

Improving the Continuity of Care for People Living with HIV Experiencing Incarceration in North Carolina Jails: Stakeholder Perspectives

Eric Juengst, Mara Buchbinder, Colleen Blue, Stuart Rennie, Lauren Brinkley-Rubinstein, David L. Rosen

BACKGROUND Jail detention can disrupt the continuity of care for people living with HIV/AIDS (PLWH). Using a state's "Data to Care" (D2C) program might help overcome this barrier, but raises important questions of data security, personal privacy, resource allocation, and logistics.

METHODS As part of a study involving in-depth expert stakeholder interviews, a 1-day workshop was convened to identify and discuss potential ethical challenges in extending North Carolina's D2C program to jail settings. Workshop participants included public health officials, community advocates, HIV clinicians, jail administrators, privacy experts, criminal justice researchers, and a formerly incarcerated PLWH. Workshop participants discussed the results of earlier stakeholder interviews with the goal of identifying the most important points to consider in assessing the merits of extending D2C surveillance to jail settings.

RESULTS Although the workshop participants expressed support for improving the continuity of HIV care for jail detainees, they had mixed perspectives on whether a jail-based D2C program should include in-jail or post-release follow-up interventions. Their positions were influenced by their views on 4 sets of implementation issues: privacy/data-sharing; government assistance/overreach; HIV criminalization/exceptionalism; and community engagement.

LIMITATIONS The limitations of this stakeholder engagement exercise include its purposive recruitment, relatively small number of participants, and limited duration.

CONCLUSIONS Improving the continuity of HIV care in particular jail settings will depend on a number of local considerations. In deciding between models featuring in-jail and post-release follow-up care, the most important of these considerations will be the possibility of establishing good partnerships between the jail, the health department, and the community. Additional research on the dynamics and impact of different models is needed.

Reengaging people living with HIV/AIDS (PLWH) who have fallen out of care is an important goal for state public health agencies. "Data to Care" (D2C) programs address that goal by linking state health departments' HIV databases with other patient data to assess retention in care and trigger follow-up contact by public health outreach agents [1]. In the United States, all states have a funding mandate to establish such D2C programs. Existing evaluations of D2C programs have found that about half of those confirmed to be out of care are re-linked to care [2-4], and community studies show high degrees of public support where they have been implemented [5, 6].

Spending time in jail can confound these efforts, both during incarceration and after release. Since most jail stays are transient, most people do not stay long enough to complete health screenings on day 14, as recommended by national correctional health care accrediting bodies. Moreover, even when screening does take place, the availability of health care for PLWH differs by each individual facility, as county jails operate independently and with large variations in county budget allocations and other resources [7, 8]. However, incarceration can also be an opportune time to reengage out-of-care PLWH.

County jail inmate rosters are public records and in one-third of North Carolina's 100 counties they are published on

jail websites. Using automated "web-scraping" programs that collect jails' online rosters daily (or more frequently) makes it possible to link these lists with the North Carolina Division of Public Health HIV/STD/Hepatitis Surveillance Unit records to locate PLWH in county jails for reengagement in care [9].

Although public health surveillance data have been used to initiate individual-level interventions for other communicable diseases such as syphilis, a number of factors (including technical data accessibility/linkage challenges, stigma concerns, and advocacy against use of personal identifiers) have traditionally limited the use of HIV surveillance data to monitoring the epidemic at the population level [5]. Despite the fact that jurisdictions across the country are using HIV surveillance data to re-link patients to care, there have been few publications reviewing the ethical and practical repercussions of this approach from the perspectives of PLWH and other relevant stakeholders [5, 6]. In these studies, while stakeholders described several concerns, they gen-

Electronically published May 5, 2022.

Address correspondence to Eric Juengst, Center for Bioethics, UNC-Chapel Hill, Chapel Hill, NC 27599 (ejuengst@med.unc.edu).

N C Med J. 2023;83(5):XXX-XXX. ©2022 by the North Carolina Institute of Medicine and The Duke Endowment. All rights reserved. 0029-2559/2023/83503

erally reported that the benefits of community-based D2C outweighed the drawbacks. But the implications of implementing jail-based D2C programs have yet to be addressed. What are the public health benefits, ethical challenges, and practical opportunities in using publicly available jail records, court records, and state health department HIV registry records to improve the continuity of care for PLWH experiencing incarceration?

Our research team convened a stakeholder engagement workshop on January 23, 2020, on the campus of the University of North Carolina at Chapel Hill, to discuss the policy and practical implications of extending North Carolina's D2C program to PLWH in jails. The workshop design was informed by a set of qualitative interviews conducted in 2018–2019 with 47 expert stakeholders and 18 recently incarcerated PLWH. These qualitative interviews examined the public health benefits, ethical challenges, and practical opportunities in using publicly available jail records, court records, and state health department HIV registry records to improve the continuity of care for PLWH experiencing incarceration [10–12]. In this report, we review this background interview study and the discussion of its results by the stakeholders from the field who participated in the 2020 workshop.

Qualitative Stakeholder Interviews

For the qualitative interviews, expert stakeholders were recruited via a purposive sampling strategy in which we aimed to recruit 3–5 participants in each of several categories of professional expertise and experience (public health, ethics and privacy, law and criminal justice, and community advocacy). Potential participants were identified using a combination of methods, including the research team's professional network, literature review and online searches, and snowball sampling. Prospective participants were invited by email to participate in the study. Semistructured interview guides included questions about the participants' professional background and perspectives on: HIV surveillance and D2C in the general population, potential use of HIV surveillance and D2C in North Carolina jails, privacy, community engagement, data governance, and research practices. We formed the interview guides based on a theoretical framework for public health ethics considering the perspectives of the individual, institutions, communities, and society at large [13]. We then identified the topics that the interviewees considered the most salient in discussing the practical implementation of HIV D2C programs in North Carolina jails, and used these topics for our expert stakeholder workshop. PLWH recently incarcerated in a North Carolina jail were recruited to participate in community and prison settings in North Carolina using a convenience sampling strategy. Semistructured interview guides for this group included questions about HIV care in jail, experiences with HIV surveillance and D2C in the community, and perspectives on potential uses of these strategies in jails.

Five members of the research team with training in qualitative interviewing conducted all interviews, after obtaining informed consent. Expert stakeholder interviews were audio-recorded and conducted either in person or via videoconference or telephone. Interviews with PLWH recently incarcerated in jail were conducted in person and were audio-recorded or, in the case of interviews conducted in the prison setting, notes were recorded. We used Dedoose software to analyze interview transcripts across 22 thematic codes for expert interviews and 24 thematic codes for interviews with PLWH. Each transcript was coded by multiple members of the research team; discrepancies were discussed and reconciled. After coding was completed, we identified salient themes for further analysis and further examined coding reports from each coding category to identify patterns across the larger dataset.

The results of our qualitative interviews have been reported and discussed elsewhere [10–12], but we briefly summarize here. Expert stakeholder interviewees included 30 participants from North Carolina; the remainder lived in other US states ($n = 15$) or outside the United States ($n = 2$). North Carolina-based expert stakeholders represented 15 distinct counties, including 6 rural and 9 urban counties. They had expertise in the following domains: ethics and privacy ($n = 9$), public health ($n = 24$), criminal justice ($n = 7$), and community advocacy ($n = 7$). Formerly incarcerated PLWH who were interviewed had spent time in 18 unique North Carolina jails. Despite their professional and disciplinary diversity, expert participants universally acknowledged the public health needs that D2C programs aim to address, and most expressed support for the public health goals such programs fulfill. In discussing the practical and ethical considerations of implementing such programs, however, they also qualified their support with a range of significant concerns in 7 key domains: permission and consent, government assistance versus overreach, privacy and confidentiality, stigma, HIV exceptionalism, criminalization, and data integrity and sharing [11].

Formerly incarcerated participants echoed these concerns at the experiential level. Although most endorsed state assistance for reengaging in HIV care and reported favorable encounters with public health outreach efforts, they also framed retention in care as an individual responsibility. Almost half (40%) were not aware that the state performs HIV surveillance and D2C [12]. A vocal minority of formerly incarcerated participants also expressed adamant opposition to the idea of jail-based D2C programs, citing concerns about violation of privacy and the threat of violence in the jail setting [12]. A central conclusion that emerged from these interviews was that there is a need to promote public trust in D2C efforts through increased transparency about the goals, methods, and risks of such programs.

Our interview findings suggest that community engagement in program implementation is critical for ensuring that D2C programs and other public health surveillance

programs are designed in contextually sensitive ways, particularly given the high degree of support for the notion that D2C could heighten stigma. These provided the basis for the 4 themes that framed our workshop discussions: privacy/data-sharing; government assistance/overreach; HIV criminalization/exceptionalism; and community engagement.

Materials and Methods

Our primary objective in holding a stakeholder workshop was to explore perspectives expressed in the qualitative interviews, generate interactive interprofessional discussion, and permit stakeholders to respond synergistically to each other's ideas. We expected that this dynamic form of stakeholder engagement would enhance our initial qualitative findings. We planned to have approximately 15–20 experts at the workshop to allow for small-group discussion and deeper dialogue around the points made in the interviews. We invited a subset of interview participants (17/65) to attend. We purposively selected participants who were highly engaged during the interviews and who could speak from experience about the risks and benefits of extending D2C to jails. Invitees were also selected to ensure participants had a range of expertise in ethics and privacy, public health and medicine, criminal justice, and community advocacy. To ensure that the perspectives of those who would be directly impacted by extending D2C in jails were included, 3 formerly incarcerated PLWH and 4 community advocates who had participated in interviews were among those invited. Ultimately, 11 of the original interviewees agreed to attend—including 2 formerly incarcerated PLWH—and 6 declined due to scheduling conflicts. We then invited 5 additional participants to ensure professional expertise in the areas of privacy and the criminal justice system, public policy, and implementing and evaluating D2C programs. Similar to the qualitative interviews, these participants were identified using the research team's professional network, literature review and online searches, and snowball sampling. Invitees were offered an honorarium in appreciation for their participation.

Final attendees of the day-long workshop included 17 experts—including 2 North Carolina jail administrators, 3 community advocates, 2 HIV linkage staff, 1 HIV clinician, 1 bioethicist, 2 privacy experts, 3 public health officials, and 1 formerly incarcerated PLWH—and 2 members of our research team who are also HIV clinicians and researchers. One of the formerly incarcerated PLWH who had initially agreed to participate was unable to attend on the day of the workshop. Eleven of the participants were based in North Carolina, and 6 came from elsewhere in the United States or Canada. Three participants, including the North Carolina jail administrators and HIV clinician, came from North Carolina counties located outside of the urban centers, and nearly all North Carolina participants had experience working in both urban and rural areas of the state. In addition, 9 participants had direct experience working with incarcerated people and PLWH, including community advocates who worked with

PLWH to promote harm reduction and to provide HIV education in North Carolina jails.

Prior to the workshop, participants reviewed a summary report of key themes from the qualitative interviews as well as a video presentation about our project. The workshop was structured to incorporate a mix of small-group and large-group discussion formats. For the small-group format, we divided participants into groups with complementary expertise to discuss 4 sets of issues that emerged as particularly salient in our qualitative analysis of interview findings: privacy/data-sharing; government assistance/overreach; HIV criminalization/exceptionalism; and community engagement. Participants were asked to discuss their reactions to the findings and identify additional considerations and questions. Their conclusions were recorded in writing for subsequent discussion by the large group. Three research staff members took simultaneous notes during both small- and large-group sessions. After the workshop, we analyzed the small-group discussion records and the notes for their common and crosscutting thematic elements, and developed consensus interpretations of the participants' views. These analyses were conducted collaboratively by the research staff and coinvestigators who attended the workshop at our regular research team meetings, against the background of the public health ethics framework and D2C literature. In what follows, we first describe the participants' general views on extending D2C to North Carolina jail populations. We then report participants' views on the 4 sets of issues identified here. Finally, we review a set of practical considerations that emerged from the workshop discussion and identify further research needs.

Results

Should D2C Programs Be Extended to the Jail Context?

Workshop participants disagreed on whether the public health benefits to be gained by jail-based D2C follow-up would be worth the potential risks of stigmatizing PLWH and the loss of public trust, given the availability of alternative ways of providing HIV care in jail- and community-based D2C efforts.

Workshop participants in favor of jail-based D2C interventions argued that many PLWH are not being identified by jails due to short stays and lack of information-sharing between jails. They also cited disincentives to voluntary disclosure during health screening interventions, such as fears of stigmatization by jail staff and other detainees. Access to people incarcerated in jails could also make public health outreach simpler and more effective than following up with people in the community. Moreover, a centralized health department program could reduce local jurisdictional inequities in HIV care, and, by reducing the number of actors and information exchanges involved, better protect the confidentiality of its findings.

Other participants were unconvinced that these benefits would outweigh the social risks of a jail-based D2C pro-

gram, given what can already be achieved through D2C after release in the community. They argued that it would be more difficult to protect the confidentiality of HIV status information if it were released to jail personnel, and that if jails were not informed, confidential public health outreach visits to the incarcerated might not be possible. Additionally, community reactions to the sharing of information about HIV status between state health departments and the criminal justice system might erode trust in both systems.

Participants widely acknowledged that jails are obligated to address the health care needs of PLWH, and that a jail-based D2C program that could help jails provide high-quality levels of HIV care would improve public trust in the system. On the other hand, they concurred that the criminal justice system should not supplant community-based public health efforts; if the continuity of HIV care after release is the primary problem being addressed, some felt it might be done more directly by improving health care support for formerly incarcerated individuals in the community.

Challenges in Extending D2C Surveillance to Jail Settings

Workshop participants' views on the overall merits of extending D2C surveillance to jails were influenced by their perspectives on the particular challenges that this development would create. These perspectives surfaced in their reactions to the 4 themes from the stakeholder interviews: privacy/data-sharing; government assistance/overreach; HIV criminalization/exceptionalism; and community engagement.

Privacy/data-sharing. Workshop participants identified 2 sets of privacy challenges in extending North Carolina's D2C program to jail settings. At the *data linkage stage* of the process are questions about the security of the data collected and the data-sharing that would be required to identify individuals incarcerated in jails who are also PLWH. At the *D2C reengagement stage*, issues of confidentiality arise if state health worker follow-up takes place within jail settings.

Data security/sharing. Workshop participants emphasized that the inherent power differentials in the context of incarceration make explicit privacy protections for health information especially important to fostering trust in criminal justice institutions. These protections might take the form of formal data security protocols to prevent inadvertent leaks along the informational pipelines a jail-based D2C program would create, as well as explicit data-sharing rules about how the information could be used by those with access to it. Participants asked if, for example, D2C surveillance data would be accessible by jail administrators, other law enforcement agencies, for-profit health care concerns providing services to jails, or even elected officials. Jail roster information is already publicly available, and the court records that would be used are discoverable, but the state's public health register of PLWH in North Carolina is confiden-

tial. If a jail-based D2C program threatened that confidentiality by increasing the number of parties and information exchanges involved, it could undermine efforts to preserve public trust in the state's public health efforts.

Confidentiality/communication. The workshop participants agreed that public health workers, jail staff, and clinical care providers all have ethical and legal duties of confidentiality regarding medical information about specific inmates. However, even those confident that existing HIPAA laws and professional confidentiality practices can be implemented effectively in North Carolina jail settings acknowledged the risk of accidental disclosures. Some pointed out that an identified health department worker's visit to a person in jail would alert staff and others to the risk of an infectious disease even if they were unaware of the D2C program. This kind of inadvertent violation of informational privacy can also happen in community settings when health worker visits are visible to others. But the risk is exacerbated in jail settings because of the lack of spatial privacy in jail, the lack of systems for confidential communications between incarcerated individuals and visitors, and visitor safety precautions that require the presence of others during visits. Additionally, most jails use nonmedical detention staff to conduct health screenings and have policies that give other jail personnel access to incarcerated individuals' medical prescription records. Many North Carolina jails are small and have relatively porous social boundaries with the surrounding communities. Inadequate HIV education among both staff and incarcerated individuals can also allow misinformation to magnify the stigma of HIV in jail settings.

Government assistance/overreach. The workshop discussions of privacy challenges were echoed in a second set of discussions about an even more fundamental question regarding the proper social role of public health agencies: would extending North Carolina's D2C program into jails represent inappropriate governmental overreach, or appropriate governmental assistance to otherwise disadvantaged PLWH?

Some workshop participants felt that jail-based D2C programs would be consistent with other uses of public health data for disease surveillance, and could be justified by the same social mandate to track and prevent disease. In addition to enabling the government to assist PLWH in jails, 1 participant argued, extending D2C to jails would allow the state to fulfill its duty to protect community health by reducing the risk of transmission from PLWH following their release. Others went further to argue that, in addition to disease control, social justice considerations create a special obligation for state health departments to extend D2C services to those who might fall out of care through incarceration. Other participants felt that incarcerated people would be more likely to view re-contact in jail as overly paternalistic or invasive and to be alarmed to discover yet another way

they were being “policed” by the state.

Regardless of their views on whether a jail-based D2C program was inappropriate overreach or legitimate assistance, workshop participants all concurred that PLWH retain the right to refuse health care even when incarcerated. They identified several factors that might make incarcerated individuals more likely to refuse HIV treatment in jail, including fear of stigmatization, anxiety, past trauma, distrust, and depression. Some participants were concerned that the jail environment would also influence the choices of incarcerated individuals, by either rewarding participation or penalizing refusal as “noncompliance.” Participants stressed that these factors underline the need for nonjudgmental and respectful approaches to soliciting participation in any follow-up activities and dealing with refusals of care.

Criminalization/exceptionalism. Workshop participants agreed that among the most harmful forms of institutionalized HIV stigmatization are statutes that make it a crime to have or to transmit HIV disease. These statutes create unjust disincentives for PLWH to disclose their HIV status or participate in follow-up care [14]. In small communities, PLWH may feel that they are at heightened risk for arrest and incarceration because of their HIV status. In the jail setting, extra attention to HIV-related care, including the implementation of D2C, could induce similar concerns about disclosure and risk for additional charges or punishments.

Some participants went further to ask whether HIV D2C programs are themselves psychologically punitive by authorizing public health officers to seek out reidentified PLWH. For example, programs that characterize out-of-care PLWH or those who decline follow-up as “noncompliant” can convey the impression that decliners deserve to be blamed for their choices. People who already have reasons to mistrust the health care and justice systems, including people of color and transgender people, are even more likely to perceive D2C programs in jails as part of a broader societal pattern of recriminatory attitudes. Participants agreed that better partnerships between health departments and jails could provide a forum for addressing and diminishing these risks.

Singling out HIV disease for criminalization over other kinds of communicable diseases is a clear example of the problem of “HIV exceptionalism” [15]. But HIV exceptionalism can also occur when PLWH receive assistance that is not available to those with comparable diseases. Some participants felt that, given medical and social progress since the inception of the HIV epidemic, HIV-specific D2C programs are no longer warranted. Others argued that HIV is, in fact, still exceptional enough in terms of social stigmatization to merit special attention. In addition, some saw HIV D2C programs as testing a model that could be extended to other diseases or could lead to overall improvements in health care in jails.

Community engagement. Finally, 1 prerequisite for a jail-based D2C program that resonated with the workshop par-

ticipants was the need for community engagement within and outside the jails. Iterative, transparent, and deliberative engagements with both PLWH and the wider communities served by the jails were seen as key to minimizing the risks the workshop identified and making a jail-based D2C program a success. Some participants stressed that consultations with PLWH who have experienced incarceration would be a very important element in this process. Such engagements could help shed light on unanticipated challenges that a jail-based D2C program would face in particular settings and build community support through transparency about the assistance that such a program can provide.

Practical Considerations

In addition to discussing the policy challenges listed here, the workshop participants raised 5 practical considerations that they felt would be critical to consider in developing a successful jail-based D2C program.

Every Jail Is Different

Participants pointed out that jails are organized, resourced, and staffed very differently depending on the communities they serve. Some jails are able to screen incarcerated individuals for HIV within 24 hours of booking and are equipped to provide HIV treatment and counseling directly. Others have established partnerships with regional health care facilities that can provide such services. For these jails, an extended D2C program may not offer compelling added value. As a result, any statewide program would require on-the-ground assessments of individual jails, so that it can be tailored to differences in organizational culture, population, and resources.

Jail and State Staff Training Is Needed

Participants concurred that ongoing training will be needed for jail staff and D2C follow-up care providers to combat the entrenched stigma that PLWH in jails can face. This training should include continuing education about privacy policies and procedures for both jail staff and public health workers. In designing such interventions, it will be important to consider the variable lengths of stay that people incarcerated in jail can experience; those incarcerated for only 1 day will have different needs than those who stay in jail longer.

Timing Is Key

Length of stay consideration also requires D2C programs to clarify the temporal criteria for being considered “out of care.” Typically, the threshold for being considered out of care is 9–12 months without follow-up. Given the number of short-term incarcerations in jails, a jail-based D2C program may help identify PLWH who have already been deemed out of care prior to their incarceration, but may not be useful for those whose care is interrupted by short-term jail stays. This means that any D2C program should be flexible enough

to tailor its efforts to reengage PLWH in care to individual needs and situations.

Incarcerated People Should Have Options

Workshop participants concurred that if jail-based HIV D2C programs are developed they should be offered to all incarcerated PLWH, but that these individuals should retain the right to choose whether or not they accept the assistance. Some participants recommended an “opt-in” system in which incarcerated PLWH would be informed about the program and how to enroll but would need to reply to receive follow-up visits. Others recommended giving incarcerated PLWH the option of receiving follow-up care during their detention or after their release, to increase the potential for positive replies. Suggestions for mechanisms included toll-free phone numbers, media infomercials, or touchpad kiosks that might be used upon release from jail.

Protect Data with Partnerships

Another approach to developing a partnership between jails and the health department that received support from workshop participants was a hybrid model in which jails would serve as a source of surveillance information that would be sequestered and protected within the public health system for use in reconnecting with people after their release. Although this could help avoid adverse consequences in the jail setting, some pointed out that this would not serve the needs of incarcerated individuals with long sentences who might need care during their incarcerations. They argued that more robust partnerships would ultimately be required to address the challenges raised here.

Discussion

On the whole, the workshop participants’ views on each of these themes echoed those of the interviewees, both in their points of consensus and in their divisions of opinion. Both sets of stakeholders concurred on the critical importance of, and challenges in enhanced data security and privacy protections for D2C programs in jail settings; the rights of people in jail to refuse medical care; the dangers of HIV criminalization and exceptionalism; and the utility of community engagement in fostering trust and transparency. Workshop participants were also similar to our interviewees in their differences of opinion regarding the extent to which concerns about inappropriate governmental overreach raised important challenges for jail-based D2C programs. Some defended the practice as a form of public assistance demanded by social justice considerations, and others pointed to how public perceptions of intrusiveness could undermine trust in the program, particularly in criminal justice settings. On several scores, however, the stakeholders involved in our interactive workshop discussions were able to build off each other’s points to offer insights that went beyond those that emerged from our 1-on-1 interviews.

First, the interactive format of the engagement workshop

allowed participants to explore important considerations that remained largely muted in the individual interviews. Examples included workshop participants’ more fine-grained analyses of the privacy risks of HIV surveillance in carceral settings across different jail staff roles; their reiteration of the relevance of people’s background legal rights to refuse health care in these contexts; their recognition of the relatively porous social boundaries of jails; and their nuanced concerns about the punitive psychological impacts of “compliance” language, which were not addressed as thoroughly in individual interviews.

Second, by having the opportunity to share their expertise and compare experiences across different roles and disciplines, the workshop participants were able to go further than individual interview participants in identifying nuanced practical considerations important to the implementation of any jail-based D2C program. Workshop participants were able to compare the important ways in which jails can differ across sites in terms of jail staff education, the implications of program timing, and the prospects for data protection partnerships in different institutional contexts.

Finally, and perhaps most importantly, by having an opportunity to discuss their views together the workshop participants were able to arrive at policy options that could help harmonize their different individual perspectives. The best example of this was the workshop participants’ idea of avoiding the privacy challenges in jail settings and mitigating public perceptions of governmental intrusiveness by developing a hybrid model in which jails would serve as a source of surveillance information that would be sequestered and protected within the public health system for use in reconnecting with people after their release.

Conclusion

Studies of community, provider, and patient perspectives on D2C approaches to HIV outside of the carceral setting have generally identified fewer ethical and logistical concerns than emerged at our workshop [5, 6]. Our findings highlight several features of jail-based D2C programs that merit special attention going forward: the potential for heightened privacy risks; the different ways in which HIV stigmatization can manifest in jail settings; and the impact of increased collaboration between the state health department and its local correctional institutions on public trust. Since the time of the workshop, killings of those in the custody of law enforcement—particularly that of George Floyd—have elevated the national conversation regarding issues of systemic racism and the role of law enforcement agencies in our society, and this will provide a critical backdrop for community responses to jail-based D2C programs.

Finally, the workshop underscored the point that, because of the contextual nature of the challenges that were identified, pilot studies of jail-based D2C programs in particular settings are needed. Since jails operate independently and their individual budgets and resources vary tremendously,

the availability of HIV treatment and care resources will need to be assessed and likely increased with any program for underresourced jails and communities. Existing projects funded by the Ryan White Comprehensive AIDS Resources Emergency Act to facilitate linkage to care after jail incarceration, such as Transitional Care Coordination (TCC) [16], could be adapted to address many of the concerns identified by participants. TCC relies on HIV testing or self-report to identify PLWH in jail, in contrast to D2C, which uses state health department data to identify out-of-care PLWH, allowing for broader identification of eligible participants. If the comparison of jail rosters with state HIV records indicates that there are actually few PLWH who are out of care in jail, then the issues of in-jail implementation are less relevant. Jail-based trials of D2C will also be needed to compare the risks and benefits of jail versus community settings for D2C in an evidence-based manner. If the hybrid model seems supported by such studies, more will need to be learned about consequences of conducting surveillance in jails without offering follow-up care in those settings. For example, it will be important to study how changes in HIV treatment, such as long-acting antiretrovirals, might impact D2C programs and policy. It could be instructive to learn from similar programs already operative in jails, such as directly observed therapy (DOT) for tuberculosis and medication-assisted therapy (MAT) for opioid use.

As medical progress produces more effective treatments for HIV disease, the need to ensure continuous access to those interventions for PLWH who experience incarceration will grow. Jail-based D2C programs can help meet that need, but also pose policy and practical challenges that will need to be addressed. Bringing a wide range of stakeholders into the conversation can help all parties appreciate the arguments and experiences that inform different points of view on those challenges. NCMJ

Eric Juengst, PhD professor, Department of Social Medicine, Center for Bioethics, UNC-Chapel Hill, Chapel Hill, North Carolina.

Mara Buchbinder, PhD professor, Department of Social Medicine, Center for Bioethics, UNC-Chapel Hill, Chapel Hill, North Carolina.

Colleen Blue, MPH research health science specialist, US Department of Veterans Affairs, Durham, North Carolina.

Stuart Rennie, PhD associate professor, Department of Social Medicine, Center for Bioethics, UNC-Chapel Hill, Chapel Hill, North Carolina.

Lauren Brinkley-Rubinstein, PhD associate professor, Department of Social Medicine, Center for Health Equity Research, UNC-Chapel Hill, Chapel Hill, North Carolina.

David L. Rosen, MD, PhD associate professor, Division of Infectious Diseases, Department of Medicine, UNC-Chapel Hill, Chapel Hill, North Carolina.

Acknowledgments

The authors wish to thank the participants in the Ethics Workshop and our local consultants for their time and perspectives: Steve Bradley-Bull, Mercedes Brown, Jessica Carda-Auten, Elena DiRosa, Kathryn Bryan, Michelle Collins-Ogle, Martin French, Melissa Goldstein, Lisa Lee, Gregorio Millett, Darren Pittman, Dee Simmons, Patricia Sweeney, James Tesoriero, Oliver Washington, Becky White, and Loftin Wilson.

Funding for the workshop was provided by the National Institute of Allergy and Infectious Diseases of the National Institutes of Health under Award Number R01AI129731 and the University of North Carolina at Chapel Hill, Center for AIDS Research (CFAR), an NIH-funded pro-

gram P30 AI050410. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

References

1. Sweeney P, DiNenno E, Flores S, et al. HIV data to care: using public health data to improve HIV care and prevention. *J Acquir Immune Defic Syndr*. 2019;82(Suppl 1):S1-S5. doi: 10.1097/QAI.0000000000002059
2. Seña AC, Donovan J, Swygard H, et al. The North Carolina HIV Bridge Counselor Program: outcomes from a statewide level intervention to link and reengage HIV-infected persons in care in the south. *J Acquir Immune Defic Syndr*. 2017;76(1):e7-e14. doi: 10.1097/QAI.0000000000001389
3. Udeagu CN, Shah S, Misra K, Sepkowitz KA, Braunstein SL. Where are they now? Assessing if persons returned to HIV care following loss to follow-up by public health case workers were engaged in care in follow-up years. *AIDS Patient Care STDS*. 2018;32(5):181-190. doi: 10.1089/apc.2018.0004
4. Tesoriero JM, Johnson BL, Hart-Malloy R, et al. Improving retention in HIV care through New York's expanded partner services data-to-care pilot. *J Public Health Manag Pract*. 2017;23(3):255-263. doi: 10.1097/PHH.0000000000000483
5. Dombrowski JC, Carey JW, Pitts N, et al. HIV provider and patient perspectives on the development of a health department "data to care" program: a qualitative study. *BMC Public Health*. 2016;16:491. doi: 10.1186/s12889-016-3152-4
6. Evans D, Van Gorder D, Morin SF, Steward WT, Gaffney S, Charlebois ED. Acceptance of the use of HIV surveillance data for care engagement. *J Acquir Immune Defic Syndr*. 2015;69(Suppl 1):S31-S36. doi: 10.1097/QAI.0000000000000573
7. Zeng Z, Minton TD. *Jail Inmates in 2019*. U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics; 2021. <https://bjs.ojp.gov/content/pub/pdf/ji19.pdf>
8. Schaeffer P, Jordan R, Chakraborty R. *Opportunities for Cost Savings In Corrections Without Sacrificing Service Quality: Inmate Health Care*. Urban Institute; February 2013. <https://www.urban.org/sites/default/files/publication/23341/412754-Opportunities-for-Cost-Savings-in-Corrections-Without-Sacrificing-Service-Quality-Inmate-Health-Care.PDF>
9. Rennie S, Buchbinder M, Juengst E, Brinkley-Rubinstein L, Blue C, Rosen DL. Scraping the web for public health gains: ethical considerations from a 'big data' research project on HIV and incarceration. *Public Health Ethics*. 2020;13(1):111-121. doi: 10.1093/phe/phaa006
10. Buchbinder M, Blue C, Juengst E, Brinkley-Rubinstein L, Rennie S, Rosen DL. Expert stakeholders' perspectives on a data-to-care strategy for improving care among HIV-positive individuals incarcerated in jails. *AIDS Care*. 2020;32(9):1155-1161. doi: 10.1080/09540121.2020.1737641
11. Buchbinder M, Blue C, Rennie S, Juengst E, Brinkley-Rubinstein L, Rosen DL. Practical and ethical concerns in implementing enhanced surveillance methods to improve continuity of HIV care: qualitative expert stakeholder study. *JMIR Public Health Surveill*. 2020;6(3):e19891. doi: 10.2196/19891
12. Buchbinder M, Blue C, Brown ME, Bradley-Bull S, Rosen DL. Jail-based data-to-care to improve continuity of HIV care: perspectives and experiences from previously incarcerated individuals. *AIDS Res Hum Retroviruses*. 2021;37(9):687-693. doi: 10.1089/AID.2020.0296
13. Childress JF, Faden RR, Gaare RD, et al. Public health ethics: mapping the terrain. *J Law Med Ethics* 2002;30(2):170-178. doi: 10.1111/j.1748-720x.2002.tb00384.x
14. Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention. HIV and STD Criminalization Laws. CDC website. Updated August 21, 2020. <https://www.cdc.gov/hiv/policies/law/states/exposure.html>
15. Smith JH, Whiteside A. The history of AIDS exceptionalism. *J Int AIDS Soc*. 2010;13:47. doi: 10.1186/1758-2652-13-47
16. US Health Resources & Services Administration Ryan White HIV/AIDS Program. Transitional Care Coordination: From Jail Intake to Community HIV Primary Care. Target HIV website. Updated 2021. <https://targethiv.org/deii/deii-transitional-care>