¹²

ILLEGALITY

Researchers have a professional duty to refrain from doing anything that would bring the University into disrepute. Nevertheless, the value of understanding illegal drug issues more fully, and the utility of the research for policy makers and practitioners drafting better laws or designing more effective policies, is likely to boost the perceived value of the research, and thus the reputability of the research institute. Researchers ought to approach the study of

the production, transportation, distribution and consumption of drugs as research into livelihoods, economies and experiences (among other factors) rather than centring criminality.

RECs have legitimate and understandable concerns regarding illegality and finding out about criminal activity. Researchers have the same legal obligations that they would have in any other context, as citizens or legal residents. There is, however, no general legal obligation in the UK to report all illegal activity one is made aware of to the relevant authorities.¹³ Researchers should prioritise their responsibilities and moral obligations to protect participants wherever possible. Participation in research should not place people in greater risk than they would otherwise experience in their daily lives. In most places in the world, participants with lived experience in a research project about illegal drugs could potentially face criminal charges if the study data revealed individual actions and identities to law enforcement. It is critical that researchers protect study participants and the confidentiality of all sensitive information that they provide to the best of our ability through diligent attention to sound research methods and data storage. Researchers should, if they anticipate that they may become aware of illegality, tell actual and potential research participants about the nature and limits of whatever confidentiality they feel they can offer.¹⁴ There may be need for additional caution if generating audio-visual data. This should be discussed and decided upon with participants as part of iterative negotiations about consent.

LANGUAGE

The drugs field includes a lot of language that is offensive to some people. People who produce, use and sell drugs are highly diverse and their relationship with drugs takes many different forms. Current prohibitionist approaches to drug use and 'war on drugs' rhetoric do little to encourage language that acknowledges this diversity. Instead, it promotes and maintains negative stereotypes that construct people who produce, transport, sell and use drugs as morally flawed, inferior, unreliable, and dangerous.

We have to be extremely careful not to use stigmatising and shaming language which makes participants feel uncomfortable, unsafe and unwelcome, and potentially causes harm. Stigmatising language and moral judgements are disempowering and dehumanising, and can reproduce cycles of trauma, violence and pain for those who use drugs and their families.

By making positive language choices in ethics applications and supporting documents, we can automatically support people who interact with drug markets. This includes prioritising humanising, personal language and emphasising the 'person' first (e.g. person who uses drugs – not drug user).¹⁵ Always check how participants would prefer to be addressed and respect their views.

PAYING PARTICIPANTS¹⁶

RECs have concerns that cash payments to people who use drugs to reimburse research participation will facilitate their illegal drug purchases. This has led some RECs to prefer vouchers as an alternative to cash payments in this group. Critics of monetary payment for people who use drugs have also argued that paying participants might undermine voluntary consent, if doing so encourages an individual's participation because it enables the person to purchase drugs. The concern is that people in this predicament may ignore any risks that participation entails that would in other circumstances make them much less inclined to participate. However, non-cash methods reinforce negative stereotypes about people who use drugs and reflect a paternalistic view that makes inappropriate assumptions around the capacity and rights of people to make their own choices. Advocates of cash payments argue that cash payments for research participation reflect respect and dignity.¹⁷ In addition, there is evidence that payment for participation in research does not promote the purchase of drugs nor lead to relapse¹⁸ and can enhance recruitment and retention in studies.¹⁹

People who use drugs should be assumed to be autonomous individuals able to make their own decisions about taking part in research and should not be treated differently to other participants in terms of payment for their participation. As in all research situations, decisions about what reimbursement should look like ought to be made on a case-by-case basis, however if cash remuneration is decided upon, RECs should not challenge it on the basis of it received by individuals who use drugs.

CONSENT

Concerns have been raised in drug use research about the ability of individuals using illegal drugs to provide informed consent, in case being under the influence of drugs or experiencing withdrawal might impede their comprehension and decision making. However, these concerns are overstated, and can be inappropriate, judgmental, and stigmatising.²⁰ If the goal of the research study involves people who use drugs, then the active participation of such people is recommended in order to improve the validity and legitimacy of the research.²¹

This is the case regardless of the legal status of the drug. Research on illegal drugs can draw on harm reduction principles and best practice. Harm reduction is an alternative approach to zero tolerance or 'drug free' approaches that 'refers to policies, programmes and practices that aim to minimise the negative health, social and legal impacts associated with drug use, drug policies and drug laws'.²² It is based on the recognition that many people who use drugs are unable or unwilling to abstain and acknowledges that many people who consume drugs often do so to treat or endure serious psychosocial or emotional problems. Importantly, harm reduction focuses on working with people without judgement, coercion, discrimination, or requiring that people stop using drugs as a precondition of support.

Researchers should assume that participants who use drugs have the capacity to make a decision regarding their participation, even if under the effects of drugs, rather than assume that they do not. Consent should be iterative - ie before each encounter ensure that the participant wants to contribute. Researchers should also consider how to work with participants who are under the influence, and at what point research should be paused.

CONCLUSION

Research on drugs, particularly illegal drugs, raises a unique set of ethical challenges that can interfere with the efforts of researchers to study people who produce, transport, sell and use illegal drugs. It is important for researchers to acknowledge these challenges and develop novel methods to protect potentially vulnerable populations participating in research and assure that this much needed research is being performed. Conducting research with these populations can promote new understandings about the factors that underlie participation in illegal drug markets and the impacts of drug policies on marginalised groups, while contributing to the development of interventions and policy that can minimise harm.

Academia ought to challenge and change the status quo around drug narratives, rather than leaning into an existing societal framework. We call for RECs to stop reducing all things drug-related as 'illegal behaviour' and to move beyond unhelpful and mistaken stigmas and preconceptions about all people involved in illegal drug markets. Academia needs to offer a platform to different voices affected by prohibition, criminalisation and the narratives these ideologies have engendered. By reshaping the ethical process around working with such groups, efforts to destigmatise and humanise people involved in illegal drug markets and a move towards harm reduction can be prioritised.

By challenging a blanket approach to drug research as necessarily 'sensitive', we can open up research on drugs and encourage collaboration into how to live well with drugs in our society. Creating a space where research shifts policy into a direction that takes care of instead of criminalising, a more progressive approach can be developed, one that does not see all drug users as vulnerable or criminal and instead honestly explores the nuances of living well with drugs in our society.

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REFERENCES

- ¹ This document draws on the findings of a workshop held in Bristol in May, 2023, in which academics and practitioners who work on drug policy issues and people with lived experiences of drug-related harms critically explored the opportunities and ethical and methodological challenges they have faced when gathering and sharing real-life stories to inform research on drugs.
- ² Michael H. Andreae et al., 'An Ethical Exploration of Barriers to Research on Controlled Drugs', *The American Journal of Bioethics* 16, no. 4 (2 April 2016): 36–47; Julaine Allan, 'Ethics and Practice of Research with People Who Use Drugs', in *Handbook of Research Methods in Health Social Sciences*, ed. Pranee Liamputtong (Singapore: Springer, 2019), 1973–89; Vereinte Nationen, ed., *Ethical Challenges in Drug Epidemiology: Issues, Principles and Guidelines; Global Assessment Programme on Drug Abuse (GAP), Toolkit Module 7* (New York: United Nations Office on Drugs and Crime, 2004).
- ³ Anyone's Child: Families for Safer Drug Policy <https://anyoneschild.org/>
- ⁴ Jane Slater and Mary Ryder, 'Challenging Stigma, Changing Minds', in *Drug Science and British Drug Policy: Critical Analysis of the Misuse of Drugs Act 1971* (Waterside Press, 2022)
- ⁵ Estefanía Ciro Rodriguez, *Levantados de la selva: Vidas y legitimidades en los territorios cocaleros* (Universidad de los Andes, 2020).
- ⁶ Drug Policy Alliance (DPA), 'Rethinking the "Drug Dealer"', December 2019, <https://drugpolicy.org/issue/rethinking-and-reducing-punishment-of-people-in-the-drug-trade/>.
- ⁷ Kate Brown and Emma Wincup, 'Producing the Vulnerable Subject in English Drug Policy', *International Journal of Drug Policy* 80 (1 June 2020): 102525.
- ⁸ Harry R. Sumnall et al., 'Effects of Media Representations of Drug Related Deaths on Public Stigma and Support for Harm Reduction', *International Journal of Drug Policy* 111 (1 January 2023): 103909.
- ⁹ Dr Jessica Hammett and Claire Nunan, 'Targeted Support Is Needed to Protect the Wellbeing of Researchers Working with Emotionally Challenging Material', 2022
- ¹⁰ Economic and Social Research Council (ESRC), 'Research That May Require Full Ethics Review', 16 January 2023, <https://www.ukri.org/councils/esrc/guidance-for-applicants/research-ethics-guidance/ethics-reviews/research-that-may-require-full-ethics-review/>.
- ¹¹ Roger Mac Ginty, Roddy Brett, and Birte Vogel, *The Companion to Peace and Conflict Fieldwork* (Springer Nature, 2020).
- ¹² University of Bristol and National University of Colombia, 'Mempaz - Memories from the Margins', Mempaz, 2023, <https://mempaz.com/>.
- ¹³ "The specific reporting obligations that exist in UK law relate to child protection offences (physical or sexual abuse of minors), the physical abuse of vulnerable adults, money laundering and other crimes covered by prevention of terrorism legislation. These obligations are concerned with serious and immediate harm to others." University College London, 'Research Involving Illegal Activities. UCL Research Ethics Policy Note', n.d., <https://ethics.grad.ucl.ac.uk/forms/Research-Involving-illegal-activities.pdf>.
- ¹⁴ Economic and Social Research Council (ESRC), 'Research That May Require Full Ethics Review', 16 January 2023, 24, <https://www.ukri.org/councils/esrc/guidance-for-applicants/research-ethics-guidance/ethics-reviews/research-that-may-require-full-ethics-review/>.
- ¹⁵ A helpful guide can be found at: <https://www.sdf.org.uk/wp-content/uploads/2020/10/Moving-Beyond-People-First-Language.pdf>
- ¹⁶ This has been adapted from the Health Research Authority ethics guidance on payments and incentives in research. NHS Health Research Authority, 'HRA Ethics Guidance: Payments and Incentives in Research', 2014, <https://s3.eu-west-2.amazonaws.com/www.hra.nhs.uk/media/documents/hra-guidance-payments-incentives-research.pdf>.
- ¹⁷ Vereinte Nationen, ed., *Ethical Challenges in Drug Epidemiology: Issues, Principles and Guidelines; Global Assessment Programme on Drug Abuse (GAP), Toolkit Module 7* (New York: United Nations Office on Drugs and Crime, 2004).
- ¹⁸ David S. Festinger et al., 'Do Research Payments Precipitate Drug Use or Coerce Participation?', *Drug and Alcohol Dependence* 78, no. 3 (1 June 2005): 275–81.
- ¹⁹ London School of Hygiene and Tropical Medicine (LSHTM), 'East London Project: The Impact of Laws and Policing on Sex Workers' Lives', The East London Project, accessed 11 August 2023, <https://eastlondonproject.lshtm.ac.uk/project/>.
- ²⁰ Jennie E. Ryan, Suzanne C. Smeltzer, and Nancy C. Sharts-Hopko, 'Challenges to Studying Illicit Drug Users', *Journal of Nursing Scholarship : An Official Publication of Sigma Theta Tau International Honor Society of Nursing* 51, no. 4 (July 2019): 480–88.
- ²¹ Vereinte Nationen, *Ethical Challenges in Drug Epidemiology*.
- ²² <https://hri.global/what-is-harm-reduction/>

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