Fanteca¹ Project Goals²

- 1) To recruit and interview 300 opiate users over 6 successive weekends at a fixed location in the South Bronx in the Fall of 2017.
- 2) Estimate the number of opiate users in the South Bronx and describe the characteristics they share using a method of recruiting vulnerable and hard-to-reach populations called Respondent Driven Sampling (see, www.respondentdrivensampling.org).
- 3) To train the next generation of experts who will address the problem, undergraduate students who are largely drawn from the same neighborhoods where the study will take place are afforded the opportunity and support to learn about the problem. Armed with first-hand data that they collect, they are at the cutting-edge of fashioning data-driven responses to the problems.

Our initial goal, of interviewing 300 opioid users was accomplished in 7 days, over 4 successive weekends. The survey team began recruiting participants and interviewing on Saturday, October 7th. The team reached a total of 329 surveys on Oct 28th, 2017. The site where the study was conducted was well-known to drug users, naturally isolated from busy streets, surrounded by public benches and spacious enough to provide interviewers and interviewees personal space to conduct confidential interviews.

Most days the team was comprised of at least 4 professors and 6-to-10 students. Professors oversaw the recruitment process using the *RDS "Coupon Manager"* software and students handled both interviews and crowd control. The team arrived at our location in the South Bronx at 12:45 each weekend day and students were interviewing subjects by 1pm, though rain forced us to cancel one Saturday. Students interviewed people until 4pm, so data collection only took place 3 hours per day, but many staff members were physically and emotionally exhausted by that time and they were grateful that our allotted funds for the day were spent.

The survey that the study used was developed by professors in the Anthropology Department at John Jay, and it collected data on user demographics and a variety of topics intended to provide insight into problems associated with their use of opiates, including the frequency and amount of drugs that they use, their awareness of and attitudes toward

they become available.

¹ Fanteca is not a word that you will find in the dictionary, at least not yet. One popular slang word for heroin in ² This report describes our progress in achieving these goals and is written for a general audience; we hope to avoid jargon and technical terms that might not enlighten some readers. For those who appreciate technical language and peer-reviewed fashion, we are preparing several papers that will be submitted to academic journals for publication early in 2018, and we will be happy to share those articles with those that have a desire to read them. We will also be posting links to the articles on social media sites, including LinkedIn, Facebook and Twitter as

fentanyl, their experiences with overdoses, their access to and knowledge about and use of naloxone, and their participation in "harm reduction" programs.

The survey tool was revised about half way through the study (after 181 of the 329 total number of surveys were completed); new questions were added and some questions that we felt had comparatively little value were omitted. Normally, survey researchers do not change questions over the course of the study since additions, subtractions or alterations may affect people's answers. But in this case, our goal was not necessarily to adhere to the gold standard of data collection, but rather, to learn more about opiate users' problems and to provide a meaningful experience for the students who helped to collect the data. The survey was revised following debriefing sessions that took place after the first week of data collection, and after consulting with a NYC policy maker who raised provocative questions for which we had no answers. To that end, we added additional questions, including the following:

- If heroin was free, how much would you use each day?
- If heroin was free, how often would you use it each day?
- If heroin was free, how would you choose to get it?
- If heroin was free, would it increase, decrease or not change your use of other drugs?
- If heroin was free, would your health and your life be better, worse or the same?

All surveys were administered on-site using cellphones to record responses into the Survey Monkey app that students accessed. There were several advantages to this data collection technique, including allowing the team to record data quickly and privately, and transition to the next interview without pause. It also allowed for real-time access to findings, so that we could monitor response rates to questions that we were of particular interest to the staff.

Students learned several valuable lessons through the process of collecting data. One lesson was that the quality of the data begins to suffer after too many successive interviews. Five interviews, each about 15-20 minutes in length, seemed to be about the limit that students could handle before they showed signs of survey fatigue. This was especially evident with our Spanish-speaking students who were kept busier than English-only-speaking interviewers. Many people recruited into the study only spoke Spanish, so students that spoke Spanish were always busy. Milagros De Jesus, a student at John Jay College, recalled her experience as a bilingual survey-team member:

Knowing a second language was helpful for the interviewees and me. Many of the interviewees were Spanish speakers, and even though some of them understand English, they felt more comfortable speaking in their first language. In the same way, I felt more confident conducting the questions in my first language. Overall, I felt useful and proud to be able to move the process faster.

Our original plan was to conduct recruitment over 6 weekends to reach our goal of 300 surveys, but the popularity of the project among users (they could potentially earn \$25) allowed us to complete the project in only 4 weekends. One tangible benefit of shortening the lifespan of the recruitment process was that it improved the quality of the data. The fidelity of our data depends on people recruiting their friends and associates into the study, and on each person getting interviewed only once. Shortening the recruitment period to decreased the likelihood that subjects got interviewed more than once, and with \$25 at stake, several subjects tried. Our research team consisted of a large number of students, many of who participated only one or two days of data collections, so it was virtually impossible for many of them to know whether someone who said that they wanted to be in the study had already done an interview.

Team leaders were there each day of the project, and they closely monitored the recruitment process to ensure that people did not participate in the study twice. Several subjects tried to participate more than once in the study, some innocently, some with guile. This is where our collective memory about who was interviewed was important, and when in doubt, the team was able to look up recruitment information on the computer (in the "Coupon Manager") to show subjects that they had already been interviewed. One particularly amusing repeater was a subject whose face was almost entirely tattooed: with such a memorable face, it was almost comical when he tried to convince us that we had not interviewed him before. The point here is that ensuring that people did not participate more than once in the study was important, and it was best accomplished by having a core number of staff members who were there on each occasion and by shortening the timespan of the recruitment process as much as possible.

Our Second Goal, estimating the number of opiate users in the South Bronx and describing the characteristics they share, is actually two goals, only one of which we can report on here. Estimating the number of opiate users in the South Bronx is a work in progress: it requires us to perform statistical calculations that, while not particularly difficult, are dependent upon comparing our data with other data (like NYC arrest data), and both of these sources of data need to be prepared before we can complete the analysis. But we can report on the characteristics or attributes that the subjects shared, and below, we offer the "frequency charts" that show what subjects said in response to our questions.

Our Third Goal of "training the next generation of experts" who will address problems associated with opiate use is an ongoing process, but below, we describe our progress:

Here is a list of students who conducted surveys for the project:

From John Jay College		
1. Adriana Loor	18. Koral Torres	36. Andres Torres
2. Amanda Lombardo	19. Kyara Velasquez	37. Andris Arias
3. Anastisia Petropoulos	20. leatrice jackson	38. Cinttia Moreno
4. Antonio Vargas	21. Luna Lovos	39. Cristian Canales-Perez
5. Ashley Park	22. Marie'Anne Lal	40. Diana Cervantes
6. Belle Stockdale	23. Marlena Szumowski	41. Eric Claudio
7. Chantal Castillo	24. Milagros de Jesus	42. Evelisse Tavarez
8. Clara Meere-Weigel	25. Paul Adams	43. Iryna Yefremova
9. Clarence Colon	26. Paul Doobay	44. Khrystyna Krytsyak
10. Del La Cruz Max	27. Petrit Haxhi	45. Luis Ramirez
11. Devante Johnson	28. Ryan Keane	46. Melissa Baptiste
12. Efstratios Giannoulakis	29. Saleh Alhaithami	47. Tyler Cox
13. Emmanuel Mendez	30. Shequila Watson	48. Zulma Valle
14. Errol Nicholas	31. Tabrina Youmans	49. Jolitina Prophett
15. Francisco Jimenez	32. Vajeea Janjua	(Rutgers)
16. Joana Bakiasi	33. Yazmine Benitez	
17. Jonathan Rupay	34. Yeirline Rodriguez	
	35. Yulya Zabaznova	

Research Team Leaders.	mstrutions.
Anjelica Camacho ³	1. CUNY Institute for Implementation
Camila Gelpi-Acosta ²	Science in Population Health
Chris Herrmann ³	2. CUNY School of Public Health
Cornelia Preda ³	3. John Jay College - CUNY
Doug Goldsmith ³	4. LaGuardia Community College - CUNY
Leo Dominguez ^{1,2,3}	5. Rutgers University
Popy Begum ^{3,5}	
Ric Curtis ³	
Rob Freeman ³	
Sheng Li ²	

Institutions

Research Team Leaders:

Tino Fuentes

Using undergraduate college students to administer surveys to active drug users is an introduduction to the field for young people who represent the next generation of professionals, researchers and activists: the project allowed us to expose dozens of undergraduate students to active opiate users, a group of people who students had heard much about via the media, but who they largely never actually met themselves so that they might form their own opinions. Anastasia Petropoulos, a student at John Jay, wrote about her experience in this regard:

Previous to the study, I had only been introduced to a stigmatized concept of views inflicted upon drug users. I was lacking in the extensive knowledge related to drug use. I would say that my perception of drug users has expanded and intensified, and that my passion to advocate for them has grown even stronger.

Many of the undergraduate students who participated in the study said that they were initially frightened by the idea of going to the South Bronx to do a study and that they were apprehensive about recruiting active heroin users who they thought could be "unpredictable," that is, until they went to the South Bronx and met the people.

Students learned that, over all, the people who participated in the study were "just like us" in the sense that they had many of the same worries and concerns; and their lives seemed, in many ways, "normal" to the students who had gone there expecting something different, something "chaotic," something even dangerous. Students listened to subjects talk about their pain, their struggles with daily living, especially their attempts to avoid the police, deal with hunger, homelessness, estrangement from family and friends, displacement (from Puerto Rico, for many), dysfunction, disease, and death, in addition to listening to them describe problems that were associated with their drug use, like overdoses, abscesses and failed attempts in drug treatment. Through listening, students learned that, far from being people who they needed to fear, drug users were a largely a woeful group whose myriad problems in life sometimes rendered them incapable of effectively dealing with their issues. One of the undergraduates, Amanda, wrote about her "just like us" moment in the field, one that had an extra, unexpected twist:

Something happened that I never thought could happen. When conducting one of the interviews a woman walked up to me and asked me, "Do you know who Donyale is?" I was completely shocked at that point. The women said I resembled Donyale so much that I could be her daughter. I told the woman, "that was, in fact, my mothers' name." I had so many questions to ask that lady, but no words were coming out of my mouth. I rushed over to Professor Camacho, she was shocked as well. It was like a scene from a movie. That probably was the closest chance I'll have of knowing where my mother might be. I blew it completely, but at least I found out she was still alive, and that's more than enough for me.

Many students discovered that participating in the Fanteca project was more than an experience that would someday occupy a line on their resume; for some, it was revelatory: they were first-hand witnesses the cumulative effects of poverty, including violence, mental illness and ailments like abscesses, skin infections, debilitating scars, missing teeth, limbs and digits. These experiences were transformative for many of the students who said that they found

themselves drawn to the work and expressed a desire to continue with the project as it moves forward.

Another lesson that students learned is that drug users' lives are filled with many tensions and problems, both personal and interpersonal, that sometimes threaten to spill out into public, but an advantage to recruiting large numbers of people at one time is that disruptive people (who were well-known to the crowd) were effectively pressured by others to moderate their behavior so that the research process could proceed. Students were reassured by the degree to which social norms and pressures constrained and structured behavior on the street, and that, in fact, drug users and others cannot act entirely wild and unrestrained without consequence.

Students also learned that there are not many other young people doing the kind of work that they did for the Fanteca Project. There are programs for drug users that provide crucial services and safe spaces for them to meet, especially harm reduction programs like Boom Health, St. Ann's Corner of Harm Reduction, NY Harm Reduction Educators and the Washington Heights Corner Project. The Fanteca Project sought to replicate a critical element that these programs champion, that is, meeting drug users "where they're at." The Fanteca Project embraced the literal and figurative meaning of the term; by conducting the study on the sidewalk adjacent to a public park that is a popular hang-out for drug users in the South Bronx, and by offering a sympathetic and fresh ear to the many drug users who wanted to talk about their problems.

The survey that the project administered to study participants was not constructed to promote extended conversations between the students and drug users, or for drug users to provide long descriptive accounts of their experiences to the researchers. Indeed, it was quite the opposite; because the interviewers were inexperienced undergraduate students with little training, the project sought minimize unstructured interactions between the researchers and drug users. But it did not turn out quite that way: between the short-answer questions, many users engaged the student interviewers with richly textured accounts that described their experiences, their hardships, their aspirations and expectations about the future. And because they were describing all this to young people who were entirely new to this world and unfamiliar with its contours and terrain, many users made an extra effort to explain themselves to the young students in ways that they would never have done with seasoned social workers or with harm reduction outreach workers. Shequila Watson, one of our interviewers, shared her experience:

One memory from the field that moved me was while interviewing a gentlemen who had undergone a pressing setback after being clean for six years. The guy had gotten into an argument with his girlfriend, which led to his arrest, and eventually, leading to him sniff heroin. He was shocked that I genuinely wanted to know and

understand him; he stated that most interviewers care more about collecting data than listening. He kindly thanked me for treating him like a human being; I felt pleased to offer a therapeutic environment.

The need to explain what drugs are all about to young people not steeped in them led many drug users who participated in the study to be self-critical, introspective and frank, and it was an eye-opening experience for many of the students.

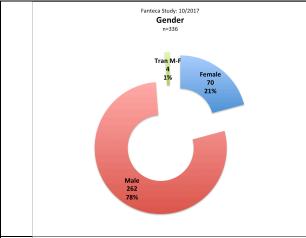
Fanteca Forward

Many of the undergraduate researchers who participated in the first wave of the Fanteca project evision themselves as researchers on the second wave that is scheduled for Spring, 2018. One student, Luna Lovos, commented on what she would like to accomplish next time:

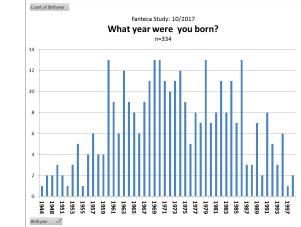
Assisting the Fanteca project in the fall, 2017, research has been a positive life-changing experience, and I look forward to this type of research as being apart of my continued efforts to change the lives of those we serve and those that suffer from opiate overdose. I hope that through this experience we can improve upon organization in administration of the coupon management as well as to hone my skills as an interviewer to help the participant feel more comfortable and safe during field surveys.

The project video-recorded short clips of many of the students conducting interviews, and elicited reactions from students immediately after they finished the day interviewing, but having time to reflect on those experiences and then write about them is critical too, and to that end, we have created a private social media page on Facebook for students who participated in the project to share their thoughts, feeling, photos and videos from the project. Going forward, when the project is revived for the Spring 2018 semester, the next group of students will have the advantage of reading and watching the experiences that the first cohort enjoyed and recorded, and learning from them first-hand.

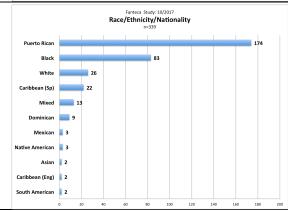
Survey Findings



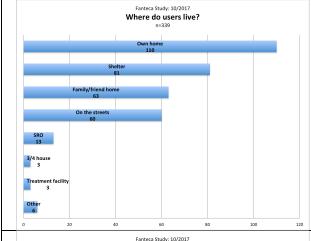
The project sample was 78% men, 21% women and 1% transgender.



The average age of subjects in the study was 44 (born in 1973); the youngest was only 19, the oldest was 73.



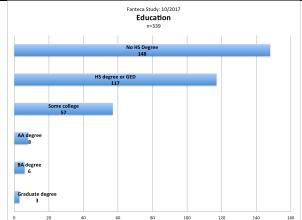
More than half of the sample (51%) was Puerto Rican; the rest were divided between Blacks (24%), Whites (8%), people from the Spanish-speaking Caribbean (6%), and smaller numbers of people from other groups.



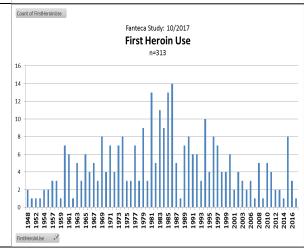
Slightly more than half of the people (51%) said that they lived in their own home (32%) or with a family member or friend (19%).

But more than 40% of the subjects said that they lived in a shelter (24%) or "on the streets" (18%).

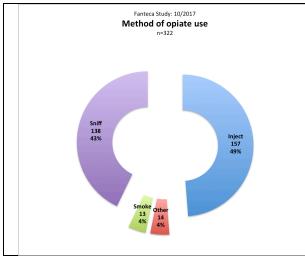
The remainder said that they lived in supervised or subsidzed residences.



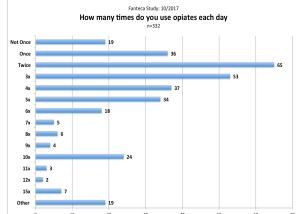
More than half of the subjects (56%) said that they had at least a high school diploma or GED, but 44% said that they did not have a high school degree.



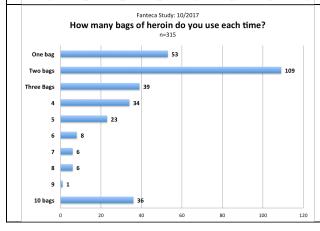
The "mean year" that users first tried heroin – the average or middle of all the combined years – was 1983.



Almost half (49%) of the people in the sample said that they "inject" the drug; 43% said that they "sniff" it; smaller numbers say that they smoke it or use it in other ways.

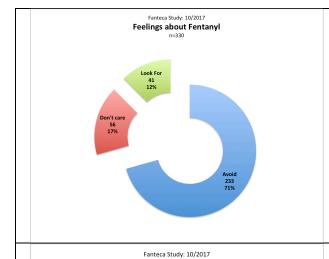


The most frequent responses for how many times people use opiates each day was "twice" and "three times." Many used it more; 55 people (17%) said that they used it more than 10 times per day.

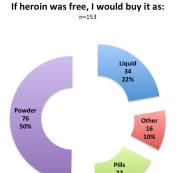


When asked how many "bags" of heroin they use each time, the most popular response was "2 bags." Each bag costs \$10.

If users buy 2 bags each time and use 2 times per day, that's \$40 per day.... every day.

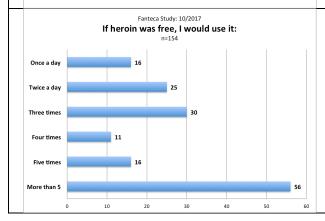


The synthetic opiate, fentanyl, is said to be added to most of the bags of street heroin for sale in the South Bronx. Most users (71%) said that they try to avoid fentanyl, but 12% said that they look for it, presumably because it offered a stronger high.

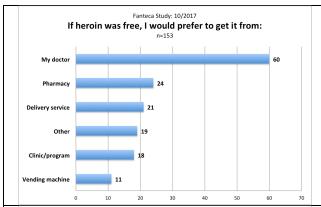


What if heroin was free? We added questions about that halfway through the study after conversations with policy makers who wondered how the state might deprive street dealers of their customers.

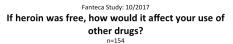
When asked what form they would prefer to get heroin in, half of them said "powder." The 22% who said that they would prefer to get heroin in liquid form, we assume, were likely to be injectors.



More than 1/3 of users (36%), the largest group of them, said that if heroin was free, they would use it more than 5 times per day.



The most frequent response for where users would like to get their heroin was from their "doctor" (39%) or from a pharmacy (16%).

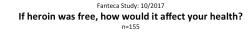


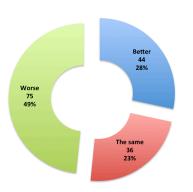
Decrease
44
29%
64
41%

Increase
46
30%

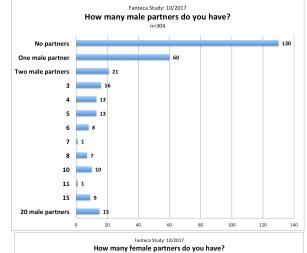
In additition to heroin, 75% of subjects in the study said that they use other drugs. We asked, if heroin was free, how would it affect the use of other drugs?

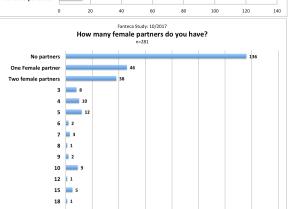
The most frequent response was "no change," but that category almost surely includes the 25% of people who do not already use other drugs. Among the remaining users, there is an even split between those who say that their use of other drugs would increase and those who say it would decrease if heroin was free.





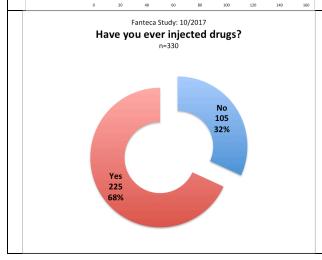
Nearly half of the subjects agreed that if heroin was free, it would negatively affect their health, but 28% said that their health would improve.



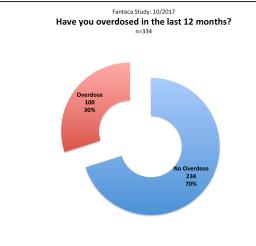


Asking about "partners" is tricky because there is a lot of stigma attached to sharing needles, and admitting to having "partners" might be seen as an admission to sharing injection equipment. That may be one reason that 43% of subjects said that they have no male partners and 48% said that they have no female partners, though people who sniff or take opiates in pill form are probably less likely to have partners.

Knowing the number of partners is important for our ability to estimate the number of opiate users.

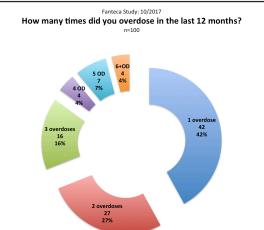


More than 2/3 of the subjects (68%) said that they had injected drugs before.

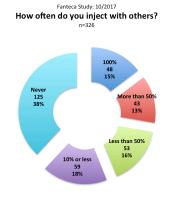


One hundred of our subjects (30%) said that they had overdosed in the last 12 months.

Non-fatal overdoses are likely to be immeasurably undercounted in official statistics. The answer to this question gives some indication of how vast the problem might be.

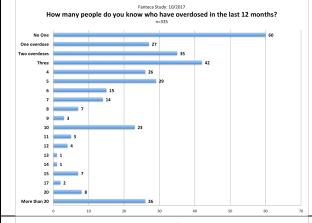


Among the 30% of subjects who said that they had overdosed in the last 12 months, 58% of them said that they had overdosed more than once; some as many as 6 times or more.

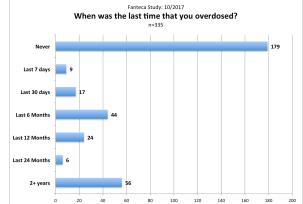


Injecting alone puts users at heightened risk of a fatal overdose, but saying that you inject with others is fraught with stigma too. More than one third of subjects said that they do not inject with others, but 62% said that they do.

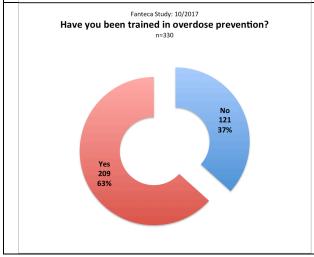
Better questions about partners are needed next time to tease out answers that are not filtered through the lens of stigma.



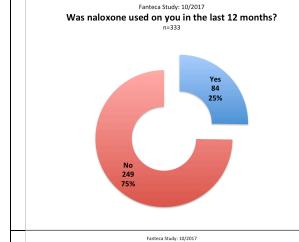
Only 18% of subjects said that they did not know anyone who had overdosed in the last 12 months, but more than 23% said that they knew more than 10 people who overdosed in the last 12 months.



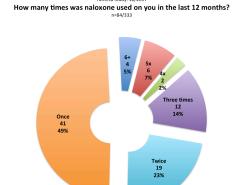
Slightly more than half (53%) said that they had never overdosed; 47% said that they had overdosed at least once.



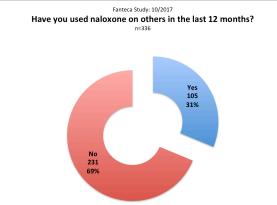
With 63% of the subjects saying that they have been trained in overdose prevention, the work of harm reduction programs in helping to build this capacity seems clear.



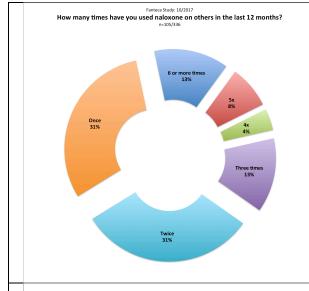
Twenty-five percent of subjects – 84 people – said that naloxone had been used on them in the last 12 months to counteract an overdose.



Half of the 84 people who overdosed in the last 12 months had naloxone used on them only once, but the other half had it used twice (23%) or multiple times; some as many as 6 times or more.



Training users in overdose prevention and providing them with naloxone appears to be paying off as nearly 1/3 of subjects (n=105) said that they had used naloxone on someone else in the last 12 months.

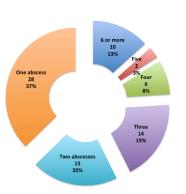


More than two-thirds of the subjects (68%) who said that they used naloxone to counteract an overdose that someone else was experiencing, did so more than once.

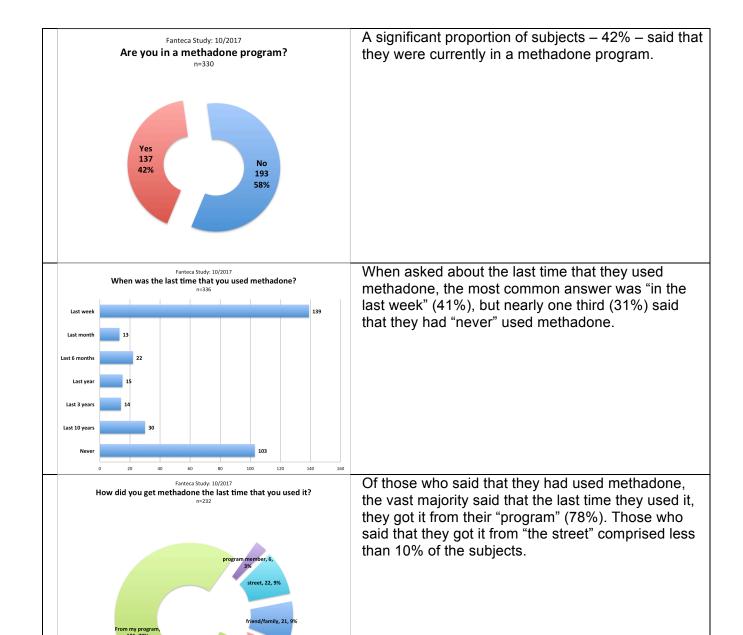


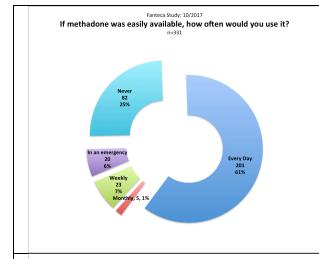
Yes 102 38% No 169 62% Among injectors, more than one-third said that they developed an abscess as the result of injecting drugs.





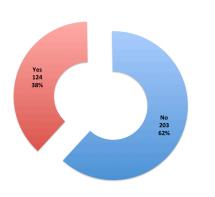
Among the 75 injectors (28% of all injectors) who said that they developed an abscess in the last 12 months, the majority of them (63%) had more than one.





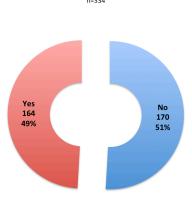
Most people (61%) said that if methadone was easily available, they would use it "every day;" but 25% said that they would "never use it."





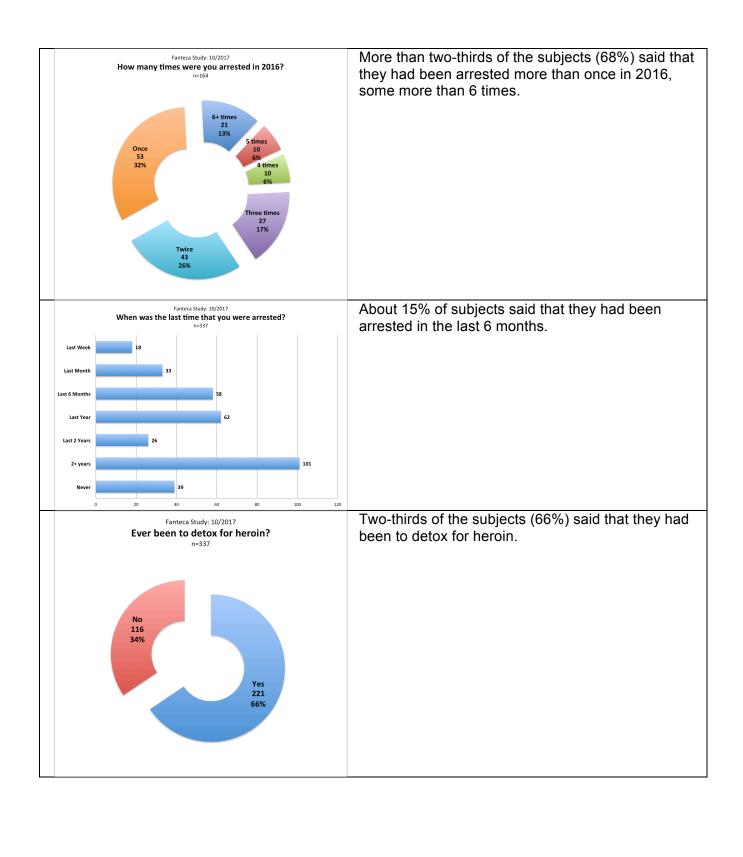
Buprenorphine and suboxone are opiate replacement therapies, like methadone, but are relatively new on the scene by comparison. Still, more than one-third of subjects said that they had been on a program for one (or both) of the substances.

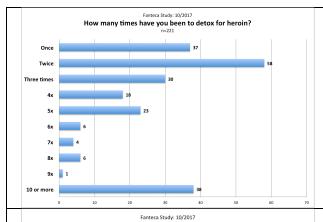




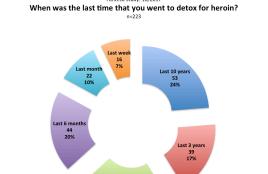
Almost half of the subjects said that they had been arrested at least once in 2016.

We asked about arrests in 2016 rather than the last 12 months (like other questions) because we hope to use official statistics on the number of arrests in NYC as a "baseline" number to help us estimate the number of opiate users in the South Bronx.

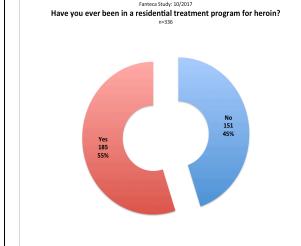




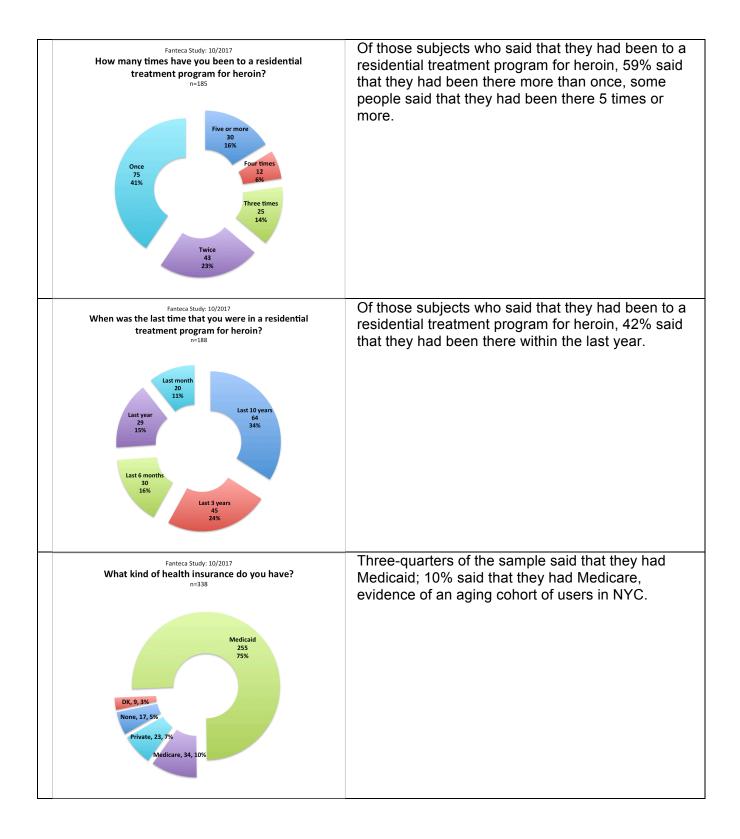
Most subjects had been to detox for heroin more than once, with 25% saying that they had been there twice; 38 people (17%) said that they had been to detox ten times or more.

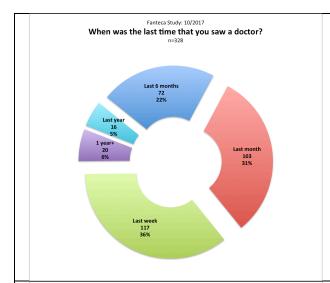


Of those subjects who said that they had been to detox for heroin, more than half of them (59%) said that they had been there within the last year.

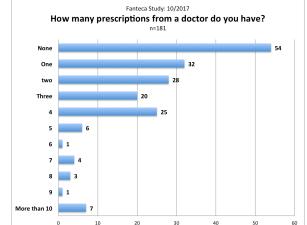


More than half of the subjects (55%) said that they had been in a residential treatment program for heroin.

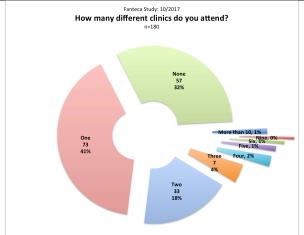




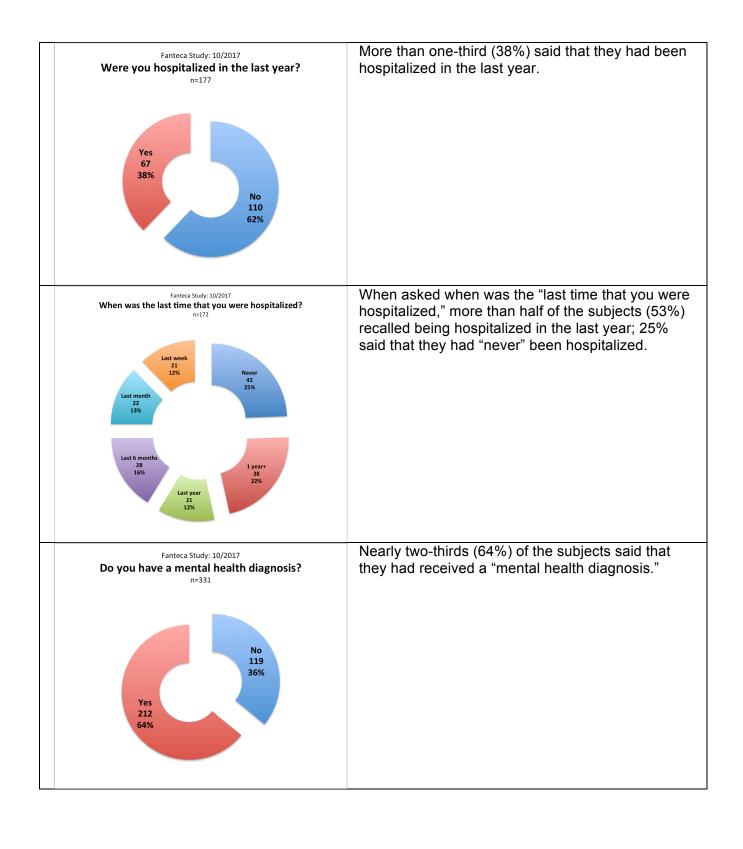
The overwhelming majority of subjects (94%) said that they had seen a doctor within the "last year;" more than one-third (36%) said that they had seen a doctor in the "last week."

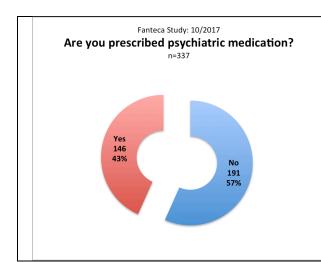


Thirty percent of the subjects said that their doctor is not currently prescribing any medication for them. Most subjects reported that between 2-4 medications are prescribed by their doctors.



Nearly one-third of the subjects said that they do not currently receive medical care at any "clinic;" 59% of subjects said that they attend one or two clinics, much smaller numbers said that they attended more than two.





A significant proportion of subjects (43%) said that they had been prescribed psychiatric medication by a doctor, but the majority (57%) said that they had not been prescribed medication.