HHS Public Access
Author manuscript
AIDS Care. Author manuscript; available in PMC 2019 January 01.

Published in final edited form as:
AIDS Care. 2018 January ; 30(1): 27–31. doi:10.1080/09540121.2017.1338656.

Research participation, trust, and fair compensation among people living with and without HIV in Florida

Christa Cook, PhD, MSN, RN, APHN-BC [Assistant Professor],
Department of Family, Community and Health System Science, College of Nursing University of Florida, PO Box 100197, Gainesville, FL 32610-0197, 352-273-6350 (office); 352-275-9565 (cell); 352-273-6577 (fax), christacook@ufl.edu

Jasmine Mack, MPH [Department of Epidemiology], and
College of Public Health and Health Professions and College of Medicine, University of Florida

Linda B. Cottler, PhD, MPH [Associate Dean for Research and Planning, College of Public Health and Health Professions and Dean's Professor and Chair]
Department of Epidemiology, College of Public Health and Health Professions and College of Medicine, University of Florida

Abstract

Florida has the second highest number of newly diagnosed cases of HIV in the United States. Sociodemographic representation that is reflective of the population is essential in developing evidence-based interventions to improve HIV outcomes and reduce disparities. Understanding HIV research trial participation, preferences for types of research, and fair compensation for research will further our understanding of someone's decision to participate in research. The purpose of this analysis was to identify differences in prior research participation, trust, interests in types of research, and fair compensation between people living with HIV and without HIV in North Central Florida. In this sample of 8340 people interviewed in the community about their health concerns and research participation, 156 reported living with HIV. Only 20.5% of people with HIV reported past participation in research, however 94.2% said they were interested in future research participation. While people with HIV were slightly more interested in higher risk/low convenience research, there were no statistically significant differences in preferences for types of research between those with and without HIV. People with HIV reported no difference in the amount they would request for fair compensation ($78.4 USD) compared with those without HIV ($72.2 USD, p=0.69). Community members are interested in participating in research, although few had previously participated. Improving our understanding of research study participation will help improve recruitment efforts and draw stronger conclusions regarding the effectiveness of interventions, as well as enhance implementation of these interventions.

Keywords

research participation; HIV; community engagement; compensation; trust

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Correspondence to: Christa Cook.

Disclosures: The authors have no conflicts of interest to disclose.

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Introduction

Sociodemographic representation in research that is reflective of the population is critically important in developing evidence-based interventions that will improve outcomes and reduce disparities for people living with HIV (PLWH). The NIH Revitalization Act of 1993 set forth requirements for the inclusion of women and minorities in clinical trials to overcome disparities in research participation (Freedman et al., 1995). Even with this statute in place, disparities in research participation remain (Castillo-Mancilla et al., 2014). Studies examining research participation of PLWH indicate a wide range,15%–74%, of previous participation (Castillo-Mancilla et al., 2014; Cobb, Singer, & Davis, 2014; Floyd et al., 2010; Grady, 2005; Heumann et al., 2015; Sullivan, McNaghten, Begley, Hutchinson, & Cargill, 2007; Webb, Striley, & Cottler, 2015). Research participation may be influenced by trust, risk, stigma, convenience, compensation, receipt of medical care, or altruism (Cottler et al., 2013; George, Duran, & Norris, 2014; Heumann et al., 2015; Oransky, Fisher, Mahadevan, & Singer, 2009; Westergaard, Beach, Saha, & Jacobs, 2014; Yancey, Ortega, & Kumanyika, 2006). In some racial and ethnic populations, mistrust may account for differences in research participation (George et al., 2014), although some may still be willing to participate in research even if trust is low (Westergaard et al., 2014). Variations exist in recruitment and participation of PLWH among specific ethnic and racial groups and geographic location (Castillo-Mancilla et al., 2014; Heumann et al., 2015).

Fair compensation has been shown to improve survey response rates, increase willingness to participate in research, promote trust, and decrease disparities in participation (Grady, 2005). Ethical review committees have shown concerns about monetary incentives for populations at risk for drug or alcohol misuse, although this has not been supported with evidence (Cottler, Compton, & Keating, 1995; Deren, Stephens, Davis, Feucht, & Tortu, 1994; Festinger & Dugosh, 2012; Festinger, Dugosh, Kirby, & Seymour, 2014; Slomka, McCurdy, Ratliff, Timpson, & Williams, 2007). Even though payment is increasingly acceptable to facilitate research participation, what constitutes a fair compensation remains a subject of debate.

Understanding demographics of research participation, preferences for types of research, trust, and fair compensation will further our understanding of decisions to participate in research. In this analysis, we sought to identify differences in prior research participation, trust, interests in types of research, and fair compensation between people living with HIV and without HIV in Florida.

Methods

Sample

This study employed the services of HealthStreet, a community engagement model that refers people to social- and health-related services as well as research studies (Cottler et al., 2013; Cottler, Striley, O'Leary, Ruktanonchai, & Wilhelm, 2012). After receiving IRB approval for the study, community health workers (CHWs) at several HealthStreet locations recruited potential participants at popular community locations, such as parks, churches, and shopping centers, and asked them to provide informed consent and complete a 20-minute

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intake assessment. Next, CHWs collected sociodemographic information such as age, gender, education, race/ethnicity, education, food insecurity, marital status, number of children, and visit with a medical provider in the previous 6 months. Trust was elicited by asking people to rank on a scale of 1–10 (with 10 being highest trust) how much they trusted research and researchers. Participants also provided data on trust 30 and 60 days after the initial intake interview. All were asked if they had previously participated in research and if they were interested in participating in future research. To determine interest in different types of research, we asked about interest in a study that would: 1) ask questions about health, 2) review their medical records, 3) require them to provide blood or a genetic sample, 4) ask them to take a medication, 5) require a stay overnight in a hospital, or 6) use or test medical equipment. Finally, participants were asked how much they thought was a fair amount for participation in an interview that lasted about an hour and involved a blood test.

Analyses

All analyses were conducted using SAS, version 9.4(*SAS for Windows, Version 9.4*, 2016). Fair compensation and number of children were analyzed as continuous variables. Interest in future research participation was dichotomized to definitely/maybe or not at all. Responses by HIV status were compared using a Chi Square for categorical variables. Two-sample t-tests and ANOVA were used for continuous variables.

Results

From 2011 to 2016, 8340 community members, from over 30 counties in Florida, consented to have HealthStreet CHWs assess health needs, concerns, and perceptions of research. Three people were excluded because they were missing HIV status on their intake form. Demographic characteristics of the sample and differences between those with and without HIV are summarized in Table 1. Compared to people without HIV, people with HIV were significantly more likely to be between 45–64 years old, black (79.5%), and have a high school diploma or equivalent (47.4%). Also, significant, people with HIV reported using drugs at some point in the past (39.0%) or using in the past 30 days (6.5%), seeing a medical provider (73.7%), reported food insecurity (62.3%), were separated, widowed or divorced (40.4%), reported a mental health problem (54.5%), received Medicaid/Medicare (55.2%), and lived in an urban area (48.1%). There were no statistically significant differences in HIV status for the variables gender, ethnicity, hazardous drinking, marijuana use, or number of children.

Trust in research and researchers was closer to “completely trust” than “no trust at all.” There were no statistically significant differences in trust in research or researchers by HIV status (see Table 1).

Respondent’s interest in research with different levels of risk ranged from 69% to 92.3% among people living with HIV. While there were no statistically significant differences in levels of risk or convenience, it may be clinically meaningful that people with HIV were more likely to participate in research involving an overnight stay in the hospital (78.9% vs. 72.3% p=.07) or medication research (69.0% vs 61.6%, p=.06) when compared to those without HIV (see Table 2). Only 20.5% of people with HIV reported past participation in

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research; however, 94.2% reported interest in future research. People with HIV reported no difference in the amount they would request for fair compensation of research involving a blood draw and interview ($78.4 USD) compared with those without HIV ($72.2 USD, p=0.69).

Discussion

Among this sample of community members recruited in Florida, people with and without HIV are interested in participating in research. Consistent with other research, most were interested in participation but had not previously participated in a research study (Cobb et al., 2014; Cottler et al., 2013). While reasons for this gap in research interest and participation were not ascertained in the community screening questionnaire, participants indicated an elevated level of trust in research and researchers, which has not been consistent with previous research examining reasons for not participating in HIV trials (George et al., 2014). This trust may have contributed to the overall interest in participation. Furthermore, HealthStreet, with its strong focus on community engagement, may have also contributed to the increased level of trust reported in this study, but may have also served as a confounder.

Regardless of the level of risk involved in the health studies, there were no differences between those with and without HIV. Consistent with other research in this area, people with and without HIV were more likely to participate in low-risk, high convenience studies (such as surveys or medical record abstraction) than high-risk, low convenience studies (such as taking medication or staying overnight in a hospital) (Cobb et al., 2014; Ripley, Macrina, Markowitz, & Gennings, 2010).

There was no difference in judgements about fair compensation between those with HIV and those without HIV. Participant perceptions of fair compensation conveyed higher amounts than previous research has indicated. A study of investigators and IRB chairpersons estimated that fair compensation for an interview would be approximately $21 an hour and a blood draw would be $16–$20 (Ripley et al., 2010). This amount was consistent with research examining over 36,000 incidents of payment at the NIH clinical research center (Dominguez, Jawara, Martino, Sinaii, & Grady, 2012). However, a direct comparison with our results indicates a large discrepancy in fair compensation, with participants indicating approximately 50% more money for a 1½-hour interview and a blood draw. Further research is warranted to explain the discrepancy among investigators, ethics boards, and participants regarding fair compensation.

This study has a few limitations. First, participants are recruited with an intercept design which may or may not resemble the demographic representation of the community. Second, data were self-reported by community members willing to participate in the Health Street survey and community members who declined participation may also be unwilling to participate in research. While HealthStreet is not a research study, if people who complete the community survey were already willing to participate in research, or interactions with HealthStreet CHWs positively influenced their opinions about research, it may be harder to detect a significance difference between those with and without HIV. However, these limitations were minimized by the large sample recruited, including those with HIV. The

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potential for selection bias was reduced since the CHW was not aware of the community member’s HIV status at the outset. Although research on trust historically focused on community attitudes towards researchers, current research recognizes trust as a complex social phenomenon (Eder, Carter-Edwards, Hurd, Rumala, & Wallerstein, 2013). Future research should include a more in-depth exploration of the participant’s perceptions of trust, choices to participate in research, and the interactions between researchers and the community.

In this study, we found HealthStreet community members were interested in research participation, although few had previously participated. Improving our understanding of research study participation will help researchers improve recruitment efforts in health-related research studies. Increased participation in research will allow us to draw stronger conclusions regarding the effectiveness of interventions, as well as enhance implementation of these interventions. Future research should include efforts to understand the best ways to promote research participation among the general population and people living with HIV.

Acknowledgments

Sources of Support:

Grant funding provided to Dr. Linda Cottler by the National Institutes of Health/National Institute on Drug Abuse [grant number DA027951] and the Clinical and Translational Science Institute and the University of Florida College of Public Health & Health Professions and College of Medicine. Clinical and Translational Science Institute is supported in part by the National Institutes of Health/National Center for Advancing Translational Sciences Clinical and Translational Science Award to the University of Florida [grant number UL1 TR001427].

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Table 1

Demographic Characteristics among People with and without HIV in HealthStreet

	Total		**HIV**		**No HIV**		***p* value**
	n = 8340	**%**	**n=156**	**2%**	**n=8181**	**98%**	
Age							**0.0016**
18–34	2723	33.2	35	22.7	2688	33.4	
35–44	1280	15.6	32	20.8	1247	15.5	
45–64	1827	22.3	49	31.8	1777	22.1	
>=55	2366	28.9	38	24.7	2327	29.0	
Gender							0.0931
Male	3472	41.7	54	36.1	3417	41.8	
Female	4860	58.3	100	64.9	4758	58.2	
Race							
Other	3195	38.3	32	20.5	3161	38.6	**<0.0001**
Black	5145	61.7	124	79.5	5020	61.4	
Hispanic	458	5.5	9	5.8	449	5.5	0.8795
Education							
< High School	1772	21.3	45	28.9	1725	21.1	**0.0001**
High School Diploma	3225	38.8	74	47.4	3151	38.6	
> High School	3325	40.0	37	23.7	3287	40.3	
Hazardous Drinking							
No Hazardous Drinking	6355	76.3	116	75.3	6237	76.4	0.7606
In past 30 days	1968	23.7	38	24.7	1929	23.6	
Any Drug Use (non-prescription)							
Never	6032	72.7	84	54.5	5945	73.1	**<0.0001**
Ever	1956	23.6	60	39.0	1896	23.3	
In past 30 days	302	3.6	10	6.5	292	3.6	

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	Total		HIV		No HIV		*p* value
	n = 8340	**%**	**n=156**	**2%**	**n=8181**	**98%**	
Marijuana Use							
Never	4252	51.1	72	46.2	4177	51.2	0.2138
Ever	2712	32.6	61	39.1	2651	32.5	0.0805
In past 30 days	1357	16.3	23	14.7	1334	16.3	0.5920
Medical provider visit in previous 6months	5526	66.3	115	73.7	5409	66.1	**0.0471**
Food Insecurity	3926	47.3	96	62.3	3827	47.0	**0.0002**
Marital Status							
Never married	4066	48.9	75	48.0	3990	48.9	**0.0040**
Married	1701	20.4	18	11.5	1682	20.6	
Separated/Divorced/Widowed	2553	30.7	63	40.4	2489	30.5	
Number of Children (mean & SD)	8324	1.8 (2.0)	155	2.1 (2.4)	8166	1.9 (2.0)	0.3592
Self-Reported Mental Health Problem	3326	39.9	85	54.5	3239	39.6	**0.0002**
Medical Insurance							
Medicaid/Medicare	2639	32.4	85	55.2	2554	31.9	**<0.0001**
No insurance	3332	40.9	49	31.8	3280	41.0	
Private	2184	26.8	20	13.0	2164	27.1	
Geographic Location							
Urban	2446	29.3	75	48.1	2370	29.0	**<0.0001**
Non-Urban	5894	70.7	81	51.9	5811	71.0	
Trust in research (mean & SD)							
Baseline	3321	7.3 (2.1)	67	7.1 (2.3)	3253	7.3 (2.0)	0.5232
30-day Follow-up	1781	7.6 (2.1)	37	6.9 (2.3)	1740	7.6 (2.1)	0.9160
60-day Follow-up	1400	7.7 (2.1)	27	7.1 (2.3)	1371	7.7 (2.1)	0.6655
Trust in researchers							
Baseline (n=3310)	3310	7.2 (2.1)	67	7.1 (2.4)	3243	7.2 (2.1)	0.6375

	Total		HIV		No HIV		***p* value**
	n = 8340	**%**	**n=156**	**2%**	**n=8181**	**98%**	
30-day Follow-up (1778)	1778	7.5 (2.1)	38	6.9 (2.4)	1736	7.5 (2.1)	0.0786
60-day Follow-up (1410)	1410	7.5 (2.1)	28	7.1 (2.3)	1380	7.5 (2.1)	0.2532

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Table 2

Types of Research, Future Participation, and Fair Compensation

	Total n (%)	**HIV n(%)**	**Non-HIV n(%)**	***p* value**
Low Risk/High Convenience				
Survey Questions about Health	7806 (93.7)	144 (92.3)	7660 (93.7)	0.48
Review Medical Records	7212 (86.6)	132 (84.6)	7078 (86.6)	0.46
Medium Risk/Moderate Convenience				
Provide Blood Sample	7077 (85.0)	135 (86.5)	6940 (84.9)	0.58
Provide Genetic Sample	7065 (84.8)	137 (87.8)	6926 (84.8)	0.29
High Risk/Low Convenience				
Take Medication	5137 (61.8)	107 (69.0)	5028 (61.6)	0.06
Overnight Stay in Hospital or Clinic	6028 (72.4)	123 (78.9)	5903 (72.3)	0.07
Use Medical Equipment	6883 (82.7)	128 (82.1)	6753 (82.7)	0.84
Participation and Compensation				
Past Participation in Research	1489 (18.0)	32 (20.5)	1457 (18.0)	0.69
Future Interest in Participating in Research	7758 (93.2)	146 (94.2)	7610 (93.2)	0.62
Fair Compensation (mean [SD])	72.3 [97.0]	78.4 [116.5]	72.2 [96.6]	0.69