Published in final edited form as:

Int J Drug Policy. 2015 January ; 26(1): 100–106. doi:10.1016/j.drugpo.2014.06.013.

Perceptions of Genetic Testing and Genomic Medicine among Drug Users

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Abstract

Background—Genetic testing will soon enter care for human immunodeficiency virus (HIV) and hepatitis C virus (HCV), and for addiction. There is a paucity of data on how to disseminate genetic testing into healthcare for marginalized populations. We explored drug users' perceptions of genetic testing.

Methods—Six focus groups were conducted with 34 drug users recruited from syringe exchange programs and an HIV clinic between May and June 2012. Individual interviews were conducted with participants reporting previous genetic testing.

Results—All participants expressed acceptance of genetic testing to improve care, but most had concerns regarding confidentiality and implications for law enforcement. Most expressed more comfort with genetic testing based on individual considerations rather than testing based on race/ethnicity. Participants expressed comfort with genetic testing in medical care rather than drug treatment settings and when specifically asked permission, with peer support, and given a clear rationale.

Conclusions—Although participants understood the potential value of genetic testing, concerns regarding breaches in confidentiality and discrimination may reduce testing willingness. Safeguards against these risks, peer support, and testing in medical settings based on individual factors and with clear rationales provided may be critical in efforts to promote acceptance of genetic testing among drug users.

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Keywords

genetic testing; drug users; racial/ethnic minorities; perceptions; HIV; HCV

Introduction

The promise of genomic medicine is that individual level genetic information can be used to tailor and optimize prevention and treatment interventions.[1–4] Genetic testing is already in use for hereditary disorders common to specific racial/ethnic groups (e.g., sickle cell disease in African Americans). More recently, specific genes have been associated with excess rates of disease (e.g., *BRCA* in breast cancer; *CCL3L1* and *CCR5* in HIV),[5,6], reduced treatment response (e.g., *IL28B* in hepatitis C virus (HCV) treatment, *EGFR* in lung cancer), [7] or with resistance to chronic infection (e.g., *CCR5* in human immunodeficiency virus (HIV); *IL28* in HCV). [5,6] Individual genetic information may allow optimization and personalization of medical care, including more precise pharmacotherapy.

Genomic medicine will likely affect clinical management of HIV and HCV infection, drug treatment and other conditions. Pharmacogenomics, the study of the influence of the genome on an individual's response to a drug, is already beginning to guide treatment for HIV and HCV [8,9]. In HIV care, testing for HLA-B*5701 is routinely performed to assess for the safety of using the antiretroviral agent Abacavir. For HCV treatment, *IL28B* testing is used to guide treatment decisions and predict treatment responses for interferon-based treatment. Interferon lambda-4 genetic variants affect HCV clearance and seem to impact the response to treatment with direct acting antiviral agents such as Sofosbuvir.[10] *IL28B* and other genetic testing may remain important in individualizing HCV treatment regimens.[11] A number of genetic variants have been identified which appear to influence both the risk of addiction to specific substances and to influence response rates to specific drug treatment pharmacologic agents.[12] No genetic tests have yet entered routine addiction medicine care however some have been marketed direct-to-consumers, raising ethical concerns.[10,13,14] As it is likely that more genetic markers with better predictive utility will be identified, more data are needed on how best to incorporate genetic testing and pharmacogenomics into systems of HIV, HCV, drug treatment and related health care for marginalized population such as drug users, including members of racial/ethnic minority groups.

Marginalized groups such as drug users, particularly those who are also members of racial/ethnic minority groups, experience substantial health disparities with respect to access to and engagement in care and clinical trials. Medical mistrust may contribute to such disparities in general, and specifically with respect to HIV. [15–19] Questions arise related to potential repercussions of genetic testing, for example, regarding privacy and confidentiality issues with employers and with health, life and disability insurance. Drug users are more likely than the general population to have had prior arrests and incarcerations, and therefore may have heightened concerns about use of medical genetic testing for forensic purposes. In addition, genetic testing is sometimes clinically advised based on gene prevalences which may vary by race/ethnicity or on associations of race/ethnicity with a specific disease or

treatment response. [7,20–23] Categorizing DNA samples by racial categories is a commonly employed practice in forensics and law enforcement. [24,25]

Prior work examining the acceptability of genetic testing for guiding clinical care has focused on community knowledge of genetics. [26–35] These studies found that greater genetic literacy and higher socio-economic status were associated with more positive attitudes towards genetic testing. The acceptance of genetic testing may require some degree of genetic literacy; disparities in genetic literacy may pose barriers to the equitable delivery of genetic testing-informed medical care. [36] Racial/ethnic minorities, specifically Black/African Americans and Latino/as, demonstrated the least genetic literacy and the most mistrust of genetic testing. [28–30,35,37] These considerations highlight the need for improved understanding of the beliefs and attitudes of drug users, particularly racial/ethnic minority drug users, toward genetic testing and toward the use of individual genetic information in medical care and drug treatment.

There are a paucity of data regarding attitudes and perceptions of genetic testing among illicit drug users (DUs), or among people living with HIV/AIDS and/or hepatitis C. Focus groups can be used to identify common perceptions of the risks and benefits of genetic testing.[38] This study addresses these knowledge gaps by exploring DUs' (including drug users with HIV and/or HCV) (1) experiences with genetic testing, (2) attitudes towards genetic testing to guide treatment of HIV/AIDS and/or HCV or other conditions, (3) attitudes towards genetic testing to guide treatment of drug misuse, and (4) attitudes towards basing decisions to do genetic testing on patients' race/ethnicity. To our knowledge, this paper presents the first data available on perceptions of genetic testing among DUs.

Methods

Focus group participants were recruited from two different settings: an HIV primary care clinic and syringe exchange programs (SEPs). Specifically, we conducted three focus groups at one HIV clinic, one with non-Hispanic Black participants, one with Hispanic participants, and one with non-Hispanic white participants. We also conducted focus groups with participants recruited from three different needle exchanges: including an Hispanic focus group at an SEP in the Bronx, a non-Hispanic white focus group at an SEP in Manhattan, and a non-Hispanic Black focus group at an SEP in Brooklyn. Each focus group was homogeneous with respect to race/ethnicity in an effort to increase participants' comfort in talking about racial/ethnic issues. Focus groups were conducted between May and July 2012.

Eligibility criteria for the focus groups included: age ≥ 18 years; self-identifying as either non-Hispanic Black, non-Hispanic white, or Hispanic; having used illicit substances, including marijuana, during the past 12 months; being a NYC resident; and speaking English.

Participants were recruited through staff referrals from among persons currently receiving services at the study sites and who met the eligibility criteria. Each participant was assigned a "unique pseudonym" and was compensated \$25 for their participation.

Focus groups were moderated by a PhD level ethnographer (CGA) and used a semi-structured focus group guide. Focus groups began with an introduction about genetic testing and the use of genetic testing for hereditary conditions, such as sickle cell disease. A focus group guide was used to steer discussions; the process of question development was iterative, based on grounded theory methodology. [39,40] The focus group guide covered themes such as general perceptions and understandings of genetics and genetic testing, past experiences with genetic testing, genetic testing based on race/ethnicity, and participant attitudes towards the implementation of genetic testing in routine medical care (with an emphasis on HIV, HCV and drug treatment).

We also conducted semi-structured individual interviews with 3 focus group participants who reported past experiences with genetic testing. Each individual interviewee was provided with \$20 cash stipend for his/her time.

Data collection

At the beginning of each focus group, participants completed a brief sociodemographic questionnaire. Genetic testing-experienced participants were asked a range of questions about their genetic testing experiences and any changes in attitudes and perceptions towards genetic testing based on these experiences. Since participants kept a unique pseudonym, we linked each interview with the sociodemographic survey completed at the beginning of the focus group.

Qualitative Data Analysis

Focus groups and interviews were digitally recorded to ensure accuracy of the information captured, with resultant mp3 files stored in password protected databases. Focus groups and interviews were transcribed verbatim. All data was hand-coded by the ethnographer. "Hand coding" refers to a coding process that is performed through in-depth review and re-review of the transcripts, rather than by use of a computer program [41]. Transcripts were coded, compared and analyzed paying particular attention to emergent themes common to all focus groups. Grounded theory analytic techniques were used to seek patterns in the data and to develop emergent hypotheses about them.[39] Potential emergent themes were identified by the study ethnographer and were enumerated in a primary data report; the ethnographer and two additional investigators (DCP and HH) together reviewed, reflected on, and further refined the identified themes.

The study was approved by the Institutional Review Boards of participating institutions. All participants gave informed consent.

Results

Sociodemographics

A total of 34 individuals were recruited into the study for the six focus groups. We also conducted individual interviews with three focus group participants who reported past experiences with genetic testing.

Forty-four percent were female and 79% were over 40 years old. Twenty six percent identified as non-Hispanic Black, 41% as Hispanic, and 33% as non-Hispanic white. Forty-one percent reported having HIV/AIDS and 6% reported having HCV, and 6% reported HIV/HCV co-infection. Twenty-six percent did not finish high school, 53% completed high school, and 21% had at least college education. Most (76%) were unemployed, and most (82%) reported incomes below \$10,000/year. All participants recruited from the HIV clinic had health insurance (Medicaid or New York State AIDS Drug Assistance Program insurance); all other participants had Medicaid or were Medicaid eligible.

All 34 participants had used at least one of the following illicit drugs: marijuana, heroin, crack/cocaine, or diazepam or alprazolam from street diverted sources.

Experiences with genetic testing unrelated to medical treatment

Participants most commonly reported being aware of genetic testing due to television shows, paternity tests, or testing in criminal justice settings. Few had personally undergone paternity testing, but many had family members or acquaintances who had undergone paternity tests, mainly for family court purposes. Twenty eight percent also reported direct experiences with forensic DNA testing while in prison, usually via a “mouth swab.”

Fear of law enforcement

If my PO [Parole Officer] finds out that I am using, I am going back to jail. So, I am not releasing anything to you if I am on parole or probation because it's a trap. I think that they [drug users] would be afraid. Any drug user is afraid that anything about them get out because if I give my DNA and I know that I did something 20 years ago and you are gonna pass it on to the police they are gonna say: 'We have been looking for that bitch for 20 years!' Not happening (63 year old White female, Fiona).

Fiona was a 63 year old Caucasian female living with HIV. Her concerns that genetic testing might adversely affect a drug user who is on parole or probation, and, that a genetic test might help law enforcement connect the drug user with an unsolved crime were shared by others regardless of HIV status.

Despite participants' concerns about law enforcement getting access to their genetic information, they did not fully reject genetic testing. Participants generally indicated that if they were persuaded that genetic testing would improve their medical care, they would feel more positive about such testing. Primary care doctors were generally more trusted than providers in drug treatment programs, and genetic testing in primary care settings was generally viewed with greater acceptance.

If my [methadone] program needs something about me they can ask my primary care doctor. As [to] giving them a sample, no! (48 year old Hispanic male, Armando).

Overall, most participants (33 of 34) preferred primary care physicians rather than drug treatment programs as settings for performing genetic testing, regardless of HIV/AIDS and HCV status.

One of the most cited issues with respect to doing genetic testing in drug treatment programs was concern about “lack of confidentiality.” Participants expressed concerns about the powerlessness of medical practitioners in drug treatment programs to resist court orders. Furthermore, participants believed that drug treatment programs might work hand-in-hand with law enforcement and might force them into undergoing criminal justice-related genetic testing.

Hell no, it’s none of his business. Why my counselor in my drug clinic has to have my DNA? Do they want to lock me into some crime that happened some 50 years ago? (50 year old African American male, Anthony)

I would not do it because I have my background. I don’t trust them [drug treatment program staff]. African Americans have been lied to for many years (43 year old African American male, Quincy).

These perceptions partly stem from their own experiences, from general feelings that drug treatment program staff may work in concert with police authorities, and from mistrust based on feeling judged by program staff. These feelings of mistrust were not only exclusive to racial/ethnic minorities. “It would look like a project against Junkies. It would look like they are trying to fuck us!” (18 year old White female, Amber).

Genetic testing to guide HIV/HCV treatment and the role of race/ethnicity

I did it already and the outcome was that I would not respond to Hep C treatment. So, it saved me the pain of going through all the shots [Interferon]. I think that it is very important; it can save a lot of lives... and time by knowing what is going to work. It’s good to know if a treatment works or not before doing it (60 year African American male, Frank).

Frank was a 60 year old HIV infected Black/African American male who underwent genetic testing as part of a clinical evaluation for interferon-based HCV treatment. Frank said that he was told that his genetic testing (presumably IL-28 testing) suggested that he would not respond to interferon treatment, and that therefore he was not treated. He perceived that genetic testing worked for him because it “saved” him from the pain from interferon injections. When asked whether they would trust genetic testing to predict the safety and effectiveness of medications, most participants expressed trust in such an approach. Further, participants noted that hearing experiences such as Frank’s, or more generally speaking to peers who had undergone genetic testing and had positive experiences with it, increased their comfort with the possibility of undergoing genetic testing themselves.

I think it’s positive, how are we are going to learn new and improve things if we don’t test things and try new things. I do have 100% faith in the medical field, I’ve had it (HIV) for 25 years. I’ve come a long way (50 year old white female, Addison).

Addison was a 50 year old Caucasian female living with HIV who was actively engaged in her medical care. She felt that genetic testing was the future and that it would help “find cures” for diseases. She had never had genetic testing for medical purposes but when she was arrested in 2010, law enforcement took a sample of her DNA. Despite this experience,

she felt confident genetic testing would advance medicine, improve treatment and find cures. All participants felt that if genetic testing could improve treatment outcomes or prevent their offspring from developing a disease, they would support and engage in genetic testing. However, most had some reservations about genetic testing.

Genetic testing is good to a certain extent, I agree that there is benefit but they have to be open about what they are doing it for. Hospitals and institutions can't just go and do it. They have to be straightforward and let me know. I have a certain disease and I don't want it to progress soI would volunteer my blood so that way it stops there. But, let me know what it is really for, what are you going to put on me and try to get out of me and so I am just real, if I think that it's going to help out I am willing to participate, If not, I can't do it (45 year old Hispanic male, Monxo).

Even among those such as Monxo, a 45 year old Hispanic male who was actively engaged in HIV care and was altruistically open to genetic research, mistrust of genetic testing stemmed from concerns about not being fully informed of the purpose of a genetic test and whether the sample might be used for any other unspecified purposes. Reacting to a question regarding using genetic testing to guide treatments that may be more or less effective among Black/African Americans, Quincy noted another concern: "They have been doing it since slavery, why not doing it with genetic testing because we are the easiest to be deceived and the poorest of all the bunches. So no, I would not do it." For some, genetic testing triggered feelings of mistrust for reasons that stemmed from law enforcement involvement, from lack of transparency on the purposes of the testing, and from the use of race/ethnicity-based genetic testing. In this excerpt, Quincy expressed his feeling that African Americans have been historically lied to and that based on that history, he would be reluctant to engage in genetic testing to guide treatments for African Americans.

Other participants expressed similar concerns with engaging in medical treatment tailored for specific racial groups. Sonia, a Puerto Rican female from the Bronx offered another example.

I would feel confused if they say that the treatment works with Latinos because there is not one pill in the world that works for one race, so I figure that there should be other solution than just one pill for one race alone, for all types of races and not only for Hispanics (26 year old Hispanic female, Sonia).

In fact, after Sonia shared these impressions, Yoly, another Puerto Rican female in this Hispanic focus group at a Bronx SEP used the phrase "race pill" to refer to such an approach. Many in the sample expressed discomfort with the idea of taking a medication that was said to only help people of a specific race because they did not understand why other racial groups could not also benefit. One participant said "we are all humans".

Perhaps the most important reaction to the question of race/ethnicity specific testing and treatment included direct and indirect references to Tuskegee, the U.S. Public Health Service study that examined the natural history of syphilis among African Americans from 1932–1972. [15,18,42] This study failed to inform participants of the study purpose, procedures, and risk; further, many study participants had treatment withheld without their knowledge, causing death. [15,18,42]

In Tuskegee what they did is they inflicted the diseases in three quarters of the population. And after they polluted three quarters of the population they did it deliberately, they said, oh, we don't have any more money to help you so we could not give you the cure (50 year old African American male, Anthony).

Tuskegee was with African Americans in the South, with Hispanics they did a test in the past but I can't exactly remember it (45 year old Hispanic male, Monxo).

Whether Monxo was referring to the recently disclosed U.S. syphilis study conducted in Guatemala, in which over a thousand Guatemalans were exposed to syphilis, hundreds were left untreated, and at least 83 died, is not known; regardless, he had an awareness of unethical research being conducted on people of his ethnicity. [43] The Holocaust was also mentioned by participants in both Non-Hispanic White focus groups as an example of the consequences of race-based genetic testing.

No doctor should judge any person by his face value without going into his history or asking him questions. That's prejudice, racism and a whole lot of stuff that you can think to put in there (50 year old African American male, Anthony).

There was nearly unanimous discomfort when participants were asked about medical providers offering genetic testing to a patient based on the provider's perception of an individual's race or ethnicity. All participants felt that regardless of perceived race/ethnicity that, medical providers should engage a person in a discussion of that individual's own medical history and family ancestry prior to suggesting genetic testing.

Doctors are so damn cocky. I would be offended if a doctor just comes to me and based on how I look he assumes that I am white and he wants to do an A, B, C and D test. So, I am not comfortable because they are arrogant without really seeing me (50 year old White female, Addison).

While participants were cognizant of the higher prevalence of sickle cell anemia among African Americans, the mere thought of having a medical practitioner offer a genetic test based on perceived race, even for a disease such as sickle cell anemia, was viewed as offensive. Genetic testing based on individual family history and ancestry was preferred to genetic testing based on perceptions of race/ethnicity. However, most felt that after discussing their own specific medical conditions, family medical history and ancestry with their doctors, they would agree to genetic testing.

Genetic testing and drug treatment

What can you tell me that I don't know already about using drugs? I have been using drugs for ten years! I wouldn't give my DNA information to him [his doctor] because it's none of his business. My doctor is only there to treat me for illnesses and to keep me healthy so he doesn't have to know of my addiction or anything else. So, if my addiction has something to do with me being sick, I understand where he is coming from, but if it doesn't, he doesn't need to know (43 year old African American male, Quincy).

These were the impressions of 43 year old Quincy, an African American male, about the association between addiction and genetics. For him, genetic testing for the medical

management of addiction did not make sense. Quincy had been using heroin and crack cocaine for ten years and believed he understood better than anyone else why he used these drugs. Most participants were uncomfortable with engaging in genetic testing for either addiction-related care or for research to understand addiction, because most did not consider addiction to be a genetic disorder. All participants were more comfortable understanding genetics as explaining physical traits rather than behavior. They viewed addiction as a behavior resulting from environment and experiences rather than genetic inheritance.

Discussion

Several important themes emerged from this study. Participants' prior experiences with forensic DNA tests in criminal justice settings made them suspicious of genetic testing in drug treatment and to some degree in medical care settings. This was true even among those who also had chronic diseases such as HIV and HCV and for whom genetic testing may potentially help guide clinical management.[44,45] While we did not find that such past experiences precluded participant acceptance of future genetic testing, as evidenced by their reporting willingness to undergo genetic testing if they were told it would impact their own specific (e.g., HCV) treatment plan, it is important to underscore that DU's attitudes towards genetic testing are impacted by concerns about the use of genetic test results by law enforcement

The obvious reason for this finding is that all participants engaged in an illicit activity, i.e., using illicit drugs. Many had already provided law enforcement with genetic testing specimens while in criminal justice settings and feared potential repercussions related to parole/probation requirements and outstanding warrants. An underlying concern was that many participants felt that medical providers could be court-ordered to release genetic information. While the 2008 Genetic Information Nondiscrimination Act (GINA) sought to prevent the misuse of patients' genetic information, its protections have not yet addressed most privacy issues.[46,47]

In *Maryland v. King*, [48] the United States' Supreme Court declared it legal for police to collect DNA samples from people arrested for serious crimes, prior to conviction. In 2012, New York became the first state to expand mandatory DNA testing to include those arrested for misdemeanors, e.g., possession of illicit substances other than marijuana. Due to racial disparities in incarceration rates in the United States, forensic genetic databases are predominately populated by information from racial and ethnic minorities. Due to disparities in inclusion in clinical trials, biomedical genetic databases are predominately populated by information from Caucasian populations. Some scholars have expressed the concern that this dichotomy perpetuates a "racial divide". [49] While DNA testing may be an important criminal justice tool, our data suggest that use of genetic testing in the criminal justice system may deter people with criminal or arrest records from accepting genetic testing as a part of their medical care.

Concerns that genetic samples may be used for purposes in addition to those for which individuals gave explicit consent, such as expressed by Monxo, have arisen before. Even for individuals consenting to genetic testing, such testing raises potential privacy concerns

because DNA contains both an individual's data as well as information about an individual's family. [46,47] In one case, the Havasupai Indians provided DNA specimens for a study of endemic diabetes mellitus. Unknown to tribal members, and without their explicit consent, the DNA samples were used for studies of schizophrenia, human migration and inbreeding, topics that had cultural implications distinct from that of diabetes. The tribe brought suit; the case ended in an out-of-court settlement providing no legal precedent to clarify how genetic consent issues should be handled. [50,51]

The variability in disease risk and treatment outcomes as a function of genetic status is central to the potential of genomic medicine. For some diseases, prior data have suggested that medication tolerance and treatment outcomes may vary by race/ethnicity. Yet race is a culturally defined, rather than biologically defined, variable. There is substantially more genetic variation within racial categories than between them. [52–54] Definitions of racial categories vary both across time and geography. For example, categories of race and ethnicity used by the U.S. Census, the U.S. CDC and the U.S. NIH have varied over time. [55–57]

Disparities in health and variability in treatment response by race/ethnicity then reflect differences among groups defined culturally and socially, rather than biologically. Further, inferences about overall clinical effectiveness based on associations between self-reported race/ethnicity and treatment outcomes may miss the substantial contributions of individual, social and structural barriers to access and adherence to care. [58]

Our focus group data are consistent with previous data reporting on mistrust of medical interventions among racial/ethnic minorities and persistent memories of historical events. [27–30,35,37] When participants discussed race-based genetic testing and race-specific medical treatment, concerns about racism consistently emerged. As such, genetic testing and medical treatment tailored to a specific race can trigger the misperception that race is a biologic fact supported by science.

While many scholars have highlighted the inadequacy of racial categories to predict genetics, it is also true that certain genetic diseases are more prevalent among specific populations with shared ancestries. [53,59–64] It has sometimes been argued that self-reported race, while not a direct predictor of a specific genetic status, may be a valuable surrogate for the presence a specific gene; the sickle cell gene is often the cited example. [46] At least 29 medicines (or combinations) have been claimed to have differences in safety or efficacy among racial or ethnic groups. [1] In 2005, the U.S. Food and Drug Administration (FDA) approved the heart failure combination drug isorbide dinitrate and hydralazine hydrochloride (BiDil-tm) for Blacks, the first time the FDA made an approval based on race. FDA approval of the anti-seizure medicine carbamazepine recommends genetic screening of Asians based on data that *HLA*B*1502* is associated with higher rates of severe skin reactions. The FDA's use of ancestry in carbamazepine labeling highlights the need for more validated measures of ancestry, and of associations between ancestry and treatment response, in order to avoid inadvertently increasing health disparities or stigmatizing marginalized populations. [65]

The predictive value of race as a proxy for genetic differences has been questioned [66] and the ethical perils of doing so have been highlighted. [1,46,67] Studies examining multiple genetic polymorphisms that vary by geographic family ancestry, i.e., multiple ancestry informative markers, find that there are ancestral similarities and differences among persons which are not captured by their racial category. [47,52,68] The comments expressed in the focus groups demonstrate that many individuals are concerned about the use of race/ethnicity as a proxy for predicting genetic differences. However, focus group data suggest that strategies of testing all persons, or of testing based on fuller ancestry measures, rather than targeted testing of specific racial/ethnic groups, may be perceived as more acceptable by individuals in marginalized groups.

Similar considerations emerged when discussing use of genetic testing for the treatment and prevention of drug misuse. Just as the biological grounds for ‘race pills’ were questioned, many also questioned the biological grounds for defining addiction as a genetic disease. Their long careers as drug users put them in the position of seeing themselves as experts on drug using behaviors. They resisted having medical professionals explain to them why they use drugs because they saw their drug use as a product of their environment, and not the result of a genetic predisposition to use drugs.

Several factors emerged were identified by participants in the focus groups as facilitating comfort and trust in genetic testing. Most participants were more comfortable with the practice of doing genetic testing within medical settings than in drug treatment settings. Most were more comfortable with genetic testing when specifically asked permission by medical providers and when given a clear rationale for testing. The rationales that resonated with participants included using genetic testing to inform treatment decisions, to prevent illness in their relatives, as well as to learn how to best treat others. Participants were more comfortable with offers of genetic testing based on their own individual histories or on specific family histories rather than on race/ethnic group membership. Participants also cited speaking with peers who had undergone genetic testing as a source of trust in genetic testing.

This study has limitations. Our study was qualitative, and therefore these data do not provide measures of the prevalence of the attitudes expressed and the concerns that were raised. Nonetheless, the data are consistent with themes raised in other studies, and provide potential areas for further study and intervention. Participants were recruited from clinical and harm reduction settings and may not fully reflect those not engaged in care or prevention. Prior to the focus groups and individual interviews, the facilitator offered an explanation of genetic testing that may or may not reflect the type of information that would be provided in a clinical setting; the specific information provided might have affected participant responses. Issues of validity inevitably arise in qualitative and other studies. We attempted to address this by recruiting participants from more than one setting, and from different race/ethnicities, and by having several investigators review and discuss the emergent themes. Our focus groups were limited to persons who spoke English, and may not reflect perceptions and concerns relevant to those not fluent in English.

Genomic medicine has the potential to improve prevention and treatment outcomes for individuals and populations. For example, Zhang, et. al. have argued that IL28b testing could improve both cost-effectiveness and public health outcomes among HCV positive drug users and that increasing provider awareness of these testing strategies may be needed. [69] Our results highlight the need for further research to both understand and address the perceptions drug users and other marginalized persons may have about the use of genetic testing in research, prevention and care. However, our results may inform further research and also preliminarily inform how programs and providers might best approach drug users, and potentially other marginalized populations, for genetic testing when appropriate. Specifically, these data indicate the need for careful attention to the strategies used to decide who to test, advise caution in the use of race/ethnicity-based testing, and suggest the potential superiority of testing based on fuller measures of family ancestry. These data also highlight the need to institute and communicate protections regarding the use of medical genetic testing data for forensic purposes. Educational materials should be developed to address the concerns raised, and perhaps this information should be included in the genetic testing consent process. Such strategies may be needed to ensure the effective and equitable implementation and dissemination of genetic testing to all populations in ways that will reduce rather than exacerbate existing health disparities.

Acknowledgments

This work was supported by the National Institute of Health grant P30 DA 011041. We gratefully acknowledge the assistance of the participating recruitment sites and all of the participants.

The findings and conclusions in the article are those of the authors and do not necessarily represent the views of the National Institute on Drug Abuse or the National Institute of Health.

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