Genetic research participation in a young adult community sample

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Received: 20 November 2013 / Accepted: 10 June 2014 / Published online: 20 June 2014
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Abstract Opposed to large nationally sponsored health initiatives or biobanks, little is known about gathering genetic samples from young adults participating in academic community-based epidemiologic studies of mental health and substance use, especially samples with a large number of minority participants. This study describes our experience of establishing a genetic arm within a longitudinal study of a cohort of young adults (mean age 29, 75 % African American, 58 % female). In total, 75 % of those interviewed in the most recent wave donated a DNA sample (31.6 % blood and 68.4 % saliva) and over 90 % provided consent for storage and sharing. Current smokers were more likely to donate a sample than nonsmokers (adjusted odds ratio (aOR)=1.59, 95 % confidence interval (CI)=1.14, 2.22). The odds of obtaining a saliva sample were increased for those who were former cannabis smokers and who drank more regularly, but decreased among participants with less education and a history with drug use. Fewer minorities (aOR=0.37, 95 % CI=0.18, 0.75; $p=0.006$) and cannabis users (aOR=0.46, 95 % CI=0.27, 0.77) consented to sharing their sample with other

investigators. Findings also illustrate there are many study parameters that are important in planning biologic collection efforts. Building strong rapport and trust with subjects, minimizing the burden involved by the respondent to obtain a biological sample, offering a choice to provide blood or saliva, and offering an incentive will increase the likelihood of obtaining a sample and, importantly, increase the opportunity to store and share the sample for the future.

Keywords Genetic research · Interviews · Minority recruitment · Data collection · Epidemiologic methods · Informed consent

Introduction

Over 10 years ago, opinion surveys noted high interest, intentions, and possible cooperation in genetic research (Wang et al. 2001). Unfortunately, research experience has found incongruence between the stated willingness to donate a biological sample and the actual participation rates in genetic research (Johnsson et al. 2010). Studies around the world often find at least 80 % of people state that they are willing to donate biological material for research purposes (Wendler 2006; Sanderson et al. 2013); however, the actual participation rates for genetic and biobank research can be closer to half of the rate of reported willingness (Johnsson et al. 2010), although some efforts have had high actual participation (McQuillan et al. 2003). In studies recruiting from general population or community samples, participation rates are lower when a consent form mentions the study of genes and DNA (Matsui et al. 2005; McQuillan et al. 2006; Melas et al. 2010). Health behaviors and sociodemographic characteristics have also been associated with willingness to participate (Skinner et al. 2008; Wang et al. 2001; Kozlowski et al. 2002; Crider et al. 2006; McQuillan et al. 2006; Alford et al. 2011; Koehly

Electronic supplementary material The online version of this article (doi:10.1007/s12687-014-0191-3) contains supplementary material, which is available to authorized users.

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et al. 2003; Ford et al. 2006; Wonderling et al. 2001; Mezuk et al. 2008).

In order to study the complex interactions between environmental factors and genes and to estimate the distribution of various alleles in specific subgroups, quality databases with sociodemographic, phenotypic, and genetic data are needed (Beskow et al. 2001; Kendler et al. 2011; James et al. 2008; Merikangas and Risch 2003). This may be particularly true when studying substance use disorders where treatment avoidance, barriers within medical and legal systems, or other concerns may keep individuals from participating in genetic research. As opposed to large nationally sponsored health initiatives or biobanks, little is known about gathering genetic samples from young adults participating in academic community-based epidemiologic studies of mental health and substance use, especially samples with a large number of minority participants (Alford et al. 2011). Minorities are often underrepresented in genetic research samples (James et al. 2008; USDHHS 1990).

Many reports offer suggestions as to what people require in order to make a decision to donate a DNA sample (Jenkins et al. 2011; Streicher et al. 2011). Ethical oversight, language preference, clarity of communications (Kozlowski et al. 2002), beliefs about benefits of participation (Halbert et al. 2006), and trust between participants and investigators (Corbie-Smith et al. 2002) should not be ignored. Contextual factors such as study design and recruitment efforts (Bhutta et al. 2013; James et al. 2008; Lanfear et al. 2011; Patterson et al. 2008), incentives (Bhatti et al. 2009; Crider et al. 2006; McCarty et al. 2007), and the method of subject interaction (Etter et al. 1998) can also influence participation rates. The type of sample and method of collection also appear to influence collection rates (Bhatti et al. 2009; Wendler 2006). There are several methods for collecting DNA in epidemiologic surveys: blood (venous blood and blood spots) or less invasive techniques (saliva, buccal swabs/cytobrush, and oral rinses).

Attention to human subjects concerns has grown as genome-wide technologies and sharing of data has become more common. Subjects are being asked to consent to having their DNA sample stored for as-yet-undetermined future analyses as well as sharing with other investigators. Concerns of trust become more prominent, as well as a need for more information regarding the purpose and mechanism for sharing genetic research data (Lemke et al. 2010; Trinidad et al. 2010); acceptability may be different for certain subpopulations, even if they are willing to donate DNA for specific analyses described in the consent form. Previous research has provided some empirical evidence on the willingness of research participants from general populations to consent to having their genetic material included in repositories for future research purposes, and important subgroup differences associated with the collection and storage of samples have been noted especially involving race/ethnicity (Chen et al. 2005; Mezuk et al.

2008; McQuillan et al. 2003; Sanderson et al. 2013). African Americans may have less trust in researchers with respect to how genetic information might be used (Sterling et al. 2006) and young adults have also expressed a greater desire to want direct control over what data can be shared (Trinidad et al. 2010).

This study explores the association between family history and personal experiences with several conditions that are mentioned in the consent form (e.g., substance use and mental health) and (1) the probability of obtaining a DNA sample, (2) the type of DNA sample (blood versus saliva) participants provided, and (3) providing consent to long-term storage and further testing of the biologic specimen in a young, largely minority sample. In addition to describing our collection strategy, we take advantage of a change occurring during the field work of the study to investigate the influence of providing an incentive and describe our experience of a small effort to request a second sample from some of the participants.

Materials and methods

Study design and sample

The data for this study are from the most recent wave of collection of a longitudinal prospective study being conducted within the context of a group randomized prevention trial that has been following the same cohort of 2,311 youth identified as entering first grade in 1985 or 1986 in 19 primary public schools selected from five areas selected to represent the sociodemographic diversity in the northeastern quadrant of Baltimore in 1985. The five geographically defined areas were selected using the 1980 Census data as well as other demographic data available from the Baltimore city planning office and overlapped with two of the Baltimore Epidemiologic Catchment areas (Eaton and Kessler 1985). All schools recruited participated. Details of the trial design and interventions are available elsewhere (Ialongo et al. 1999; Kellam et al. 1991, 2008). Except for early school observations and teacher reports, a substantial proportion of the cohort (approximately 17 %) never participated in any personal interviews over the years or had participated in only one interview early in childhood. Twenty five years later, in the most recent data collection wave, 90 decedents were identified (by relative reports as well as a search of the National Death Index through 2013 for verification) and nearly 65 % of the surviving cohort ($n=1,434$) participated in a follow-up interview that inquired about their general and mental health, including alcohol, tobacco, and other drug involvement. At least another 16 % of the sample was located but not interviewed because they declined to participate, were living out of the state of Maryland, in the military, or were incarcerated, with access denied by the state Department of Public Safety and

Correctional Services. The study protocol was approved by the institutional review board for protection of human subjects at the Johns Hopkins University.

Baseline characteristics of the entire cohort and of those participating in the most recent interview are shown in Table 1. The mean age at the follow-up interview was 29.1 years (95 % between 27–31 years old). The sample was largely comprised of minority participants (72.5 %, of which 99 % were African American) and slightly more than half (57.7 %) were female. Subsidized lunch status in the first grade has been used as a proxy for SES: 55 % of the participants had been eligible for free or reduced price meals.

Attrition in the cohort was slightly greater among males, non-minorities, and those who paid for their lunches in the first grade (all $p < 0.01$). Among those with known family characteristics such as the educational attainment of the head of household, and whether the child was being raised by a single household member, there were no differences in who was successfully followed-up ($p > 0.05$); yet attrition was greater among those missing information about the parent ($p < 0.01$). No differences in follow-up were noted if the young adult had been in an intervention or control classroom; however, attrition was slightly higher among those absent for initial target intervention behavior assessments ($p = 0.02$).

Table 1 Description of sample characteristics at baseline and the follow-up engagement

		Baseline ^a		Interviewed		Biologic sample obtained	
		<i>N</i>	%	<i>N</i>	%	<i>N</i>	%
Total		2,311		1,434		1,075	
Cohort	1985	1,196	51.8	740	51.6	550	51.2
	1986	1,115	48.2	694	48.4	525	48.8
Gender	Male	1,151	49.8	607	42.3	446	41.5
	Female	1,160	50.2	827	57.7	629	58.5
Race/ethnicity ^b	Minority	1,550	67.1	1,040	72.5	787	73.2
	Non-minority	761	32.9	394	27.5	288	26.8
Subsidized or free lunch	Yes	1,212	52.4	786	55.1	606	56.6
	No	1,093	47.3	644	44.9	466	43.4
	Missing	6	0.3	4	0.3	3	0.3
Number of adults in household ^c	Single adult	655	28.3	440	30.7	338	31.4
	2 or more adults	1,153	49.9	747	52.1	566	52.6
	Missing*	503	21.8	247	17.2	171	16.0
Highest education of adult(s) in household	Non HS graduate	618	26.7	399	27.8	313	29.1
	HS graduate or higher	1,192	51.6	789	55.0	590	54.9
	Missing*	501	21.7	246	17.2	172	16.0
Intervention group	No	1,339	57.9	836	58.3	628	58.4
	Yes	972	42.1	598	41.7	447	41.6
Targetted intervention behavior: aggressive/disruptive behaviors ^d	Lowest quartile	580	25.1	382	26.6	296	27.5
	Second quartile	486	21.0	302	21.1	216	20.1
	Third quartile	494	21.4	318	22.2	231	21.5
	Highest quartile	495	21.4	282	19.7	220	20.5
	Missing*	256	11.1	150	10.5	112	10.4
Targetted intervention behavior: anxious/depressed moode ^e	Both low	590	25.5	370	25.8	278	25.9
	High on either one only	754	32.6	481	33.5	360	33.5
	Both high	441	19.1	286	19.9	209	19.4
	Missing*	526	22.8	297	20.7	228	21.2

^a Fall first grade except for family structure and parent education collected 3 years later

^b Minority defined as African American, Hispanic, and other non-Hispanic White

^c 4.5 % of the households had a single female head other than mother

^d Based on teacher-rated report fall of first grade

^e Child self-report of anxious and depressed feelings in previous 2 weeks; scores divided at median

*Possible reasons for missing baseline data included refusal (parent interview), denying consent (child interview), or absent or no longer enrolled in the school on the scheduled assessment date

Collection procedures

After locating and establishing contact with young adults who were part of the cohort, trained interviewers (majority African American) met with the individual to obtain consent and collect the interview information. An NIH-issued Certificate of Confidentiality emphasized the protection of the results from subpoena. The approximately 90-min computerized interview involved modalities in which the interviewer asked questions and recorded answers, and a section on involvement with drugs in which the participant responded to questions directly from the computer, without the interviewer seeing the responses. Then, the interviewers discussed the collection of the biological sample for the study. We first sought to obtain a blood sample, but if respondents were unwilling and/or unable to donate blood, they were then asked if they would donate a saliva sample instead (Oragene™ DNA collection kit, DNA Genotek, Inc., Ottawa, Ontario, Canada). Optimally, the phlebotomist would arrive at the same appointment when the interview was being conducted, but often, follow-up arrangements were made for the study phlebotomist to contact the participant to obtain a blood sample at a later date (usually within 2–7 days). In these instances, the interviewers requested a “back-up” saliva sample in the event that the participant would change their mind or never respond to the phlebotomist’s attempts to meet with them. Thus, regardless of the participant’s desire to have blood drawn, if consent was obtained to also collect a saliva sample, the interviewer collected a saliva sample at the end of the interview.

For the first 13 months of data collection, participants received an honorarium of US\$75 for participating in the interview, but did not receive any additional compensation for agreeing to donate a biological sample or consenting to genetic testing or storage of that sample. Concerned about the rate of response and after additional monies were obtained, we obtained institutional review board (IRB) approval to change the protocol to provide a separate honorarium for the biological sample. During another 15-month period of data collection, in addition to the interview honorarium, participants were also offered US\$25 for a biologic sample (either blood or saliva). Previous participants who provided a biologic sample were mailed the additional honorarium and those who had not donated a biological sample were offered the opportunity to receive the honorarium if they now choose to provide a biological sample (six participants converted). During an additional 6-month period, a single interviewer attempted to locate and engage additional participants. These participants did not have the option of providing blood but they did receive the honorarium for providing a saliva sample.

Three separate consent forms were used in the survey to obtain permission for subject participation involving: (1) the study questionnaire, (2) collection of a blood sample, and (3) collection of a saliva sample. Both the blood and saliva

consent forms contained this description about the genetic analyses: “The genes we think may affect risk for addiction to drugs are called DRD2, DRD4, CNR1, HTR1B, NrCAM, and COMT. Everyone has these genes but people have different versions and there is no normal or abnormal result from the tests.” These forms also described why storage and sharing of their sample could be important: “Important genes no one knows about yet are being identified all the time, and will be in the future. It will help the success of the study if you allow us to store your blood sample to study genes and other measures of health that have not yet been identified. We would also like your permission to share the DNA and other data from the study with other researchers approved by the National Institutes of Health.” Both forms contained these three options concerning the genetic analysis of the sample indicated by individual check boxes: (1) consent to give a biologic sample for DNA and other biologic measures, including the following genes that may affect the risk of drug and alcohol and mental health problems (these genes are named DRD2, DRD4, CNR1, HTR1B, NrCAM and COMT) by researchers at Johns Hopkins; (2) consent to have sample and DNA stored for future research studies at Johns Hopkins about the risk of drug, alcohol, mental health, and other health/medical problems like heart disease and diabetes; and (3) consent for sample and DNA to be shared with future investigators approved by the NIH to look for genes and other measures associated with risk of drug, alcohol, mental health, and other health/medical problems like heart disease and diabetes.

Measures

DNA sample and consent for future use The collection of a DNA sample was determined by a signed consent form and successfully obtaining a specimen. A person who donated both a blood and saliva sample was categorized as donating a blood sample. As mentioned previously, it was possible that a participant indicated interest in consenting to have a blood sample drawn at the time of the interview but then, when contacted by the phlebotomist, they had changed their mind. These people were categorized as providing a saliva sample only. Participants who were interviewed but who declined to donate a biological specimen, neither blood nor saliva, were counted as a refusal for this analysis. Consent to allow storage and further testing was determined by whether or not the participant had checked the boxes allowing further testing by researchers within our institution or outside of our institution. Participants could mark both, one, or neither.

The interview collected around the same time as the DNA specimen provided self-report information on personal, family history, substance use, and mental health characteristics that could influence decisions made in regards to participating in DNA research. Data from the interview included the following:

Educational status Educational status was derived from information obtained from several items that inquired about the highest grade in school or year in college completed, if they had received a high school diploma or passed a high school equivalency test (GED), and if they had a college degree.

Family history and social influence Several questions of a module focusing on family and anybody that the participant lived with assessed whether participants had any biological family members (parents or siblings; dead or alive) who had ever been depressed for a period of at least 2 weeks, had other mental health problems (such as suicide, delusions, or mania for at least 1 week), problems resulting from their drinking of alcohol at any time in their life, as well as problems resulting from their use of drugs at any time in their life. Other questions assessed whether anyone else in their family (e.g., step, foster, adopted or grandparents or other family members) or if anyone they lived with (e.g., spouse or roommate) smoked tobacco, or had any alcohol or drug problems. Participants were classified as having none, a user in their social network only, or regardless of users in the network having a biologic family member with problems.

Substance use The alcohol, tobacco, and drug modules of the interview were modeled after the National Epidemiologic Survey on Alcohol and Related Conditions Alcohol Use Disorder and Associated Disabilities Interview Schedule-IV (NESARC AUDADIS-IV) where measures of alcohol consumption, and tobacco and drug use have been shown to have good reliability in the general population (Grant et al. 1995, 2003). Items allowed us to classify whether participants ever smoked tobacco products (cigarettes and cigars) as well as if they were current smokers. Categories of alcohol use were based on a history of use and the frequency of alcohol consumption: never or seldom drinks, someone who currently drinks alcohol daily or nearly daily, or someone who consumes alcohol but less than 3–4 days per week. The drug module inquired if an individual had ever used drugs and medicines on their own without a doctor's prescription, in greater amounts, more often or longer than prescribed. An array of drugs were assessed, including sedatives, tranquilizers or anti-anxiety drugs, stimulants, painkillers, cannabis, cocaine, hallucinogens, inhalants, and heroin, and a write-in option was available to note any other type of drug (e.g., steroids). Follow-up questions inquire if the use took place within the past 12 months.

Mental health Lifetime history of major depressive episode (MDE) and anxiety disorders was assessed using modules from the Composite International Diagnostic Interview-University of Michigan Version, CIDI-UM (World Health Organization 1997). The responses to two items in the phobia section (being afraid of needles and being afraid of seeing

blood), were combined to create a variable that might be associated with less willingness to have a phlebotomist obtain a blood sample. An antisocial symptom scale adapted from the NESARC consisted of 30 questions that assessed behaviors experienced since turning 18 years of age (Grant et al. 2003). Reliability of the symptom scale has been reported to be good (ICC=0.79). We summed the positive responses and identified participants as those with three or more or those with less than three antisocial behaviors.

Demographic characteristics Gender, race, and date of birth were obtained from school records when the cohort entered first grade. Age at the time of interview was collected and verified by calculation.

Study factors—previous participation status and offering an incentive The frequency and pattern of previous participation in interviews during childhood, adolescence, and 10 years previously as the cohort entered young adulthood was used to create a measure representing the history of engagement and rapport with the longitudinal study. We speculated that someone more involved in the context of the overall research project or who had participated in the last interview collected 10 years previously might be more willing to provide a DNA sample than someone less engaged with the project over time. Participants were classified into the following previous interview history groups: (1) those who had participated in nearly every interview over all three life stages, (2) those with missed interview waves but who had participated during childhood and as a young adult, (3) those whose only previous participation was as a young adult (10 years prior), (4) those who had participated only during childhood, and (5) those with no previous interview at any wave (e.g., child moved out of school system between the time the sampling frame was established and the first childhood interview). We divided our participants into two groups based on the incentive condition mentioned at time of consent: (1) a sample was obtained in the first 13 months when no financial incentive was offered versus (2) those who received an incentive immediately at the time of collection.

Analyses

Differences in the association between various dichotomous outcomes (consent to donate a biological sample, type of sample (blood versus saliva), consent to allow storage, and consent to allow further testing) and three sets of participant factors: (1) sociodemographic characteristics, (2) family history (of conditions mentioned in the consent form), and (3) participant mental health and substance use behaviors (conditions listed in the consent form) were explored via contingency table analyses (chi-square $p < 0.05$) and odds ratios (OR, 95 % confidence intervals (CI)). We also evaluated the

relationship between obtaining a sample and several study factors. Final logistic regression models explored whether factors found to have a crude association with our outcomes ($p \leq 0.1$) would continue to be significant in the presence of other factors now also included as covariates (adjusted Odds ratio). All analyses were conducted using STATA (version 11) statistical software.

Results

Obtaining a sample and type of sample

Of the 1,434 participants interviewed, 340 donated a blood sample and 735 donated a saliva sample. In total, 1,075 participants (75 % of the sample interviewed) agreed to donate a biological specimen in some form (Table 2). No associations were found between gender, race, or education and obtaining a sample, but in a model holding other covariates constant, those with a high school or less education were 64 % more likely to provide a blood sample than their peers who sought further education (adjusted OR (aOR)=1.64, 95 % CI=1.14, 2.35; $p=0.008$). A family history of problems with mental health issues was not associated with either obtaining a sample or which type of sample, nor were there any associations between substance use occurring in an individual's close social network and donating a sample once other covariates were held constant (Table 2).

Current tobacco product smokers (but not former smokers) were more likely to donate a sample as compared to non-smokers and no other differences were noted for any other substances (Table 3). Among those providing a sample, an association between the type of sample obtained and their own substance use was noted. Participants who consumed alcohol daily at some point in their life or who were former cannabis users were almost twice as likely to provide a saliva sample than those who reported never drinking. Personal history of mental health issues, such as a major depressive episode or antisocial behaviors, were not associated with providing a sample. Respondents indicating a fear of needles or seeing blood were more likely to prefer donating a saliva sample than those with no fears.

Storage and sharing

A majority of participants who donated a biological sample consented to allow storage (96.0 %) and sharing for future research (93.6 %). There were no associations between any of the variables we examined and providing consent to allow storage or additional genetic testing by investigators from our academic institution in our sample; however, since nearly everyone provided consent for it, the power to detect

differences is greatly reduced (see [Online Resource](#)). Two variables were associated with obtaining consent to share the sample and DNA with future investigators approved by the NIH. Our minority participants were 60 % less likely to consent to sharing as compared to those with non-minority status (aOR=0.37, 95 % CI=0.18, 0.75; $p=0.006$). Fewer cannabis users, current or former users, consented to sharing their sample with other investigators (OR=0.46, 95 % CI=0.27, 0.77; $p=0.002$).

Study factors and obtaining a sample and the kind of sample

Participants more involved and active in the project over time were more likely to donate a sample (Table 4). Adjusting for other factors, we still found a strong relationship with the individual was important, as the odds of obtaining a biologic sample were four times greater if a strong history was established with the individual (e.g., active participant over many waves of the longitudinal study) or double if they had at least participated in the previous young adulthood interview approximately 10 years ago as compared to those who were interviewed for the first time. Previous participation history was not found to be associated with the type of sample the participant provided.

More than half of those interviewed were asked to provide a sample under the condition of not being offered an extra incentive during the first 13 months of collection (Table 4). We were able to successfully obtain a sample from two thirds of those participants. One might expect refusals to be higher at the start of data collection, that is, until the interviewers became more experienced with addressing and alleviating concerns; however, the refusal rate was fairly consistent across these 13 months. Providing the US\$25 incentive increased the odds of providing a DNA sample by threefold (aOR=3.65, 95 % CI=2.70, 4.92). The proportion of refusals dropped to half that of when no incentive was offered (33.6 % of the 843 interviewed before vs 12.9 % of the 591 interviewed after the change in protocol). The distribution of the kind of specimen provided (blood or saliva) didn't change appreciatively among those providing a DNA sample; 30.5 % donated a blood specimen without the incentive vs 32.8 % donating a blood specimen when offered the incentive ($p=0.265$). Participants who were offered an incentive at the time of collection were less likely to consent to sharing than those who were not offered an incentive at the time of consent (90.9 versus 96.1 % respectively, (aOR=0.42, 95 % CI=0.25, 0.71; $p=0.001$). In exploratory analyses that examined interactions with the incentive, we found that offering the incentive encouraged more non-drug and non-cannabis users to participate.

Replacement sample

The quality of the majority of the samples was sufficient for the lab to extract useable DNA. However, over time, we

Table 2 Success of obtaining a biologic sample and the type of sample (blood as reference), according to sociodemographic and family characteristics

	Number	Sample obtained			Type of sample: odds of obtaining a saliva sample				
		Yes (%) n=1,075	OR (95 % CI)	p value	aOR ^a (95 % CI)	p value	OR (95 % CI)	p value	aOR ^b (95 % CI) p value
Overall total	1,434	75.0							
Personal characteristics									
Gender									
Male	607	73.5	1.00				1.00		
Female	827	76.1	1.14 (0.90, 1.46)	0.265			0.95 (0.73, 1.23)	0.684	
Race/Ethnicity									
Non-minority	394	73.1	1.00				1.00		
Minority	1040	75.7	1.14 (0.88, 1.49)	0.315			0.78 (0.58, 1.05)	0.101	
Highest education by age 28									
Less than HS	276	79.4	1.24 (0.89, 1.73)	0.202	1.12 (0.78, 1.60)	0.549	0.70 (0.51, 0.97)	0.030	0.69 (0.49, 0.97) 0.031
HS grad or GED	844	75.6	1.00		1.00		1.00		1.00
Some college	96	72.9	0.87 (0.54, 1.40)	0.565	0.91 (0.54, 1.52)	0.715	1.56 (0.87, 2.80)	0.012	1.53 (0.84, 2.78) 0.166
College grad	209	69.4	0.73 (0.52, 1.02)	0.066	0.94 (0.64, 1.36)	0.726	1.45 (0.96, 2.20)	0.076	1.48 (0.96, 2.29) 0.078
Family history/social influence ^c									
No one	878	74.2	1.00		1.00		1.00		1.00
User in social network	166	71.1	0.86 (0.59, 1.24)	0.412	0.90 (0.63, 1.28)	0.553	0.93 (0.70, 1.24)	0.629	0.82 (0.58, 1.16) 0.266
Problems among a biologic family member	390	78.5	1.27 (0.96, 1.69)	0.100	0.66 (0.41, 1.08)	0.101	1.78 (1.11, 2.86)	0.016	1.28 (0.72, 2.26) 0.401
Alcohol use									
No one	870	72.6	1.00		1.00		1.00		1.00
User in social network	172	73.8	1.06 (0.73, 1.54)	0.748	1.33 (0.92, 1.90)	0.124	1.09 (0.82, 1.45)	0.559	1.12 (0.80, 1.59) 0.505
Problems among a biologic family member	392	80.6	1.56 (1.17, 2.10)	0.003	1.24 (0.76, 2.03)	0.395	2.09 (1.31, 3.33)	0.002	1.55 (0.88, 2.73) 0.130
Tobacco product use									
No one	385	71.2	1.00		1.00		1.00		
User in social network	128	67.2	0.83 (0.54, 1.27)	0.394	1.09 (0.79, 1.51)	0.588	0.90 (0.66, 1.22)	0.497	
Daily use among a biologic family member	921	77.6	1.41 (1.07, 1.84)	0.013	0.76 (0.46, 1.25)	0.284	0.88 (0.53, 1.49)	0.644	

Participants with missing information not included in the table totals

^a Model included the four variables shown plus tobacco, cannabis and other drug use; incentive status, and previous interview participation^b Model included the three variables shown plus own alcohol, cannabis and other drug use; fear of needles; incentive status, and previous interview participation^c A positive social network included use among non biologic family members only (e.g., step, adoptive, foster, or grandparents or other family); problems among biologic family (e.g., mother, father, full brothers, and full sisters) regardless of social network use^d Other mental health conditions include: ever had problems with mania that lasted for a period of at least 1 week or problems with delusions or hallucinations not resulting from drug use

Table 3 Success of obtaining a biologic sample and type of sample (blood as reference), according to substance use and mental health of respondents

	Number	Sample obtained				Type of sample: odds of obtaining a saliva sample						
		Yes (%) <i>n</i> =1,075	OR (95 % CI)	<i>p</i> value	aOR ^a (95 % CI)	<i>p</i> value	Blood (%) <i>n</i> =340	Saliva (%) <i>n</i> =735	OR (95 % CI)	<i>p</i> value	aOR ^b (95 % CI)	<i>p</i> value
Overall total	1,434	75.0					31.6	68.4				
Tobacco use												
Non-smoker	778	70.8	1.00		1.00		29.2	70.8	1.00			
Former smoker	153	74.5	1.18 (0.80, 1.76)	0.405	1.31 (0.84, 2.04)	0.231	33.9	66.1	0.80 (0.52, 1.23)	0.315		
Current smoker, past year	480	79.6	1.76 (1.33, 2.32)	<.001	1.59 (1.14, 2.22)	0.007	34.2	65.8	0.79 (0.60, 1.05)	0.103		
Alcohol use												
Non drinker/rarely drink	731	73.5	1.00				36.2	63.8	1.00		1.00	
Drink <3–4 days/week	538	73.8	1.09 (0.84, 1.41)	0.515			28.4	71.6	1.43 (1.08, 1.89)	0.011	1.07 (0.77, 1.49)	0.683
Current or past history of drinking nearly daily	165	76.4	1.37 (0.90, 2.08)	0.137			22.7	77.3	1.93 (1.24, 3.01)	0.004	1.81 (1.07, 3.07)	0.027
Cannabis use												
Non-smoker	910	72.2	1.00		1.00		33.8	66.2	1.00		1.00	
Former smoker	295	79.7	1.53 (1.11, 2.11)	0.010	1.11 (0.75, 1.62)	0.602	25.3	74.7	1.50 (1.08, 2.10)	0.016	1.75 (1.16, 2.66)	0.008
Current smoker, past year	214	76.6	1.44 (1.00, 2.08)	0.051	0.91 (0.58, 1.42)	0.681	30.4	69.6	1.17 (0.81, 1.67)	0.403	1.27 (0.80, 2.00)	0.302
Lifetime drug use ^c												
Never	1,215	72.7	1.00		1.00		30.7	69.3	1.00		1.00	
Former user	138	81.2	1.84 (1.15, 2.96)	0.011	1.64 (0.94, 2.84)	0.080	33.6	66.4	0.87 (0.58, 1.31)	0.520	0.42 (0.25, 0.70)	0.001
Current user, past year	81	80.2	1.57 (0.88, 2.79)	0.124	1.59 (0.82, 3.08)	0.170	40.9	59.1	0.64 (0.38, 1.06)	0.086	0.37 (0.20, 0.68)	0.001
Lifetime major depressive episode												
No	1,293	73.4	1.00				32.0	68.0	1.00			
Yes	127	82.7	1.08 (0.03, 1.25)	0.325			28.7	71.3	1.03 (0.87, 1.22)	0.719		
Antisocial symptoms												
Less than 3	941	74.4	1.00				31.2	68.8	1.00			
3 or more	493	73.0	0.99 (0.77, 1.28)	0.942			32.4	67.6	0.95 (0.73, 1.24)	0.714		
Afraid of seeing blood or needles												
No	1321	76.7	1.00				33.1	66.9	1.00			
Yes	105	74.0	0.78 (0.48, 1.29)	0.335			13.4	86.6	3.20 (1.67, 6.11)	<0.001	3.29 (1.67, 6.47)	0.001

Participants with missing information not included in the table totals

^a Model included the three variables shown plus education; family history of tobacco, alcohol and drugs; incentive status, and previous interview participation^b Model included the four variables shown plus education; family history of tobacco alcohol and drugs; fear of needle; incentive status, and previous interview participation^c Excludes cannabis, includes nonmedical use of sedatives, tranquilizers or anti-anxiety drugs, stimulants, and painkillers, cocaine, hallucinogens, inhalants, heroin

Table 4 Success of obtaining biologic samples and type of sample according to study design factors among those interviewed ($n=1,434$)

	Number		Type of sample: odds of obtaining a saliva sample							
	Sample obtained		Blood (%) $n=340$				Saliva (%) $n=735$			
	No (%) $n=359$	Yes (%) $n=1,075$	OR (95 % CI)	p value	aOR ^a (95 % CI)	p value	OR (95 % CI)	p value	aOR ^b (95 % CI)	p value
Participation pattern in previous interview waves										
Every wave	346	21.4	78.6	2.73 (1.55, 4.82)	0.001	3.94 (2.09, 7.42)	<.001	30.9	1.77 (0.68, 4.60)	0.241
Almost all waves	709	22.3	77.7	2.59 (1.51, 4.43)	0.001	3.71 (2.04, 6.76)	<.001	35.2	1.12 (0.63, 2.00)	0.699
Last adult only	196	31.1	68.9	1.64 (0.91, 2.97)	0.099	1.93 (1.00, 3.70)	0.049	24.4	1.35 (0.82, 2.22)	0.237
Youth only	122	32.8	67.2	1.52 (0.81, 2.87)	0.193	1.61 (0.81, 3.23)	0.176	28.0	0.72 (0.52, 1.00)	0.053
Never	61	42.6	57.4	1.00	1.00			17.1	1.00	
Financial incentive offered during time of consent										
No	843	33.6	66.4	1.00	1.00			30.5	1.00	
Yes	591	12.9	87.1	3.42 (2.59, 4.53)	<.001	3.65 (2.70, 4.92)	<.001	32.8	0.81 (0.62, 1.07)	0.142

^a Model included the two variables shown plus education; family history of tobacco, alcohol and drugs; and use of tobacco, cannabis and other drugs^b Model included the two variables shown plus education; family history of alcohol and drugs; own use of alcohol, cannabis and other drugs; and fear of needles

accumulated 44 samples that had leaked or were identified as having insufficient DNA extraction. After obtaining IRB approval, we sent these participants a packet that included a letter explaining what had happened and asked if they would consider sending us a replacement sample. The mailing included another consent form, an Oragene™ DNA collection kit, and a self addressed pre-stamped envelope in which to send us another sample via the postal service. (They also received another US\$25 incentive if they mailed us a sample.) Despite it having been up to 2–3 years since completing the interview with us, 11 participants (25 %) sent us a replacement sample. Wondering if the time since we last contacted them mattered as to whether we would obtain a replacement sample, we also sent the packet to the last 34 participants who had given a sample (interviewed 6–9 months previously). A similar proportion (26 %, $n=9$) of these young adults sent us a replacement.

Discussion

In a community sample of young urban adults, 75 % were willing to donate DNA samples for a federally funded project and over 90 % of those donating also consented to storage and sharing the results. Several findings regarding participant characteristics were associated with providing a sample and the storage of the DNA. The findings of the effects of ethnicity, gender, and education on obtaining a DNA sample have been contradictory in the literature (Kozlowski et al. 2002; Nishita et al. 2009). Often, participation rates of minority groups are lower than other racial/ethnic groups (Chen et al. 2005; Kozlowski et al. 2002; McQuillan et al. 2003; Meisel et al. 2012), but we did not detect any racial/ethnicity or gender differences within our study sample. On the other hand, as seen in this cohort, African Americans have been found to be less likely to grant permission to save and share their samples in the future with other investigators (Mezuk et al. 2008; McQuillan et al. 2003, 2006). As for education, a surprising finding was that education was associated with the type of sample provided but not associated with the likelihood of providing a sample. This is contrary to the belief that those with more education are the ones likely to participate in genetic research. This study made efforts to engage those regardless of their social economic status via bringing the study out to them and explaining the purpose and thus, we may have succeeded in encouraging those living in poorer communities with less education to participate. Others stress that ensuring access to the opportunity to participate by promoting active contact and recruitment would encourage greater involvement especially among minorities (Hartz et al. 2011; Helgesson 2011; Patterson et al. 2008). Community-based participatory approaches have also been found to engage minorities (Hohl et al. 2014).

Family or personal experiences are also factors often associated with who may participate in research. In this study, a family or personal history with mental illness was not associated with obtaining a sample or consenting for storage and future use. A history, either family or personal, or having someone in their close network using substances tended to increase the probability of contributing a biological sample, but was no longer significant in models that adjusted for other factors. Genetic testing for alcohol dependence has been found to be as important as testing for other multifactorial diseases like cancer among a community sample of African Americans (Marshall et al. 2012). The consent form specifically mentioned our interest in both conditions and the influence of a family or personal history on the decision to donate a sample may be akin to recruiting for a cause (e.g., clinical genetic studies). A desire to understand their addiction might have encouraged smokers to be more likely to donate a sample, but potential underlying factors of mistrust and legal ramifications may still create barriers for users of other types of substances to allow sharing of DNA samples.

In this sample, study design and procedural aspects influenced participation and providing consent more than individual characteristics. Two procedural factors strongly influenced increased participation rates. The first was presenting participants the option of providing saliva samples instead of only blood specimens. This offered those with a fear of needles or seeing blood the opportunity to avoid doing something they disliked. Other studies find participation is higher for less invasive DNA collection options (e.g., saliva or buccal) than those asked to donate a blood sample in population studies (Hansen et al. 2007; Johnson et al. 2011); saliva return rates often vary between 52–80 % (Etter et al. 1998, 2005; Nishita et al. 2009). Second, providing an incentive also increased the chance of obtaining a biologic sample. Gifts and money have been found by others to modestly improve DNA returns (Etter et al. 1998; Bhatti et al. 2009); however, monetary incentives have not always enhanced the recruitment of African Americans into genetic research studies (Johnson et al. 2011). The amount provided in this study was comparable to the US\$20 amount found to have greatly influenced people's decision to participate in a database being assembled to support research in the areas of genetic epidemiology, pharmacogenetics, and population genetics (McCarty et al. 2007). In this study, the incentive did not seem to influence the type of sample that people choose to provide. However, providing an incentive decreased the odds of consenting to allow sharing with other NIH investigators, even when other factors associated with sharing were held constant. Perhaps, people willing to donate a sample without any kind of incentive are more altruistic and already open to granting permission to share (Sanderson et al. 2013).

Several other procedural factors may have also contributed to the high rates of consent within this study. Foremost is the

fact that DNA collection was conducted within an ongoing community-based cohort study. The investigative team had an established relationship with the majority of the sample and participants who were more involved and active in the project over time were more likely to donate a sample as well as more likely to agree to provide a blood sample. Strong relationships have been found to be important for involving minorities in genetic research (Yancey et al. 2006). A history with a project requesting samples may contribute to the participants' level of trust or comfort in providing biological samples and willingness to agree to a procedure that is more invasive (Corbie-Smith et al. 1999, 2002; Cox et al. 2007; Halverson and Ross 2012). Our collection procedure also optimized building rapport, trust, and personalization. Interviews were done in person at the participant's convenience and the composition of our tracking and interview team matched the same racial/ethnic make-up as the cohort, both factors found by others to facilitate participation among minority populations (Satia et al. 2005). All aspects of study participation were described in detail during the consent phase. Interviewers took time in addressing questions and the consent form described individual assurance of confidentiality and anonymity of participation. Our experience with obtaining replacement samples also indicates that personal contact is beneficial to have a participant actively respond rather than rely on a somewhat passive approach via the mail. The time since the personal contact of the interview, which varied from several years to just a few months ago was not a large factor in successfully obtaining a replacement sample. Despite the non-invasive nature of collecting salivary samples and sending them through the mail, studies using this approach have variable return rates; even if participants express a high agreement to participate, the actual return of saliva samples is often low (Bhutta et al. 2013). Furthermore, even though other studies have been able to obtain a second saliva sample from half of their attempted requests, many of the initial low-yield samples also had a low-yield in the second sample too (Nishita et al. 2009). Thus, benefits of the recruitment approach for additional samples must be weighed against other factors, such as collection cost and DNA yield and quality.

The use of separate consent forms for the main study (interview only) may have also helped foster trust by allowing participants to choose minimal involvement, declining to participate in the genetic portion. Our rates of consent to allow us to store and create an immortalized cell line for future research studies, including other health/medical problems like heart disease and diabetes, were comparable to rates found in other community studies adding a genetic arm (Levy et al. 2010). Others, too, have found that sharing data and samples with others remains a concern for participants (Trinidad et al. 2010). Non-Hispanic black individuals have been found to be less likely to consent to storage and future genetic research and did not want their sample to be shared and included in

national repositories (Chen et al. 2005; Mezuk et al. 2008; McQuillan et al. 2003). These studies also found that personal characteristics such as age or gender and a history of themselves or a family member having been affected by disease did not appear to influence the allowance of storage and future testing. Our results do indicate nonetheless that there are participants who refuse banking and sharing when asked.

The generalizability of the results is the main limitation of this study. This research was conducted at a single site, in a single region of the country and consisted of a particular sample, albeit consisting of the entire population of first graders in a geographic area, all approximately the same age and many having participated in previous interviews. In the past, we have been more successful in interviewing a greater proportion of our cohort. Possible explanations for the decline in our interview rate include factors commonly associated with attrition in a longitudinal study of a cohort being followed over time, environmental influences (e.g., societal views regarding greater privacy), and perhaps the procedure change as this was the first time the interview also had a genetic component (Banks et al. 2012; Matsui et al. 2005). Studies have found that response rates to questionnaires decrease when the study also includes a DNA component (Matsui et al. 2005; McQuillan et al. 2006; Melas et al. 2010), although those who participate are willing to donate biologic samples for DNA testing (Hansen et al. 2007). DNA collection experiences may be different when offered after longstanding participation, and these results may not generalize to samples where DNA sampling is offered from the outset. Attrition is important to monitor in longitudinal studies as others have found that ethnicity, male gender, low social class, and mental health problems have not only been associated with lost to follow-up but also with failure to provide DNA (Bjertness et al. 2010).

In conclusion, research participants are more likely to consent to answer questionnaires than provide DNA samples; however, many also provide a DNA sample and allow storage and future testing. Factors that affect willingness to donate a DNA sample may not be the same as those associated with allowing storage and sharing.

Our experience illustrates there are many study parameters that are very important in planning biologic collection efforts. Not all studies are designed to involve cohort samples, but evidence is emerging that paying extra attention to building strong rapport and trust with subjects, reaching out to insure access and minimizing the burden involved to obtain a biological sample, and offering an incentive will increase the likelihood of obtaining a sample and more importantly increase the opportunity to store and share the sample for the future.

Acknowledgments This work was supported by several National Institute of Health grants over the span of the prospective study: National Institute of Mental Health MH71395 and National Institute on Drug Abuse DA09897, DA04392, and DA019805.

Conflict of interest Carla Storr, Flora Or, William Eaton, and Nicholas Ialongo declare that they have no conflict of interest. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all participants included in the study.

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