**Supplemental Digital Content**

**Appendix I:**

**Survey Instrument for Assessing Interest and Attitudes of Youth Living with HIV Towards Long-acting Parenteral Nanoformulated Antiretroviral Therapy**

***Please enter your Unique Identifier Here:* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

Start of Block: Default Question Block

Q1 Question 1 ***We are going to start by asking you some questions about yourself:***     **1.      Below is a list of terms that people often use to describe their gender. Using the terms below, how would you best describe yourself?**    *(Please check all that apply.)*

* Male (1)
* Female (2)
* Transgender male-to-female (3)
* Transgender female-to-male (4)
* Other (5)

Display This Question:

If Question 1 We are going to start by asking you some questions about yourself:     1.      Below i... = Female

Q2 **If you are female, in the past have you ever been on Depo-Provera (a “shot” of birth control which you get every 3 months from your doctor)?**

* No (1)
* Yes (2)

Display This Question:

If  If you are female, in the past have you ever been on Depo-Provera (a “shot” of birth control whi... = Yes

Q3 **If Yes, how did that go? (please describe whether you liked it or not, and what the problems were, if any):**

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Display This Question:

If  If you are female, in the past have you ever been on Depo-Provera (a “shot” of birth control whi... = Yes

Q4 **Would you be willing to try Depo-Provera again?**

* Yes (1)
* No (2)

Display This Question:

If Question 1 We are going to start by asking you some questions about yourself:     1.      Below i... = Female

Q5 Have you ever had an implantable form of birth control such as Implanon (this is a plastic "implant" that is surgically inserted under the skin of your arm and releases birth control hormones).

* Yes (1)
* No (3)

Display This Question:

If Have you ever had an implantable form of birth control such as Implanon (this is a plastic "impla... = Yes

Q6 If yes, how did that experience of having the "implant" go? Please describe whether you liked it or not, and why.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Display This Question:

If Have you ever had an implantable form of birth control such as Implanon (this is a plastic "impla... = Yes

Q7 If yes, would you be willing to try it again?

* Yes (1)
* Maybe (2)
* No (3)

Q8 **Are you of Hispanic origin or Latino/ Latina?**

* Yes (1)
* No (2)

Q9 **What is your race?**

* White or Caucasian (1)
* African-American or black (2)
* Asian or Pacific Islander (3)
* Native American or Alaska Native (4)
* Other (5)

Q10 **In what year were you born?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q11 **In what year were you diagnosed with HIV?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q12 **How did you get HIV?** *(Please choose all that apply)*

* From my mother when I was a baby (perinatally) (1)
* By using IV drugs (2)
* From sex with men (3)
* From sex with women (4)
* Other (5)

Q13 **Where do you receive HIV care?**

* St. Jude Children's Research Hospital, Memphis (1)
* University of Maryland (2)
* Johns Hopkins (3)
* Emory (4)

Display This Question:

If Where do you receive HIV care? = St. Jude Children's Research Hospital, Memphis

Q14 What is your most recent HIV viral load?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q15 **The following questions ask about your drug use, past and current. All of your answers will be kept completely confidential**. (*For each drug listed, please tell us whether you have used the drug within the past 6 months, used the drug in the past but NOT within the past 6 months, or never used.)*

|  |  |  |  |
| --- | --- | --- | --- |
|  | Used in past 6 months (1) | Used in past, but NOT in the past 6 months (2) | Never Used (3) |
| Marijuana (pot, weed, ganja, blunt, 420, chronic) (1)  |  |  |  |
| Cocaine (powder, crack, blow, yayo) (2)  |  |  |  |
| Heroin (smack, tar, chiba, junk, white, dragon, dope, boy) (3)  |  |  |  |
| Amphetamines (meth, speed, crank, tina, tweak, ice) (4)  |  |  |  |
| Alcohol (5)  |  |  |  |
| Prescription pain drugs (Oxy, Cotton, Percs, Vike, oxycodone, OxyContin, Dilaudid) (6)  |  |  |  |
| Ecstasy (MDMA, e, X, thizz, roll) (7)  |  |  |  |
| Amyl nitrate/ poppers (8)  |  |  |  |

Q16 **Have you ever injected drugs into your body with a needle?**

* Yes (1)
* No (2)

Display This Question:

If Have you ever injected drugs into your body with a needle? = Yes

Q17 **If Yes, have you used drugs intravenously within the past 6 months?**

* Yes (1)
* No (2)

Q18 **Are you currently in methadone or Suboxone (buprenorphine) treatment?**

* Yes (1)
* No (2)

Display This Question:

If Are you currently in methadone or Suboxone (buprenorphine) treatment? = No

Q19 **Have you ever been in methadone or suboxone (buprenorphine) treatment?**

* Yes (1)
* No (2)

Q20 Many people with HIV have lots of pills to take at different times during the day. Some people find it hard to always remember their HIV pills. Some people get busy and forget to carry their pills with them. Some people find it hard to take their pills exactly as prescribed (for example, three times a day, or “with food” (after eating a meal)). Some people decide to skip doses to avoid side effects or just to not be on pills for that day.   We want to understand how young people with HIV are **really** doing with their HIV pills. Please tell us what you are **actually** doing. Don’t worry about telling us that you don’t take all your pills. We need to know what is really happening, not what you think we “want to hear.” **Your answers will be kept strictly confidential.**   ***The next section asks about your HIV medications:***

Q21 **Are you currently being prescribed medication for your HIV?**

* Yes (1)
* No (2)

Display This Question:

If Are you currently being prescribed medication for your HIV? = Yes

Q22 **How many HIV pills are you supposed to take each day and how often?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Q23 ***This part of the survey asks about HIV medications that you may have missed taking over the last four days.*** *(If you took only a portion of a dose on one or more of these days, please report the dose(s) as being missed.)* **When was the last time you missed any of your medications?**

* Within the past **week** (1)
* 1-2 **weeks** ago (2)
* 3-4 **weeks** ago (3)
* 1-3 **months** ago (4)
* more than 3 **months** ago (5)
* I **never** skip medications (6)

Q24 **During the past 4 days, on how many days have you missed taking any of your doses?**

* None (1)
* One day (2)
* Two days (3)
* Three days (4)
* Four days (5)

Q25 **Most anti-HIV medications need to be taken on a schedule, such as "2 times a day" or "3 times a day" or "every 8 hours". How often did you follow your specific schedule over the last four days?**

* Never (0 days out of 4) (1)
* Some of the time (1 day out of 4) (2)
* About half the time (2 days out of 4) (3)
* Most of the time (3 days out of 4) (4)
* All of the time (4 days out of 4) (5)

Q26 **Do any of your anti-HIV medications have special instructions, such as "take with food" or "on an empty stomach" or "with plenty of fluids"?**

* Yes (1)
* No (2)

Q27 **How often did you follow those special instructions over the last four days?**

* Never (0 days out of 4) (1)
* Some of the time (1 day out of 4) (2)
* About half of the time (2 days out of 4) (3)
* Most of the time (3 days out of 4) (4)
* All of the time (4 days out of 4) (5)

Q28 **Some people find that they forget to take their pills on the weekends. Did you miss any of your anti-HIV medications last weekend— last Saturday or Sunday?**

* Yes (1)
* No (2)

Q29 We are working to make a new way of taking a new kind of anti-HIV medication. Instead of taking pills every day, you would get an injection (or "shot") of the new medicine in your muscle at regular intervals. This would mean you would not have to take any pills.

 **If this new way of taking your medication was available as an option for you, *how likely* would you be to try this method?**

* Definitely **would** try it (1)
* Probably **would** try it (2)
* Probably **would not** try it (3)
* Definitely **would not** try it (4)

Display This Question:

If We are working to make a new way of taking a new kind of anti-HIV medication. Instead of taking p... = Definitely <strong>would</strong> try it

Or We are working to make a new way of taking a new kind of anti-HIV medication. Instead of taking p... = Probably <strong>would</strong> try it

Q30 **This new way of taking your medicine would require injections from time to time. *How likely* would you be to try this new method if you were required to come to the clinic for injections...**

 *(Please mark one box in each row).*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Definitely **would** try it (1) | Probably **would** try it (2) | Probably **would not** try it (3) | Definitely **would not** try it (4) |
| Once every **week**? (1)  |  |  |  |  |
| Once every **two weeks**? (2)  |  |  |  |  |
| Once every **month**? (3)  |  |  |  |  |
| Once every **two months**? (4)  |  |  |  |  |
| Once every **three months**? (5)  |  |  |  |  |

Q31 **How concerned are you about each of the following things about this new way of taking your medication?**

 *(Please mark one box in each row.)*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Not at all concerned (1) | A little concerned (2) | Somewhat concerned (3) | Very concerned (4) |
| Possibility of side effects (rash, upset stomach) (1)  |  |  |  |  |
| Might have to have 2 injections at once (2)  |  |  |  |  |
| Might cause skin swelling or pain at the place where the shot was (3)  |  |  |  |  |
| Side effects might last longer than side effects from a pill (4)  |  |  |  |  |

Q32 We are working to make a new way of taking another new kind of anti-HIV medication. Instead of taking pills every day, you would get a small plastic "implant" inserted surgically under the skin in your arm that would slowly release drug into your body. This would mean you would not have to take any pills.

 **If this new way of taking your medication was available as an option for you, *how likely* would you be to try this method?**

* Definitely **would** try it (1)
* Probably **would** try it (2)
* Probably **would not** try it (3)
* Definitely **would not** try it (4)

Q33 **How concerned are you about each of the following things about this new way of taking your medication?**

 *(Please mark one box in each row.)*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Not at all concerned (1) | A little concerned (2) | Somewhat concerned (3) | Very concerned (4) |
| Possibility of side effects (rash, upset stomach) (1)  |  |  |  |  |
| The medicine might not work to treat my HIV (2)  |  |  |  |  |
| Might cause skin swelling or pain at the site of the implant (3)  |  |  |  |  |
| Side effects might last longer than side effects from a pill. (4)  |  |  |  |  |

Q34 **Do you have any other thoughts or concerns about these new ways of taking your medications that you would like to share with us? What else do you need to know, to decide whether this new (injection or implant) way of taking medicine would work for you? Don't worry about spelling; just write down everything you can think of:**

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Q35
**You're Done!
Thank you so much! We really, really appreciate your time and thoughts!!**

End of Block: Default Question Block

**Appendix II: Supplementary Tables**

**Table 1b. Baseline characteristics stratified by Site**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **Emory****n (%)** | **Johns Hopkins****n (%)** | **St. Jude****n (%)** | **Total****N** | **P-value†** |
| **Mode of Transmission** |  |  |  |  | **0.01** |
|  Perinatally | 34 (25.6%) | 26 (39.4%) | 19 (18.3%) |  |  |
|  Non-perinatal | 99 (74.4%) | 40 (60.6%) | 85 (81.7%) |  |  |
| **Viral Load** |  |  |  | 289 | 0.06 |
|  Undetectable | 79 (60.3%) | 38 (60.3%) | 68 (71.6%) |  |  |
|  Low Detectable | 11 (8.4%) | 8 (12.7%) | 13 (13.7%) |  |  |
|  High Detectable | 41 (31.3%) | 17 (27.0%) | 14 (14.7%) |  |  |
| **Age in years** (Mean (SD) | 21.05 (2.28) | 20.80 (2.91) | 19.77 (2.42) | 296 | **<0.001** |
| **Age Category** |  |  |  | 296 | <0.001 |
|  13-16 years | 7 (5.5%) | 8 (12.1%) | 11 (10.8%) |  |  |
|  17-20 years | 36 (28.1%) | 12 (18.2%) | 50 (49.0%) |  |  |
|  21-24 years | 85 (66.4%) | 46 (69.7%) | 41 (40.2%) |  |  |
| **Gender** |  |  |  | 303 | **0.04** |
|  Male | 104 (78.2%) | 39 (59.1%) | 68 (65.4%) |  |  |
|  Female | 28 (21.1%) | 24 (36.4%) | 32 (30.8%) |  |  |
|  Transgender M-F | 1 (0.8%) | 3 (4.5%) | 4 (3.8%) |  |  |
| **Race** |  |  |  |  | 0.76 |
|  African-American or black | 114 (86.4%) | 56 (86.2%) | 92 (89.3%) | 300 |  |
|  Non-African-American | 18 (13.6%) | 9 (13.8%) | 11 (10.7%) |  |  |
| **Hispanic or Latino** |  |  |  |  | 0.86 |
|  No | 121 (91.7%) | 61 (93.8%) | 96 (92.3%) | 301 |  |
|  Yes | 11 (8.3%) | 4 (6.2%) | 8 (7.7%) |  |  |
| **Missed Pills** |  |  |  | 303 | 0.060 |
|  Never missed | 39 (29.3%) | 20 (30.3%) | 45 (43.3%) |  |  |
|  Ever missed | 94 (70.7%) | 46 (69.7%) | 59 (56.7%) |  |  |
| **Currently on HIV Drug** |  |  |  | 303 | **0.02** |
|  No | 11 (8.3%) | 2 (3.0%) | 1 (1.0%) |  |  |
|  Yes | 122 (91.7%) | 64 (97.0%) | 103 (99.0%) |  |  |
| **Marijuana Use** |  |  |  | 302 | 0.03 |
|  Never Used | 35 (26.5%) | 15 (22.7%) | 41 (39.4%) |  |  |
|  Ever Used | 97 (73.5%) | 51 (77.3%) | 63 (60.6%) |  |  |
| **Cocaine Use** |  |  |  | 292 | 0.09 |
|  Never Used | 104 (83.9%) | 59 (90.8%) | 97 (94.2%) |  |  |
|  Past 6 months | 9 (7.3%) | 1 (1.5%) | 3 (2.9%) |  |  |
|  Not in the past 6 months | 11 (8.9%) | 5 (7.7%) | 3 (2.9%) |  |  |

†P-values based on Chi-square test

**Table 1c. Baseline characteristics stratified by viral load**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **Undetectable n (%)** | **Low Detectable****n (%)** | **High Detectable****n (%)** | **Total****N** | **P-value†** |
| **Mode of Transmission** |  |  |  | 303 | 0.69 |
|  Perinatally | 53 (28.6%) | 8 (25.0%) | 17 (23.6%) |  |  |
|  Non-perinatal | 132 (71.4%) | 24 (75.0%) | 55 (76.4%) |  |  |
| **Clinic** |  |  |  | 303 | 0.06 |
|  Emory | 79 (42.7%) | 11 (34.4%) | 41 (56.9%) |  |  |
|  Johns Hopkins | 38 (20.5%) | 8 (25.0%) | 17 (23.6%) |  |  |
|  St. Jude | 68 (36.8%) | 13 (40.6%) | 14 (19.4%) |  |  |
| **Age Category** |  |  |  | 296 | 0.09 |
|  13-16 years | 19 (10.4%) | 3 (10.0%) | 2 (2.8%) |  |  |
|  17-20 years | 62 (33.9%) | 13 (43.3%) | 19 (26.8%) |  |  |
|  21-24 years | 102 (55.7%) | 14 (46.7%) | 50 (70.4%) |  |  |
| **Gender** |  |  |  | 303 | 0.69 |
|  Male | 126 (68.1%) | 21 (65.6%) | 54 (75.0%) |  |  |
|  Female | 56 (30.3%) | 10 (31.3%) | 16 (22.2%) |  |  |
|  Transgender M-F | 3 (1.6%) | 1 (3.1%) | 2 (2.8%) |  |  |
| **Race** |  |  |  | 300 | 0.32 |
|  African-American or black | 160 (87.9%) | 30 (93.8%) | 60 (83.3%) |  |  |
|  Non-African-American | 22 (12.1%) | 2 (6.3%) | 12 (16.7%) |  |  |
| **Hispanic or Latino** |  |  |  | 301 | 0.44 |
|  No | 168 (91.3%) | 31 (96.9%) | 67 (94.4%) |  |  |
|  Yes | 16 (8.7%) | 1 (3.1%) | 4 (5.6%) |  |  |
| **Missed Pills** |  |  |  | 303 | 0.42 |
|  Never missed | 67 (36.2%) | 10 (31.3%) | 20 (27.8%) |  |  |
|  Ever missed | 118 (63.8%) | 22 (68.8%) | 52 (72.2%) |  |  |
| **Currently on HIV Drug** |  |  |  | 303 | **<0.001** |
|  No | 4 (2.2%) | 0 (0.0%) | 10 (13.9%) |  |  |
|  Yes | 181 (97.8%) | 32 (100.0%) | 62 (86.1%) |  |  |
| **Alcohol Use** |  |  |  | 295 | 0.27 |
|  Never Used | 59 (32.8%) | 13 (41.9%) | 16 (22.9%) |  |  |
|  Past 6 months | 99 (55.0%) | 15 (48.4%) | 41 (58.6%) |  |  |
|  Not in the past 6 months | 22 (12.2%) | 3 (9.7%) | 13 (18.6%) |  |  |
| **Marijuana Use** |  |  |  | 302 | **0.005** |
|  Never Used | 60 (32.4%) | 14 (43.8%) | 11 (15.5%) |  |  |
|  Ever Used | 125 (67.6%) | 18 (56.3%) | 60 (84.5%) |  |  |

†P-values based on Chi-square test

**Table 3: Female participants’ willingness to try IM and implantable LAARV based on past experience with contraceptive technologies**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Interest Level High** | **Never LARC** | **Ever LARC** | **P-value\*** | **Never Depo** | **Ever Depo** | **P-value\*** |
| **IM LAARV** | 85.5%(59/69) | 100% (14/14) | **0.002** | 87.9% (29/33) | 88% (44/50) | 0.987 |
| **SD Implant LAARV** | 78.3% (54/69) | 92.9% (13/14) | 0.081 | 81.8% (27/33) | 80% (40/50) | 0.837 |

\*Poisson with robust variance; the impact of future willingness to use Long-Acting Reversible Contraception (LARC) or Depo on willingness to use subdermal (SD) or intramuscular (IM) Long-Acting Antiretrovirals (LAARV) was also tested and was not significant.

**Figure 2: Youth concerns about LAARV**

**a. Intramuscular Injection**

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**b. Subdermal Implant**

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