University of Southampton

# Conducting Ethical Health Research in Prisons: Guidance for Prison Health Researchers

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# Preface

## Purpose and rationale

This guidance was developed specifically for those who conduct health research in adult prison settings. Whilst its primary audience is health researchers new to prison research, it is also likely to be of value to those conducting evaluations in prison settings and to ethics or other regulatory bodies that review research proposals. It is also intended to be applicable to prison research worldwide.

This document supplements, not supersedes, existing international guidance on research ethics and on how to conduct high quality research. It aims to aid ethical approval processes and research design by identifying specific considerations for approaching health research conducted in a prison setting and to act as a reflective tool for researchers by highlighting key areas for consideration in a systematic way, in order to promote the human rights and the interests of people living in prisons. We also recommend use of this guidance for those conducting evaluations even if formal ethical approval is not considered necessary as it captures relevant principles for anyone collecting data in prison settings.

The history of unethical health research in prisons, research that has contravened the human rights of those in prison, underscores the need ethical guidance specific to prison settings. We also recognise that many current international and national guidelines aiming to protect people living in prisons from the harms of unethical research unintentionally prevent people living in prison from meaningful participation and prevent them benefiting from research progress. This systematic exclusion represses the voices and distorts research findings, denying people living in prisons the benefits of research conferred on people in the community. Hence, this international guidance supports the aim of **Worldwide Prison Health Research and Engagement Network (WEPHREN)** to improve the health outcomes of people living in prison through the equitable development of an evidence base and health-related capacity-building initiatives and highlights the need to balancing the rights of both protection and participation.

## Preferred terminology and choice of language

Whilst the term *prisoner* is commonly used in related literature, we advocate for person-centred language.[1, 2] Therefore, throughout this document, we use the term *people living in prison*. In this guidance, prison specifically refers to contemporary, physical detention facilities that house remand and sentenced adults both before and after trial such as jails.[3] It does not include other closed or custodial settings such as police holding cells, psychiatric institutions, drug rehabilitation centres, migration detention centres, or forced labour camps. *Prison administration* in this document refers to: government departments responsible for funding, operating, and overseeing prison systems; the administrative heads or superintendents of individual prisons; and administrative staff (not including correctional officers and prison healthcare staff) within prisons who are directly involved in the day-to-day management of prison staff and people living in prisons.

Our choice of language also aims to reflect the impact prison settings will have on the people living in prisons, and the power dynamics at play. We advocate that people living in prisons should be empowered and given autonomy as active stakeholders, not passive subjects. We also write this with a critical perspective on who determines 'what is ethical', acknowledging that those living in prison settings should be represented on formal ethics committees or boards, but often are not.

## Knowledge equity

The experiences of people living in prison have consistently been of interest to researchers and people in prison are often sought out as participants in research studies. Yet people currently in prison (and those subject to probation in the community) are rarely given opportunities to participate in shaping the focus of any research or in the design and conduct of the research. This consistent exclusion raises ethical concerns. Some researchers and people with lived experience have argued that the inability of people living in prison to suggest topics of research themselves is deeply problematic, as are methodological approaches which anonymise contributors and do not involve them in analysis nor dissemination. They consider these practices as extractive and exploitative.

In addition, some researchers have explored concerns as to how prison research needs to consider its relationship to the concept of epistemic injustice. Epistemic injustice is injustice linked to modalities of knowledge production.[4] Epistemic injustice occurs in exclusionary practice and in silencing and can manifest in systematic distortion or misrepresentation of one's meanings or contributions; undervaluing of one's status or standing in communicative practices; unfair distinctions in authority; and unwarranted distrust.[4]

For prison research to respond to the pitfalls of epistemic injustice, researchers should reflect carefully on how their research and approach might be founded in "an equitable epistemology" an approach to knowledge creation that allows for academic enquiry and personal lived experiences together to reflect on hierarchical structure, and think through how the research might explore participatory and collaborative approaches that respond to concerns raised and acknowledge the concerns of the lived experience movement.[4]

## Document layout

We structured this document in the chronology of the research process. Its content includes best practice or recommendations shaped by expert opinion. We also include quotations from relevant sources and three types of prompt boxes:

- ‘Consider this example’ boxes in purple are included throughout to share relevant research or examples where they exist and highlight aspects of note.
- ‘Reflective questions’ boxes in pink are used to prompt reflective thought particularly where limited good practice examples in past prison health research exist.
- ‘Key resources’ boxes in green signpost readers to additional materials that may be of relevance.

## Guidance limitations

This document focuses on adult prison settings and does not capture the nuances of child and youth detention settings. This limitation was a conscious choice during the development of this work. Guidance for child and youth detention settings would be strongly welcomed but should involve an additional set of experts in its development. In addition, for countries or settings where guidance exists for interactions with specific communities, such as indigenous or minority groups, we recommend this document be used to complement such guidance as with other existing guidance on how to conduct high quality research.

This guidance was developed collaboratively with prison health research experts and reviewed by people with lived experience of imprisonment. Because of resource constraints, the involvement of people with lived experience was not as extensive as initially hoped and we hope to remedy this in future iterations of this document. Resources for those with lived experience to participate in every meeting were not available and their engagement would have been invaluable in shaping the numerous authors’ thinking and content. This document’s audience is therefore predominantly researchers without a background of lived experience. We acknowledge that additional guidance focusing on the specificities for researchers with lived experience should be considered in future iterations.

Being collaboratively developed by the many prison health researchers means that this document benefits from a wide variety of perspectives and experiences. However, despite being reviewed by two separate editors and ratification by our international steering group of experts, being authored by almost 30 different voices with varied professional, disciplinary and geographic backgrounds may result in some inconsistencies in language.

Acknowledging these limitations, we welcome feedback on the content, utility, and application of this guidance which can be addressed to **wephren@ukhsa.gov.uk**.

## Financial disclosure

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# 1

# Introduction

## Impact of historic injustices

Historically, people in prisons have been used as populations of convenience and subject to horrific acts in the name of research. Subsequent national and international guidelines acknowledge the vulnerabilities that living in a prison, and being deprived of liberty, create and contribute to protecting people living in prisons from the harms of unethical research.[5, 6] However, vulnerability is not static but depends upon the environment and other physical and emotional factors at any specific time[7], and ″vulnerable populations″ should not be prevented from participating in appropriate and ethically designed research by overprotective practices.[8]

## Prison health is a public health imperative

The intrinsic overlap and intersection between the social determinants of health and the determinants of imprisonment and criminalisation mean people who experience marginalisation, discrimination, poverty, and poor health are more likely to be criminalised and imprisoned. Hence people living in prisons have often experienced economic, cultural and socially disadvantage and are more likely to have greater and more complex healthcare needs, fewer health resources, and face more barriers accessing healthcare in the community. These persistent systemic inequalities perpetuate the imprisonment of a disproportionate number of marginalised and vulnerable people, concentrating the impacts of wider social determinants and influencing global disease epidemiology. Therefore, prison health should be seen as an extension of essential inclusive population-level public health efforts.

> ***"The large and growing population of people who experience incarceration makes prison health an essential component of public health and a critical setting for reducing health inequities. People who experience incarceration have a high burden of physical and mental health care needs and have poor health outcomes. Addressing these health disparities requires effective governance and accountability for prison health care services, including delivery of quality care in custody and effective integration with community health services"***[9(p303)]

## Unique prison health challenges

People living in prisons bear a disproportionate burden of morbidity and mortality across diverse health indicators.[10] A significant proportion of people living in prison have faced poverty[11, 12], food insecurity[13], violence, histories of physical, sexual[14], emotional, and psychological abuse[15 16], and childhood and intergenerational trauma[17], exacerbated by structural barriers to accessing education[0], healthcare, and other services prior to imprisonment. Compared to rates in the wider general population, people living in prison have higher rates of substance and alcohol use, mental health conditions[20], and communicable[21] and non-communicable chronic conditions [22], as well as higher risk of all-cause mortality compared to those who are not in prison[23, 24]. Some of the most common infectious diseases are severalfold more common in people living in prison than in the general population, and include human immunodeficiency virus (HIV)[25], hepatitis B and hepatitis C viruses[26], other sexually transmitted and blood-borne infections27, and respiratory infections such as tuberculosis[28, 29], influenza[30, 31], SARS-CoV-2.[32] In addition, during imprisonment, people can experience sexual violence and other forms of violence and intimidation from other people living in prison and staff, high levels of stress, lack of agency and autonomy, and punitive and unfair practices and procedures.[33, 34] Provision and quality of prison health care also varies between developed and developing countries and within individual country prison settings.[35]

Therefore, research that does not include people living in prison should be considered as selection bias and a violation of the principle of equivalence.

## Imperative to conduct ethical prison health research

Even though people living in prison face a higher burden of disease and international agreements state they should "be allowed, upon their free and informed consent and in accordance with applicable law, to participate in clinical trials and other health research"[36] (p10), people living in prison are underrepresented in health research.

Systematically preventing people in prisons from participating in research unjustly deprives them of benefiting from research advancement, interventions, and provision of care aimed at improving their health and wellbeing.[37] This exclusion causes harm by repressing voices[38] and distorting research findings through the systematic omission of this population and denying them the benefits of research conferred on people in the community. Therefore, not only is there an ethical imperative to undertake high-quality research to yield meaningful findings,[39] improve health service organisation, health care outcomes, and address disparities for people living in prison, but there is also an ethical imperative to prevent the exclusion of this group.[40] Hence, research in prisons with people living in prison is vital and requires balancing the rights of both protection and participation.[8, 41]

This guidance aims to support ethical prison health research by identifying specific considerations for approaching health research conducted in a prison setting and to act as a reflective tool for researchers by highlighting key areas for consideration in a systematic way.

# 2

# Ethically grounded research foundations

Any researcher considering conducting or collaborating on research in a prison setting should be familiar with the field's history, international regulations and guidance for research with human subjects as well as guidance focused on research in prison settings. The most relevant publications are summarised in Table 1. Before embarking on a research project in a prison setting it is important to consider several aspects related to why and how the research should be conducted. Researchers should be mindful of how to actively address ethical issues. This document therefore addresses the pragmatic and operational elements that are ethically significant in prison settings.

*Table 1: Overarching prison research ethics guidance or health research ethics guidance, by year*

| **Guidance related to research in prison settings:** |
|---|
| **The Nuremberg Code** (1947) – a foundational document developed by a war crimes tribunal that established a new standard of general ethical medical behaviour predicated on the requirement of voluntary informed consent. |
| **Declaration of Helsinki** (World Medical Association, 1964) – an international statement of ethical principles for medical research involving human participants. |
| **Research Involving Prisoners** (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1976) – established following infamous prison experiments in the USA, the national commission reports are widely referenced in prison research ethics literature and influenced US Federal Regulations (known as Common Rule) and subsequent international practice. |
| **International Ethical Guidelines for Health-related Research Involving Humans** (Council for International Organisations of Medical Sciences [CIOMS], 1977) – international guidelines which highlight general research principles as well as specific considerations for 'institutionalised persons' including people living in prisons. |
| **The Belmont Report** (United States Department of Health and Human Services, 1979) – build upon the Common Rule by highlighting respect for the persons involved in research, beneficence (or non-maleficence) of research and justice in terms of fair distribution of burdens and benefits of research. |
| **Ethical considerations for research involving prisoners** (Institute of Medicine Committee on Ethical Considerations for Revisions to DHHS Regulations for Protection of Prisoners Involved in Research, 2007) – seminal work that focuses specifically on ethical research in prison settings. |
| **United Nations Rules for the Treatment of Women Prisoners and Non-custodial Measures for Women Offenders (the Bangkok Rules)** (United Nations Office on Drugs and Crime, 2011) – an international guide for the treatment of women living in prisons, including specific rules related to research and evaluation. |
| **Prisons and health** (World Health Organization Europe, 2014) – the World Health Organisation's vision and approach to improve the health of those in prison and to reduce both the health risks and risks to society of imprisonment. |
| **United Nations Standard Minimum Rules for the Treatment of Prisoners (Nelson Mandela Rules)** (United Nations Office on Drugs and Crime, 2016) – United Nations principles that set out what is generally accepted as being good principles and practice in the treatment of people living in prisons and prison management. |

## 2.1. Lived experience and community

### 2.1.1. Lived experience and perspectives

Historically, research has positioned people with lived experience as research subjects, rather than as leaders and partners in the co-production of knowledge and research. This undervalues the embodied knowledge and wisdom people with personal experience of imprisonment and criminalisation have and leads to epistemic injustice.[4] Research designed and conducted without meaningfully engaging people with lived experience of imprisonment risks being detached, biased, incomplete or harmful. People with lived experience have first-hand knowledge of the criminal legal system, its realities and impacts, and have unique perspectives on solutions. Recognising that limitations and constraints exist within and across contexts and projects, to the extent feasible, each stage of research design, from developing research questions and methodologies to conducting analyses and sharing findings, should include perspectives and ideas from people and/or groups who could experience the benefits (and/or harms) from research. In this context, lived experience may include people currently in custody, with previous experiences of the criminal legal system, or family members. The insight of people with lived experience is important for conducting research that is grounded, responsive to need, and able to drive meaningful change in policy, practice and health outcomes.

> ***"[A]dults in custody have the wisdom of experience that no "outsider" without similar experience can truly understand or appreciate. The inclusion of these "insider" voices not only strengthens the research process... but potentiates the impact of the research by empowering the research participants..."*** [42 (p60)]

### 2.1.2. Ensuring meaningful engagement of people with lived experience

People with lived experience should be empowered as active and equal partners in all aspects of research where possible, including in design, analysis and interpretation of results, and implementation.

Engaging individuals and communities with lived experience of imprisonment in the research design process may take many forms including partnerships with organisations or people with lived experience leading research in academic positions, contributing as advisories or as part of teams, or in other formal roles such as research assistants or community investigators. Frameworks that distinguish the commitments and responsibilities of different levels of engagement, and the extent of power-sharing, co-design and co-leadership can be helpful in understanding how levels of engagement may influence research practices, validity and impact.[43, 44] Together with people who have lived experience, researchers should discuss and decide what the costs (emotional, practical and opportunity) and benefits are to engaging in the research process. Researchers should ensure that appropriate structures are in place such as considerations for other responsibilities, for example childcare and accessibility, access to a physical space or technology, regular check-ins and compensation that is fair, timely and reliable.

> ***"[R]esearchers must be prepared to expend additional time and effort to fully engage incarcerated individuals as co-researchers. This includes a willingness to question some of their own beliefs..."*** [42 (p61)]

### 2.1.3. Reciprocity, accountability, respect and autonomy

Research should be mutually beneficial to both researchers and participants. Ethical and equity-informed design requires thoughtful consideration of how benefits, risks and responsibilities of research are distributed. This includes explicitly acknowledging and addressing power imbalances, biases, and how intersecting identities may affect experiences of the research process and its outcomes. Accountability to people and communities participating in, and impacted by, research requires design processes to demonstrate trustworthiness and build trust, foster open communication and share decision-making and ownership. It means being open to changing course to respond to feedback, identified harms or needs. It also includes careful consideration of how findings will be owned by or shared with people participating in, and impacted by research, and how research will be mobilised to create change. Ownership in this context means ensuring that people with lived experience have meaningful control over how findings are interpreted, used, and shared, in ways that reflect their priorities and contribute to their ability to drive change.

Research design should also consider the risk of further harm, including re-traumatisation, and how approaches may dismantle or reinforce oppression. Some methodologies, such as Participatory Action Research, explicitly challenge dominant research paradigms through power sharing in the co-production of knowledge. Similarly, arts-based methodologies may be employed within a framework of co-creation to promote autonomy and authority over narratives. Respect for lived experience within research design should prioritise safety, equity, and self-empowerment of participants and collaborators.

#### CONSIDER THIS EXAMPLE

The Lost Mothers Project studied the impacts of separating mothers and their infants in the criminal legal system.[45] The research was co-produced by researchers, a civil society organisation and a Lived Experience Team of mothers with their own experiences of the system. The project team collaboratively identified seven recommendations for researchers on how to manage co-production authentically and inclusively:

**1) Engage from the Offset:** The project is to be shared, and lived experience is not to be used as an add-on.

**2) Payment:** Set up contracts early; handle paperwork and legalities promptly to ensure smooth payment to lived experience members.

**3) Activities:** Plan inclusive and enjoyable activities with productive outcomes such as writing retreats.

**4) Permissions and Check-Ins:** Revisit consent regularly to ensure ongoing approval. Ensure confidentiality at all times.

**5) Value Proposition:** Always consider the benefits for the lived experience team members as a whole.

**6) Child Care Consideration:** Account for childcare needs, aligning activities with school hours and providing mutually convenient venues.

**7) Accessibility:** Ensure venues and activities are accessible to all members, considering mobility and other accessibility requirements.

## REFLECTIVE QUESTIONS

- How are people with lived experiences meaningfully involved throughout the research process?
- How has the research been informed by lived experience?
- What are the motivations and reasons for considering this research?
- Who benefits from this research?
- Could this research purpose be perceived as exploitative or extractive by participants or staff?
- How is trust and respectful long-term connection being fostered with experts through experience?
- How does this research build capacity among people with experience of imprisonment?
- What processes are in place to ensure that partners with lived experience can identify and address learning or training needs (for example in research methodologies)?
- Are there processes to ensure that feedback is respected and addressed?
- What processes are in place to resolve disagreements and work through conflict?
- How will people in prison be informed or involved in its outcomes?
- How will people with lived experience have agency and choice in how they are identified or acknowledged in publications and presentations?

## KEY RESOURCES

**Service users being used: thoughts to the research community** in *Critical Reflections on Women, Family, Crime and Justice* (Booth and Harriott, 2021).[46]

## 2.2. Research purpose

### 2.2.1. Morally justifiable research

> ***"In medical research... considerations related to the well-being of the human subject should take precedence over the interests of science and society."***[5]

Prominent medical ethics and human rights guidance and legislation indicates that the wellbeing of individual participants should take precedence over societal interests and that people living in prisons should not be subjected to research detrimental to their health or exposed to more than minimal risk.[5, 47, 48] Furthermore, people living in prisons should not be unjustly excluded from research that may benefit them or their community.6 In line with the equivalence of care principle, people living in prisons should also have access to participation in clinical and other research, provided their involvement is not exploitative but rather aligned with their right to health and potential benefit to their communities. Yet, whilst researchers have a duty to do no harm (non-maleficence), involvement in any form of research poses risks. Therefore, the ethical and moral justification of exposure to such risks depends on the balance between the risks to those participating and the potential benefits to the individual and society (beneficence). Hence, research in prison settings should seek an ethically grounded balance, prioritising the protection of individuals from harm while ensuring equitable access to research.

In a prison setting, researchers should consider the extent and immediacy of potential benefits of a research project against the expected risks. In addition, the potential harm of including people deprived of their liberty should be considered against the potential harm of excluding them from the research. Hence, all partners in prison setting research (people living in prison, researchers, research ethical committees, sponsors, publishers and authorities) should consider how such activities will improve, reinforce or worsen existing inequities.[49] It should be clear how the prison health research aims to improve the understanding of health and wellbeing of people living in prisons, contribute to improving health and the wellbeing of imprisoned populations, or achieve representation for people living in prisons in population health research. Considering that most of this population will be reintegrated into society, researchers should also consider the wider social benefits of enhancing the health of prison populations as part of the research rationale.[50]

Research questions and objectives should be shaped in collaboration with people who have lived experience of imprisonment. Researchers should develop a research protocol (section 3.2) that clearly outlines how the study will be conducted, including how potential risks and benefits will be communicated to participants to ensure informed consent (section 4.2) prior to research approval. Guidance on practical aspects of risk assessment and mitigation is discussed in section 3.4.

### 2.2.2. Research to address the specific health needs of people living in prison

Prison health research should be guided by the goal of addressing unmet health needs and improving the wellbeing of people living in prison. This should respect researcher autonomy and the diversity of scientific inquiry but may involve exploring areas that disproportionately impact people living in prisons such as mental health, substance use, infectious diseases, chronic conditions, and the health effects of imprisonment itself. It is also important to understand the challenges and specific methodological issues for populations who are disproportionately represented or disadvantaged within prisons, for example:

#### Women

Although women represent a small proportion of prison population, they have distinct health needs that are often overlooked in prison systems primarily designed for men. In several countries, the number of women living in prison has been rising[51], underscoring the urgency of addressing gender-specific health issues. Their underrepresentation in both the prison population and research requires targeted inclusion and methodological approaches that reflect a gender-sensitive perspective.

#### Gender minorities

The term 'gender minority' can include anyone whose gender transcends the defined limits of the cisgender binary, meaning that the sex they were assigned at birth does not align with their gender identity or expression. Research involving gender minorities, who often face heightened stigma, discrimination, and violence in prison settings, should ensure appropriate representation, confidentiality, and culturally competent methodologies that address their specific vulnerabilities.

#### Older people

The number of people over 65 years old in prison is rapidly increasing worldwide, making them the fastest-growing demographic in many correctional systems.[52] Older people in detention are particularly susceptible to abuse, neglect, and exploitation, with limited legal protections and few clear pathways for reporting or recourse. Older people living in prisons in particular face compounded vulnerabilities due to age-related physiological decline and the cumulative impact of inadequate healthcare access, stress, and poor living conditions. Some countries have adopted a lower age threshold to define older individuals in prison, enabling earlier identification of risk and more proactive health interventions tailored to this population.[53]

#### People living with disability

Up to two-thirds of imprisoned individuals report some form of disability—whether mental, cognitive, sensory, or physical[54] – which prisons can concentrate and exacerbate through inadequate care, structural neglect, and punitive segregation.

#### People with substance use disorders and severe mental health conditions

The prevalence of substance use disorders in the general population is estimated around 5% but rises to 50–80% in prison settings. Prison health research should also account for the high comorbidity with mental illness, the complexity of care needs, and the impact of the prison environments.

#### Migrants, refugees, and culturally and linguistically diverse people

With prisons becoming increasingly multicultural spaces, this diversity presents research challenges related to linguistic barriers and discrimination.

#### Indigenous peoples

Indigenous peoples are often disproportionately represented in prisons. Prison research should consider culturally safe approaches, the relevance of traditional medicines, and the importance of Indigenous self-determination in health research.

People living in prisons are likely to experience compounded forms of vulnerability, exclusion and discrimination due to intersections with other social dimensions, such as age, ethnicity, Indigenous identity, gender, migration status, sexual orientation or drug use. Health research should actively seek to identify and address these intersecting inequalities, generating evidence that can inform more inclusive, equitable, and responsive policies and practices within prison settings.

#### CONSIDER THIS EXAMPLE

**The RISE-Vac project**[55], funded by the European Union, aimed to enhance vaccine access and uptake among prison populations across Europe. Recognising that people living in prison face a higher burden of infectious diseases and lower access to health information, the project aimed to co-develop educational tools to address vaccine hesitancy and promote informed decision-making. The research purpose was aligned with the documented health needs of people living in prison, particularly the lack of reliable information on vaccination and low vaccine uptake, as reported by World Health Organisation (WHO) and other institutional frameworks. To ensure that interventions were both effective and ethically grounded, the project engaged people in detention and those with lived experience at every stage—from defining information needs to shaping the language, format, and delivery of the materials.

Consultations were conducted across partner countries (the UK, France, Moldova, Italy, Cyprus, and Germany), utilising both written surveys and focus groups. Over 300 people living in prison participated, expressing a desire for more detailed, accessible, and trustworthy vaccine information, particularly regarding side effects, manufacturing, and efficacy. Based on their input, the team **developed and piloted an illustrated brochure and planned multilingual, multimedia dissemination.**

The RISE-Vac project demonstrates a research purpose that is both needs-driven and grounded in ethical principles, such as participation, relevance, and empowerment. It aligns with the broader objective of reducing health inequalities in closed settings and improving the overall quality of care, as advocated by the WHO Health in Prisons Programme. Rather than being externally imposed, the research was shaped by the population it sought to serve.

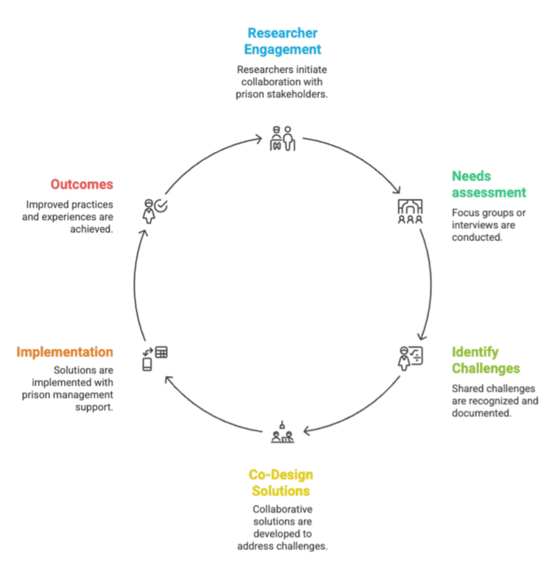
### 2.2.3. Whole-of-prison approach to health research

Prison environments have an important impact on people living in prison and can contribute to long-term physical and psychological harm. Health research should therefore adopt a whole-of-prison approach that not only addresses the needs of individuals in detention but also considers the broader institutional ecosystem, including staff wellbeing and the structural determinants of health within custodial settings. Crucially, this approach requires the active engagement of prison governance and management structures. The involvement and ownership of prison governors, administration and custodial staff are essential to ensure that research activities are feasible, contextually relevant, and that their outcomes lead to meaningful and sustainable improvements in practice and policy (see section 3.3).

## REFLECTIVE QUESTIONS

- → How does this research align with the health needs and priorities identified in official strategies and frameworks, such as the WHO Health in Prisons Programme (for Europe) and national prison health strategies (when available), as well as with the priorities identified by people living in prison?
- → Have the harms and benefits been considered at the individual participant and wider societal levels?
- → How does the research contribute to improving health outcomes or equity for people living in prison?
- → Could the research reinforce stigma or stereotypes about people living in prison?
- → Could the research unintentionally cause unacceptably high risks?
- → How will people with lived experience have agency and choice in how they are identified or acknowledged in publications and presentations?

## CONSIDER THIS EXAMPLE



This diagram illustrates how researcher engagement with both people living in prison and staff could co-identify challenges, co-design interventions and implement them in collaboration with prison management resulting in improved practices, policies, and health outcomes within the prison system. This pathway from collaborative prison research to system-level change was conceptualised following RISE-Vac – Co-Production of Vaccine Education Materials with Persons Living in Prison.[55]

## 2.3. Research funding and resources

### 2.3.1. Overall viability of the research project

Prior to seeking funding, it is important to consider the overall feasibility and viability of a research project. For example, engaging with prison administration during the design phase to identify safety and logistical challenges is important as a project infeasible for prison authorities will likely not be approved. If the research cannot be implemented safely or ethically, then applying for funding or commencing the project would be both inappropriate and a poor use of resources.

### 2.3.2. Access to research funding

Evidence suggests funding for health research in prison settings is disproportionately low.[56, 57] This reflects a significant gap in funding for a population with significant and often overlooked health needs which highlights the need for greater investment and targeted research support. Researchers should proactively seek possible sources of prison health research funding. Research that notes prison health is an extension of the public health system, given that most people in prison will be released back into the community, and acknowledges potential benefits such as reducing the long-term social and economic costs of repeated imprisonment58 may also be viewed more favourably.

### 2.3.3. Realistic and comprehensive costing

Prison research is likely to be more costly than equivalent research conducted in the community. As it would be unethical to embark on research that cannot succeed, research budgets should be realistic and factor in everything required to make the research successful. Prison health research funding should therefore not omit resources for: community engagement (section 2.1), access to prison partners and participants, unique logistical demands of prison-based research (such as transport, security clearance, staff coordination, staff security training), security coordination, logistical support and research evaluation.[58]

### 2.3.4. Independence and transparency

Funding sources should respect academic freedom and not influence the research question, study design, conduct, interpretation, dissemination or outcomes in any way. This is important to ensure the credibility of research results. Researchers should pay attention to funding sources and reflect on perceived or real conflicts of interest which they should disclose transparently. Consideration should also be given to ethics surrounding the application of research findings, in addition to the ethics of the research question and process.

### REFLECTIVE QUESTIONS

- → Is the research feasible and will it be permitted and supported by research partners?
- → Are the required resources (such as time, funding, training) available to support involvement?
- → How will conflicts of interest between researchers and funders be identified and managed?
- → Are all sources of funding transparent and disclosed in applications and publications?
- → Are there further support mechanisms in place from within research partner organisations?
- → Are there plans for monitoring, mentoring and technical assistance?
- → Does the funding include capacity-building or infrastructure development (such as health staff training or improved data systems)?
- → Is the research likely to produce reliable, valid and valuable knowledge?
- → Is there a plan to sustain or share benefits after research ends?

## 2.4. Research partnerships and governance

Health research in prisons involves collaborations between researchers and prison systems. Partnerships refer to the collaborative relationships between researchers and key stakeholders including, for example, prison authorities, health ministries, healthcare services, academic institutions, non-governmental organisations, community-based organisations with relevant mandates and people with lived experience of imprisonment.59 These partnerships are essential to ensure research is relevant and respectful of local needs and priorities and to build mutual trust and shared ownership. Partnerships can also facilitate access and logistical support as well as enable knowledge sharing.

Researchers should build partnerships that benefit people living in prison, not just funders or research institutions. Partnerships should be based on mutual respect, clear roles, and equitable distribution of benefits, responsibilities, and authorship. Formal agreements such as a Memorandum of Understanding can be used to outline roles, responsibilities, and ethical obligations of all parties are encouraged. However, it is important research remain scientifically and ethically independent from funders, prison administrations or political pressures. This includes independence – the meaningful ability to participate in the research process without coercion, undue influence, or manipulation – in the design analysis, interpretation and dissemination of findings.

Power imbalances in the prison setting and partnership structures should be acknowledged and mitigated if possible. Partnerships should aim to build and strengthen local capacity for ethical research within the correctional system. This includes training prison health staff, supporting ethics committees, developing research infrastructure, and training and empowering imprisoned individuals to co-lead or contribute to the research.

### 2.4.1. Partnerships and research governance structures

Research governance plays a critical role in ensuring that participants are safeguarded throughout the research process. It also protects researchers by providing a clear and structured framework within which to operate. By enhancing both ethical and scientific standards, research governance helps to minimise risks, monitor performance, and promote responsible conduct. Additionally, it supports continuous improvement by encouraging reflection on practice and the integration of lessons learnt.[59]

As in all health research studies, researchers should establish appropriate governance structures. Steering committees provide advice to the study's principal investigator on all aspects of the conduct of the study. The membership should be independent of the research team and the institutions where the research is taking place. Appropriate members of a steering committee for a prison health study might include relevant ministries (such as the Ministry of Health), external agency or civil society or non-governmental organisations if applicable (such as the World Health Organisation or International Committee of the Red Cross), people with lived experience of imprisonment and health researchers with the necessary expertise. Technical groups including people with lived experience, health professionals working in prisons, prison staff representative, academic/research partners can help ensure sound participatory, ethical and context-relevant research.

Researchers should consider setting up mechanisms for people living in prison and prison staff to report concerns about the research partnerships or funding-related influence such as regular oversight, documentation and feedback loops.

## CONSIDER THIS EXAMPLE

**Research capacity building and collaboration between South African and American partners for HIV/AIDS research in prison** explores how South African and American researchers worked together to build research capacity through a collaborative prison-based project aimed at reducing HIV/AIDS rates in South Africa.[60] It focuses on how an intervention model, originally developed and applied successfully in U.S. prison health research, was adapted to be culturally relevant and suitable for the South African correctional context.

This partnership model emphasised equitable participation, cultural sensitivity, and shared governance, including co-authorship, data ownership, and financial control. The project also involved:

- **Capacity-building workshops** for prison staff and junior researchers on topics like research design, evaluation, grantsmanship, and data dissemination.
- **Peer-led research teams**, with Zulu-speaking local researchers trained to collect data and engage participants, enhancing trust and data quality.
- **Ongoing training and mentorship**, using a "learning by doing" model to strengthen individual and institutional research skills.

## REFLECTIVE QUESTIONS

- Do funding and prison administration arrangements preserve researcher independence?
- Are there written agreements preventing funder and prison administration interference?
- Are there any conflicts of interest that may affect the independence or neutrality of the research?
- Are partner roles, responsibilities, and ethical commitments clear and agreed upon?
- How are policymakers and health systems being engaged to implement or adopt research findings?

## 2.5. Researcher training and skills

### 2.5.1. Researcher competence and qualifications

Researchers should consider relevant training before engaging in prison research, particularly in safeguarding, power sensitive communication and trauma informed approaches. When working with people living in prison this training can help researchers create a safe and respectful environment between the researcher and the participants. Having the appropriate skills may also help researchers manage power imbalances, safely evoke participant responses and minimise the risk of triggering trauma. Researchers should adopt a non-judgmental attitude and be emotionally equipped to engage with people sharing emotionally challenging life histories. This helps to protect both the participants and the mental health of the researcher. Researchers could demonstrate their competence through completion of relevant training or qualifications before engaging participants or entering prison settings.[61]

### 2.5.2. Reflexivity, positionality, and power dynamics

Researchers should think critically about their own positionality, power, or assumptions when conducting prison research. Continual reflection, often called reflexivity, is recommended as an important prison health research skill. This can be encouraged through use of researcher diaries, for example. Reflexivity involves thinking critically about how personal background, beliefs and position in society might affect the research conduct. During this process, researchers are expected to assess their positionality (identity) and how it is related to their research.[62] They should also consider institutional power which refers to the influence they carry during the research. Even if unintentional, researchers will bring in prejudices which are assumptions shaped by their own beliefs and culture, which can affect how they interpret the data they collect.[63] By analysing these factors researchers can reduce the risk of biasing participants' responses or making them feel unsafe during the research process, creating a more ethical, respectful and trustworthy environment.[64] Researchers should be transparent about their positionality statements and reflexivity practices throughout the research process.

### 2.5.3. Training in trauma, ethics, and consent

Where feasible, researchers are encouraged to adopt trauma-informed approaches in prison settings. Trauma informed training can help researchers to understand how past trauma may influence participant behaviour, recognise signs of emotion and allow them to respond with sensitivity to questions that may unintentionally re-traumatise individuals. While formal training in trauma-informed care is ideal, alternative options such as guided reading, peer-to-peer discussions, mentorships or free internet resources may help researchers build awareness, appropriate skills and capacity. This can enhance researchers' ability adopt a non-judgemental approach and create an emotionally safe research space.

**KEY RESOURCES**

**Understanding Trauma-Informed Care in Correctional Facilities: A Scoping Review.** (Gaber, Scallan & Kouyoumdjian, 2025).[65]

### 2.5.4. Cultural competency and communication skills

Researchers should have strong communication skills and cultural awareness for working in prison settings. This includes understanding cultural humility by learning from others' experiences, knowledge of prison-specific norms, social hierarchies, and codes or slang language used inside the prison. These cultural factors can shape how participants respond during research. Researchers should demonstrate emotional intelligence especially in cross-cultural or emotionally charged interviews with participants. Effective interpersonal skills are crucial for building trust, particularly with those distrustful or cautious of authority, and involves being able to read emotions and show empathy.

**CONSIDER THIS EXAMPLE**

The Thai **Pan Suk project**[66] which involves training people living in prisons to serve as Prison Health Volunteers (PHVs), provides an example of a model with capacity building in health promotion through community-based participation. PHVs were trained in tuberculosis symptom recognition, health risk communication, and peer engagement techniques. Such training underpinned core public health capabilities amongst the imprisoned individuals; as well as increased health awareness and self-efficacy, engrained potential to better integrate post-release.

The model also promoted horizontal dissemination of health information through peers, through which health information could be shared in ways that were culturally and socially credible. For instance, PHVs conducted informal health education in their residential blocks and motivated symptomatic residents to seek care. This peer interaction is especially powerful in confined environments where there is significant lack of trust in the establishment, and stigma still hinders early help seeking. This research demonstrates the benefits of peer-led surveillance in creating trust, encouraging health-seeking behaviour, and inculcating shared responsibility for population health in prison settings. The effort is consistent with the WHO Strategy for Strengthening Health Systems, in which community participation in health is a fundamental principle, based on the premise that all persons, including people living in prisons, have the right to participate in health planning, delivery and monitoring.

## KEY RESOURCES

Learn practical steps – guided by formerly imprisoned people themselves – on how to cultivate research with, by, and for those impacted by incarceration through this **free web-based learning module on Participatory Research with People Impacted by Incarceration**, University of Minnesota.

### 2.5.5. Supervision and support structures

Prison health researchers should have broad exposure to prison settings where possible and specific training opportunities, as well as strong supervision and support systems. Senior researchers should ensure adequate supervision, regular check-ins, peer reflection spaces, and access to mental health support for their research teams. This might include establishing regular reflective or debrief meetings, discussing ethical challenges and identifying actions needed. Creating a space for collective reflection allows researchers to share concerns and reflect on challenges which can inform their ethical decision making.

Any team member may require guidance and support, particularly when handling sensitive information. Providing a designated mentor with relevant expertise in trauma-informed practice can help guide them through these challenges safely and ethically. It is important that senior researchers ensure that those working under their supervision can obtain a respectful and professional relationship with people living in prisons and prison staff, and that they have appropriate safeguarding clearance.

## REFLECTIVE QUESTIONS

→ How will coercion (from either the institution or peer dynamics) be recognised and responded to?

→ How will signs of trauma, distress or emotional withdrawal in participants be identified and managed?

→ How will signs of trauma, distress or emotional conflict in researchers be identified and managed?

→ What challenging emotional issues are likely to arise during this research?

→ What strategies could be built into research processes to support emotional health during the project?

# 3

# Planning and applying

## 3.1. Research ethics committees

Prison health research projects should be reviewed and approved by an appropriate multidisciplinary committee such as a Research Ethics Committee (REC) or Institutional Research Board (IRB) to ensure appropriate protections are in place, relevant regulations have been considered and to support voluntary participation in ethical research.[3, 8] Early consideration of the most appropriate ethics committee(s) to apply to is advised, specifically when specialist independent committees such as Indigenous human research committees or specialist data safety monitoring committees are required, depending on the study context and methods.

> ***"Research ethics committees should identify their independence from sponsors, investigators and prison administrations by statements of absence of conflicts of interest for each member, should be composed of a fair distribution of scientists and lay members of different gender, race, cultural and social background and should be obliged to include… [people living in prison] representatives as members of their boards."*** [67 (p196)]

Ethics committees that review and approve prison health research should include representatives of all stakeholders including health and social staff working in prison, people with lived experience of imprisonment and researchers, with additional members being consulted depending on the research topic. However, it is acknowledged there are limited examples of committees that include people with lived experience of imprisonment to date.[67] Depending on the country or context, human research ethics committees may not be directly familiar with prison research. Therefore, this guidance could be used to support research ethics committees review any prison health studies submitted to them, although it is recommended protocols are reviewed and approved by the bodies most qualified to do so.

### CONSIDER THIS EXAMPLE

The US Department of Health Services **Office for Human Research Protections Section 46.304** (2024) states that a representative of the imprisoned population be included as a member of the institutional review board to give opinions regarding the design and conduct of research involving imprisoned populations to ensure ethical oversight. The involvement of a representative of imprisoned population in research is rooted in principles of social justice and equity and aims to recognise the lived experiences, knowledge, and expertise of people living in prisons; promoting a more balanced exchange of information between researcher and participants, leading to better quality, contextually relevant, and more valid research.[68]

### 3.1.1. Research registration

As with other research, it is best practice to register a protocol for planned prison health research (see section 3.2) by submitting the approved protocol to a platform, such as **Open Science Framework**. Currently, there is no central registration for prison health research; however, a central registration platform could be of substantial value for international prison health research networks through increasing awareness of emerging research and enable relationship building between relevant researchers and organisations.

## 3.2. Writing a protocol

> ***"The design and performance of all medical research involving human participants must be clearly described and justified in a research protocol."*** [5 (p1)]

### 3.2.1. What is a research protocol?

A research protocol is a document that provides a comprehensive, but concise, overview of all aspects of a research study, like a blueprint that details the research project from the planning to execution to dissemination of findings. There is plenty of guidance on how to write a protocol for health research in the public domain.[69] Some research ethics committees recommend a specific format; therefore, it is important to be familiar with the requirements of the local research ethics committee. At a minimum, a research protocol should include:

- Research team members, qualifications, conflicts of interest, and their roles.
- Study objectives and hypotheses.
- Detailed methodology for the research project.
- Ethical considerations such as participant recruitment and reimbursement, informed consent, potential risks and benefits, participant burden, incentives, information equity, and provisions to protect data security and confidentiality.
- Detailed plans for data collection, secure storage, management, access, and analysis.
- Participant facing materials for consent, recruitment, and data collection.
- Provisions for mitigating the risk of harm and responding to any harms or distress experienced by participants due to participation.
- Strategies to identify and respond to participant and researcher distress.
- Research timeline.

- Research collaborators and partners, and how they will be involved.
- Plans for the translation and dissemination of research findings.
- Any post-trial provisions for clinical trials.
- Funding source(s).

### 3.2.2. Writing a protocol for prison-based research

While a research protocol is important for research conducted both within and outside of prison settings, a well thought out protocol is particularly important for prison-based research. Developing a research protocol will help identify and plan for the unique complexities of conducting research in prison settings, many of which have ethical underpinnings. For example, a protocol will help to identify key stakeholders and participant groups; logistical challenges to participant recruitment, access, consent, and reimbursement that arise from prison-specific schedules or policies; sensitivities due to the potential vulnerabilities of prison-based research participant, such as those relating to physical and mental wellbeing, disability, trauma, low literacy levels; and relevant power dynamics between participants (such as people in custody), facility staff (such as correctional or prison health staff), and researchers that can impact participant engagement and trust. Intersectional considerations should also be explicitly mentioned within research protocols, ensuring that research methodologies do not unintentionally perpetuate exclusion or discrimination. The protocol is therefore a critical document to ensure that your research is both feasible and ethically sound. A well-thought-out protocol will give your research the best chance of success.

Given the importance of the research protocol as a guide for implementation, it is important to develop the research protocol early, ideally before preparing other aspects of the research ethics application. A key reason for this is that writing a protocol will help to confirm or identify relationships with key stakeholders, such as department heads, wardens, prison health management and other correctional staff, who will play a key role in approving and providing access to facilities, data, and/or participants. These relationships will take time to develop and are essential for successful prison-based research (see section 3.3 for further details).

### 3.2.3. What questions should the protocol consider?

There are specific, additional questions that should be considered when developing a protocol for a prison-based health research study. The protocol should address the following questions:

#### Stakeholders

- Who are the key stakeholders and research partners facilitating research implementation in the prison setting (for example government departments, wardens, other prison management, correctional officers, prison health staff) and what is their role in the research?
- How will you work with key stakeholders and research partners to facilitate access to prisons, research participants, and implement the research protocol?

#### Participants

- What are the relevant characteristics or potential vulnerabilities of research participants in addition to their imprisonment status that need to be considered (for example age and ability to provide consent, intellectual ability, literacy, neurological difference, trauma, mental health issues)?
- Are participant-facing study materials easily understood by study participants and do they consider their potentially unique characteristics and needs of people in custody? Are multiple options provided to meet these needs?
- Will you seek approval to safely disseminate study materials in the prison facility?
- Are there any additional challenges to participant informed consent introduced by the prison setting or participant characteristics?
- How will the study team ensure confidentiality of imprisoned participants, build trust, and navigate participant concerns around disclosure of information in justice settings?
- How can the study team ensure long-term follow up of study participants in the community (for longitudinal primary research studies) or to keep participants notified of study outcomes after release?

#### Setting

- What are the ethical issues or logistical challenges inherent to conducting the research in a prison setting? This may be in relation to power dynamics within the prison setting, access to facilities, or access to research participants.
- How will the study team navigate power dynamics in the justice setting?
- What is the researcher positionality relative to imprisoned participants?
- How will the study team navigate schedules and daily life in the prison setting in terms of accessing participants, as well as attrition due to planned and unplanned release?

## REFLECTIVE QUESTIONS

→ Is the protocol detailed enough for another researcher to replicate the study thoroughly and ethically?

→ Have the necessary prison specific aspects been addressed in the protocol?

## KEY RESOURCES

The World Health Organization has published a freely available **recommended format for a 'research protocol'** and guidelines on submitting research proposals for ethics review. Furthermore, the United Kingdom's Health Research Authority provides **protocol templates tailored for different study designs.**

## 3.3. Prison administration engagement and involvement

Engaging with prison administration is essential at many stages of the research process, especially during the early phases of conceptualisation and design (see section 2.4 and 3.2.2). This engagement helps ensure that the research is not only feasible but also safe and ethical for participants, prison staff, researchers, and the broader prison community.

### 3.3.1. Why engagement is important

Safety is a foundational concern in both prison operations and the ethical conduct of research within them. Research must comply with the legal, procedural, and physical requirements established by prison authorities. This may include limitations on physical access, movement within the prison, and the use of electronic or recording devices. Researchers may also be subject to conditions regarding the review or reporting of results, particularly findings that reflect unfavourably on the institution. Such conditions need careful discussion; such restrictions are unlikely to constitute good ethical practice. Researchers should anticipate this possibility and, where possible, should document through a research agreement the right for the researcher to publish the findings. It may be helpful for researchers to provide findings to the prison administration in advance of publication. In any case, careful discussions at the start of the research process can allay the fears of the prison administration to ensure that restrictions are not imposed and that high ethical standards are maintained.

Some prison administrations feel they reserve the right to terminate studies that they believe depict them unfavourably. Again, this highlights the need for researchers to engage with the prison administration early to ensure there is agreement over the reasons for and mechanisms by which there is the early termination of study.

## REFLECTIVE QUESTIONS

→ How will prison administration been engaged from the start?

→ What agreements are required to ensure there are no restrictions on publication?

### 3.3.2. Ensuring feasibility and ethical conduct

Early consultation with prison authorities helps ensure that research protocols are aligned with institutional safety requirements and are also respectful of participants' rights and wellbeing. Failure to engage with the prison administration during the design phase can result in significant ethical and logistical challenges. If the research cannot be implemented safely or ethically, then applying for funding or commencing the project would be both inappropriate and a poor use of resources.

For example, in many prisons, private conversations between people living in prison and visitors may be restricted unless the visitor is a legal representative. This limitation has direct implications for the informed consent process and the type of data that can be safely collected. In addition, the prison administration may need to make special provisions to facilitate research activities. This can include allowing the temporary use of secure rooms, approving the introduction of digital devices, or providing staff support to manage access and movement. All these arrangements require early negotiation and clear communication.

### 3.3.3. How to collaborate with the prison administration

Prison research is subject to varying legal, policy, and procedural requirements depending on the jurisdiction and type of correctional facility. Early outreach to prison authorities, such as the administrative head of a facility or the relevant government department, is essential for understanding what is legally and logistically possible. Effective collaboration may involve:

- Initial contact via email or formal letter to introduce the proposed project and request guidance on institutional requirements.
- Site visits to observe the physical environment, assess available facilities and begin collaborative discussions with staff.

- Joint planning of the research logistics, including where and how data collection will occur, what support will be needed from prison staff, and agreement on follow up for any participants who become distressed or experience any harm (this usually involves the joint development of ‘distress protocols’ that recognise that participants would typically access support through prison staff).

For instance, if a participant becomes distressed during an interview, how feasible is it for prison staff to implement the study’s distress protocols in that environment? It is likely that any distress protocol will need adapting to the specific prison and will need input from the local prison administration. Having these discussions early helps to align researcher and institutional expectations and ensures that neither participant nor researcher wellbeing is compromised.

## 3.4. Risk assessment and mitigation

Every prison-based research project will have context-specific considerations for assessing risk that vary depending on the setting (for example the type of prison facility). A detailed risk assessment should be conducted as part of the ethics application process for the protection of everyone involved. It should identify potential harms to participants, researchers, prison staff, and institutions. Mitigating incident response protocols and emergency procedures should be designed in advance as part of this process. Individuals carrying out the risk assessment should be appropriately trained and understand the prison environment.

### 3.4.1. Risks to participants

#### Coercion and voluntary consent

Institutional pressure will compromise genuine voluntary consent. For example, power dynamics between staff and people living in prison will influence participation decisions, and people living in prison may feel unable to refuse or withdraw. Potential participants may also fear repercussions if they are being asked questions about the prison service or the staff working within it. Mitigating these issues will be important and should be outlined in any applications, participant information or consent forms that are submitted for ethics approval (see section 0 for more details).

#### Stigmatisation

Participation in certain health studies (such as studies focused on mental health conditions, substance use or infectious diseases) could lead to labelling or discrimination by staff or other people living in prison. Strategies for mitigating the risk of stigmatisation should be outlined in the ethics application.

#### Emotional distress

Research involving mental health assessments or questions on trauma and other sensitive topics such as suicide or self-harm may lead to psychological distress. Mental health, psychosocial or therapeutic support should be available as required. The distress protocol should detail how this is organised during and following the research contact and (as outlined in section 3.3.3) the prison service should be consulted during the development of the protocol to ensure that any support needed in the period after participation in the research is adequately planned for and resourced.

#### Self-harm and suicide risk

Research may identify and, rarely, exacerbate suicidal ideation or self-harm behaviours. Because of the threat to the participant’s wellbeing, if identifying data are collected, the researcher will need to disclose this information to the relevant staff member within the prison. All research participants must be informed of this potential for disclosure in advance of providing consent to participate. If the researcher intends to disclose this to a staff member the participant must also be informed of this, requiring immediate intervention while balancing confidentiality obligations. There should be an agreed self-harm and suicide protocol in place before the start of the research, as well as a distress protocol. For serious adverse events resulting from participation in the research, there may be an obligation to report these as soon as possible to the overseeing institutional research board or ethics committee. Researchers should be guided by local policies and include this in any protocol or ethics application (see section 3.2).

#### Physical safety

Participation could inadvertently expose people living in prison to retaliation from other people living in prison, particularly if research topics are sensitive or create perceived advantage (see section 3.6.4 on reimbursement). Again, this potential (but rare) issue highlights the need for researchers to gain a thorough understanding of the social environment in which they propose to work prior to the start of the study so that they are confident that they can facilitate a safe space for participants.

### 3.4.2. Risks to researchers

Risks to researchers should be minimised through adequate risk assessment, appropriate training and supervision (as noted in section 2.5). Processes should be in place to minimise the risk of researchers encountering a physical threat or emotional harm within the environment.

#### Risk assessment and researcher safety

Individuals carrying out the risk assessment should be appropriately trained (section 2.5) and understand the prison environment (section 4.1), and consider both physical and emotional safety.

### Training and supervision

Appropriate training and supervision should be provided for researchers to ensure that they can conduct the study effectively and safely both for participants and themselves (section 2.5). Training needs should be identified as part of the ethics application process and reviewed and updated where appropriate during the study. The level and type of training will depend on the researcher's characteristics (such as experience, level of skills and qualifications). Training should include health and safety when relevant. Adequate supervision should be provided for everyone in the research team, commensurate with their level of experience, particularly their experience working in a prison environment. A facility orientation and safety training for research staff should be conducted.

> ***"Supportive clinical supervision where a researcher is facing potential emotional harm through hearing anguished voices and carrying stories with them needs to be accessed as part of the research journey to avoid negative emotional burden"*** [70] (p1438)

Clinical supervision may be required for researchers. Particular attention should be paid to the training and support needs of researchers who are conducting research during their own imprisonment (for example see **User Voice studies**). When the regular supervisor(s) will be away, an alternative source of support should be put in place in case of the need to debrief or to seek advice.

Where imprisoned people are involved in conducting the research, specific consideration should be given to what potential risks and harms they might face, whether physical, practical and emotional. The User Voice study in 2022 notes the particular difficulties that imprisoned peer researchers may face for example in storing material confidentially and analysing information related to their peers.[71]

### Physical safety for researchers

Research in prisons is generally safe in relation to physical safety. However, it is important to identify any risks and put mitigations in place, however rare they may be. These risks may vary depending on the country or community context, and the specific institutional environment, as well as on the type of research. For example, there may be different risks for the researcher in conducting ethnographic research compared with quantitative studies.

Risks to researchers include physical harm, including accidental injury or injury through violence although deliberate injury to researchers is rare in most jurisdictions. It is important to have seen the institution prior to conducting the research to be able to assess any risks. Through a visit to the institution the research team can liaise with prison staff and identify where the best sites will be to conduct research safely, taking account of the need for privacy for interviews or focus groups.

Prisons can be volatile environments where aggression and violence can occur although rarely at researchers. However de-escalation training before entering the prison environment may be helpful in ensuring that researchers do not contribute to any stresses for people living in prison and that they are able to keep themselves safe by effectively dealing with difficult situations in a constructive way. A lone worker policy should be developed for researchers who will be travelling or working alone, especially when the prison is in an isolated location and when travelling at night or early morning. This would typically include a commitment to telling an agreed-upon person of plans and the timeframe for prison visits.

### Infection and disease

Prevention of infection was a particular concern within prisons during the COVID-19 pandemic, which highlighted the heightened risk of disease transmission is closed institutional environments such as prisons. A study protocol should include appropriate hygiene measures to be followed to mitigate the risk of infectious disease transmission for researchers.

## CONSIDER THIS EXAMPLE

In the context of COVID-19, the **User Voice study** provided an important example of user-led research, involving 100 prison-based researchers during its conduct.[71] In their study, User Voice note some of the preventive measures which were taken, including social distancing and focus group facilitators wearing face coverings. In general, relevant local public health information should be considered when drawing up the risk assessment and followed.

### Psychological and emotional impact of doing prison research

Exposure to traumatic prison narratives, witnessing institutional conditions, or ethical conflicts may cause secondary (vicarious) trauma or moral distress for researchers. The emotional impact may be heightened within health-focused research, particularly when dealing with illness or death. While the primary trauma is experienced by the imprisoned person, it can also be emotionally difficult to attentively listen and appropriately respond to traumatic testimony.

Emotional impacts, including potential for distress, should be considered as part of the ethical application process and risk assessment, and measures should be put in place to prepare researchers through adequate training and through support and supervision during the study.

> ***“Support is required before you enter the prison site... [and] researchers should be trained to anticipate the emotionality of, and the emotional labour required, for their research”*** [72] (p2).

## CONSIDER THIS EXAMPLE

Psychological harm may occur as a result of the participants’ descriptions of their life experiences, or emotional fatigue resulting from undertaking extensive data collection within a short period.[73] Therefore, consideration should be given to working in pairs to prevent emotional exhaustion and fatigue. When conducting research likely to be emotionally taxing, it is recommended that a researcher distress protocol is developed, including mitigations such as keeping a journal to note any distressing issues and seeking support. Individuals transcribing qualitative data should also be alerted in advance about any distressing material.[74]

Debriefing and support are vital throughout the research process, through methods such as ‘Community of Coping’. [72] There are also likely to be emotional issues when a study is ending, such as ‘sadness and loss’, and so attention should be paid to support both for participants and researchers towards the end of the study, such as clinical or therapeutic supervision (see section 4.7).[70]

## KEY RESOURCES

**The Palgrave Handbook of Prison Ethnography**
(Drake, Earle and Sloan, 2015)[74]

### 3.4.3. Institutional and systemic risks

#### Data security

Sensitive health data requires robust protection against breaches that could affect participants or other stakeholders and violate privacy regulations. Consideration should be given to how data security will be preserved, particularly while in the prison setting.

#### Physical access

Researcher use of keys or fobs is an area of contemporary prison health research practice in which different opinions exist, including amongst the authorship of this guidance. As environments characterised by high levels of control and unequal power relationships, new researchers should consider carefully the practical and symbolic aspects of using keys. Prison research can be very slow, with the prison staff needing to unlock doors and arrange for participants to attend interview venues. Having keys or other methods of accessing areas with research participants can speed up and ease the process. However, it raises ethical issues such as responsibility for not only opening doors but also locking people inside, and practical issues such as inadvertently leaving doors open or losing the keys.

> ***“Carrying keys is convenient. It also, perhaps unexpectedly, may assist researchers become invisible within the institution. This time at any rate, it felt as though their jiggling presence at my side accorded me some legitimacy with staff and detainees alike. While I remain ambivalent about carrying them, I appreciate their symbolic if painful reminder of quite simple but profound questions about liberty, rights and belonging. Tools designed to lock people up should be uncomfortable to carry.”*** [75] (p1)

## REFLECTIVE QUESTIONS

- How will privacy and confidentiality be ensured safely for researchers and participants?
- What strategies can be put in place to minimise the risks of harm to researchers and participants?
- In what circumstances might a researcher consider reporting a concern to the prison authorities?
- In what circumstances might a researcher report the treatment of a person in prison, or the behaviour of a prison official, to an outside body?
- If available, what are the advantages and disadvantages of researchers having authorised forms of locking and unlocking doors and gates within the prison?

## 3.5. Institutional governance and approval applications

Conducting research in the prison setting requires institutional approvals to access participants who are imprisoned, and the approval process may be formal or informal. What these approvals consist of can vary greatly between correctional jurisdictions, between individual institutions, or even between security levels in the same institution. Some of the work in doing research with a new prison jurisdiction is determining where the approval needs to come from. It may be centrally organised, such as from decision-makers in a federal correctional authority, or arranged at the individual institution level, such as a prison warden or superintendent. Additionally, separate approvals from the relevant health authorities may be required. However the institutional approvals happen, be prepared for a multi-step process that can take a long time, usually considerably longer than an equivalent study in the community.

Institutional research approvals should not be confused with ethical review. These approvals may instead be centred more on acceptability, feasibility, and resource implications for the prison or correctional authority rather than ethics. While it is important to follow the details of the institutional approval application, it is important that the requirements do not violate ethical or methodological standards of research.

## CONSIDER THIS EXAMPLE

Reflections on institutional application and approval processes (including obtaining written sponsorship, building trust with operational staff and proactively considering oversight processes) are offered in **Negotiating the waves: Challenges of conducting in-prison and follow-up research with women**[76] and **Twenty years in prison: Reflections on conducting research in correctional environments**.[77]

## REFLECTIVE QUESTIONS

→ Who needs to be contacted to get the appropriate approvals?

→ What does the correctional authority or individual institution require to allow researchers to enter the institution and permit people who are imprisoned to participate in research?

→ Are there any requirements from the correctional authority that compromise any ethical or methodological standards or feasibility of the planned methods? If so, what could be done differently?

→ In the event of ethical or methodological issues, is there a process to request changes in the correctional authority's processes for consistency with best practices? Or is there a way to answer your research question in a different way that would be feasible from the perspective of a correctional authority and compatible with research ethics and standards?

## 3.6. Research methodology

### 3.6.1. Study design

Considerations of study design should include meaningful engagement of people with experience of imprisonment (as described in section 2.1). In addition, as with any research with humans, the study design should align to the research question and objectives. However, the prison setting introduces complexities. The constraints and control of the prison setting may mean that different research designs are more or less feasible than those conducted outside prisons. Two key considerations when planning a study design for research in prisons in addition to the usual consideration for any study, are:

1. **Access** – Will the study require access to people living in prison and if so, will this be face-to-face, over the phone, or by some other means? Or is it their data that is needed? How will researchers gain access to the setting, is security clearance needed for example?
2. **Privacy** – Are there any study designs that would result in others discovering confidential information, such as if there were correctional staff in the room when a focus group is happening, institutional recording of data collection through phone calls, or staff reading completed paper surveys or notes?

As in the community, quantitative research studies should be adequately powered and able to produce the most robust level of evidence possible. So, when testing interventions, randomised controlled trials should be considered first but given the constraints of the environment and ethical issues, other non-randomised study designs such as stepped wedge studies might also be considered when randomised controlled trials are not acceptable or feasible. Given the challenges of data collection in prisons, using administrative data and data linkages across multiple sources could generate valuable evidence at the population level and on multiple outcomes,[78, 79] which may be particularly informative when supplemented with primary data collection. However, in many countries, these data do not exist or are not available.

### 3.6.2. Participant recruitment

Health research in prison settings demands rigorous adherence to ethical standards, especially concerning voluntariness, equity, and the mitigation of coercion. People living in prison should be clearly informed that their participation is entirely voluntary, and that choosing to participate will have no impact on their legal status, sentence, treatment, or access to services. Given the risk of coercion in correctional environments – whether subtle or overt – this emphasis is crucial [80, 81]. Factors such as threats (for example of being placed in isolation) or inducements (such as better housing unit) to influence eligible people living in prison to enrol in a study by prison staff highlight these risks.[80] Prison administration should make available the necessary data for the researchers to conduct sampling (if used) and to access potential participants, but not be involved in selection procedures.

## REFLECTIVE QUESTIONS

- → Are the right research questions being asked, and how do we know?
- → Is the chosen study design optimal to answer the research question and objectives?
- → Although scientifically valid, does the design in any way compromise or expose participants to harm?
- → Is there another research method that can answer the research questions whilst minimising harm?
- → Do the study design and research aims maximise benefit to the study population as much as possible?
- → Can primary research designs benefit from integrating linked data?
- → Are there any elements within the prison that may impact the success of the chosen design?

## CONSIDER THIS EXAMPLE

The 1973 US National Commission considered "the contemporary realities of prison life, including conditions of social and economic deprivation and the possibility and even likelihood of manipulation or corruption on the part of prison authorities and prisoners in positions of privilege".[80]

#### Avoiding coercion and ensuring independence

Inclusion and exclusion criteria should be transparent and justified. The selection of participants should be protected from arbitrary intervention by prison authorities. If prison staff are involved in identifying or approaching participants, a clear and justified rationale should be provided. Building alternative recruitment pathways, such as peer referrals or community advisory boards, can help mitigate coercion and build trust.[65, 82]

#### Voluntariness and participant understanding

Understanding institutional culture is critical. Institutional culture significantly impacts recruitment and participation. Correctional settings exhibit power dynamics and informal sanctions (for example restricting access to services as punishment) which can skew voluntary participation or deter involvement altogether. Understanding these dynamics through preliminary field engagement (as discussed in section 3.3.1) is essential to designing ethical studies. Additionally, those with limited literacy or communication skills, and members of cultural minority groups, may face additional barriers to participation. Language and cultural sensitivity should be actively addressed to ensure equality of access. Recruitment practices and communication

To minimise the risk of any coercive influence, recruitment processes independent of prison staff should be considered. In some studies, alternative recruitment strategies, such as outreach through prison newspapers or approved communications to governors, have facilitated access. Advisory boards or peer contacts have also successfully helped connect potential participants with researchers, maintaining participant autonomy and trust.[65, 82] Researchers should consult the host institution's research governance and ethics policies, confirm whether guidance is in place, and ensure that their methods align with institutional requirements.[83] Recruitment materials should be transparent, accessible and institutionally approved. They should include:

- University or institutional logos and verified departmental contact details.
- A plain-language explanation of the study's background, aims, and questions.
- Justification for why individuals are being invited to take part.
- A clear statement that participation is voluntary, may be withdrawn at any time without penalty or reason, that it will not affect parole, trial, or treatment.
- A clear outline of what participation involves (duration, location, frequency, language).
- Multilingual materials, as relevant, for inclusion of participants with limited English proficiency.
- Researcher identification, where allowed, and a statement emphasising the right to withdraw without consequence.
- The limits of confidentiality.

### Inclusion, representation and sampling

Ethical research in prison settings should ensure that selection criteria are fair, inclusive, and reflective of the population likely to benefit from the findings.[82, 84] Selection processes should account for sociodemographic characteristics (such as gender or ethnicity), instrumental factors (such as literacy and language proficiency), and morbidity factors (such as disability or mental health conditions). Failing to identify social subgroups within the population can compromise the integrity and relevance of research, particularly in the context of publicly funded health studies conducted in prisons.[84] Convenience sampling is often necessary in prisons due to practical constraints but it should be transparently reported and justified, especially in settings where mistrust of researchers exists. Researchers should examine:

- Whether all potentially eligible participants are being informed.
- If certain groups are consistently excluded or underrepresented.
- Whether gatekeepers are influencing who is approached.
- The best way to address cultural barriers such as through community collaboration.
- Whether the use of advisory boards or peer advocates to support recruitment is appropriate.

### Equality of access and enabling participation

Conducting ethical health research with people living in prison requires deliberate strategies to ensure equal access and meaningful participation as well as enhance representation and strengthen the validity of research findings. Structural inequalities, institutional cultures, and intersecting vulnerabilities, such as language barriers, foreign nationality, limited literacy, and stigma can all limit the capacity of some individuals to engage in research.[82, 84] Excluding foreign nationals or individuals with limited English proficiency can result in missed opportunities to explore their unique experiences and may compromise the overall quality of the research.[84] Therefore, ensuring broad and inclusive access is not only a logistical concern but a core ethical obligation. Researchers should actively reduce barriers to participation and design studies that reflect the diversity of prison populations:

- Avoiding exclusion based solely on language, security classification or nationality.
- Providing translated materials and interpreters where needed.
- Building trust through culturally sensitive recruitment practices.
- Protecting the autonomy of participants and ensuring informed, voluntary participation.[80, 85]
- Considering the use of cultural mediators to upport comprehension and engagement.

Study materials and consent processes should be tailored to the literacy levels and linguistic backgrounds of potential participants. Transparency about rights, withdrawal, and the non-impact of participation on legal status is essential.[81, 86] To ensure equitable access and minimise bias, researchers should reflect upon the need to move beyond administrative convenience and embed social justice into recruitment strategies.[82, 87]

## REFLECTIVE QUESTIONS

→ Do study recruitment strategies effectively reach, engage, and support access for the target population?

→ Are there groups systematically excluded due to language, visa status, mental health, or other factors?

→ Has anyone influenced participant selection in ways that may introduce bias or reduce diversity?

→ Are there culturally adapted strategies to engage marginalised populations within the facility?

→ Is participation feasible for those in segregation, remand, or temporary holding units?

→ Are advisory or peer-led recruitment models available to reduce perceived coercion and foster trust?

### 3.6.3. Sampling strategy and power calculations

A key challenge in prison settings is to use a sampling strategy that incorporates a representative sample of the population being studied and that also protects the anonymity of participants. Researchers should use sampling methods that are feasible and plausible within prison settings. The sampling strategy should be equitable and based on scientific merit and research needs, not on ease of access, vulnerability, or social status within the prison (see section 3.6.2).

Sampling strategies should be equitable and avoid systematically excluding or over-representing certain sub-groups of the prison population unless scientifically justified (such as specific age groups, ethnic minorities or those with specific health conditions) so that the benefits and burdens of the research are fairly distributed, and findings are relevant to the diverse prison population. Likewise, the sampling strategy should address linguistic and cultural diversity among imprisoned individuals, emphasising the ethical imperative to make reasonable efforts for inclusion rather than exclusion, and the implications for generalisability if specific groups are excluded.

Researchers should be transparent about their sampling methods and ensure fairness and justice in participant selection and data analysis and include robust justification process for any exclusions, acknowledging the trade-offs between feasibility and representativeness. Sampling strategies should be defined or supervised by the research institution conducting the study, rather than by the prison service administration, to minimise the risk of bias.[88]

Qualitative studies involving imprisoned individuals should consider an appropriate purposive sample in a way that ensures inclusiveness, and voluntary agreement.[89]

## REFLECTIVE QUESTIONS

→ Does the research provide equitable access to opportunities and benefits of participation?

→ How is recruitment bias minimised?

→ Is the sampling method equitable? Will it avoid systematically excluding or over-representing certain subgroups within the prison population unless scientifically justified?

→ Are there any "convenience" factors in the sampling that might inadvertently lead to a biased or unrepresentative sample, and if so, how will this bias be acknowledged and addressed?

### 3.6.4. Reimbursement

Guideline 13, Reimbursement and Compensation for Research Participants, in the **International ethical guidelines for health-related research involving humans** should underpin consideration of reimbursement and compensation for imprisoned research participants.[6] Blanket bans on reimbursement and compensation for research participants in prisons are neither acceptable nor ethical. However, in many countries, prison authorities do not allow reimbursement or compensation of any kind.

What might be considered 'reasonable reimbursement' or 'reasonable compensation' needs careful consideration in the prison context. Sums of money that would be considered small in the community could be large in the prison economy where imprisoned people often undertake paid work at rates much lower than minimum wage rates in the community. Therefore, a sum that would be viewed by potential participants in the community as reasonable compensation might be perceived as undue inducement by an imprisoned person.

Reimbursement of costs directly incurred during participation might include a financial payment if a participant is taking time out of paid work to participate. The sum reimbursed should be equivalent to the sum lost because of research participation.

Compensation, which can be either monetary or non-monetary, requires careful consideration and an understanding of the prison environment. Certain materials might hold great value in prison environments and could therefore be viewed as undue inducement rather than compensation by potential participants. Facilitating access to training, qualifications or skills has been used as an alternative form of compensation.

Ensuring appropriate reimbursement and compensation requires knowledge of the local situation and careful discussions with the appropriate authorities and people with lived experience of imprisonment. In situations where researchers have been prevented from providing recompense of any kind to participants, researchers have instead:

- Sent a letter of gratitude to participants.
- Asked participants if they wanted the research team to donate an honorarium on their behalf to a not-for-profit organisation.
- Sent participants a certificate of research participation with the relevant university logo.

## REFLECTIVE QUESTIONS

→ Is the study ethical if it is not possible to reimburse participants and provide reasonable compensation?

→ What is fair reimbursement and compensation for study participation in this specific prison setting?

→ Have reimbursement and compensation plans been discussed and agreed with all appropriate authorities and individuals?

# 4

# Conducting research

## 4.1. The prison environment

When considering the conduct of health research within prisons, emphasis should be placed on flexibility, responsiveness, contextual awareness (including understanding of innate power dynamics), building rapport and trust, and navigating conflicting priorities between research and prison operations. Navigating the tension between research goals and custodial priorities is a continuous balancing act. Ethical and effective research depends on sustained negotiation, cultural competence, and the ability to work within (and sometimes against) the constraints of the prison environment.

Conducting research in these settings requires an understanding that access, timing and methods are often shaped by the operational demands of the institution (such as scheduled activity, meals, lockdowns and staff availability). Researchers should be prepared to adapt their approach in response to unexpected operational issues which will take priority and could limit the time they have each day to conduct the research. This is likely to impact both the study design and planned timeline of research activities. Researchers should be clear about how their study design can be flexible and adaptive but maintain ethical considerations and scientific integrity. Additional time should be factored into each research activity, and timeline feasibility should be continuously monitored.

As previously noted, relationship-building between researchers, research partners in prisons and participants can be valuable. Researchers should explore opportunities to build rapport and gain trust prior to undertaking data collection. Gaining the trust of both staff and people living in prisons takes time, consistency and a respectful, person-centred approach.

Researchers should take time to understand the institutional hierarchies and routines that shape daily life within each specific prison. Prison research usually requires some level of resource from operational staff or management, such as providing escorts to researchers or research participants, providing training on safety or other protocols, or providing infrastructure or venues for research activities. Researchers should be clear about the resourcing required and how this may impact daily routines (such as disrupting programs that the people in that prison may favour) and the perceived affiliation of researchers to the prison administration.

### REFLECTIVE QUESTIONS

- → What is known about the specific prison facility and how does it differ from other facilities?
- → What does a typical daily routine look like in this prison?
- → What are the regular staffing shifts and responsibilities, and how might research activities impact on these routines and staff responsibilities?
- → Who could act as gatekeepers, and who could act as supporters or advocates for the research?
- → How can rapport and relationships be built with people living in prison and staff prior to data collection?
- → What resources are required from the prison service and staff for the research activities to go ahead?
- → How will research activities be adapted if impacted by operational changes? For example, to what extent can research timelines and design be flexible?
- → How should accurate information be communicated to research partners?
- → Are there existing communication channels that could be utilised?
- → Have operational constraints and ethical sensitivities specific to the environment been considered?

## 4.2. Obtaining free, uncoerced and informed consent

Anyone participating in research must make a free and informed decision to do so (provide consent). In a prison setting, care should be taken during the consent process to ensure participants have the capacity to consent, do not experience coercion and their decision is appropriately documented. The approach to these factors should be considered in the research design and detailed in the protocol (section 3.2).

### 4.2.1. Capacity to consent

Researchers should always ensure that each participant has the capacity to consent and that an appropriate method of obtaining consent is used.

Research with people without the capacity to give informed consent (such as people with dementia) requires careful consideration and additional safeguards in the community.

However, in the inherently coercive prison environment, such research should not be undertaken by people new to research in prisons. Contributors to this guidance shared grave ethical concerns with the imprisonment of people who lack capacity (such as those with severe mental impairment). This has implications for the conduct of research in these populations.

Contributors to this guidance held different opinions about whether people without the capacity to give informed consent should be included in prison health research at all and were unable to reach a consensus on this complex matter. Whilst research considering these populations is rare, it is important to acknowledge and respect this diversity of opinion. Expert contributors were united in the view that people new to prison health research should not undertake research people without the capacity to give informed consent. They were however unable to reach a consensus on whether people without the capacity to give informed consent should be included in prison health research at all, even with the involvement of experienced prison health researchers. Therefore, we do not endorse one approach but present both sides of the argument to enable those using this guidance to reflect carefully.

Some contributors were emphatic that people who lack capacity are especially vulnerable and in prison – a coercive, rights-restricting setting in which power imbalances are amplified and conventional safeguards may not sufficiently mitigate coercion. Their inclusion in research may exploit their vulnerability. Therefore, given there are alternative ways to study these conditions (such as observational service-level data, or research conducted in non-prison environments), the principle of autonomy should be respected at this unique intersection of vulnerability, and if a participant cannot provide fully informed consent, they should not participate. Hence, no exception from personal informed consent should be made in research in prison, and research on people lacking the capacity to consent should exclusively be done in environments where coercion is not a feature.

Other contributors took the view that a blanket exclusion of people in prison who lack capacity would be disproportionate and risk erasing the experiences and needs of some of the most vulnerable people in custody. Complete exclusion might mean that important questions about such as prevalence and effective service design go unanswered, which could result in data gaps that perpetuate health inequalities and deny access to appropriate care, thereby being detrimental to the very people we are trying to protect. Therefore, their view was that research involving such people would be ethically permissible in very limited circumstances with robust safeguards that specifically counter the coerciveness of the prison environment, such as:

- Strict necessity – that the question cannot be answered with capacity-giving participants or in non-custodial settings and the research is designed specifically for their benefit.
- Minimal risk and clear, direct potential benefit to the participant group – exceptions are only made for observational, non-invasive studies that seek to benefit the group and never research that poses more than minimal risk.
- A consent pathway aligned with capacity law. For example, obtaining permission from a family member or other responsible adult, such as a caregiver or guardian, independent of the custodial chain, with ample time for explanation and reflection, might be considered alongside modified communication methods or consent processes, such as ongoing consent or assent. Prison staff should not act as a responsible adult for research purposes.
- Independence – research leadership, governance and advocacy clearly outside operational prison hierarchies.
- Enhanced protections in practice – continuous monitoring of voluntariness, ongoing assent where meaningful, an uncomplicated right to withdraw, and routine involvement of independent advocates.
- Strengthened ethics oversight, including a research ethics committee with prison and capacity expertise and proactive monitoring.

Where these conditions cannot be met, the research should not proceed. Again, it is stressed that people new to prison health research should not undertake research with people without the capacity to give informed consent.

Given the absence of a clear consensus, it is advisable that future studies employ rigorous approaches, such as scoping reviews, consensus-building methods, or Delphi studies, to provide more directive and actionable recommendations. These approaches can help map the range of ethical positions, identify areas of agreement, and clarify where safeguards are most critical.

### 4.2.2. Informing the decision to participate

It is essential that people participating in research are aware of their rights as well as the risks and benefits of involvement. It is important that researchers explain to participants what research is and what role it plays in affecting policy and practice, as well as the detail of the actual research project at hand. In this way participants will understand the context in which research takes place and be better able to make an informed decision about consent.

Researchers and their institutions are primarily responsible for communicating this information honestly in an accessible, comprehensible and appropriate way for participants throughout the research. Researchers should consider carefully how this information is communicated, for example the language or medium used, such as written or oral communication, should be appropriate to the participants and their cultural and educational background. Participants should be aware, and should be reminded, that they can withdraw from the study at any time, without any consequences for them and without giving a reason. They should also be made aware of how to withdraw their data from the research and any limitations regarding data withdrawal.

## KEY RESOURCES

Useful information that can be included in a consent form can be found in University of Oxford Central University Research Ethics Committee's **Research involving staff or offenders in UK prison establishments or under supervision of the Probation Service.**

### 4.2.3. Obtaining uncoerced consent to participate

The prison environment restrictions upon liberty detrimentally influence the principle of free, uncoerced, consent. However, respecting individual autonomy is paramount and even in detention settings individuals should be able to make decisions related to their rights. Care must be taken to ensure that participants are not unduly influenced or coerced into research participation and that they understand their right to ask the researcher questions about participation. It is crucial for the safety of those involved and the integrity of the research that participants understand that participation, or lack of, will not have any impact on their sentence, parole or status within the prison – which should be part of the approved informed consent documentation. Researchers should also ensure that any benefits or incentives associated with research participation (if permitted) do not unduly influence people's decision to participate, overriding other considerations. This could be facilitated by seeking independent oversight when obtaining consent. During prolonged research, periodic consent renewal might also be considered.

### 4.2.4. Documenting consent

The process for documenting participants' informed consent (for example written, oral or a mixture of both) should be adapted based on factors such as participant literacy, study methodology (for example recorded telephone interviews) and risk to participant anonymity, and outlined in the study protocol (section 3.2). The Helsinki Declaration indicates that if "consent cannot be expressed on paper or electronically, the non-written consent should be formally witnessed and documented." The method of obtaining and recording consent should be part of the information provided and agreed to by participants.

## CONSIDER THIS EXAMPLE

**"Teach-to-Goal" to Better Assess Informed Consent Comprehension among Incarcerated Clinical Research Participants** describes how modified informed consent processes can be used to assess comprehension of study materials and informed consent document and help people living in prisons better understand the risks and benefits of their participation in research.[8]

## REFLECTIVE QUESTIONS

- → How will participants understanding of the nature of the research and their rights be ensured?
- → Could willingness to participate be unduly influenced and how will this be mitigated?
- → Does the informed consent process reflect participants' cultural, literary or educational needs?
- → Have modified processes for obtaining consent been carefully considered, if required?
- → Has the consent process been approved by a research ethics committee?
- → How will capacity to consent be determined?
- → Is a process in place to address fluctuating capacity, if appropriate?
- → Has the participant's consent been appropriately documented?

## 4.3. Participant safety and wellbeing

> ***"It is the duty of [those] involved... to protect the life, health, dignity, integrity, autonomy, privacy, and confidentiality of personal information of research participants. The responsibility for the protection of research participants must always rest with physicians or other researchers and never with the research participants, even though they have given consent."*** [5 (p1)]

### 4.3.1. Trust and rapport

Participants should be treated with respect, fairness and equity. When conducting research in a prison setting, it is important to understand that many people living in prison may have experience of maltreatment. Some participants might distrust healthcare and prison staff,[87] or experience more widespread distrust of others. This means that it is particularly important to work towards building trust and rapport and transparency within the research relationship. Prior to conducting the research, researchers should read as much as possible about what life is like in prison from the perspective of those who have experienced imprisonment. Researchers could engage with people's personal accounts of prison and testimonies relating to prison life and the prison experience. Engaging with this material can allow researchers to gain an insight of the prison experience, develop their approach to best practice when interviewing people in prison, and to build empathy and solidarity.

Researchers should stress their independence so that participants understand that the nature of the researchers' relationship with the institution differs from the nature of the relationship for institutional staff.  Researchers should work towards establishing rapport by engaging with participants as equals, finding common ground, adopting a person-centred approach, being adaptable and fostering an open dialogue,[91] whilst being mindful of over-disclosure of certain personal information. Just as in the community, sharing stories and finding common ground with others is positive, but it is important researchers reflect on what they feel comfortable sharing.

## CONSIDER THIS EXAMPLE

This example from an ethnographic study demonstrates how researchers can build rapport and relationships with people living in prison and prison staff prior to formal data collection activities. However, it is acknowledged spending this much time or performing these activities may not be acceptable or feasible in many prison contexts or for many researchers:

> *"The researcher spent around five months visiting the prison… meeting [imprisoned people] and staff and learning about prison life… with the objectives of becoming accustomed to prison life and the regime, overcoming personal fears and prejudgements and becoming increasingly socially engaged with research participants… Prolonged periods were spent by the researcher in the prison, often playing pool, darts or board games, watching television or spectating at outdoor football and softball tournaments between the wings. This also involved making tea for the wing officers, thereby enabling the researcher to chat informally with them, listen to gossip and arrange meetings with new contacts. The level of trust built up with staff enabled the researcher to move about the prison unmonitored, abiding by certain rules concerning personal safety and security. It meant that the researcher was able to access staff and [imprisoned people] at short notice and use certain contacts to check out information gleaned from discussions and interviews."*[92] (p120)

### 4.3.2. Power imbalances

Researchers should be aware of and have an understanding of the power imbalances inherent in prison settings and how they influence interactions between researchers, participants and prison staff.[91]  Researchers should try to mitigate power imbalances by positioning themselves as a learner and acknowledging participants' expertise.91 Power dynamics present in prisons underscore the importance of obtaining uncoerced involvement as discussed above.

### 4.3.3. Trauma informed practice

As noted in section 2.5.3, researchers should engage in trauma-informed practice when they are working with people living in prison to minimise the risk of inadvertently re-traumatising participants.[93] Prior to undertaking research, take time to learn about trauma-informed research practice and consider how best to apply within the parameters and constraints of a prison environment. Consult trauma-informed qualitative research guidelines for designing and implementing trauma-informed qualitative studies. Before conducting interviews, take time to understand how trauma affects individuals, the way they navigate the world, social interactions, and ways in which the prison environment impacts people's trauma. Trauma-informed research does not mean shying away from asking difficult questions or discussing sensitive subject matters.  It is about taking the time to understand how to try to foster a safe and trusting space in a prison environment, so that the participant feels secure and confident in sharing their story.[93]

Researchers should ensure that participants understand that they have the right to choose what information they share. Remind each participant that there is no pressure for them to speak about anything they do not want to, and that they are free to decline answering a question. They should feel empowered to stop a conversation if they want to, for example if they are finding it distressing. Before the research conversation, participants should be reminded that they are free to say "can we move on" for any topic or question that may be triggering or difficult to answer. Researchers should remind participants that it is okay to pause the interview or stop the interview completely if they feel overwhelmed at any point. There should be a safeguarding protocol in place to manage participant distress and ensure their safety during and after the research.

Researchers should always be mindful that they are working within a prison environment, and participants will have to return to their cells once the research has concluded. Once the interview has come to an end, it is important to engage in post-interview follow-up care if feasible. Researchers should spend a little time with the participant and check-in with them as to their wellbeing, signposting to sources of additional support within the institution if appropriate. Try to end on a casual or positive note, perhaps by thanking participants for their time and reiterating the importance of their contribution.

The researcher has a duty of care and should ensure that appropriate people are made aware of any safeguarding concerns that arise during the research visit. This could be immediate participant safety issues or serious concerns about the participant's health and wellbeing (such as intention to self-harm). Researchers should not withhold information that could have serious implications for the participant. Safeguarding protocols should be discussed with the participant to ensure they understand what a researcher's duty of care entails, including situations in which safeguarding concerns must be raised and the reasons behind the researcher's decisions.

### REFLECTIVE QUESTIONS

→ What do I know about the experiences of people living in prison?

→ How will engaging with testimonies of those with prison experience shape research practices?

→ What do I know about power imbalances in research and power-sensitive communication?

→ What do I know about trauma-informed practice?

→ What preparation has been undertaken for interviewing people who may have experienced trauma, discrimination and marginalisation?

→ What safeguarding protocols will be implemented prior to the interviews?

→ Could this research result in physical or emotional harm for the participant or researcher?

→ How will I practice ongoing self-reflection concerning my position as a researcher?

→ How have the risks of emotional harm for participants been considered and mitigated?

## 4.4. Researcher safety and wellbeing

Researcher safety should be considered thoroughly in advance of any research (as covered in section 3.4.2). However, it is possible that during research, events may occur that were not foreseen or could not be planned for. It is therefore important that researchers are prepared to address risks that may arise outside of the protocol and that procedures are in place for regularly revisiting ethical considerations in response to practical challenges or significant contextual changes that may occur during the research. In the prison setting, a researcher may face ethical dilemmas because they must simultaneously maintain effective relationships with individuals living in prison and prison staff, safeguard participants from harm, and achieve specific research objectives.

### 4.4.1. Monitoring risk assessment and safety plans

The risk assessment conducted before undertaking research in a prison (section 3.4) should detail how the research team will recognise indicators of threat from the environment, identifying escape routes, and informing prison officials or gatekeepers of their schedules and when to expect the researcher's return. During research, the researcher should also maintain a point of contact outside the prison setting, so that if they do not call at the specified time, the contact person will be aware that something is amiss and take agreed-upon action. The employer or research manager also should ensure that there is additional ongoing formal interaction between the academic institution and the prison administration to officially ensure that researchers have safe access to the prison.

Legal issues may also arise during the conduct of the research in prison settings.94 Researchers should be familiar with current prison rules and procedures related to materials, behaviour and access. They should complete ongoing relevant training as required to remain up to date, recognising that policies and practices may evolve since research protocol approval.

### 4.4.2. Professional boundaries

While rapport building is crucial, the researcher should establish limits on sharing personal information and find a balance between risk and relationship building. During research, professional boundaries are necessary to protect researchers from the risks associated with oversharing. They also ensure that the participant clearly understands the limits of the research relationship.

### 4.4.3. Measures to minimise psychological impact

Researchers should be prepared to face emotional challenges when they are conducting research in prisons. Listening to the experiences of people living in prison can be upsetting, sometimes shocking or distressing, and in some cases lead to secondary trauma. A protocol should be in place to help researchers to actively manage the emotional dimension of the research relationship. During the research process, researchers should reflect on their emotional limits and maintain realistic expectations of what they can achieve during a prison visit. Debriefing sessions with supervisors or peers can offer a space to work through the emotional challenges of working in a prison environment. Researchers should consider keeping a reflexive journal to document their emotional experiences, allowing them to critically reflect on the impact of the research on their emotions and vice versa.[72] There should be an established support system, including access to mental health resources, to help researchers deal with the emotional impact of the work, if needed.[95]

## REFLECTIVE QUESTIONS

- → What are the risks that one might face within the prison environment during the conduct of research?
- → What personal boundaries do the researcher need to set while working in prison environment?
- → Does the researcher have a support system in place to follow in case of risks to safety and wellbeing?
- → Who should the researcher contact if there is emotional distress resulting from the data collection?

## KEY RESOURCES

The Social Research Association ***Good practice guides*** (2025) provide valuable information including on **Safety for Social Researchers**.

## 4.5. Respect for privacy and confidentiality

Managing privacy and confidentiality in prison health research requires sensitivity and the establishment of clear protocols for confidentiality limits and reporting requirements.96, 97 Participation in research should be entirely voluntary and confidentiality should be strictly maintained before, during and after their participation. Whilst participants may choose to self-disclose, for example for contribution recognition, researchers are responsible for ensuring the identity of participants and their data collected during the research are protected. It is also important to avoid any potential disclosures to a person in a position of authority or on whom the participant may need to rely for assistance, or risk re-identification for research participants. For example, whilst prison staff may need to facilitate survey or interview attendance, prison authorities should not be aware of who was interviewed or refused to participate in the research, as well as the individual research results. Using anonymised questionnaires collected like voting ballots may be one way to obtain such sensitive information confidentially. If the research is being led by or involves a health care provider in the institution, researchers may not even know or have direct dealings with participants to avoid conflicts or concerns that participation may affect access to services. Ultimately, human rights must be upheld in accordance with international standards.

### 4.5.1. Setting expectations and mandatory disclosures

The purpose, methodology and intended use of the research findings should be clearly explained and researchers should ensure that participants have understood this information. This is particularly important given that research can be unclear or difficult to understand, even for native speakers and those without literacy issues.98 Participants should also be informed that, while the data may be analysed externally, no personally identifiable information will be shared. Researchers should also mitigate the risk of compromising confidentiality if qualitative findings contain substantial information, particularly in cases involving uncommon or unique conditions.[89]

Despite the importance of privacy, there may be limits to confidentiality, particularly in cases involving risk of self-harm, suicide or criminal activities, such as terrorism, drug trafficking or other serious threats. Requirements to disclose may be influenced by national laws, as well as ethical principles. There should be a protocol in place to guide the researcher on how to respond if a participant reveals information about a crime during a research visit. Information sheets and consent forms should make clear the circumstances in which confidentiality will have to be breached and researchers should clearly communicate these limitations, both in writing and orally, before the research begins. Any such cases should be addressed on an individual basis, with minimal and exceptional use of disclosed information.

> ***"[I]t was not possible to guarantee participants' privacy or confidentiality on phone calls or in mail sent to or from the prison system, and we explicitly acknowledged this risk in study information and consent materials."***[83 (p5)]

### 4.5.2. Ownership of confidential materials

Completed consent forms should be kept solely by the researcher and not disclosed to prison authorities. These forms should specify the duration of data storage and provide contact information for any queries regarding data protection (section 5.2). Researchers may follow templates aligned with data protection standards. Research methods should also safeguard privacy. For example, paper-based surveys could be returned in unmarked envelopes and placed in secure boxes, while digital interviews should be encrypted and inaccessible to third parties. If interviews are recorded, access should be restricted exclusively to the researcher. At the same time, participants should be protected from potential harm resulting from the disclosure of personal information. Research participants and members of focus groups should be asked not to share others' comments.[99] Participants should be informed of all benefits and risks associated with being cited as research contributors, including potential identification in prison and post-release, before being offered the opportunity to be publicly acknowledged.[46] If they decline, research findings should be published anonymously, without names or identification numbers in any outputs or questionnaires.

### 4.5.3. Safe, private and confidential environments

The research setting should support confidentiality; however, the researcher should consider the impact that prison environment restrictions will have on the research process through the use of reflexivity. During data collection, prison staff should be absent or, at the very least, remain at a distance, and no recording devices should be present without the participant's explicit consent.[87] Research should be conducted in a secure and private room. Interviews or focus groups should take place in settings where participants feel most comfortable and where both the participant and the researcher feel safe.

**REFLECTIVE QUESTIONS**

→ How will the anonymity of individual participants be protected?

→ Could the description of findings lead to inadvertent data disclosure or be stigmatising?

→ Does the research team know when confidentiality should be breached, for example when an intention or harm is disclosed?

→ If private interviews are not permitted, can participants give meaningful informed consent knowing that staff may overhear their responses?

→ If participants' answers could place themselves or others at risk, will interview questions need to be adapted to ensure safety?

**KEY RESOURCES**

The **European Questionnaire on Drug Use among People Living in Prison (EQDP) Methodological Guidelines** offers detailed guidance on conducting drug research in prison settings and include tools and checklists which comply with European Parliament General Data Protection Regulations, which represent best practice in the field of privacy and data protection.

## 4.6. Member checking and participant validation

Member checking, also known as participant validation, is a method used to enhance the transparency and credibility of research findings. Researchers present preliminary results to participants to evaluate and assess the accuracy of interpretations and to rectify misunderstandings. Researchers who do not validate their findings risk misrepresenting or misinterpreting participants' voices and experiences. This can unintentionally reinforce stereotypes, overlook nuances, or present oversimplified or erroneous conclusions that may be far from the participants' experiences or realities. Researchers should examine and mitigate potential emotional impacts on the individuals involved in the validation process by providing access to support services or allowing participants to opt out of reviewing specific content, if necessary.[100]

Member checking serves to verify that participant voices are appropriately represented and confirms their approval for the use of interview quotations. This can contribute to the credibility of preliminary study findings by addressing misunderstandings and accurately portraying participants' opinions and experiences.[101] However, member checking feasibility in prison settings may be impacted by institutional restrictions, participant transfers, or participant release from prison. In such cases, researchers may consider alternative methods, such as reflexive journaling or peer debriefing, to minimise researcher bias.[101, 102]

## 4.7. Closing and leaving research projects

Once data collection is complete, it is important to close or leave prison health research projects in a way that is ethically sensitive and trauma-informed. Drawing on the concept of "researcher departure ethics," there is an emotional weight and ethical responsibility that come with ending research relationships in prison settings.[70] People living in prison often carry complex histories of trauma, loss and marginalisation, and for some participants, withdrawal from their lives could risk replicating patterns of abandonment. A trauma-informed approach recognises the power dynamics at play and consciously resists extractive models of research. Instead, it is important to consider sustained relationships, collective meaning-making and ethical closure that honours participants' voices and dignity.[45, 70] It is also important when leaving the research relationship to have a process in place to facilitate the dissemination of research findings to the study participants (section 0), and ensure follow-up support is available if possible and desired.[46]

# 5

# Post-research responsibilities and provisions

Prison health research interactions should not end after data have been collected and published. Researchers should return to their rationale for conducting the research, consider how the findings will be communicated and identify any ongoing responsibilities to those involved and to the overall impact of the research.

## 5.1. Participant and research aftercare

In prison health research, participant and researcher aftercare remains a relatively neglected but vital area to consider. Where possible, foreseeable consequences of conducting prison health research should be planned for and mitigated at the outset (section 3.4). Aftercare strategies that are co-designed with participants, supported by institutions and guided by trauma-sensitive practices should be systematically integrated into projects where possible to protect the dignity and wellbeing of study participants and researchers conducting prison health research.

### 5.1.1. Participant aftercare

Projects should consider developing a source of support sheet to give to participants for reference after any data collection has taken place. Additionally, should a participant become distressed during an interview or focus group, care must be taken to ensure that the participant can access appropriate support after the researcher has left (as discussed in section 4.3).

Examples of support can be broad from formal mental health support services to self-guided grounding and mindfulness exercises for example. Where people living in prison have access to digital resources many more options for potential support are possible through online support services. Researchers should consider how people in prison will access sources of support such as telephone or digital services, especially if there are associated costs or prison imposed restrictions. Support sheets should be developed by researchers in consultation with prison institutions and with any community-based organisations that deliver programs, particularly with prison healthcare providers, and indicate sources of support currently available within the prison setting. This might include signposting support services available in the community if people living in prison are able to access them. If necessary, funding should be included for participants to access counselling or other support services not available in the prison setting, should participants become distressed after they have participated in a research project.

Availability of post research support should shape the design and implementation of the study. For example, if a project is exploring a sensitive topic (for example drug use, bereavement or suicide in prison) and the research team believes that support available after data collection would be inadequate, this might mean that it is not ethical to conduct a study at all. Researchers should liaise closely with prison health colleagues and prison staff, and talk to senior colleagues regarding the most appropriate course of action, putting participant harms and aftercare at the centre of all considerations.

### 5.1.2. Researcher aftercare

As noted in sections 3.4.2 and 4.4, undertaking research in prison can be challenging and upsetting, and the impact of this can last long after data collection has been completed. Research leaders should check in and conduct a debrief conversation with researchers after any data collection in prison. This is to ensure that researchers are okay, and that they can discuss anything that they found challenging or upsetting.

Burnout is foreseeable and common in prison health research so mitigation measures should be included in research protocols (section 3.2) to prevent this. Funding should be allocated for researcher mental health support and counselling, should this be required, and information about available employer or partner institutional support should be present throughout. Training on issues such as vicarious trauma and grief should be considered to further protect researchers and provide them with the resources to identify and address it if they are struggling with any consequences from conducting the research.

### REFLECTIVE QUESTIONS

→ How should research relationships be maintained after data collection?

→ How long should researchers remain contactable by participants?

→ What resources could support participants if they experience emotional or other harms?

## 5.2. Data protection and retention

It is important that the principles of data management and protection are upheld beyond the end of the study, as for any piece of research. However, it is particularly important in such populations where identification is possible, to be mindful of how the data are handled and potentially archived. This includes following the relevant national or other applicable guidance for data protection or best practice where applicable. Additionally, it includes the institutional procedures of partner organisations (academic, industry or otherwise), for any establishment where the research was conducted (prison or similar centre) or where accompanying data were extracted from. It is possible that these may have alternative requirements, such as data retention periods, but it is important to follow all requirements of establishments where data have been shared.

Researchers should take reasonable steps to preserve the confidentiality of participants, their families, and other associated individuals.[103] It is best practice to de-identify or pseudonymise the research data if not already done so, unless there is a good reason to retain the identities of the participants. If possible, anonymisation is always the safest way to protect identities. If identifiable information is no longer required, it is best to destroy this data to prevent any avoidable data breaches. Internal confidentiality or 'deductive disclosure' to protect anonymity should also be considered. This could involve changing names or perhaps the type of health conditions of participants if they are within a narrow scope and increase the chance of identification. Specific conditions may carry increased sensitivity and stigma if shared, so it is important to take protective measures.

### CONSIDER THIS EXAMPLE

**Scraping the Web for Public Health Gains: Ethical Considerations from a 'Big Data' Research Project on HIV and Incarceration** offers information and reflections on how data protection and retention can be considered, including for research involving novel publicly available data extraction methods.[49]

The researcher or research agency is responsible for secure storage and handling of all primary data (such as transcripts, audio tapes and video tapes). Care should be taken to ensure confidentiality of participants within audio and video recordings. Audio recordings should be deleted from the audio recorder between prison visits (if there are multiple visits to the research site) to prevent inadvertent disclosure of any data. At the close of the study, if recordings have been transcribed and it is appropriate to do so, the researcher may consider destroying these original recordings if no longer needed. If it is necessary to retain them, they could be labelled with code numbers and date only and kept in a secured or encrypted format. Electronic devices such as laptops, tablets and mobile phones should also be password-protected and encrypted.

If other researchers or stakeholders request to use the data, it is important to understand the extent to which data can be 'reused' and the regulations on how long this is possible, by whom and for what purpose. If researchers do intend to disclose results to anyone outside the research team, this should be made clear at the outset of the project in the participant information sheet or script and must have approval of the research ethics committee. Participants should also have consented to other parties seeing or using their data beyond the scope of the study, and there should be a clear justification.

Researchers should be aware of any relevant institutional or national data protection regulations or legislation guidelines, or those to do with research data management and regulations outlined in data sharing agreements (or similar).

### REFLECTIVE QUESTIONS

- → What is the earliest time that the data can be anonymised or pseudonymised?
- → Could participants be easily identified if the data were accessed?
- → What strategies can be used to mitigate the risk of inadvertent data disclosure/breaches?
- → How will the data be retained in a secure setting with access restricted?
- → Are all relevant data protection laws and guidelines being followed?
- → Are relevant approvals in place for this, including consent from the participants, for data reuse?
- → How long should data be retained for before it can be destroyed?

## 5.3. Transfer of knowledge

The transfer of knowledge can be defined as the "dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge… to improve health, provide more effective health services and products and strengthen the health care system".[104] (p1) Knowledge transition also supports the development and application of feasible and effective research.

### 5.3.1. The transfer, not dissemination, of knowledge

People living in prison should benefit directly from research they participate in, and research results should be published and publicly available.[5] There is growing recognition among prison researchers for the translation of the best available evidence into practice rather than deferring action pending further research.[105] This shift recognises the pragmatic need to solve pressing issues in criminal justice with the best available evidence.[105, 106] Therefore, the primary challenge is no longer the availability of research but rather the translation and implementation of this knowledge.[107]

Developing practical advocacy materials such as synopses and briefs tailored to policymakers and practitioners may effectively inform criminal justice policy and practice.[108] These advocacy materials could be accessible and rich in practical, policy-relevant information, presenting clear results and actionable recommendations.[109]

### 5.3.2. Returning research findings to research participants

To ensure the ethical conduct of health research with people living in prison, it is best practice to return research findings to participants, allowing them to engage with and respond to the study's findings and outputs and share the work they were involved in if desirable. Participants should be informed of the research dissemination plan at the outset.

Researchers should be aware of the added complications when considering returning research findings to participants in prison settings, given the provision of physical or digital materials to people who are imprisoned as well as the movement of people around prison systems, and people being released and thus difficult to contact in the community.

Additional considerations are necessary when returning research findings in prison settings, taking into account diverse language, educational, and literacy needs as appropriate. It should not be assumed for example, that participants have a high level of reading comprehension, so in some instances the translation of research findings will need to be undertaken. A summary of research findings, using plain language could be developed and shared with participants.

Study findings, for example, academic papers with a covering letter, should be shared with participants if participants have indicated that they would like to see such outputs. This is another opportunity to thank participants for their contribution. If posting research outputs to people living in prison, consider including a pre-paid envelope so responses can be returned without any cost to the participant. Participants should then be given a specific timescale to respond to ask any questions that they might have and a realistic means of reaching the research team (emails remain inaccessible for many people living in prison).

Sharing research findings via non-academic written sources available in a prison system can also be an inclusive means of returning research findings, such as in prison newspapers if available or via places in the prison such as clinics or common areas, with events held to share or discuss research results. Ensuring participants can meaningfully engage with and reflect on project outputs that include aspects of their narratives or data demonstrates trustworthiness and could also give people living in prison more confidence to participate in any future research.

### CONSIDER THIS EXAMPLE

Following the end of a project analysing the experiences of transgender people in Scottish prisons the paper and a covering letter were sent to all participants, although a year after data collection.[110] However, by then almost half of the participants had been released or had been moved to other prisons, creating problems for the extent to which participants were able to engage with this key project output. Additionally, one participant did have questions about how their narrative had been portrayed. Consequently, a meeting was arranged well over a year after data collection, at which it became clear that the participant wanted their name and the name of the prison they were in to be more explicitly included. However, given the commitment to anonymity this wasn't possible, which created some frustration. This example is not intended to dissuade researchers but outline the ways in which prison settings can make representing and sharing research findings challenging. Additionally, this example illustrates the significant resource implications of engaging participants to validate and returning research findings.

### Creative methods and returning research findings

Creative methods might be explored to share research findings in visual and verbal formats, given that academic outputs are not always overly accessible. For example, researchers might consider recording a podcast outlining the findings of their study, while ensuring that participants can access this. Additionally, researchers might agree to discuss research findings on prison radio platforms (if one is available). With the increased digital connectivity within many prisons, it might be possible to email participants findings or share them on digital repositories. Prison libraries can also be an important source of information for many people living in prison, if for example a study produces a book or printed report, best practice would be to send a copy to all prisons within which the research took place.

Infographics can be powerful means of sharing research findings.[111, 112] Researchers might consider developing an infographic relating to research findings and sharing this with research participants. This might be posted or distributed to all participants by researchers or printed in poster form and put on notice boards within prisons where data collection took place. The significance of arts-based projects is also becoming increasingly recognised within prison settings.[113] Within this context, there are examples of theatre being used as a means of communicating research findings within prison and in community settings.

## CONSIDER THIS EXAMPLE

The *Beside Me* prison-based community theatre project developed and implemented in Scotland, by the Dundee Rep and Scottish Dance Theatre and partners, developed some end of project performances. These particularly meaningful performances were a means for the research team and participants to share insights from this project with their families, prison staff and management, researchers and other stakeholders.[114]

## REFLECTIVE QUESTIONS

→ What processes are in place for participants to review data interpretation?

→ What feedback mechanisms are in place to share findings and hear back from those involved?

### 5.3.3. Returning research findings to partners

Returning research findings to the prison administration and all other relevant partners is an essential step to promote change and implementation of research outputs in the medium-to-long term. Information about individual participants should not usually be reported back to the prison and this should be made clear within information provided to participants and prison staff. It is up to the researcher to decide whether general feedback should be offered about the results from the study as a whole. Often ethical clearance to conduct research in prison comes with conditions (see section 3.3.1). After data collection has been completed, researchers must ensure that they meet all the obligations that were committed to when a project was given ethical clearance. In some instances, this might include sharing project outputs with prison authorities for review and/or approval before publication or presentation. Researchers might also offer to present research findings to participants and partners in the form of a seminar. Sharing research outputs (such as dissertations or academic papers) with the relevant prison staff and authorities in accessible language and formats should also be considered. Researchers should be mindful that post-research communication will likely impact future research projects.

> ***"Successful collaborations may depend on an open and enlightened perspective by administrators and a sensitive and supportive style by researchers."*** [115]

### Integrity of research findings

Research findings should not be compromised in the knowledge transfer process. Researchers should ensure, through agreement, that they maintain the right to share the study findings. It may be reasonable for the prison authority to request the opportunity to review findings in advance to provide feedback, but the researchers should maintain control over the decisions for whether/how to disseminate findings. Even if it is not possible for a prison authority to prevent a publication, displeasure with research outputs can introduce tensions within relationships, jeopardise future research opportunities or put participants at risk.115 Researchers should therefore be mindful of political structure of institutions and the implications of publishing or not, and the implicit messages that sends (as noted in section 3.3).

### 5.3.4. Responsibility of impactful research

Researchers have the responsibility to deliver research that will be impactful. This extends beyond publication in peer reviewed journals and career self-interest. Research for the sake of research will not address prison health inequalities; it is the responsibility of the researchers (and funders) to ensure the findings or research then impact policy and health outcomes appropriately.

The identification and adoption of effective knowledge transfer and advocacy strategies is crucial to ensure that research findings are conveyed to and utilised by the intended audience.116 The conventional reliance on academic journals as the primary dissemination channels is increasingly viewed as insufficient due to their limited reach, accessibility (particularly in prison settings when not published through open access arrangements), and impact among practitioners and policymakers.[109] Alternative strategies, such as tailored summaries and targeted bulletins, have been proposed to facilitate broader engagement and enhance the influence of research findings.[116] These more succinct communication methods could better serve time-pressed practitioners who benefit from concise, focused synopses of relevant research. Fundings agencies and institutions should therefore ensure that knowledge transfer and 'impact' are explicit requirements and conditions in funding bids.

## CONSIDER THIS EXAMPLE

One effective strategy is the engagement of "pracademics", or practitioner-academics – partnerships involving collaboration between academic researchers and practitioner champions who work together to facilitate the tailored dissemination of research findings. Pracademics have been used in translational criminology to play a crucial role as internal resources within their organisations, continuously identifying and providing the most relevant research findings to meet the specific needs of their institutions, which can overcome observed deficiencies in both executive summaries and full-text articles.[117] Pracademics are responsible for distilling complex academic research into accessible, concise formats that can quickly inform decision-making processes.[108]

### 5.3.5. Researchers' responsibilities for policy advocacy

Effective knowledge transfer of research findings is crucial for enabling decision-makers and practitioners in prison systems to adopt evidence-based practices, programs, and interventions.[118] Although there is a critical need to maintain policymakers' and administration' awareness of scholarly evidence, prison research can struggle with effectively communicating to these stakeholders.[109] This highlights a pressing need for focused research that can develop and evaluate methods to effectively translate academic research into practice.[119]

Prison health researchers are encouraged to explore effective ways to translate their research into actionable and context-specific recommendations, such as policy briefs, policy forum, meeting with stakeholders and lay summaries. Researchers should share information with those with relevant interests to support awareness and action, which may include for example people with lived experience of imprisonment, policymakers, those involved in delivering relevant programs in custody and in the community.

Dynamic and sustained engagement strategies that go beyond the initial dissemination of information can be useful in prison contexts.[117] This process could include follow-up communications, interactive components, or ongoing support to help practitioners integrate research findings into their daily practice, as applicable. Without such strategies, even the most accessible forms of knowledge translation may fail to maintain practitioner engagement, thereby limiting their potential to effect meaningful change in the field.

## CONSIDER THIS EXAMPLE

Following a comprehensive research project, Nieva and colleagues developed a policy brief that outlined the main challenges faced by pregnant women in a Philippine prison and provided policy recommendations to explore alternatives to imprisonment.[120] They also organised a policy forum with prison officials, legislative staff, women's advocates, and academe to discuss the situation of pregnant women and mothers with babies in custody, policy barriers, and recommendations.

## REFLECTIVE QUESTIONS

- → What are the responsibilities of a researcher beyond publication?
- → How will the research team disseminate research findings to participants?
- → How will research participants access information about the study findings?
- → Who are the stakeholders that can translate the research findings into impactful results?
- → What strategies can be used translate the research into impactful results?

# Appendix

## Researcher reflective question checklist

**REFLECTIVE QUESTIONS:**

### Ethically grounded research foundations

- ☐ How are people with lived experiences meaningfully involved throughout the research process?
- ☐ How has the research been informed by lived experience?
- ☐ What are the motivations and reasons for considering this research?
- ☐ Who benefits from this research?
- ☐ Could this research purpose be perceived as exploitative or extractive by participants or staff?
- ☐ How is trust and respectful long-term connection being fostered with experts through experience?
- ☐ How does this research build capacity among people with experience of imprisonment?
- ☐ What processes are in place to ensure that partners with lived experience can identify and address learning or training needs (for example in research methodologies)?
- ☐ Are there processes to ensure that feedback is respected and addressed?
- ☐ What processes are in place to resolve disagreements and work through conflict?
- ☐ How will people in prison be informed or involved in its outcomes?
- ☐ How will people with lived experience have agency and choice in how they are identified or acknowledged in publications and presentations?
- ☐ How does this research align with the health needs and priorities identified in official strategies and frameworks, such as the WHO Health in Prisons Programme (for Europe) and national prison health strategies (when available), as well as with the priorities identified by people living in prison?
- ☐ Have the harms and benefits been considered at the individual participant and wider societal levels?
- ☐ How does the research contribute to improving health outcomes or equity for people living in prison?
- ☐ Could the research reinforce stigma or stereotypes about people living in prison?
- ☐ Could the research unintentionally cause unacceptably high risks?
- ☐ Is the research feasible and will it be permitted and supported by research partners?
- ☐ Are the required resources (such as time, funding, training) available to support involvement?
- ☐ How will conflicts of interest between researchers and funders be identified and managed?
- ☐ Are all sources of funding transparent and disclosed in applications and publications?
- ☐ Are there further support mechanisms in place from within research partner organisations?
- ☐ Are there plans for monitoring, mentoring and technical assistance?
- ☐ Does the funding include capacity-building or infrastructure development (such as health staff training or improved data systems)?
- ☐ Is the research likely to produce reliable, valid and valuable knowledge?
- ☐ Is there a plan to sustain or share benefits after research ends?
- ☐ Do funding and prison administration arrangements preserve researcher independence?
- ☐ Are there written agreements preventing funder and prison administration interference?
- ☐ Are there any conflicts of interest that may affect the independence or neutrality of the research?
- ☐ Are partner roles, responsibilities, and ethical commitments clear and agreed upon?
- ☐ How are policymakers and health systems being engaged to implement or adopt research findings?
- ☐ How will coercion (from either the institution or peer dynamics) be recognised and responded to?
- ☐ How will signs of trauma, distress or emotional withdrawal in participants be identified and managed?
- ☐ How will signs of trauma, distress or emotional conflict in researchers be identified and managed?
- ☐ What challenging emotional issues are likely to arise during this research?
- ☐ What strategies could be built into research processes to support emotional health during the project?

## REFLECTIVE QUESTIONS:

### Planning and applying

☐ Is the protocol detailed enough for another researcher to replicate the study thoroughly and ethically?

☐ Have the necessary prison specific aspects been addressed in the protocol?

☐ How will prison administration been engaged from the start?

☐ What agreements are required to ensure there are no restrictions on publication?

☐ How will privacy and confidentiality be ensured safely for researchers and participants?

☐ What strategies can be put in place to minimise the risks of harm to researchers and participants?

☐ In what circumstances might a researcher consider reporting a concern to the prison authorities?

☐ In what circumstances might a researcher report the treatment of a person in prison, or the behaviour of a prison official, to an outside body?

☐ If available, what are the advantages and disadvantages of researchers having authorised forms of locking and unlocking doors and gates within the prison?

☐ Who needs to be contacted to get the appropriate approvals?

☐ What does the correctional authority or individual institution require to allow researchers to enter the institution and permit people who are imprisoned to participate in research?

☐ Are there any requirements from the correctional authority that compromise any ethical or methodological standards or feasibility of the planned methods? If so, what could be done differently?

☐ In the event of ethical or methodological issues, is there a process to request changes in the correctional authority's processes for consistency with best practices? Or is there a way to answer your research question in a different way that would be feasible from the perspective of a correctional authority and compatible with research ethics and standards?

☐ Are the right research questions being asked, and how do we know?

☐ Is the chosen study design optimal to answer the research question and objectives?

☐ Although scientifically valid, does the design in any way compromise or expose participants to harm?

☐ Is there another research method that can answer the research questions whilst minimising harm?

☐ Do the study design and research aims maximise benefit to the study population as much as possible?

☐ Can primary research designs benefit from integrating linked data?

☐ Are there any elements within the prison that may impact the success of the chosen design?

☐ Do study recruitment strategies effectively reach, engage, and support access for the target population?

☐ Are there groups systematically excluded due to language, visa status, mental health, or other factors?

☐ Has anyone influenced participant selection in ways that may introduce bias or reduce diversity?

☐ Are there culturally adapted strategies to engage marginalised populations within the facility?

☐ Is participation feasible for those in segregation, remand, or temporary holding units?

☐ Are advisory or peer-led recruitment models available to reduce perceived coercion and foster trust?

☐ Does the research provide equitable access to opportunities and benefits of participation?

☐ How is recruitment bias minimised?

☐ Is the sampling method equitable? Will it avoid systematically excluding or over-representing certain subgroups within the prison population unless scientifically justified?

☐ Are there any ″convenience″ factors in the sampling that might inadvertently lead to a biased or unrepresentative sample, and if so, how will this bias be acknowledged and addressed?

☐ Is the study ethical if it is not possible to reimburse participants and provide reasonable compensation?

☐ What is fair reimbursement and compensation for study participation in this specific prison setting?

☐ Have reimbursement and compensation plans been discussed and agreed with all appropriate authorities and individuals?

## REFLECTIVE QUESTIONS:

### Conducting the research

☐ What is known about the specific prison facility and how does it differ from other facilities?

☐ What does a typical daily routine look like in this prison?

☐ What are the regular staffing shifts and responsibilities, and how might research activities impact on these routines and staff responsibilities?

☐ Who could act as gatekeepers, and who could act as supporters or advocates for the research?

☐ How can rapport and relationships be built with people living in prison and staff prior to data collection?

☐ What resources are required from the prison service and staff for the research activities to go ahead?

☐ How will research activities be adapted if impacted by operational changes? For example, to what extent can research timelines and design be flexible?

☐ How should accurate information be communicated to research partners?

☐ Are there existing communication channels that could be utilised?

☐ Have operational constraints and ethical sensitivities specific to the environment been considered?

☐ How will participants understanding of the nature of the research and their rights be ensured?

☐ Could willingness to participate be unduly influenced and how will this be mitigated?

☐ Does the informed consent process reflect participants' cultural, literary or educational needs?

☐ Have modified processes for obtaining consent been carefully considered, if required?

☐ Has the consent process been approved by a research ethics committee?

☐ How will capacity to consent be determined?

☐ Is a process in place to address fluctuating capacity, if appropriate?

☐ Has the participant's consent been appropriately documented?

☐ How will engaging with testimonies of those with prison experience shape research practices?

☐ What do I know about power imbalances in research and power-sensitive communication?

☐ What do I know about trauma-informed practice?

☐ What preparation has been undertaken for interviewing people who may have experienced trauma, discrimination and marginalisation?

☐ What safeguarding protocols will be implemented prior to the interviews?

☐ Could this research result in physical or emotional harm for the participant or researcher?

☐ How will I practice ongoing self-reflection concerning my position as a researcher?

☐ How have the risks of emotional harm for participants been considered and mitigated?

☐ What are the risks that one might face within the prison environment during the conduct of research?

☐ What personal boundaries do the researcher need to set while working in prison environment?

☐ Does the researcher have a support system in place to follow in case of risks to safety and wellbeing?

☐ Who should the researcher contact if there is emotional distress resulting from the data collection?

☐ How will the anonymity of individual participants be protected?

☐ Could the description of findings lead to inadvertent data disclosure or be stigmatising?

☐ Does the research team know when confidentiality should be breached, for example when an intention or harm is disclosed?

☐ If private interviews are not permitted, can participants give meaningful informed consent knowing that staff may overhear their responses?

☐ If participants' answers could place themselves or others at risk, will interview questions need to be adapted to ensure safety?

## REFLECTIVE QUESTIONS:

### Post research responsibilities and provisions

☐ How should research relationships be maintained after data collection?
☐ How long should researchers remain contactable by participants?
☐ What resources could support participants if they experience emotional or other harms?
☐ What is the earliest time that the data can be anonymised or pseudonymised?
☐ Could participants be easily identified if the data were accessed?
☐ What strategies can be used to mitigate the risk of inadvertent data disclosure/breaches?
☐ How will the data be retained in a secure setting with access restricted?
☐ Are all relevant data protection laws and guidelines being followed?
☐ Are relevant approvals in place for this, including consent from the participants, for data reuse?
☐ How long should data be retained for before it can be destroyed?
☐ What processes are in place for participants to review data interpretation?
☐ What feedback mechanisms are in place to share findings and hear back from those involved?
☐ What are the responsibilities of a researcher beyond publication?
☐ How will the research team disseminate research findings to participants?
☐ How will research participants access information about the study findings?
☐ Who are the stakeholders that can translate the research findings into impactful results?
☐ What strategies can be used translate the research into impactful results?

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