Perspectives of Women in Prostitution diversion program on DNA Collection for a High-Risk DNA Database

Sara H. Katsanis
Duke University, United States of America

Martha Felini
University of North Texas Health Science Center, United States of America

Joyce Kim, Mollie Minear & Subhashini Chandrasekharan
Duke University, United States of America

Jennifer K. Wagner
Geisinger Health System, United States of America

Abstract
DNA can be collected from women at high risk of violent crime as a pre-emptive biometric for post-mortem identification. We conducted focus groups with women in a prostitution diversion program that offers pre-emptive DNA collection. In general, the women supported the program but voiced concern for law enforcement collecting DNA. These data provide insights into the challenges of collecting DNA from women whom law enforcement might consider alternately to be victims or vilified. Hearing the voices of these women provides the forensic community an opportunity to design programs to minimize harm and maximize utility of DNA for victim identification.

Keywords: DNA Database, Sex Workers, Sex Trafficking, Human Trafficking, Focus Groups.

1 Duke Initiative for Science & Society, Duke University, Box 90222, Durham, NC 27708, USA. Email: sara.katsanis@duke.edu
2 Department of Obstetrics and Gynecology, University of North Texas Health Science Center, martha.felini@unthsc.edu
3 Duke Initiative for Science & Society, Duke University, Box 90222, Durham, NC 27708, USA. Email: joyce.kim29@gmail.com
4 Duke Initiative for Science & Society, Duke University, Box 90222, Durham, NC 27708, USA. Email: mollie.minear@gmail.com
5 Duke Global Health Institute, Duke University, Durham, NC 27708, USA. Email: shubha.c@duke.edu
6 Geisinger Health System, 100 North Academy Ave. Danville, PA 17822-4910, USA. Email: jwagner1@geisinger.edu
Introduction

Genetic information is an ideal biometric tool for identification, particularly when compared to biological relatives through kinship analysis. Too often, unidentified remains are of vulnerable populations, including local and transient persons such as vagrant youth, homeless persons, drug users, sex workers, and undocumented migrants. Oftentimes, individuals of these populations travel with no identification or with false identifiers, making biometrics a necessity for investigating post-mortem identity. Preemptive DNA collection from high-risk populations is one approach to allow law enforcement to identify victims that may be challenging to identify post-mortem. Emergent programs within law enforcement have developed with a sampling of identifications made.

Forensic communities keen to use biometrics for identification benefit from social science data to document the perspectives of the populations whom they seek to serve. Assessing high-risk populations’ perspectives on the use of biometrics for identification is challenging, particularly when individuals might be incarcerated, easily coerced, fearful of deportation, or non-English speaking. Women engaged with a prostitution diversion program provide an opportunity to engage with such a vulnerable population as a sample set of vulnerable populations’ perspectives. Social science research on the social implications of forensic applications is vital to maximize success of humanitarian-based efforts for applying biometrics for identification.

Sex workers are at an elevated risk for becoming victims of violent crime, and DNA forensic analysis can be crucial for identifying these victims. National, state, and local efforts to coordinate law enforcement and victim services have escalated in recent years (Etchegaray et al., 2013), but our understanding of the effectiveness of these efforts to decriminalize sex workers and re-conceptualize their status as sex trafficking victims is limited (Seidenberg, 2013). Because prostitution remains a criminal offense in most jurisdictions, sex workers (whether voluntary actors or human trafficking victims) are unable or reluctant to seek assistance from victims’ support providers, law enforcement, or the judicial system due to fear of prosecution for their acts of prostitution, fear of retaliation from their traffickers (such as pimps and madams), and general distrust of authorities.

Sex workers often avoid carrying legal forms of personal identification and might use false identities (i.e., aliases) when working “on the street,” when confronted by law enforcement, and even when being treated by health care providers. Because sex trafficking victims might come into police contact using different aliases and without verifiable identification, identity is difficult to establish consistently for a single individual across jurisdictions. Sex workers have been referred to as the “missing missing,” that is, missing persons who are never reported as missing (Quinet, 2007).

Because crimes against this population are scarcely reported, law enforcement lack sufficient information necessary to pursue investigations and connect crimes involving sex workers (Quinet, 2007). Homicide victims might be transported across state lines, and unfortunately, prostitution-related homicides represent a significant proportion of all homicides. Law enforcement officers have reported that sex workers servicing the long-haul trucking industry are most vulnerable. Sex workers and their clients are mobile, and this mobility, which frequently involves traversing jurisdictional boundaries, hinders law enforcement’s ability to link related crimes (Ferris, 2015). Investigators often are unable to
identify murdered sex workers, leaving hundreds of homicides unsolved (Potterat et al., 2004).

Forensic DNA approaches for human identification could vitally aid investigation of human trafficking cases (Kim & Katsanis, 2013). The use of DNA to investigate cases related to sex trafficking have broad applications from identifying homicide victims to connecting evidence of repeat offenders (e.g., sex customers), and potentially to identifying trafficked missing persons (Katsanis & Kim, 2014). Yet the effectiveness and social implications of this technological application are unexplored. While the general public seems to accept the use of DNA for investigating crimes, the collection and storage of DNA from non-criminal individuals by law enforcement or any other governmental agency (Couzin-Frankel, 2015) might be both unpopular and ethically challenging (Langreth, 2011). One jurisdiction in the U.S. has attempted use of DNA for investigating sex trafficking-related crimes via the Dallas Prostitute Diversion Initiative (PDI) and Positive Recovery Intensive Divert Experience (PRIDE) Court (Felini et al., 2012).

Diversion programs are utilized throughout the world as alternatives to traditional criminal justice systems for offenders of certain crimes (Wahab, 2006). The Dallas PDI offers support services to women working as sex workers (e.g., offering alternative housing options, financial advice, alternative career options) to facilitate permanent exit from the sex industry (Felini, Talari, Ryan, & Qualls-Hampton, 2013). The Dallas PDI performs a collaborative monthly field operation at various area truck stops, offering counseling and treatment services and an alternative to incarceration. Additionally, in response to the large number of women arrested for prostitution who have substance abuse issues and/or mental illness, Judge Hoffman of Dallas County developed the PRIDE Court (Positive Recovery Intensive Divert Experience). The PRIDE Court is a drug diversion specialty court for women charged with misdemeanor prostitution aiming to address the underlying causal and contributory factors for sex and drug crimes.

In collaboration with the Dallas PDI and PRIDE Court, the University of North Texas Health Science Center’s Center for Human Identification (UNTHSC-CHI) launched the High Risk Potential Victims DNA Database (HRDNA), establishing a database of voluntary DNA samples from women working as sex workers participating in the diversion programs. The database is used to assist with post-mortem identification and might be used by law enforcement as a “cold association” to open or pursue an existing criminal investigation. Law enforcement officials collect samples in order to maintain the chain of custody necessary for evidentiary purposes and post-mortem identification. Samples are stored and processed at UNTHSC-CHI. In this way, the HRDNA design is based on the notion that a chain of custody is essential to preservation of evidence for admissibility in court to pursue prosecution of crimes. Jurisdictions have adopted clear protocols to ensure authenticity for DNA evidence. Access to samples and information is confined to UNTHSC-CHI, because current state and federal protocols prevent samples collected outside of an open law enforcement case from being entered into the national DNA database (CODIS). When law enforcement suspects the victim of a violent crime,
homicide, or missing persons case could be an individual who has provided a DNA sample through the program, UNTHSC-CHI will compare the DNA profile from the crime victim to those profiles generated from DNA collected for the HRDNA. Collaboration with the Dallas diversion programs has contributed to the identification of at least one victim and is a potentially valuable resource for identifying future victims.

The development of similar DNA databases has the potential to improve detection and investigation of sex trafficking. However, the social ramifications of collecting DNA from vulnerable populations (e.g., children, vagrant youth, sex workers, and victims of criminal acts) are considerable, and questions remain unanswered as to how best to protect individuals from misuse of their voluntarily provided DNA. Cross-jurisdictional collaborations present the nontrivial challenge of sharing sensitive identification information, DNA profiles, and genetic information in a secure manner and with cultural sensitivities distinct to each population. Concerns have been voiced about the security of DNA profile systems, the possible disclosure of personal information, and the risk for misuse and/or malfunction (Thomas, 2006). Individuals sampled for such a database might be considered part of a vulnerable population, in that their ability to make an autonomous and informed decision (i.e., provide voluntary consent) might be limited compared to the general population. Cultural and political differences around the world mean that different communities might hold varying attitudes toward DNA collection and profiling (Jonassaint et al., 2010). Some populations might differ in concerns regarding DNA submission and fear of retribution for reporting suspicions or evidence of ongoing crimes.

Mistrust of law enforcement officials among sex workers is high, rooted in a history of brothel raids and sting operations that targeted sex workers for arrest. Often, trafficking victims are traumatized, stigmatized or fearful of retaliation by their traffickers (Antonopoulou & Skoufalos, 2006) and might, accordingly, be reluctant to cooperate with law enforcement investigations (Ferris, 2015). Existing programs using DNA assail concerns of DNA misuse by authorities through partnerships between law enforcement and academic or social services. However, further delineation between authorities might be necessary to assuage participation to maximum benefit of victims. The provision of DNA samples from women in these programs is voluntary; however, as these individuals might be considered by law enforcement to be both victims and criminals in some cases, this introduces complex considerations regarding autonomy, confidentiality and privacy.

Women working as sex workers in Western society often are victimized or vilified and their opinions and experiences stereotyped or demeaned as invalid (Ferris, 2015). Little research on women working as sex workers actually assesses the voices of the population, which are as varied as the women and the motivators behind their profession.

The use of DNA for humanitarian purposes is conceptually complex and developmentally nascent. As such, it is important to gather qualitative data on victims’ perspectives to understand the vulnerabilities of high-risk populations and the interests of those who are intended to be beneficiaries of such a program. Because surveys of the sex industry can be prone to false and coerced responses, compromising the quality of the data and because data on perspectives are needed, we conducted focus groups with women in the Dallas programs to gather a sampling of in-depth perspectives data.
Methods

Permission to conduct this study was granted by the Duke University Medical Center Institutional Review Board (DUMC Protocol 00050922) in keeping with guidelines for human subjects research on prisoners. Focus groups were chosen as the appropriate research method because very little research has been done in this area to date and such methods enable us to explore a variety of topics from several individuals with greater flexibility than surveys, allow an opportunity to explore topics in greater depth and complexity than surveys, and allow for collection of data that could inform design and interpretation of other methods to explore perspectives from larger sampling frames. The focus group process facilitated the expression of common ideas and shared opinions as well as highlighted areas of discordance and diverse perspectives within the groups.

Two focus groups were conducted: one with “Residents,” women currently in rehabilitation following a PDI intervention, and one with “Graduates,” women who had gone through rehabilitation and were being monitored by the court upon release from the program. The two subpopulations were chosen to provide insight both from women recently enrolled in one of the diversion programs and from women who had completed one of the programs. We made our decision to hold two focus groups of up to twelve participants in each based on logistical limitations (to ensure participants a meaningful opportunity to contribute during the discussion), an interest in having policy discussions informed by data—however limited in scope—rather than assumptions of the stakeholder perspectives on these topics, and intentions to use the findings to inform the design and interpretation of future research.

Participants

Focus group participants were recruited from the PRIDE Court and the Nexus Recovery Center. All potential and recruited participants were women. Participants might or might not have been offered participation in a DNA program. External coordinators (specifically the PRIDE Court Probation Officer and the Case Manager at the Nexus Recovery Center) invited potential participants to attend the focus group discussions. “Graduate” participants referred from the PRIDE Court had completed 14–45 days of the in-residence recovery program within the past three years. “Resident” participants referred from Nexus were currently in residence in the second half of their program. On the day of each focus group, the two moderators met with the potential participants to review the consent documentation and answer any questions. The participants then had four hours to ask questions of the study team and decide whether to participate. Twelve participants joined each group for a total of 24 focus group participants. An incentive was provided in the form of a gift basket filled with personal care items valued at $50 USD. In addition, participants were provided educational materials on the relevance of genetics to women.

Instrumentation

Each individual was provided an alias to use during the session. Participants selected from a collection of potential aliases for use in the focus groups, which consisted of notable, inspiring females throughout history (e.g., Marie Curie, Harriet Tubman). The session began with participants completing a demographic questionnaire. A semi-structured focus group discussion guide included ten questions to explore previous experiences with law enforcement, concepts of trust, and perceived benefits or concerns.
about uses of DNA. The selection of questions for use in the focus group discussion was informed by our previous workshops on DNA and human trafficking (Katsanis, Kim, Minear, Chandrasekharan, & Wagner, 2015). The guides were reviewed and refined by the research team, an affiliate with the Dallas PDI, and approved by the Nexus Recovery Center Board of Directors prior to Duke IRB review to ensure appropriateness of compensation and that questions used to moderate the focus group discussions were unbiased.

Sessions
In April 2014, two focus groups were held, each with twelve participants. The sessions were moderated by the principal investigator (SHK) and audio recorded. A second study team moderator (JKW) attended both sessions and took detailed notes. The opening questions were more general, some quantitative (e.g., “raise your hand if…”) to get the participants engaged in the topics. As the discussion progressed, the questions became more sensitive with more qualitative, opinion questions. Each focus group discussion lasted 1.5 hours.

Data Analysis
Digital audio recordings were transcribed and thematic analysis applied. We identified emerging themes and then grouped them to form broader categories. Two project investigators independently generated a list of potential themes based on the transcripts. Individual quotes were categorized according to topic and questions and grouped into discussion themes. The investigators then applied the themes to the quotes, developing rules to make coding consistent. Findings are summarized below, using direct quotes to illustrate focus group members’ thoughts.

Results
Each focus group comprised twelve individuals with the characteristics shown in Table 1.

1. Women working as sex workers use multiple identities
We opened the sessions by asking the women’s experiences with working in different jurisdictions and using false identities. By show of hands, half of the women in the two groups (13/24) indicated knowing women who had worked as sex workers in more than one state. All of the participants admitted to using fake names, indicating use of several names, even when admitted to hospital, injured, or jailed.

No one knew [my real name]. Cops. All my friends. If something ever happened to me, nobody knew me. In fact, I had family members come to look for me, but they didn’t know who they were talking about so… No one. Everybody I’ve ever known, we all had fake names. – Eva, Graduate

The people I hung with knew me as my name, but when I got, you know, got in contact with police I would use a fake name. – Susan, Graduate
Table 1. Focus Group Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Residents (N=12)</th>
<th>Graduates (N=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How old are you?</td>
<td>26 – 38 (median 32)</td>
<td>25 – 49 (median 38)</td>
</tr>
<tr>
<td>Which description best identifies you?</td>
<td>Heterosexual female 8 (67%) 10 (83%)</td>
<td>Bisexual female 4 (33%) 1 (8%)</td>
</tr>
<tr>
<td></td>
<td>Homosexual female - 1 (8%)</td>
<td>- 1 (8%)</td>
</tr>
<tr>
<td>What gender do you know or feel yourself to be?</td>
<td>Very feminine 7 8</td>
<td>Mostly feminine 5 2</td>
</tr>
<tr>
<td></td>
<td>Both masculine &amp; feminine - 1</td>
<td>- 1</td>
</tr>
<tr>
<td></td>
<td>Decline - 1</td>
<td>- 1</td>
</tr>
<tr>
<td>With which group to you most closely identify?</td>
<td>White 5 4</td>
<td>Black, African, or African American 4 7</td>
</tr>
<tr>
<td></td>
<td>Hispanic/Latina 2 1</td>
<td>American Indian or Native American 1 -</td>
</tr>
<tr>
<td>Which description best identifies you?</td>
<td>US citizen 12 11</td>
<td>Decline 12 11</td>
</tr>
<tr>
<td>What is your country of origin?</td>
<td>US 10 10</td>
<td>Decline 2 2</td>
</tr>
<tr>
<td>What is your native language?</td>
<td>Decline 12 12</td>
<td>English 12 12</td>
</tr>
<tr>
<td>What is your highest level of education?</td>
<td>Graduate or Professional school - 2</td>
<td>Completed college 2 -</td>
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<td></td>
<td>Some college 6 4</td>
<td>Completed high school 3 3</td>
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<td>Some high school 1 3</td>
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2. Some women are forced to prostitute

Ten of the twelve (83%) Graduate participants indicated that they knew women that went missing while working on the streets. Six Residents and ten Graduates (16/24, or two-thirds of all focus group participants) stated that they knew women who were forced to work against their will. All of the Graduates and five Residents (or 17 of 24, or 70.8%, of all participants) reported knowing women that wanted to leave the sex trade but a pimp or someone controlling her would not allow her to leave.

I was 20 years old, and my friend, she had a pimp. And I went with her to the store and he kidnapped me and he took me to Florida and he made me. – Marie, Resident

I also have a friend of mine who was kidnapped by a pimp and, well, he actually lured her, like acted like he wanted to date her or whatever. And she went out with him or whatever. And then he took her to his house, and he locked her in a
cage and then kept her there until she agreed that she would sell her body for him. – Maya, Resident

My… The guy that I worked with… He started out as a boyfriend. And we worked together and then towards the end… I think it was more manipulation, where I felt I couldn’t just leave him, because he doesn’t have a job. So it wasn’t out of abuse, but – more or less – manipulation where I felt I had to take care of him. – Eleanor, Graduate

3. Women working as sex workers have few people they can trust with their true identities

Given the vulnerability of the women when working on the streets, we asked them whom they trusted or to whom they turned in time of need, and with whom they entrusted their true identities. Resident participants listed strangers on the street, police, bus drivers, neighbors, the garbage man, and health care professionals. Graduates listed individuals with closer relationships to themselves, including the shelter, mothers, dope dealers, special clients, and God.

If I saw anyone that worked for like the government or the city, I would hope that that would be someone I could trust, being that they’re in a position where for the city they would hopefully be trustworthy. – Florence, Resident

I would turn to customers or clients that had bonded me out of jail. Or that had been there for me. You know. The regulars that I didn’t have to do anything with anymore. – Eleanor, Graduate

The dope dealer. I was being raped, and the dope dealer, he’s the one that rescued me. That’s who I had. – Pearl, Graduate

4. Many women working as sex workers do not trust law enforcement

When asked specifically about trust in law enforcement, both groups expressed much animosity. Distrust of law enforcement was evident across both groups; as one Graduate stated, “there’s crooks in the law.” Two Residents echoed the sentiment stating, “They treat us like shit," and “They treat us like we're nobody.”

I think the law enforcement twists information to go where they want it to go. And even if it could be true or not true, they’re going to make it true because they want it to be true. – Barbara, Graduate

I was raped by three men at one time. My door was kicked in. My bed was set on fire and I went to the police for help and they just treated me worse and sent me to San Antonio State Hospital. I tried to turn them in and everything and they wouldn't listen to me. They wouldn't do anything about it – Sally, Resident

5. Women working as sex workers want to be identified in case of death

We asked the participants their reasons for choosing to participate or declining to participate in the HRDNA offered through the Dallas PDI and PRIDE court to assist post-mortem identification. Some of the participants in each group were unaware of the
DNA database, but several in each were aware and some had provided DNA samples. We asked those who had provided DNA their thoughts.

I went ahead and did it because I want to be identified. I think it’s a cool idea – Rosa, Resident

My guy, the few times that I did talk to him while I was on the street, he always used to joke about the fact that they were going to tattoo my social security number and my address on my foot so that if I died that somebody knew who I belonged to. That was one of the reasons why I did it. And then I’ve had two friends that have actually been identified through the program. – Eva, Graduate

One of the girls… they found her mutilated and chopped up, and in a trash can in a whole other city. ... But they were able to identify her. … We knew her fake name and I knew she was missing. That’s all I could tell them. I could describe what she looked like, but that was all I could do. But, … she was smart enough to get her DNA. And that’s how they found her. – Eva, Graduate

After a general explanation of the HRDNA program, several Residents and Graduates that did not know about the program expressed a desire for their loved ones to know their fate or have their own crimes be resolved, both through identification of a victim and perpetrator. Several Graduates, however, expressed concern for the reasons for DNA collection.

“I would be glad. You know, there’s two aspects of it for me. Number one, I would definitely want to participate in it for the simple fact that I would want them to be able to identify me in the event that something horrible happened. But number two, … I’ve heard of cases where people have been… their DNA was found somewhere where they had never been. So that would be a concern to me is who has access to it because you never know how crazy a person can be to take your DNA, put it somewhere, and implicate you in a crime just by doing so.” – Florence, Resident

“I know in some cases forensics are using [DNA] to help solve mysteries. But they’re also using people’s DNA. Nothing’s perfect. It could place you in a crime scene you weren’t even in… And I believe, I believe in let God and that will be. I don’t believe in that. I won’t be giving mine up. Personally.” – Pearl, Graduate

6. Most women working as sex workers do not trust law enforcement to take voluntary buccal swabs

We asked to whom participants would feel comfortable providing a sample, under what circumstances, and what type of sample they preferred be collected. When we asked how many participants would be willing to provide buccal swabs to police/law enforcement for identification purposes (outside of an arrest requirement), five Residents agreed (41.7%) but none of the Graduates agreed. A few Residents stated a bit more trust in law enforcement.
…if something was to happen to me, I trust the police enough to do their investigation and, if they have my DNA, I think that would make it a little easier. – Maya, Resident

Ok, so instance. My mom goes missing, but a cop that I know that I’ve seen his face – if he’s arrested me, I’m not gonna do it. Because I know the police, I’m not gonna do it … I would ask another officer. If he had another officer that I didn’t know with him and he said the same thing, then OK, I’m gonna give it to him. But if an officer that I know is by himself then no I’m not gonna give it. – Marie, Resident

7. Women working as sex workers might trust healthcare providers or employers to take voluntary buccal swabs

Several participants indicated trusting healthcare professionals, trauma counselors, and researchers (e.g., “Researchers like y’all” –Georgia, Resident). When we prompted the Graduates as to whether they might trust a social worker, we got a negative response, “Why would they want it?” and another Graduate claimed she wouldn’t trust hospitals or doctors, “Not even them.” Interestingly, in each focus group a participant suggested that she would trust her employer with her DNA sample. For example, dancers should consider providing DNA samples to club owners, according to Eleanor, a Graduate who discussed her experiences as a dancer, her desire to have her mom know if something happens to her, and who had warned “this is a lifestyle, people get roofied all the time. Stuff happens.”

I would feel comfortable providing my DNA to someone who is maybe doing research on someone or for something or even, you know, the health care field, doctor, professional, I mean there are some stipulations to that but for the most part, yeah. – Maya, Resident

I think that any time when I was getting a job, if they were offering me employment and wanted to take my DNA, that would be perfectly fine with me … If they asked for a DNA sample, I would have no problem giving them one. – Florence, Resident

8. HRDNA participants might be concerned by who could access their genetic information and for what purpose

With the discussion turning to distrust in authorities, a Resident posed several questions as to how information is or would be accessed. One Graduate voiced fear that her sample could be used for nefarious purposes. Another Graduate expressed fear of cloning.

One of my concerns would be who would have access to this information, once they got the DNA sample or whatever, who else would have access to it? Like would it be just for this simple organization or would everyone – police, doctors, you know like people who go and donate sperm, sperm banks, stuff like that – like who would have access to DNA? – Maya, Resident

The only reason why I truly gave [my DNA] was because [the person who requested it] told me it was in a locked facility. And the only reason why, that they would have to go into it, was if it was some type of sex crime. And that was
the only reason why. Plus if it was me and I died, I want to let my parents… my parents need to know where I was at. But other than that, for any other reason – no… I wouldn’t have never given my DNA. – Eva, Graduate

9. HRDNA samples should be processed and compared to DNA from relatives of missing persons

When the HRDNA was established, the program operated a privacy protection policy whereby the laboratory would store unprocessed samples and only process the swabs for DNA once a post mortem identification case was reported that implicated a PDI participant. We asked the focus group participants how they felt about storing versus processing their samples prior to a case report.

I want mine processed. – Rosa, Resident

I would prefer mine being processed. I would just want to make sure it’s not cross-contaminated, but I definitely would want mine processed because then it does no good if it’s sitting in a cooler and I go missing and they run my DNA, they’re not going to find out who I am. – Florence, Resident

Since the existing HRDNA does not allow for comparisons of DNA profiles to missing persons databases, we asked the participants how they felt about comparing their DNA profiles to other databases for identification purposes.

You can take me DNA and run it through a missing persons database, but I would have to sign some kind of consent forms or they would pass some sort of law that says they can’t take this DNA and use it to prosecute me. – Maya, Resident

10. Samples collected for HRDNA should not be accessible to law enforcement

The discussion of implementation led several participants to iterate their concerns that the samples collected for identification should not be use by law enforcement for purposes other than identifying sex workers as victims of crime.

If something happens to me I do want to get to be identified. But if it’s for a crime and something happens and a guy finds something of mine in a particular place where I’m at? Uh-uh. I don’t want my stuff to be used to send me to jail if I am alive. – Marie, Resident

Like, you can use if for purposes of identifying me, but not for purposes of, you know, prosecuting me. – Florence, Resident

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8 The UNTHSC-CHI and Dallas law enforcement established a two-step process to protect privacy of participants: UNTHSC-CHI stores and processes the direct DNA samples that would be de-identified except for a random assigned numeric value. Law enforcement maintains a Biographical Database with a corresponding numeric value with no DNA profiles. When a victim sample is submitted to UNTHSC-CHI and a positive match is made, UNTHSC-CHI submits the numeric value to the law enforcement agency maintaining the Biographical Database for further investigation. UNTHSC-CHI does not have access to any biographical information and law enforcement does not have access to DNA profiles.
Over the course of the discussions, one Resident repeatedly voiced her desire to help police solve crimes and was not concerned how her sample might be used for other law enforcement purposes. However, she was concerned that crooked police might use the information.

Well if I’m guilty of a crime, I want to be prosecuted though, I mean, because people should be responsible for their own actions. – Sally, Resident

I’m concerned about some people, like crooked cops or something getting in the database and then using our information. – Sally, Resident

11. Consent should be obtained for an HRDNA

When asked what kind of protections they would like to see, participants brought up consent processes and suggested a program be run outside of law enforcement but with their cooperation.

I just wouldn’t be comfortable with it. … if I put [my DNA] in [a database] for the purposes of missing person or something like that, family or whatever, I would prefer that if law enforcement wants to have access to my DNA that I have to consent to it at the time that they’re asking. – Florence, Resident

It doesn’t need to be run by law enforcement. That’s the biggest thing. – Eva, Graduate

I would say that much like you need to have a warrant to come into my home, or whoever above law enforcement who – if somebody above law enforcement could have our DNA and lock it, and law enforcement, law enforcement has to have either some kind of – shoot, the President said you can have my DNA, you know. Right, you know, some top person has to have a warrant. – Eleanor, Graduate

12. A consent process over time is essential for ensuring access

In the Resident group, one woman voiced concern that some women working as sex workers would be reluctant to provide DNA for identification because their low self-worth might influence them to discount the prospect of post-mortem identification. This prompted other Resident participants to discuss mechanisms of consent and ways to approach women with sensitivity.

If I was working on the streets, I don’t know if I would want anyone to take my DNA, ’cause I don’t know if I even care that much about myself. You know, I mean, I may just not care and just say no, or another day I may care and say yeah, you can have my DNA. – Sally, Resident

Because it’s such a serious thing, the whole DNA - the idea of someone taking your DNA sample … if it was a rape counselor or, you know, I think that immediately the decision shouldn’t be demanded to be made right then or that should be the only opportunity. I think they should say ‘Hey look, we would like to get a sample of your DNA, you know we understand you have a history of prostitution,’ or whatever. And here’s our card or our number you know how to get in contact
with me and you have until such-and-such date to decide and even if you change your mind, you can come to this place and you can decide if it was for your family. … Then at that point you may want to go and give your DNA sample because you’re still living this dangerous lifestyle you know that they think could happen to you. – Maya, Resident

Several participants in both focus groups devised strategies for managing a system to allow for consent of high-risk participants and rolling re-consent.

I would say [to re-consent] every, say, five or ten years,… 'cause I may change my mind about things, or I may experience something terrible in my family and I think that’s a horrible idea ten years from now, you know what I mean? – Maya, Resident

I think it outta be just a small building exactly for that. Come if you wish, they have the doors open for the people who do want [to provide DNA samples]. – Clara, Graduate

13. A universal population-based DNA database might be more egalitarian than a high-risk population database

Both groups discussed whether a universal database with rolling re-consent might be important or desirable for missing persons and high-risk populations. By show of hands, six of the Graduates (50%) said they would consider a universal DNA database (i.e., a database for the entire population) as an option rather than a database just for sex workers.

I’m a mother; a five-year old. Maybe it’s – until the child is 18 then it’s destroyed, and it’s their choice after 18. If they want to make their DNA and put out there again. – Eleanor, Graduate

… if you’re put into the database at birth and then about the time you turn 18 … I feel like at 18 or as an adult that becomes a personal choice… I think that at one of those events that there should be an opportunity for you [to change your mind, re-consent, and provide or remove your DNA]...Because you’re no longer a child … There should be an awareness about it first and then that they should be able to make their own decision. I think that you should opt-out though. – Maya, Resident

14. Participants’ willingness to provide DNA for a High-Risk DNA Program

By the end of the session, by show of hands, all twelve Residents indicated that they would agree to provide a DNA for post-mortem identification.

Because sometimes [pimps] will take [women]. They’ll strip them of their drivers’ license, their social security card, their name – make them use another name. And if they have them all drugged up… But at some point, if you have me hopped up

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9 The concept of a universal database was brought up by one of the Resident participants in the context of how the high-risk database we were discussing would be useful for everyone. In the Graduates session, one of the participants mentioned a child identification program and how collecting DNA from all children would be beneficial. Following these prompts, the investigators questioned further whether a universal database approach might be preferable to a high-risk database approach.
on enough drugs, and I’m up for enough days and have, you know, a little amount of food and no sleep, I mean, after a long period of time, I’m sure that anyone could forget who they are. – Florence, Resident

If someone was forced [to prostitute] and they had their name attached to their DNA, and maybe they were beaten or maybe they, you know, had some kind of mind-altering drugs where they didn’t come back to their regular state of being that it would be good because if they couldn’t actually like she said say who they were or identify themselves, or maybe in a state of mental incompetence and that. Like in that state of mind, … they may be still afraid; they may be traumatized, maybe even after the entire situation, they still don’t wanna say who they are, or they completely ashamed because of trauma and it will be good to be able to identify them. – Maya, Resident

Personally, from experience, I guess like with anybody, I think I would want my DNA because there’s been situations in my life in the past where I was dragged behind a vacant motel and I was raped and I ended up pregnant. And I never, they never found the guy or anything. You know what I mean…I just have to move on with my life and I have no idea, you know… – Jane, Resident

The Graduates were not as enthused by the end of the session, with a couple of the participants re-stating that law enforcement should not have access to their DNA samples, “Just don’t do it. … That’s what I would say,” (Gloria, Graduate). But some participants found merit in the need to protect themselves given the risky lifestyle that they live.

I think, seriously, if you’re in the life – you’re in a lifestyle any type of way whatsoever. …We’re at risk for diseases, we’re at risk for all types of stuff. …Because we are in the lifestyle. I didn’t seen my parents, or talk to my parents for five-six years. They knew nothing. Not where I was, and if I had kids, you know, nothing. But if I turned up dead, they’d at least know. … And so, I would say being in this lifestyle, somebody should offer me the opportunity. You should offer me the opportunity. I shouldn’t have to, it shouldn’t be mandatory and anything like that. But I should have the opportunity to say, ‘DNA me, just in case.’ – Eva, Graduate

Discussion and Conclusion

The focus group discussions presented here offer a window into the lives and perspectives of a high-risk population that could benefit from genetic technologies. The provision of DNA by women whom law enforcement might consider alternately to be victims or vilified introduces complex challenges regarding voluntariness of participation, the boundaries of authorized uses, confidentiality requirements, and reasonable assurances of privacy. The majority of the discussants were supportive of the DNA collection programs in general, citing the desire to be identified post-mortem and acknowledging that their high-risk lifestyles place them at great risk of crime and victimization. The women all admitted using fake names routinely and including with authorities, such that identification is a key challenge in this population.

Key to success of a DNA-based identification program for this high-risk population is their trust in the authorities collecting genetic information and retaining the associated
records, including their DNA. The women in our focus groups were concerned with law enforcement being tasked with the collection of their DNA for the HRDNA. The HRDNA program has attempted to mitigate this challenge by housing DNA samples and identifiers outside of law enforcement at the UNTHSC-CHI, rather than maintaining a law enforcement database. The samples collected from the women are not for criminal purposes but for victim identification, which might or might not eventually be linked to a criminal case. Nevertheless, the program by Texas and U.S. law implies that samples used for evidence in a homicide case be collected by law enforcement authorities to maintain a chain of custody. DNA evidence that has been collected and analyzed by trained professionals not associated with law enforcement might still be admissible in court in certain circumstances. Thus, the presumption that a DNA database with legal implications must be designed in such a way that requires law enforcement involvement during specimen or data collection could be unfounded. Women offered DNA collection via a prostitution diversion program might be influenced by the authorities running the program that includes police, judges, social workers, and medical professionals. The samples collected from the women working as sex workers are not for criminal purposes but for victim identification, which might or might not eventually be linked to a criminal case.

At the time of DNA collection, the participants are either already under court supervision from an arrest or in a treatment program, which places them in a position under law enforcement authority, and perhaps less able to provide true consent. Trust in the law enforcement officer collecting the DNA sample is understandably weak at this time, as demonstrated by the discussants’ concerns with DNA being collected and used against them (e.g., by planting their DNA in an unrelated case or cloning them). While these attestations might be far-fetched in today’s U.S. law enforcement, the fears the women expressed are representative of a public vantage that is a real perception, if unwarranted. Such fears can only be addressed by massive public awareness; dismissing the fears with paternalistic “just trust us” procedures will not be sufficient to gain the trust of the masses. Rather, a mutual partnership and trust via a thorough consent process is essential.

As one such measure to protect the identities of participants, the HRDNA program in Texas only stores the unidentified processed DNA. The women in the focus groups attested that they would prefer their samples be processed and compared to missing persons’ databases in order to be more useful in investigation of their potential violent crime cases.

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10 Federal Rule of Evidence 901 (FRE901) regarding authentication and identification of evidence generally requires the party offering the evidence to show chain of custody in order to demonstrate it is improbable that the evidence was exchanged with another or tampered with. The purpose of the rule is to ensure that the evidence is in substantially the same form it was at the time it was obtained. A broken chain doesn’t automatically render the evidence inadmissible and an unbroken chain doesn’t automatically render the evidence admissible. For Texas specifically, see TX Rules of Evidence 901. Law enforcement routinely uses medical professionals to help (e.g., when blood samples are required, a phlebotomist takes the sample and then gives it to law enforcement). The rules do not require all persons who touch the sample to be law enforcement officers. Certain protocols might require/allow only certain individuals (e.g., law enforcement employees) to be part of the chain of custody (such as determining whether a sample meets the requirements so that it can be uploaded into CODIS).
Despite the stated mistrust of law enforcement in collecting their samples, the women were keen to assist law enforcement to solve crimes, both of their friends/family and their own potential victimhood. Furthermore, they recognized the use of genetic information for identification in paternity cases, missing persons, and mass disasters. Interestingly, both groups attested that a universal DNA database for the U.S. population might be preferable to a database specific for high-risk populations.

This population represents an accessible high-risk population that might help to define the perspectives of human trafficking victims and other high-risk populations that encounter law enforcement, and for whom a DNA database might be beneficial. However, the discussants in our focus groups were all women and U.S. citizens, so the findings might not be representative of male sex workers or non-U.S. citizens. It is important to determine whether these populations might have varying perspectives on trust in authorities and fear of their genetic information being used against them. In particular, our findings should not be applied to non-English speaking communities where a language barrier might inhibit consent, nor to immigrant populations who might fear expulsion.

As mentioned earlier, the focus group approach introduces a weakness to our data in that the group dynamic can influence an individual’s response that might be different if asked one-on-one. The Residents were living in a group home at the time, so might have interacted in social and group therapy sessions prior to the focus group. The Graduates were among the women with whom the PRIDE Court judge routinely meets as part of their formal surveillance; these women appeared to the study team to know each other well and appeared to have a street hierarchy (where one or two women seemed to be thought leaders, inciting others to agree, whether or not they actually did). These group dynamics undoubtedly influenced conversation and tone in each focus group, although we cannot assess to what extent. Nevertheless, the commonalities in themes between the two groups highlight the integrity of our process. However, individual interviews would better tease out individual’s perspectives on the controversial issues that arose.

Ultimately, these women respect the HRDNA program and recognize the power of DNA in forensic application to their own lives. They value an ongoing process of consent to provide their varying voices with options on data retention and use. To address concerns of trust in authorities arising in the focus groups, measures can be developed to acknowledge the awkward partnership of law enforcement with high-risk women through consent processes and protocols that minimize unauthorized use and identification of participants.

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Author Contributions and Disclosure

SHK and JKW led the focus groups, analyzed data and drafted this manuscript; SHK, JKW, MF, and SC devised the focus group guides. MM and JK provided IRB materials. SHK, JKW, and JK transcribed the audio. All authors reviewed this manuscript.

MF led the Program Evaluation for the Dallas PDI. She was not present for the focus groups, nor did she review any data prior to the manuscript. All other authors have no interests to disclose.

References


Seidenberg, S. (2013). Slavery continues to haunt the modern world, but efforts to eradicate it are growing. *ABA Journal* (April 2013).
