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Key Stakeholders' Perceptions of Motivators for Research Participation among Individuals who are Incarcerated

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Abstract

Understanding motivations of research participants is crucial for developing ethical research protocols, especially for research with vulnerable populations. Through interviews with 92 IRB members, prison administrators, research ethicists, and researchers, we explored key stakeholders' perceptions of what motivates incarcerated individuals to participate in research. Primary motivators identified were a desire to contribute to society, gaining knowledge and healthcare, acquiring incentives, and obtaining social support. The potential for undue influence or coercion were also identified as motivators. These results highlight the need for careful analysis of what motivates incarcerated individuals to participate in research as part of developing or reviewing ethically permissible and responsible research protocols. Future research should expand this line of inquiry to directly include perspectives of incarcerated individuals.

Keywords

correctional research; motivations; incarceration; qualitative research

Most medical and social science research studies depend on the willingness of individuals to participate as human subjects. Federal regulations provide protections for human subjects in general and additional protections for those participants who are deemed to be especially vulnerable, such as children, individuals with mental disabilities, and individuals who are incarcerated (Office for Human Research Protections, 2009). Investigators conducting human subjects research take on a variety of responsibilities related to participant protections and conduct in accordance with legal requirements, with added responsibility if the work involves vulnerable populations.

Developing research protocols that protect the rights of participants requires an attuned understanding of participant circumstances, including determination of actual benefit to

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potential participants as well as determination of possible undue influence **or** coercion. Understanding motivations for participation is key in considering participants' circumstances and crucial in the development of ethical research protocols in accordance with professional standards, legal requirements, and protections for participant rights.

Understanding the motivation of any participant is important; however, considering the motivations of vulnerable participants is especially important given their protected status and the likelihood that their motivations may differ from those of non-vulnerable populations. Although evaluation of risk is important when determining whether to participate in research, research participation can be potentially helpful, rather than only harmful, for participants. Previous research has explored motivations of several vulnerable groups. For example, participants in schizophrenia research reported participating for personal benefit, for altruistic reasons, and to advance science (Warner, Roberts, & Nguyen, 2003). Patients in genetics research reported participating for the benefit of society in general by advancing science, for the benefit of family members by advancing healthcare, and for personal benefits (Hallowell et al., 2009). Motivations among adults with cystic fibrosis indicated that research participation choices were influenced primarily by patients' health condition, type of research, and patients' risk assessment of the study (Lowton, 2005). Working with terminally ill patients, Alexander (2010) identified numerous benefits that may motivate research participation, including the altruistic benefit of helping others and the psychological benefit that comes from having an active, empathic listener, particularly among individuals for whom such a listener is a rare occurrence.

To date, one vulnerable group has been largely ignored in the empirical investigation of motivations for research participation, namely, individuals who are incarcerated. These individuals are vulnerable primarily due to compromised autonomy as a result of the considerable potential for undue influence **or** coercion inherent in the correctional environment (Eldridge, Johnson, Brems, Corey, 2011; Eldridge, Robinson, Corey, Brems, & Johnson, 2012). Despite their increased vulnerability as participants in research, individuals who are incarcerated must be afforded the opportunity to safely participate in research (DuBois et al., 2012). Like everyone else, vulnerable or not, individuals who are incarcerated deserve appropriate access to research participation and its potential benefits (Elger, 2008).

Exploring motivations for research participation among individuals who are incarcerated may provide evidence as to whether other common motivators such as altruism and a desire to advance science hold true for this particular vulnerable group. Further, understanding motivations among these individuals is vital to the ethical conduct of research with this population.

As part of a larger study investigating the interpretation and application of ethical principles in correctional research, this paper presents the perceptions of various professionals, all experts in HIV/AIDS research in corrections, as to what motivates incarcerated individuals to participate in research. Given their expertise in HIV/AIDS research in correctional settings, these individuals were uniquely positioned to comment on considerations

associated with research with vulnerable and doubly vulnerable participants, such as those who are incarcerated and who have HIV/AIDS or risk factors for HIV/AIDS.

Method

Participants

Professionals with experience in designing, implementing, or providing ethical oversight for HIV/AIDS research in correctional settings were recruited for participation in this study. The final sample consisted of 92 professionals from across the United States: 15 prison administrators, 16 IRB members, 16 IRB prisoner representatives, 15 research ethicists, and 30 researchers. The relatively large sample size overall allowed for an adequate number of participants within each of the professional groups to achieve redundancy (Sandelowski, 1995).

Of the 92 participants, 50 were men and 42 women; average age was 50.8 years ($SD = 9.2$); seven (7.6%) were African American, one (1.1%) Asian/Pacific Islander, 80 (87.0%) Caucasian, two (2.2%) Hispanic, one (1.1%) Native American, and one (1.1%) other ethnic heritage. Participants were well-educated, with 21 (22.8%) possessing a medical degree, 48 (52.2%) a doctoral degree, 17 (18.5%) a master's degree, and six (6.5%) less than a master's degree. Work settings included academia ($n = 44$; 47.8%), corrections ($n = 16$; 17.4%), medicine ($n = 15$; 16.3%), public health ($n = 7$; 7.6%), and other settings ($n = 10$; 10.9%).

Procedure

Multiple methods were employed to identify and recruit potential participants, including literature reviews, internet searches, and snowball sampling. Semi-structured telephone interviews lasting approximately one hour were conducted; participants were compensated \$100 for their time. Interviews were audio-recorded, transcribed, and imported into NVivo software for qualitative data analyses. All procedures were approved by the Institutional Review Board at the [institution].

Interview Protocol

Participants were interviewed using a semi-structured interview guide that consisted of 18 questions related to HIV/AIDS research within correctional settings. Topics related to the correctional system (physical environment, policies and procedures), application of ethical principles (vulnerable populations, informed consent, compensation, confidentiality, benefits, and risks for harm), and regulatory oversight (IRB oversight, IRB prisoner representative, adverse events, federal regulations, and minimal risk). A copy of the protocol is available from the first author.

Data Analyses

Qualitative interview data were coded using procedures designed to ensure thoroughness and reliability. For initial data coding, a sub-sample of five interviews, one from each professional group (prison administrators, IRB members, IRB prisoner representatives, research ethicists, and researchers), was selected for line-by-line open coding by three trained research staff members. Based on this sub-sample, an initial set of free nodes

(themes) was created. The coding team met regularly with the principal investigators to discuss emerging themes and define free nodes based on consensual decision-making. Based on this process, an initial node dictionary consisting of 73 defined free nodes was developed and two coders were assigned to code all 92 interviews (including recoding the initial subset).

The two coders independently coded all interviews, question-by-question, and line-by-line, meeting daily to ensure inter-coder reliability. Prior to the daily meeting, separate coding results were merged to allow for quick and efficient identification of coding disagreements. Disagreements were settled by discussion, with the two coders reviewing whether a code was applied appropriately or applied inappropriately. If the two coders could not resolve a particular coding disagreement, they consulted with the principal investigators. Existing free node definitions were refined to accommodate evolving themes and incorporate new themes. New free nodes were created only if it was not possible to incorporate a theme into an existing free node definition. Three new free nodes were added, resulting in a final node dictionary of 76 free nodes. The coding process was iterative; any changes to the node dictionary were incorporated via recoding the previously coded interviews.

After initial coding of all interviews was completed, a second round of coding specific to motivation was conducted. As there was no specific question related to motivation in the interview protocol, free nodes related to participant motivation were selected for further analysis. Text to be recoded was chosen liberally, with any node that might contain a reference to participant motivation being included. Twenty free nodes were selected with agreement by the research team consisting of one of the original coders, one new coder, and the principal investigators. Selected nodes included those related to participant characteristics, as well as nodes focused on research factors and correctional environments. In the second round of coding, these selected nodes were coded for any direct or indirect reference to participant motivation. The participant motivation node was then further analyzed and thematically categorized. A second coder reviewed the motivation nodes for concurrence with the themes. No formal a priori hypotheses had been formed; thus, codes and theme development arose from the data, relying on principles of grounded theory (Strauss & Corbin, 1990).

Results

Five major themes emerged to describe the key informants' beliefs surrounding incarcerated persons' motivations for participating in research. Detailed below, these five themes are altruism, access, social support, compensation and incentives, and coercion.

Altruism

Key informants discussed the inherent altruistic value of research participation for incarcerated individuals. They spoke about the positive impact of participation, including that research participation may provide participants with an opportunity to feel good about their contributions to society. One researcher described it succinctly as "... they like giving back" while another described "They appreciate being part of something bigger than them." The idea that incarceration typically focuses on individuals' negative impact on society and

leaves little opportunity for incarcerated persons to give back was salient, particularly among prison administrators and ethicists, who discussed how participation in research can provide a unique opportunity chance for individuals to contribute to society. As one ethicist described:

I mean there just aren't a whole lot of things you can do to make a meaningful positive impact on your community or your country or the world or whatever. And I think prisoners spend a lot of time focusing on the bad things they've done and don't really have a whole lot they can do to balance that out and I think the opportunity to advance research, the opportunity to contribute to the knowledge base is a benefit that prisoners realize...

Access

The ability to gain access to resources that are otherwise not available in the correctional environment was frequently mentioned as a reason incarcerated persons may choose to participate in research. Access was broken down into two main subcategories: access to knowledge or information and access to healthcare.

Access to knowledge or information—Respondents believed that incarcerated people may be motivated to participate in research by the potential for gaining useful and important knowledge. Key informants perceived that research participants benefitted from the health promotion and health education aspect of research, such as learning about disease prevention and management. One prison administrator described “...the subject gains more knowledge about something that is vitally important to them.” A prisoner representative provided an example, saying research participants gain “... increased skills and hopefully safer sex behaviors once they're released.”

One prison administrator described how research subjects valued their engagement in research programs and that these individuals felt they benefitted not only from the knowledge they gained but also from their subsequent ability to share this information with others, including family members and peers who are incarcerated. Although the first participants in a research project may not be fully aware of extent of the potential gains from research participation, subsequent subjects are likely to have heard from earlier participants about this benefit, thereby motivating their own participation. A prison administrator described this informal advertising of the educational and informational gains of research participation, saying that participants “take this back to the unit with them... So it also made other inmates interested in coming and participating and we always had a waiting list for our programs and they were saying ‘How do I get in it?’”

Access to healthcare—Key informants frequently mentioned their perception of access to healthcare services as a motivator for incarcerated persons to participate in research. They presented two viewpoints on research participation as a means of accessing healthcare: (1) incarcerated persons receive more effective treatment if they are involved in research than if they are not; and (2) regardless of the actual efficacy of the treatment, incarcerated persons *perceive* participation in research as a means to receiving more effective treatment than the standard care. As noted by a prison administrator:

Many inmates want to participate in clinical trials because they don't think that they're getting standard of care and they think that the only way that they can get it is by being treated by these researchers and doctors who are from the community not by the prison doctor.

Additionally, the perception that incarcerated people are motivated by access to new treatments through research participation was mentioned specifically with respect to individuals who had not responded to any of the available standard treatments. In that way, the potential for effective treatment resulting in prolonged life can be a motivator to participate, particularly for incarcerated persons with severe illness. The benefit of research participation was described by one prison administrator as “the possibility of prolonged life because so many of the clinical trials, to be a candidate they have to have failed other regimens and they don't have a lot of treatment options left.”

Social Support

Key informants described their perception that incarcerated persons may value the social interaction received by participating in research. Overlapping somewhat with the mention of incentives and access to healthcare, key informants discussed how the chance to speak with researchers, interact with new faces, and be treated with respect encourages potential subjects. Participating in research “means that people often have greater access to psychosocial supports,” said an ethicist. One prison administrator also noted the potential for group participation in research, saying “It just gave the women a chance to be together.”

Many key informants recognized the significance for incarcerated persons of having someone express concern about their well-being, pay attention to them, and provide dignified interaction. The chance to speak frankly about their health conditions and health behaviors was also identified as valuable. One prisoner representative described the lack of trust most incarcerated people have for correctional staff and administrators, including medical professionals, explaining that “... an outside researcher might be the only person that they feel comfortable talking to...”

Compensation and Incentives

Overall, prison administrators indicated that their facilities do not permit research participants to be directly paid for being in a study. However, many of them indicated that subjects can receive credit on their commissary account or can be monetarily compensated upon their release. Many of the key informants believed that incarcerated persons might choose or feel compelled to participate because of offered monetary or other compensation. A prison administrator discussed monetary compensation as:

This is just sort of another factor that would urge an inmate to consent to something that he wasn't sure was in his best interest because you don't earn a lot of money when you're in prison and here's an opportunity.

Another reason incarcerated persons might be motivated to participate in research is due to incentives offered to subjects. Key informants discussed a plethora of incentives used to encourage participation, including food products and additional recreation time. One researcher described offering practical and accessible incentives, saying “We've also worked

with facilities to provide incentives that the facility can offer. So we've offered inmates a voucher for a free haircut." Most often, however, the influence of unintentional incentives was communicated. Opportunities for incarcerated persons to leave their cells, tell their stories to an interested listener, and relieve boredom were each mentioned as motivations toward participating in research. As indicated by one researcher, "... they were more motivated to go ahead and take part in the study just because it was something to do so they weren't so bored all the time." A prison administrator discussed limiting incentives as much as possible, but that indirect incentives may still remain simply due to the logistics of conducting some types of research:

The one thing that we can't restrict is that for the most part they would have to get a trip off of their prison unit down to the prison hospital to see the researcher... If they like getting off the unit for a few days and seeing some different scenery, I guess that could be a perk and we can't avoid that one.

Within the discussions of incentives, the issue of undue incentives frequently arose. Key informants indicated great concern over the types of incentives presented to potential participants, specifically related to the likelihood that an incentive could become inappropriately persuasive and unduly influence an individual to participate. For individuals living in the deprivation of correctional settings, even small incentives may appear so valuable that they individual does not feel he/she can refuse participation. As noted by one IRB prisoner representative, even seemingly simple incentives can be powerful in a correctional environment:

... to you or I, someone offering you a can of soda for filling out a questionnaire, I mean that's not likely to influence whether or not we're going to fill out the questionnaire, unless we're dying of thirst, right? But, to a prisoner who maybe hasn't had a soda in fifteen years, getting the opportunity to taste the Pepsi again might be something that is pretty coercive.

Coercion

Given the nature of the institution, key informants perceived that incarcerated persons may feel forced into participating in research, with an implicit motivation being compliance with the environment's expectations. Described by one prisoner representative as "the power of the warden", the concern of coercion was most frequently mentioned by prisoner representatives and ethicists, but was noted by key informants from each professional group. They explained that incarcerated individuals are not accustomed to having the opportunity to refuse anything within the correctional environment; thus, even when research invitations are presented as optional, it can be difficult for potential participants to truly understand and believe that they can decline without negative repercussions. Explained one prisoner representative:

Because prisons are inherently coercive environments, and prisoners aren't used to saying no to things, when they're approached about a study, they might believe that they don't have the right to say no because they generally don't have the right to say no to much of anything.

And as noted by a researcher, “No matter how careful you are... they may think there may still be some kind of subtle perceived pressure...”

Discussion

Key informants’ comments regarding their perceptions of what motivates incarcerated persons to participate in research related to five core themes. Generally positive themes of access to knowledge and information and access to healthcare, altruism, and social support were described. Compensation and incentives were described as motivators that could be appropriate or could result in undue influence. Coercion to participate was identified as another negative motivator. While the key informants in this study were recruited due to their specific experience with HIV/AIDS research in correctional settings or their specific expertise in the ethics of correctional research, their discussions of motivations for research participation among individuals who are incarcerated were typically more general and likely can be applied to various types of correctional research.

Consistent with previous studies with other vulnerable groups (e.g., Alexander, 2010; Warner, et al., 2003), altruism was identified as a potential motivation for participating in research. Altruism is particularly relevant as a motivator among individuals who are incarcerated, as their incarceration prevents most opportunities for making positive contributions to society. Although abundant possibilities exist for people who are not incarcerated to make altruistic contributions to society through volunteering time or resources, the same is not true within the correctional setting. Therefore, not only do research studies conducted in correctional settings allow for increases in knowledge relevant to the group, but they may also benefit individuals who are incarcerated by allowing them a means by which they can make altruistic contributions.

Another factor that was perceived as a motivator is access to resources that are not otherwise available to individuals who are incarcerated. Access to knowledge and information motivates individuals to participate in research projects. On the face of it, this may appear to be a very personal benefit for each individual. However, in this study, interestingly, key informants indicated that this access to information also encouraged participation by others. That is, individuals who participated in research shared their new knowledge with peers and this sharing, in turn, became motivating for other individuals who then chose to take part in the research because they wanted to gain the same access to knowledge and education. Access to information has been identified as a motivator for other research participants as well, including injection drug users who sought more information about their drug use and resources that might assist them (Fry & Dwyer, 2001). For potential volunteers to be motivated by information-seeking, they must be aware that participation in research will provide such information. Previous research subjects are logical sources of this insight, particularly among members of a specific unique group, like individuals who are incarcerated and users of certain drugs. Interestingly, for the individual who shares information with peers in the correctional system, access to information becomes a means of altruism as information can then be shared with others in similar constraining circumstances. Information-seeking may thus interact with altruistic motivations to produce meaningful human interactions.

Consistent with previous research (e.g., Kass, Maman, & Atkinson, 2005), access to healthcare-related resources emerged as a potentially important motivator for research participation among individuals who are incarcerated. Since key informants were interviewed about their experience with HIV/AIDS research specifically, it is not surprising that access to treatment emerged as a motivator. As sophisticated, cutting-edge medical treatment in general, and HIV treatment specifically, is less accessible for individuals in correctional environments than the general population (Springer & Altice, 2005; Springer & Bruce, 2008), research participation may be viewed as the only avenue for obtaining such resources. Interviewees were careful to indicate that individuals who are incarcerated may perceive that research participation will result in improved healthcare, and such a perception, even if false, may motivate participation.

The specifics of the correctional environment also factored into participants' decisions, and perhaps less explicit motivations, to participate. Key informants recognized the coercion inherent in the correctional environment and faced every day by individuals who are incarcerated. Interviewees from the prisoner representative and ethicist professional groups discussed the power of coercion most often. Given the work of these groups protecting the interests of individuals who are incarcerated, it is not surprising that the coercive environment was especially salient for them. The reality of possible compliance with research participation requests by individuals who are incarcerated is a crucial consideration in how to communicate with potential subjects about volunteerism and their rights as human research subjects.

Related to coercion, the key informants noted that any compensation or incentive has the potential to unduly influence individuals who are incarcerated. Because of the fundamental deprivation of correctional environments, levels of compensation and types of incentive that are considered minimal or average in free society can be unduly influential for persons who are incarcerated (Elger, 2008; Eldridge et al., 2011; Eldridge et al., 2012). Many key informants noted that correctional environments are not typically allowed to offer payment while individuals are incarcerated, but that does not eliminate the potential for money offered upon release or non-monetary incentives to act as motivators for participation. Indeed, even unintentional incentives can be motivations for participating. Individuals in free society are not likely to be swayed by the technical aspects of participating in research, such as changing one's normal routine to attend the research session or the opportunity to speak with a researcher; however, for people who are incarcerated, these natural consequences of participation can serve as compelling motivators for participation.

One particular type of incentive, and also a component of access to healthcare, is the social support that incarcerated persons experience as a byproduct of participation. As incarceration is an environment rife with deprivation, the opportunity for interaction, particularly with new people who are likely to be interested listeners, can be a strong motivator for research participation. The thorough discussion of unintentional incentives and potential for undue influence due to incentives highlights the key informants' attitudes surrounding the importance of understanding the types and appropriateness of incentives for incarcerated persons.

Limitations

While the key informants interviewed for this study were knowledgeable about research with individuals who are incarcerated, they were not incarcerated themselves and it is not known to what degree they had previously communicated with incarcerated people about their experiences as actual or potential research participants. The key informants presented their perceptions regarding the motivations of incarcerated individuals to participate in research, but their perceptions may not match the true motivations of incarcerated people themselves. An additional limitation stems from the use of snowball sampling to recruit participants for this study. It is possible that key informants who referred their colleagues for participation had shared experiences and similarity in their responses. The community of professionals working in correctional HIV/AIDS research is small; therefore even without snowball sampling, recruitment of the sample would result in participants who had worked together and had similar experience. Finally, because the key informants were speaking specifically about their experiences with HIV/AIDS research in correctional settings, these results may not generalize to research with other vulnerable or doubly vulnerable populations or to other kinds of research in correctional settings.

Despite these limitations, understanding the perceptions of professionals is a first step in exploring the question of motivation for research participation among individuals who are incarcerated and the results are important for the development of ethical research protocols.

Best Practices

The current study explored the perceptions of motivators for research participation among people who are incarcerated by analyzing data received from qualitative interviews with professionals with experience in designing, implementing, or providing ethical oversight for HIV/AIDS research in correctional settings. The range and extent of these professionals' experiences provide interesting and insightful viewpoints for exploring issues related to participation in research by people who are incarcerated and contribute to the development of consistent guidelines for the conduct of ethical health research with individuals who are incarcerated (Freudenberg, 2007; Gostin, et al., 2006). The potential for coercion and incentives of various kinds to motivate research participation among individuals who are incarcerated underscores the need for correctional researchers to have a complete understanding of the principle of respect for persons and act accordingly to protect potential participants' autonomy.

Research Agenda

By interviewing professionals about their perceptions of what motivates incarcerated individuals to participate in research, this study represents the first step in an important line of research. The next critical step is to include individuals who are currently or were previously incarcerated, including individuals with and without experience participating in research while incarcerated. These individuals will provide valuable information that may confirm, disconfirm, or augment what we learned from professionals. Additionally, future research might explore variation in motivators for differing types of research studies, such as comparing medication trials to one-time survey research.

Educational Implications

For investigators to design ethical research protocols and for IRB members to appropriately review, they must understand the unique circumstances of vulnerable research participants. Training for research professionals should include consideration of the motivations that drive individuals to participate in research and how those motivations are likely to differ for incarcerated persons and other vulnerable groups. Examination of case studies would promote the type of in-depth understanding of circumstance necessary to recognize likely motivations.

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Biography

Bridget L. Hanson is a Research Assistant Professor at the Center for Behavioral Health Research and Services, University of Alaska Anchorage. An applied social psychologist, her primary research interests lie in legal and health-related research. Dr. Hanson served as a Co-Investigator on this project, leading the theme analysis and writing of this manuscript.

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References

- Alexander SJ. 'As long as it helps somebody': Why vulnerable people participate in research. *International Journal of Palliative Nursing*. 2010; 16:173–176.
- DuBois JM, Beskow L, Campbell J, Dugosh K, Festinger D, Hartz S, Lidz C. Restoring balance: A consensus statement on the protection of vulnerable research participants. *American Journal of Public Health*. 2012; 102:2220–2225. [PubMed: 23078487]
- Eldridge GD, Johnson ME, Brems C, Corey SL. Ethical challenges in conducting psychiatric or mental health research in correctional settings. *American Journal of Bioethics Primary Research*. 2011; 2:42–51. [PubMed: 21766046]
- Eldridge GD, Robinson RV, Corey S, Brems C, Johnson ME. Ethical challenges in conducting HIV/AIDS research in correctional settings. *Journal of Correctional Health Care*. 2012; 18:309–318. [PubMed: 22952319]
- Elger BS. Research involving prisoners: Consensus and controversies in international and European regulations. *Bioethics*. 2008; 22:224–238. [PubMed: 18405321]
- Freudenberg, N. Health research behind bars: A brief guide to research in jails and prisons.. In: Greifinger, RB., editor. *Public health behind bars: From prisons to communities*. Springer; New York: 2007. p. 415-433.
- Fry C, Dwyer R. For love or money? An exploratory study of why injecting drug users participate in research. *Addiction*. 2001; 96:1319–1325. [PubMed: 11672496]
- Gostin, LO.; Vanchieri, C.; Pope, A. *Ethical considerations for research involving prisoners*. National Academies Press; Washington, DC: 2006.
- Hallowell N, Cooke S, Crawford G, Lucassen A, Parker M, Snowdon C. An investigation of patients' motivations for their participation in genetics-related research. *Journal of Medical Ethics*. 2009; 36:37–45. [PubMed: 20026692]
- Kass NE, Maman S, Atkinson J. Motivations, understanding, and voluntariness in international randomized trials. *IRB Ethics & Human Research*. 2005; 27:1–8. [PubMed: 16425478]
- Lowton K. Trials and tribulations: Understanding motivations for clinical research participation amongst adults with cystic fibrosis. *Social Science & Medicine*. 2005; 61:1854–1865. [PubMed: 15913858]
- Office for Human Research Protections. Protection of human subjects, 45 C.F.R. Part 46. 2009. Retrieved from <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html>
- Sandelowski M. Sample size in qualitative research. *Research in Nursing & Health*. 1995; 18:179–183. [PubMed: 7899572]
- Springer SA, Altice FL. Managing HIV/AIDS in correctional settings. *Current HIV/AIDS Reports*. 2005; 2:165–170. [PubMed: 16343373]
- Springer SA, Bruce RD. A pilot survey of attitudes and knowledge about opioid substitution therapy for HIV-infected prisoners. *Journal of Opioid Management*. 2008; 4:81–86. [PubMed: 18557164]
- Strauss, A.; Corbin, JM. *Basics of qualitative research: Grounded theory procedures and techniques*. Sage; Thousand Oaks, CA: 1990.
- Warner TD, Roberts LW, Nguyen K. Do psychiatrists understand research-related experiences, attitudes, and motivations of schizophrenia study participants? *Comprehensive Psychiatry*. 2003; 44:227–233. [PubMed: 12764711]