

Form Approved

OMB No. 0920-New

Expiration Date: XX/XX/XXXX

## **Cooperative Re-Engagement Controlled Trial (CoRECT)**

### **Attachment #5**

#### **Massachusetts Barriers to Care Survey**

Public reporting burden of this collection of information is estimated to average 30 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; Attn: OMB-PRA (0920-New)

## Appendix 5: Massachusetts Barriers to Care Survey

### Informed Consent

I am \_\_\_\_\_ and I work here at:

OR

I am \_\_\_\_\_ and I work for the Massachusetts Department of Public Health

We would like you to be in a research study being done by the Massachusetts Department of Public Health, your health care providers and the Centers for Disease Control and Prevention (CDC). This study is to help us learn whether services offered by the health department and health care providers can help people to get in, and stay in, medical care for their HIV infection. We would like to ask you about the things that may keep you from going to the clinic for your HIV infection, as well as the things that might help you get care.

As part of this study, some people have been offered extra services that we do not ordinarily offer. The people who were offered extra services were chosen randomly. In order to see if these extra services helped to improve people's health, we would also like your consent to collect and use information about your medical care and coordination of that care to better understand how we can assist people in getting health care. This will include information that is routinely collected, as well as information about your medical visits. The visit information we will collect will be about the timing and costs of your medical visits. You may choose not to have this information collected and used. The information we collect in the questions you answer and for your medical visits will be kept with the information that the Department of Public Health routinely and confidentially keeps. All of this information will be stored in a secured database, with access limited to authorized individuals.

If you agree to be in the study, I will ask you a series of questions. This should take less than 30 minutes. The questions we will be asking may be personal. You may choose not to answer any questions, if you feel uncomfortable. We will interview you only this once, but will be collecting information about your medical visits for up to one year.

There are no direct medical benefits to you by participating in this research, but the results from this study may help us to provide better services to patients in the future. You may also benefit from the direct assistance provided as part of this study, but otherwise this study will not directly affect your medical care. You may be uncomfortable with some of the questions we ask. The time it takes to ask you questions and to record your answers may keep you at your clinic visit longer than expected.

We understand that participating in this survey takes time and may be inconvenient. To compensate you for the inconvenience, we are offering you a CVS gift card/certificate for the amount of \$25. Should you agree to take the survey, you will receive this compensation immediately upon agreement and may keep the gift card/certificate, even if you cannot complete the survey.

All of the information you give us and that we collect will be kept private and protected to the full extent of the law. This [Massachusetts Department of Public Health has a Federal Certificate of Confidentiality](#). This means we cannot be forced to give out any information such as medical information, survey information, or other information that can identify you. The information collected from you today as part of this interview will be destroyed within 12 months after you are interviewed. After your information is destroyed, there will be no way to link you personally to your interview. All information shared with the CDC will be shared without any information that will allow them to know who you are.

You can agree to be interviewed or not, or agree to allow us to collect information about your care or not. If you decide not to agree to either or both, you will not lose any services or medical care at the clinic. If you do agree, you may refuse to answer any question or simply not talk about a matter that you do not wish to discuss. In that case too, you will not lose any services or medical care at the clinic. We will not let you be a part of the study if you are not able to give consent to be in the study. You may take away your consent at any time.

The collection of information on care and care coordination that is part of this study may continue for up to one year.

There is no cost to you for being in this study.

If you have any questions about this research study, you may contact Alfred DeMaria, M.D. at 617-983-6550. If you have any questions about your rights as a research participant, you may contact the Massachusetts Department of Public Health IRB at 617-624-5621.

Do you have any questions about this study or the information I provided?

**Checked box indicates that the statement has been read to the participant, all of the participant's questions have been answered, and the participant verbally agrees to be interviewed and to participate in the study, except with the following conditions:**

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People can have many different types of problems getting their HIV care. Think of the reasons why you may not have gotten the HIV care you needed or that was recommended for you. Please indicate "Yes" or "No" for all of the following reasons for why you may not have gotten necessary HIV care in the past 6 months (or 3 months for linkage to care patients).

1. I felt good/healthy

1Yes 2No 7Don't Know 8Decline 9Missing

2. My CD4 count and viral load are good	1Yes	2No	7Don't Know	8Decline	9Missing
3. I did not think I was HIV positive	1Yes	2No	7Don't Know	8Decline	9Missing
4. I didn't want to think about being HIV positive	1Yes	2No	7Don't Know	8Decline	9Missing
5. I did not know when to follow up with my healthcare provider	1Yes	2No	7Don't Know	8Decline	9Missing
6. I felt sick/ill	1Yes	2No	7Don't Know	8Decline	9Missing
7. Medication side effects	1Yes	2No	7Don't Know	8Decline	9Missing
8. I felt depressed/sad	1Yes	2No	7Don't Know	8Decline	9Missing
9. I didn't like the way that I was treated at the clinic in the past	1Yes	2No	7Don't Know	8Decline	9Missing
10. The clinic (hours, location, or wait-time) is inconvenient	1Yes	2No	7Don't Know	8Decline	9Missing
11. I did not want to be seen at the HIV clinic	1Yes	2No	7Don't Know	8Decline	9Missing
12. I do not trust doctors	1Yes	2No	7Don't Know	8Decline	9Missing
13. I did not know where to go for medical care	1Yes	2No	7Don't Know	8Decline	9Missing
14. I had problems getting through to someone in the clinic/office to make an appointment	1Yes	2No	7Don't Know	8Decline	9Missing
15. I couldn't get an appointment with the provider I like	1Yes	2No	7Don't Know	8Decline	9Missing
16. It took too long to get an appointment	1Yes	2No	7Don't Know	8Decline	9Missing
17. I had problems finding a provider who speaks my language	1Yes	2No	7Don't Know	8Decline	9Missing
18. I forgot about my appointment	1Yes	2No	7Don't Know	8Decline	9Missing
19. I had problems getting child care	1Yes	2No	7Don't Know	8Decline	9Missing
20. I didn't have health insurance	1Yes	2No	7Don't Know	8Decline	9Missing
21. I did not have enough money to pay my co-pay	1Yes	2No	7Don't Know	8Decline	9Missing

22. I was afraid it might cost too much	1Yes	2No	7Don't Know	8Decline	9Missing
23. I couldn't get the time off work or school	1Yes	2No	7Don't Know	8Decline	9Missing
24. I had other responsibilities	1Yes	2No	7Don't Know	8Decline	9Missing
25. I had problems getting transportation to my appointment	1Yes	2No	7Don't Know	8Decline	9Missing
26. I was too drunk or high	1Yes	2No	7Don't Know	8Decline	9Missing
27. There is no cure for HIV so I don't need to go to the doctor	1Yes	2No	7Don't Know	8Decline	9Missing
28. I didn't want to go to the doctor until I told my friends/family	1Yes	2No	7Don't Know	8Decline	9Missing
29. I don't need to go to the doctor because God will cure me	1Yes	2No	7Don't Know	8Decline	9Missing

**How much did the following help you in getting to the clinic today?**

30. Having someone make the appointment for me	4 A lot	3 Somewhat	2 A little	1 Not at all
31. Having someone talk to me about my health	4 A lot	3 Somewhat	2 A little	1 Not at all
32. Having someone talk to me about HIV	4 A lot	3 Somewhat	2 A little	1 Not at all
33. Having help in finding a doctor/clinic	4 A lot	3 Somewhat	2 A little	1 Not at all
34. A reminder about my appointment	4 A lot	3 Somewhat	2 A little	1 Not at all
35. Having someone come to my appointment with me	4 A lot	3 Somewhat	2 A little	1 Not at all
36. Getting help w/ transportation to my appointment	4 A lot	3 Somewhat	2 A little	1 Not at all
37. Getting help with child care	4 A lot	3 Somewhat	2 A little	1 Not at all
38. Getting help with drugs or alcohol	4 A lot	3 Somewhat	2 A little	1 Not at all
39. Getting help with housing	4 A lot	3 Somewhat	2 A little	1 Not at all
40. Having someone help me get health insurance	4 A lot	3 Somewhat	2 A little	1 Not at all
41. Other: _____	4 A lot	3 Somewhat	2 A little	1 Not at all

In this next section, I will list some services that you may have needed to help you get medical care. For each service, please indicate "Yes", "No", "Don't know", or decline to answer whether you

tried to access this service in the past 6 months (or within 3 months for linkage-to-care patients). If you needed the service, please indicate whether you were able to get the service when you wanted it.

	A. Did you need [Interviewer: insert service] during the past 6 months?	B. Were you able to get [Interviewer: insert service] during the past 6 months?
42. Counseling services. <i>These are services for when you need someone to talk to when you feel anxious, sad, down in the dumps, depressed or have emotional problem.</i>	<input type="checkbox"/> 1 Yes (Go to the box to the right) <input type="checkbox"/> 2 No (Skip to the box below) <input type="checkbox"/> 7 Don't know <input type="checkbox"/> 8 Decline <input type="checkbox"/> 9 Missing	<input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 0 No
43. Drug or alcohol treatment. <i>This includes treatment or counseling for drugs or alcohol.</i>	<input type="checkbox"/> 1 Yes (Go to the box to the right) <input type="checkbox"/> 2 No (Skip to the box below) <input type="checkbox"/> 7 Don't know <input type="checkbox"/> 8 Decline <input type="checkbox"/> 9 Missing	<input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 0 No
44. Housing services. <i>These are services to help you find a suitable place to live. These do not include financial assistance for paying your rent or mortgage.</i>	<input type="checkbox"/> 1 Yes (Go to the box to the right) <input type="checkbox"/> 2 No (Skip to the box below) <input type="checkbox"/> 7 Don't know <input type="checkbox"/> 8 Decline <input type="checkbox"/> 9 Missing	<input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 0 No
45. Emergency financial assistance. <i>These are emergency services to help you pay for things like</i>	<input type="checkbox"/> 1 Yes (Go to the box to the right)	<input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 Sometimes

<p><i>utilities (electricity, heating oil, natural gas), housing (rent or mortgage payment), and medications, when other resources are not available.</i></p>	<p><input type="checkbox"/> 2 No (Skip to the box below)</p> <p><input type="checkbox"/> 7 Don't know</p> <p><input type="checkbox"/> 8 Decline</p> <p><input type="checkbox"/> 9 Missing</p>	<p><input type="checkbox"/> 0 No</p>
<p>46. Employment assistance. <i>These are services to help you find a job or get work.</i></p>	<p><input type="checkbox"/> 1 Yes (Go to the box to the right)</p> <p><input type="checkbox"/> 2 No (Skip to the box below)</p> <p><input type="checkbox"/> 7 Don't know</p> <p><input type="checkbox"/> 8 Decline</p> <p><input type="checkbox"/> 9 Missing</p>	<p><input type="checkbox"/> 1 Yes</p> <p><input type="checkbox"/> 2 Sometimes</p> <p><input type="checkbox"/> 0 No</p>
<p>47. Transportation. <i>These are transportation services provided directly to you or through a voucher to help you get to HIV medical appointments or go to HIV-related health services such as case management.</i></p>	<p><input type="checkbox"/> 1 Yes (Go to the box to the right)</p> <p><input type="checkbox"/> 2 No (Skip to the box below)</p> <p><input type="checkbox"/> 7 Don't know</p> <p><input type="checkbox"/> 8 Decline</p> <p><input type="checkbox"/> 9 Missing</p>	<p><input type="checkbox"/> 1 Yes</p> <p><input type="checkbox"/> 2 Sometimes</p> <p><input type="checkbox"/> 0 No</p>
<p>48. Help with getting groceries, meals. <i>This includes things like food vouchers or food stamps, food pantry packages, or pantry bags, meals delivered to your home.</i></p>	<p><input type="checkbox"/> 1 Yes (Go to the box to the right)</p> <p><input type="checkbox"/> 2 No (Skip to the box below)</p> <p><input type="checkbox"/> 7 Don't know</p> <p><input type="checkbox"/> 8 Decline</p> <p><input type="checkbox"/> 9 Missing</p>	<p><input type="checkbox"/> 1 Yes</p> <p><input type="checkbox"/> 2 Sometimes</p> <p><input type="checkbox"/> 0 No</p>
<p>49. Help with getting benefits. <i>This includes help qualifying for things like health insurance (Medicaid, Medicare, or private insurance), Ryan White services, social security, welfare or</i></p>	<p><input type="checkbox"/> 1 Yes (Go to the box to the right)</p> <p><input type="checkbox"/> 2 No (Skip to the box below)</p> <p><input type="checkbox"/> 7 Don't know</p>	<p><input type="checkbox"/> 1 Yes</p> <p><input type="checkbox"/> 2 Sometimes</p> <p><input type="checkbox"/> 0 No</p>



<i>unemployment.</i>	<input type="checkbox"/> 8 Decline <input type="checkbox"/> 9 Missing	
50. Other: _____	<input type="checkbox"/> 1 Yes (Go to the box to the right) <input type="checkbox"/> 2 No (Skip to the box below) <input type="checkbox"/> 7 Don't know <input type="checkbox"/> 8 Decline <input type="checkbox"/> 9 Missing	<input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 Sometimes <input type="checkbox"/> 0 No

***The next 3 questions are about where you have stayed or lived in the past 6 months.***

51. In the past 6 months, at how many different places have you lived?

- 1  1      2  2      3  3 or more      7  Don't know      8  Decline      9  Missing

52. Where are you currently staying or living?

- 1  In my own home or apartment  
2  In someone else's (friend, relative, etc.) home or apartment  
3  In a shelter, motel or other temporary housing  
4  In a residential program/group home  
5  On the street or in my car  
6  Some other type of living arrangement (e.g., multiple people's homes/moving from

house to house)

***The following questions are about recent drug or alcohol use. I would like to remind you that your responses will be kept confidential. You may decline to answer any item***

53. In the past 30 days, have you used the following drugs?

a. Crack (rock, gravel):

- 1  Yes    2  No    7  Don't know    8  Decline    9  Missing

b. Powder cocaine (snort, blow):

- 1  Yes    2  No    7  Don't know    8  Decline    9  Missing

c. Heroin, not injected (horse, smack, tar)

- 1  Yes    2  No    7  Don't know    8  Decline    9  Missing

d. Methamphetamines (meth, crystal meth, speed, crank, ice)

1  Yes    2  No    7  Don't know    8  Decline    9  Missing

e. Marijuana or hashish (pot, weed)

1  Yes    2  No    7  Don't know    8  Decline    9  Missing

f. Party drugs (Ecstasy, Special K, GBH)

1  Yes    2  No    7  Don't know    8  Decline    9  Missing

g. Prescription painkillers without a prescription (ex. Codeine Morphine, Demerol, Darvon, Oxycontin, Vicodin, Dilaudid))

1  Yes    2  No    7  Don't know    8  Decline    9  Missing

54. In the past 30 days, have you injected drugs (e.g. injected heroin or cocaine)?

1  Yes    2  No    7  Don't know    8  Decline    9  Missing

55. In the past 30 days, have you had 5 or more alcoholic drinks (beer, wine, or hard liquor) in 1 day?

1  Yes    2  No    7  Don't know    8  Decline    9  Missing