

Translational Research, Design and Analysis Special Communication

Cite this article: Glenn J, Wickliffe J, and Kelly PJ. Getting started in jail, prison, and legal system research. *Journal of Clinical and Translational Science* 6: e144, 1–5. doi: [10.1017/cts.2022.504](https://doi.org/10.1017/cts.2022.504)

Received: 21 March 2022
Revised: 30 October 2022
Accepted: 9 November 2022

Keywords:

Prison/jail; research; mass incarceration; health inequities

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Getting started in jail, prison, and legal system research

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Abstract

Extensive health inequities exist for persons with criminal-legal involvement in the USA. Researchers, both novice and experienced, are critical in documenting these inequities and implementing programs that address the many health and social problems of this population. However, working with currently or formerly incarcerated persons brings new challenges to researchers that may have not been previously considered as necessary. Because incarcerated persons were systemically exploited by biomedical researchers until reform following the Civil Rights Movement, resulting in their designation as a vulnerable population in the Code of Federal Regulations, enhanced protections are necessary in implementing contemporary research involving incarcerated persons. These enhanced protections can delay or prolong the regulatory approval process, particularly to the novice carceral system researcher, which may discourage some from engaging with this important population. Drawing on the many years of experience working with incarcerated persons accumulated by the Sexual Health Empowerment (S)HE Team at the University of Kansas Medical Center (KUMC), this article offers some concrete steps toward getting started in this work.

Introduction

Prisons and jails can be important sites for educational interventions and preventive health services research conducted with vulnerable populations that are otherwise difficult to access [3]. Many health and social science researchers now appreciate the extensive health inequities which exist for persons with criminal-legal involvement. One striking inequity is the fact that African-Americans are incarcerated at five times the rate of White individuals [1]. Chronic and infectious diseases and mental health problems are present at rates far higher among those currently or previously incarcerated than in the general US population [2]. Incarceration itself, and its overcrowding, poor nutrition, minimal opportunity for healthy behaviors, and the constant risk of violence, serve to exacerbate existing health problems. Even when released, the transition from incarceration into community settings has its own challenges, including gaining employment and housing and in reuniting with family [3]. These themes have been the focus of the Sexual Health Empowerment (S)HE team which works with women and men in Kansas City, Birmingham, and Oakland to improve health outcomes both during and after incarceration. (S)HE team projects include cervical health literacy, human papillomavirus vaccine implementation, and COVID-19 prevention programs. Their experiences over the past 12 years inform the ideas presented here.

Background

With the opportunity for meaningful research programs comes the reminder that research involving incarcerated persons, any research for that matter, has not always had ethical guidelines to hold the researchers accountable. Until the enactment of new regulations in the 1970s, investigators throughout the history of human biomedical research often chose as objects of study persons confined and/or institutionalized: persons in jails, asylums, mental hospitals, and sometimes those held as slaves [4]. The institutionalized populations were often mentally ill, terminally ill, or orphans, but most were prisoners, and often people of color.

Incarcerated people have been particularly vulnerable to exploitation and coercion. The history of abuse has demonstrated that researchers have had a propensity for exploiting incarcerated persons to assume all the risks for research that was meant to solely benefit others. So extensive has been the exploitation of prisoners that, by 1969, clinical trials involving prisoners accounted for up to 50% of *all* Phase 1 drug testing in the US [5]. The exploitation of these persons often drifted into lethal experiments and procedures amounting to a near total disregard for their human value. This history also clearly demonstrated that the ability of incarcerated persons to make truly voluntary decisions was severely compromised by the conditions of jails and prisons.

Revelations of this systemic exploitation and abuse during the Civil Rights Movement led to the passage of the National Research Act of 1974, which called for the creation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission was charged with identifying the basic ethical principles that should guide all biomedical and behavioral research involving human subjects and developing guidelines to assure that all research is conducted in accordance with those principles. *The Belmont Report*, released in 1978, was the result of the Commission's work [6]. The Report named respect for persons, beneficence, and justice as the three foundational principles and identified pregnant women, fetuses, children, the mentally disabled or incapacitated, and prisoners as populations particularly vulnerable, thus requiring enhanced protections. The enhanced protections for each of these groups is written into the Code of Federal Regulations (45 CFR §46) which guides how Institutional Review Boards (IRBs) operate to enforce these protections [7].

With these vulnerabilities in mind, 45 CFR §46 outlines 4 categories of approvable research involving incarcerated persons: 1) research into the causes, effects, and/or processes of incarceration, and of criminal behavior; 2) research on prisons or jails as institutional structures or on the lived experience of incarceration; 3) research on the health, living, or social conditions particularly affecting incarcerated persons; and 4) research on interventions which have the intent and reasonable probability of improving the health or well-being of the incarcerated subject [7].

If qualifying under one of these four categories, proposed research involving incarcerated persons must meet the following conditions: 1) any rewards or advantages accruing to the incarcerated person cannot be of such magnitude as compared to the overall conditions of incarceration as to be coercive; 2) incarcerated persons cannot be asked to assume risks greater than would be acceptable to free-world persons; 3) the procedures for selecting subjects has to be fair and immune from arbitrary intervention by prison authorities or other incarcerated persons; 4) any information about the study or provided during the consent process has to be in language understandable to incarcerated persons; 5) participation in research cannot be taken into consideration by parole boards, (a previously common coercive practice); and 6) the research has to make adequate plans for follow-up care or examinations when appropriate [7].

The main idea of these protections is to ensure that research with incarcerated persons is for the benefit and well-being of incarcerated persons, with the intended application for people who are incarcerated or who have criminal-legal involvement, and not for the benefit of others but using prisoners only out of convenience.

For researchers for whom the well-being of incarcerated persons is at the heart of their research agenda, there are many methods available that can be used to document conditions in jails and prisons, provide a voice for those who are embroiled in the criminal-legal system, and/or implement interventions to address health inequities faced by persons who are incarcerated. These include as follows:

- Cross-sectional or formative research that documents a practice such as the nutritional inadequacy of meals offered in a carceral setting [8], or a specific health problem not previously acknowledged among administrators in the system [11].

- Focus groups that can illuminate stakeholder opinions about potential new mental health services for people involved in the criminal-legal system [9].
- Pilot health education interventions that can aid in cancer prevention and screening [10].
- Quasi-experimental designs or natural designs (because randomized control trials are generally not practical, given the strong possibility of participants discussing intervention content) that provide both education and benefits to both intervention and comparison groups [12,13].

Health services researchers, facility administrators or correctional officers, community agencies working with incarcerated populations, as well as groups of individuals currently or previously involved in the criminal-legal system, can be part of the process to change and raise awareness about policies and conditions. A public health researcher can offer and study programming that is accurate and respectful, and that has the potential to serve some humane or educational purpose. Even in brief encounters, it is possible to reach some members of this very vulnerable population.

Ethical research involving criminal-legal involved persons must be carried out by both researchers and stakeholders who do not harbor the stigmas against incarcerated persons that are common in society. This requires the researcher to have a degree of structural competency about the determinants of mass incarceration in the US A major challenge to including law enforcement and corrections officers as stakeholders in criminal-legal health research is that, often by default in the USA, they are trained and socialized to dehumanize persons with criminal-legal involvement, especially persons of color [14]. This is not to argue against their inclusion, simply to state that they should be chosen and included with care.

For novice researchers or those without the guidance of an experienced investigator, initiating work with criminal-legal populations may seem daunting. The goal of this article is to break down the process and provide some concrete steps toward getting started in this important work.

Seven Recommendations (Table 1)

Consider Reasons/Research Questions

Why use a criminal-legal population to study a health question? If the answer to this question is simply because the population is easy to access, the plan needs rethinking and is indeed a major reason that this is a protected population. Research based on incarcerated people being conveniently accessible, with no benefit to the population, will not, and should not, be acceptable. The research should center on the needs of the population and clearly explicate the benefit to people who are incarcerated and formerly incarcerated. From an ethical perspective, backed up by the requirements of university IRBs, research in jails and prisons should provide a benefit to the population being studied or to similar populations [7]. Examples of research beneficial to incarcerated persons include documenting the interplay between early sexual activity and violence among juvenile offenders, which offers the opportunity to move beyond "just say no" in adolescents' sex education [13], or, perhaps demonstrating that healthcare providers experience dual loyalty conflicts in their work with correctional systems, and offering methods to mitigate this potential conflict [15].

Familiarity with at least some of the needs of the population and how results might benefit them, either directly or indirectly, is

Table 1. Seven recommendations

- Consider reasons/research questions
- Do essential background reading
- Use a variety of strategies to gain initial access
- Work with the university's Institutional Review Board
- Carefully select and train the research team
- Carefully negotiate the initial encounters
- Debrief after each session

important. Involvement in the community, perhaps as a volunteer in a local jail or prison facility, as a member of the community advisory board that works with individuals with lived experience of incarceration, and/or hiring staff with this lived experience, can help to shape relevant research questions.

Do Essential Background Reading

Because the history and current situation of incarceration in the USA may not be familiar to all members of a research team, some background reading is strongly suggested for novice researchers or those new to working with incarcerated people. *The New Jim Crow* by Michelle Alexander [1] is one essential reading because of its excellent outline of the social and historic context of incarceration in the USA. Working inside of the criminal-legal system demands a critical understanding of the role of racism as a structural determinant of mass incarceration. Discussing one or more of the readings as a research team can help to build and strengthen such understanding. Other suggested readings about the overall impact of incarceration on US communities are as follows:

Imprisoning Communities: How Mass Incarceration Makes Disadvantaged Neighborhoods Worse by Todd Clear [23] documents how high rates of incarceration in very poor communities contributes to the very social problems it is ostensibly intended to solve. *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* by Harriet Washington [20] details much of the systemic exploitation and abuse of incarcerated persons, often people of color, in the history of biomedical research.

Are Prisons Obsolete? by Angela Y. Davis [16] is a prison abolition manifesto that encourages readers to imagine alternatives to imprisonment by illuminating the broader structural issues that propel mass incarceration.

Golden Gulag: Prisons, Surplus, Crisis, and Opposition in Globalizing California by Ruth Wilson Gilmore [17] focuses on California's prominent role in the exponential increase of incarceration in America, from 1980 to the present, with a particular focus on the role of capitalism in fueling the system.

Jailcare: Finding the Safety Net for Women behind Bars by Carolyn Sufrin [18] provides details about the healthcare available inside jails and prisons. While focused on women, researchers can gain insight into the overall poor state of healthcare available for all incarcerated persons.

For researchers interested in working with women both during and after incarceration, three readings are suggested:

Arrested Justice: Black Women, Violence, and America's Prison Nation by Beth E. Richie [19] investigates how criminal-legal policies and a racist legal system, together with intimate partner violence, sexual molestation, and poverty, collide to land African-American women in prison at an alarmingly disproportionate rate.

Doing Time Together: Love and Family in the Shadow of the Prison by Megan Comfort [21] details the ways that prisons shape

the lives of the women left behind when their partners are among the nation's two million inmates

- *The Ex-Prisoner's Dilemma: How Women Negotiate Competing Narratives of Reentry and Desistance* by Andrea Leverentz [22] provides an in-depth, first-hand look at how former prisoners manage their return to the community.

For researchers interested in the policing of a specific, marginalized community consider:

- *Queer (In)Justice: The Criminalization of LGBT People in the United States*, by Joey L. Mogul, Andrea J. Ritchie, and Kay Whitlock [24] illuminates how outdated and prejudicial notions of gender and sexuality lead to hyper-policing of queer communities and profound carceral violence against them as targets of harassment, stigma, and punishment.

For doing research in a specific area, setting up a PubMed database search will email weekly notifications with any new article on the topic. If time is very tight, identifying one or two reviews on the topic area is helpful.

Use a Variety of Strategies to Gain Initial Access

Initiating access to populations in the criminal-legal system can begin in different ways. Direct contact with the administrator, the health officer, and the program coordinator at the facility may or may not be successful. Sometimes access can be gained through the circle of colleagues, neighbors, and friends in the community, including the sheriff, community attorneys, health workers, and academics who might have access to officials in the facility. Contacts often may not say yes on the first encounter; it may require building a relationship of trust with corrections officials and correctional health directors, coming to a mutual understanding and shared goals. Persistence will often pay off.

In starting this work, share the project's objective(s) with students, colleagues, coworkers, and formerly incarcerated persons in the community, as well as those impacted by having a family member incarcerated. The goal here is to get the word out and establish a broad social network that can help to facilitate access. In discussing the proposed work, framing is important. Rather than calling it a "research" project, consider describing a health education program with an evaluation – this provides a clear advantage to a facility and will facilitate access.

Finally, remember the human side of interacting with corrections staff. When meeting with facility or agency administrators, consider arriving with at least light snacks. Send Christmas cards, send regular emails, and solicit their feedback to make them feel like important members of the team. Offer to provide in-service education and send project updates and results. These small actions can be beneficial in developing and maintaining relationships.

Keep an Open Communication Channel with the IRB

University IRBs have federal requirements that must be followed when reviewing proposals that involve incarcerated persons. Such IRBs must have or appoint a prisoner representative whose role is to make sure the board adheres to federal guidelines and to provide contextual perspective and research expertise. Novice researchers should seek out their IRB's prisoner representative and consult with them before submitting an application. IRBs without an

established prisoner representative may ask for help in identifying a qualified person. This could be any individual who has a close working knowledge, understanding, and appreciation of prison conditions from the perspective of someone incarcerated (e.g., prison chaplain, prison social worker, prison healthcare worker, and formerly incarcerated person). If asked to suggest a prisoner representative, researchers should consider those who are familiar with the research of protected populations, the criminal-legal system, and community services.

Many IRBs will not have experience with such proposals and tend to be extra cautious in their reviews, often not distinguishing between minimal and high-risk types of studies, such as an education program on parenting vs. a Phase 1 drug trial. IRBs without an established prisoner representative or who are new to reviewing protocols for research involving incarcerated persons may benefit from an educational session on federal policy and relative risk of other types of research distinct from clinical trials. Educating the IRB takes time. Be clear in all communication and be willing to meet in person with the IRB Chair to explain the importance, goals, and needs of the proposed research.

The IRB process is fluid, requiring multiple clarifications, modifications, and revisions. In the beginning, put together the best application possible, but understand that the process may take time if the IRB asks for clarifications or modifications. Reporting requirements may differ with each funding source and IRB. Some IRBs require a yearly review to check enrollment numbers, records of adverse events, and withdrawals. Some funders may want a quarterly report VS and annual report. Suggestion: *Don't wait until the last minute; leave a lot of time for the IRB process!*

Carefully Select and Train the Research Team

While it is difficult to do any type of research alone, having a team of at least two or three other researchers is especially important in prison and jail work. Collaborators must agree about the overall goals and the specific purposes of the research. In addition to required human subjects protections training, the facility or agency with which the research team is working may have specific requirements for entry, including background checks, fingerprinting, or TB screening. Time should be factored in for completion of all these requirements, which may be online, in-person or submitted, and awaiting approval. *Again, leave enough time!*

In creating a team, it is important to consider that while someone may be passionate about this work, not everyone will be comfortable inside of a jail or prison. An honest conversation should be had about the physical realities of carceral spaces, (generally dreary, not of highest hygiene standards), the handing over of all purses and phones, removing belts, walking through a sally port, and being escorted through groups of both correctional officers and men and women in institutional clothing. Any one of these factors can be enough to keep an otherwise-avid researcher from being comfortable in a carceral setting. While the ethics training provided by the IRB can be helpful, an open, nonjudgmental conversation is essential here.

Some specific training objectives might include the following: the importance of inclusive and non-stigmatizing language – while a bit of a mouthful, "people involved in the criminal-legal system" is less pejorative than "prisoners" or "inmates"; basic instruction about the culture of jails and prisons; and the importance that no member of the research team attempt to look up individual's criminal records. Such knowledge serves no valid research purpose and may bias interactions with the study population.

Carefully Negotiate the Initial Encounters

After completing the ethics and institutional hurdles, actually beginning data collection is an exciting event. Every facility will have its own requirements, but it is critical to pay careful attention to what is brought inside a facility. For example, paper copies of surveys should not have staples. Generally, ballpoint pens without removable caps or moving parts are acceptable, but this must be checked with each facility. Count the number of pens that are being brought in and make sure to leave with the same number; if pens go missing, they must be found. In one experience, researchers had to recount their pens several times, while incarcerated participants were held outside of their cells until all items were accounted for.

Recruitment and data collection generally occur at the same time in group settings with the researcher(s) giving a brief explanation of what they are asking from each individual. The setting is generally noisy, and it may be helpful to move between small groups and explain the project multiple times..

Correctional officers' proximity to researchers can make it difficult to provide confidentiality. Ideally, correctional officers should be present in the larger space but not close enough to listen to any individual conversations with participants. Negotiating the space is important; researchers will have permission to be in the correctional system but are not there as part of that system. Researchers want to be able to run their programs but not be adversarial with the officers. Good relationships with correctional officers are necessary for successful recruitment and implementation, so tact and negotiation are essential.

If participants are gathering in a specific room for a program or intervention, greet each individually. One of the most moving program evaluation comments that the (S)HE team received was from a woman who wrote, "You treated us like humans. You said 'good morning' to us." When introducing the team, it has been helpful to embrace our positions, that is, to state where we are from and whether we are teachers or students. The latter group is often very welcome, as in "I'm a medical student or a nursing student and doing this for my training (or education)." People appreciate and respect understanding what the position of the researcher is in relation to them.

During the consent process, do not make literacy assumptions. Because up to 75% of incarcerated persons in the USA are functionally illiterate, consent forms should be written at a fourth-grade reading level [25]. These forms should also be available in Spanish or other languages spoken by persons in the facility, with bilingual research staff available to answer questions. The whole content of the consent form can be read aloud to participants to allow the consent process to take place as an interactive discussion rather than feeling like a legal transaction. Participants should be given the choice of reading through the form, but a verbal summary of the key points is important – the purpose of the study, voluntary participation, confidentiality, and that it is okay to stop at any point.

Be sure that the data collection instruments have been pre-tested with the target population. While many validated instruments report they are written at a fourth-sixth grade reading level, specific words and phrases may not have the same meaning to everyone. Do not ask, "Can you read this?" but rather offer individual assistance for anyone who may "not have their glasses with them," a tactful way to bypass reading ability. Try not to embarrass anyone, read the survey out loud to everybody. If people can read, and wish to, they can complete the documents at their own pace.

Debrief after Each Session

Debriefing with all team members should occur immediately after each visit to a facility. While privacy is important, so is the ability to relax a bit over coffee or a snack, perhaps in a booth in the back of a restaurant or somewhere where conversations will not be overheard. The process can be initiated with a review of the objectives of the visit, followed by three specific questions: *What went well? What were difficulties? What can we do differently next time?* Each team member should be given a chance to briefly discuss how the experience went for them, specifically mentioning any positive and negative encounters. This debriefing provides an opportunity for critical reflection and to share personal feelings or concerns, such as like being uncomfortable, angry, or frustrated with participants and/or correctional staff. A record of issues needing follow-up with the lead investigator or facility administrator can help work through any lingering problems.

Conclusion

Even a few hours spent inside of a jail or prison provides an appreciation for the many injustices of the US carceral system. While they are incremental, research-based programs and their findings are important steps toward improving the health and well-being of the over two million men and women on any given day who are under the control of this system [26]. This article presents strategies for researcher willing to engage in this critical work.

Acknowledgements. This work was supported by the National Institutes of Health, National Cancer Institute, United States, grant R-21-CA204767, Megha Ramaswamy, PI.

Disclosures. The authors declare no conflicts of interest.

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