

2009 CONSUMER FOCUS GROUP DEMOGRAPHIC & ASSESSMENT OF SERVICES SURVEY

Thank you for participating in the 2009 Consumer Focus Group Project. The New York City Department of Health and Mental Hygiene administers Ryan White Part A funding, federal funds used to provide HIV services to the community. The New York City Department of Health and Mental Hygiene is interested in hearing from consumers of Ryan White Part A services regarding the utility, priority, impact, accessibility, and quality of Ryan White Part A funded HIV care, treatment, or housing services. You have been asked to participate in this project because you are the recipient of services at a Ryan White Part A funded HIV care, treatment, or housing agency.

Please tell us a little about yourself...

1) What is your date of birth (mm/dd/yyyy)? _____

2) What is your zipcode? _ _ _ _ _

3) Where do you live? (please check one)

- Manhattan
- Brooklyn
- Bronx
- Queens
- Staten Island
- Westchester County
- Rockland County
- Putnam County
- New Jersey
- Some other neighborhood or county (please specify: _____)

4) What was your sex assignment at birth? (please check one)

- Male
- Female
- Intersex (both male and female)

5) What is your primary gender identity today? (please check one)

- Male/Man
- Female/Woman
- Transgender Male to Female
- Transgender Female to Male
- Transsexual Male to Female
- Transsexual Female to Male

6) What is your ethnicity? (please check one)

- Not Hispanic/Latino(a)
- Hispanic/Latino(a)

7) What is your race? (check all that apply)

- African American/Black
- White/Caucasian
- Asian
- Native Hawaiian/Pacific Islander
- Native American/Alaskan Native
- Some other race (please specify: _____)

8) What is your current HIV/AIDS status? (please check one)

- Current AIDS diagnosis
- Living with HIV - no current AIDS diagnosis

9) How long (in months) have you been receiving Ryan White funded HIV care, treatment, or housing services? (1 year = 12 months, 4 weeks = 1 month) _____ months.

10) Are you a member of a Consumer Advisory Board (CAB) or Consumer Advisory Group (CAG) at an HIV service agency? (please check one)

- Yes
- No

For the next few questions, we would like you to think about the average person living with HIV/AIDS in New York (rather than yourself) and how important or useful each service is for them to be able to access HIV primary care services. When we say important for accessing HIV primary care, we mean how much the particular service would help a person to get connected to a medical care provider for HIV related blood work and medications or other HIV related medical visits.

The federal agency, Health Resources and Services Administration (HRSA), responsible for Ryan White services, defines the list of service types below as “Core” services, and defines another list of service types as “Support” services. We will deal with the “Core” services first and the “Support” services next.

11) For each of the Core Services listed, please tell us how *important* or *useful* this service is for the average person living with HIV/AIDS in New York to access HIV primary care. **Please check one option per category to show whether you think the service is Not Very Important, Somewhat Important, or Essential for enabling the average person living with HIV/AIDS in New York to access HIV primary care.** If applicable, please indicate when you “don’t have an opinion” or “have an opinion, but based solely on personal experience,” using the separate check boxes to the right of each category. Please see example below.

Check only if response applies to your answer

Core Service Category	Not Very Important	Somewhat Important	Essential
Example: Oral Health Care	✓		
Example: Home Health Care			✓

I don't have an opinion

I have an opinion, but based solely on personal experience

Access to HIV Primary Care (Core Services)

Check only if response applies to your answer

Core Service Category	Not Very Important	Somewhat Important	Essential
Outpatient /Ambulatory Health Services (services from your doctor in an outpatient setting like a clinic or medical office)			
AIDS Drug Assistance Program (ADAP) Treatments (assistance with medications for people with limited or no medical insurance)			
AIDS Pharmaceutical Assistance (local) (local pharmacy assistance with medications)			

I don't have an opinion

I have an opinion, but based solely on personal experience

Check only if response applies to your answer

Access to HIV Primary Care (Core Services) continued...

Core Service Category	Not Very Important	Somewhat Important	Essential
Oral Health Care (dental care)			
Early Intervention Services (HIV testing & counseling)			
Health Insurance Premium & Cost Sharing Assistance (financial assistance in form of premium payments, co-pays)			
Home Health Care (medical services in the home offered by licensed health care worker)			
Home and Community-based Health Services (home health aides)			
Hospice Services (end of life care in a residential setting)			
Mental Health Services (psychological and psychiatric treatment and counseling)			
Medical Nutrition Therapy (nutrition services provided by a dietician)			
Medical Case Management (including Treatment Adherence) (coordination of medical care)			
Outpatient Substance Abuse Services (substance abuse services provided in an outpatient setting)			

I don't have an opinion

I have an opinion, but based solely on personal experience

12) On the chart above (pages 3 and 4), please circle the **three (3) most important** Core Services for the average person with HIV/AIDS in New York to access HIV primary care. Please see below for an example.

Check only if response applies to your answer

Core Service Category	Not Very Important	Somewhat Important	Essential
Example: Oral Health Care	✓		
Example: Home Health Care			✓

I don't have an opinion

I have an opinion, but based solely on personal experience

Again, for these questions, we would like you to think about the average person living with HIV/AIDS in New York (rather than yourself) and how important or useful each service is for them to be able to access HIV primary care services. When we say important for accessing HIV primary care, we mean how much the particular service would help a person to get connected to a medical care provider for HIV related blood work and medications or other HIV related medical visits. This time, we will ask about the service types defined as Ryan White “Support” services.

13) For each of the Support Services listed, please tell us how *important* or *useful* this service is for the average person living with HIV/AIDS in New York to access HIV primary care. **Please check one option per category to show whether you think the service is Not Very Important, Somewhat Important, or Essential for enabling the average person living with HIV/AIDS in New York to access HIV primary care.** If applicable, please indicate when you “don’t have an opinion” or “have an opinion, but based solely on personal experience,” using the separate check boxes to the right of each category. Please see example below.

Check only if response applies to your answer

Support Service Category	Not Very Important	Somewhat Important	Essential
Example: Child Care Services			✓
Example: Outreach Services			

I don't have an opinion	I have an opinion, but based solely on personal experience
<input type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Check only if response applies to your answer

Access to HIV Primary Care (Support Services)

Support Service Category	Not Very Important	Somewhat Important	Essential
Non-medical Case Management (support in obtaining services like legal and financial assistance)			
Child Care Services (child care services while at treatment related appointments)			
Emergency Financial Assistance (emergency assistance for short term expenses like a utility bill)			
Food Bank/Home-Delivered Meals (actual food or meals)			
Health Education/Risk Reduction (HIV transmission education)			

I don't have an opinion	I have an opinion, but based solely on personal experience
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Check only if response applies to your answer

Access to HIV Primary Care (Support Services) continued...

Support Service Category	Not Very Important	Somewhat Important	Essential
Housing Services <i>(temporary or transitional housing assistance)</i>			
Legal Services <i>(power of attorney, DNR orders)</i>			
Linguistics Services <i>(translation services)</i>			
Medical Transportation Services <i>(pick-up service or voucher for transportation)</i>			
Outreach Services <i>(finding people with unknown HIV status or to connect people to HIV services)</i>			
Psychosocial Support Services <i>(support groups)</i>			
Referral for Health Care/Supportive Services <i>(connecting client to services in person or by calling)</i>			
Rehabilitation Services <i>(physical or occupational therapy, low-vision training)</i>			
Respite Care <i>(relief to the primary caregiver of client living with HIV/AIDS)</i>			
Residential Substance Abuse Services <i>(substance abuse treatment in a residential setting)</i>			
Treatment Adherence Counseling <i>(counseling by non-medical professionals to ensure adherence to treatment regimen)</i>			

I don't have an opinion I have an opinion, but based solely on personal experience

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

14) On the chart above (pages 5 and 6), please *circle* the **three (3) most important** Support Services for the average person with HIV/AIDS in New York to *access* HIV primary care. Please see below for an example.

Check only if response applies to your answer

Support Service Category	Not Very Important	Somewhat Important	Essential
<i>Example: Child Care Services</i>			<input checked="" type="checkbox"/>
<i>Example: Outreach Services</i>			<input checked="" type="checkbox"/>

I don't have an opinion I have an opinion, but based solely on personal experience

<input type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

For the next questions, we would like you to think about the average person living with HIV/AIDS in New York (rather than yourself) and how important or useful each service is for them to be able to remain HIV primary care services. When we say important for remaining in HIV primary care, we mean how much the particular service would help a person to continue to go to their provider for HIV related blood work and medications or other HIV related medical visits. We will start with the “Core” services and then ask about the “Support” services.

15) For each of the Core Services listed, please tell us how *important* or *useful* this service is for *the average person living with HIV/AIDS* in New York to *remain in HIV primary care*. **Please check one option per category to show whether you think the service is Not Very Important, Somewhat Important, or Essential for enabling the average person living with HIV/AIDS in New York to remain in HIV primary care.** *If applicable*, please indicate when you “don’t have an opinion” or “have an opinion, but based solely on personal experience,” using the separate check boxes to the right of each category. Please see example below.

Check only if response applies to your answer

Core Service Category	Not Very Important	Somewhat Important	Essential
<i>Example: Oral Health Care</i>			✓
<i>Example: Home Health Care</i>	✓		

I don’t have an opinion	I have an opinion, but based solely on personal experience
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Remaining in HIV Primary Care (Core Services)

Check only if response applies to your answer

Core Service Category	Not Very Important	Somewhat Important	Essential
Outpatient /Ambulatory Health Services (<i>services from your doctor in an outpatient setting like a clinic or medical office</i>)			
AIDS Drug Assistance Program (ADAP) Treatments (<i>NY State assistance for medications for people with limited or no medical insurance</i>)			
AIDS Pharmaceutical Assistance (local) (<i>local pharmacy assistance with medications</i>)			

I don’t have an opinion	I have an opinion, but based solely on personal experience
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Check only if response applies to your answer

Remaining in HIV Primary Care (Core Services) continued...

Core Service Category	Not Very Important	Somewhat Important	Essential	I don't have an opinion	I have an opinion, but based solely on personal experience
Oral Health Care (dental care)				<input type="checkbox"/>	<input type="checkbox"/>
Early Intervention Services (HIV testing & counseling)				<input type="checkbox"/>	<input type="checkbox"/>
Health Insurance Premium & Cost Sharing Assistance (financial assistance in form of premium payments, co-pays)				<input type="checkbox"/>	<input type="checkbox"/>
Home Health Care (medical services in the home offered by licensed health care worker)				<input type="checkbox"/>	<input type="checkbox"/>
Home and Community-based Health Services (home health aides)				<input type="checkbox"/>	<input type="checkbox"/>
Hospice Services (end of life care in a residential setting)				<input type="checkbox"/>	<input type="checkbox"/>
Mental Health Services (psychological and psychiatric treatment and counseling)				<input type="checkbox"/>	<input type="checkbox"/>
Medical Nutrition Therapy (nutrition services provided by a dietician)				<input type="checkbox"/>	<input type="checkbox"/>
Medical Case Management (including Treatment Adherence) (coordination of medical care)				<input type="checkbox"/>	<input type="checkbox"/>
Outpatient Substance Abuse Services (substance abuse services provided in an outpatient setting)				<input type="checkbox"/>	<input type="checkbox"/>

16) On the chart above (pages 7 and 8), please *circle* the **three (3) most important** Core Services for the average person with HIV/AIDS in New York to *remain in* HIV primary care. Please see below for an example.

Check only if response applies to your answer

Core Service Category	Not Very Important	Somewhat Important	Essential	I don't have an opinion	I have an opinion, but based solely on personal experience
<i>Example: Oral Health Care</i>			✓	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<i>Example: Home Health Care</i>	✓			<input type="checkbox"/>	<input type="checkbox"/>

For these questions, we would like you to keep thinking about the average person living with HIV/AIDS in New York (rather than yourself) and how important or useful each service is for them to be able to remain in HIV primary care services. When we say important for remaining in HIV primary care, we mean how much the particular service would help a person to continue to go to their provider for HIV related blood work and medications or other related medical visits. This time, we will ask about the service types defined as Ryan White “Support” services.

17) For each of the Support Services listed, please tell us how *important* or *useful* this service is for the average person living with HIV/AIDS in New York to remain in HIV primary care. **Please check one option per category to show whether you think the service is Not Very Important, Somewhat Important, or Essential for enabling the average person living with HIV/AIDS in New York to remain in HIV primary care.** If applicable, please indicate when you “don’t have an opinion” or “have an opinion, but based solely on personal experience,” using the separate check boxes to the right of each category. Please see example below.

Check only if response applies to your answer

Support Service Category	Not Very Important	Somewhat Important	Essential
<i>Example: Child Care Services</i>			✓
<i>Example: Outreach Services</i>		✓	

I don't have an opinion	I have an opinion, but based solely on personal experience
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>

Remaining in HIV Primary Care (Support Services)

Check only if response applies to your answer

Support Service Category	Not Very Important	Somewhat Important	Essential
Non-medical Case Management (<i>support in obtaining services like legal and financial assistance</i>)			
Child Care Services (<i>child care services while at treatment related appointments</i>)			
Emergency Financial Assistance (<i>emergency assistance for short term expenses like a utility bill</i>)			
Food Bank/Home-Delivered Meals (<i>actual food or meals</i>)			
Health Education/Risk Reduction (<i>HIV transmission education</i>)			

I don't have an opinion	I have an opinion, but based solely on personal experience
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Check only if response applies to your answer

Remaining in HIV Primary Care (Support Services) continued...

Support Service Category	Not Very Important	Somewhat Important	Essential	I don't have an opinion	I have an opinion, but based solely on personal experience
Housing Services <i>(temporary or transitional housing assistance)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Legal Services <i>(power of attorney, DNR orders)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Linguistics Services <i>(translation services)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Medical Transportation Services <i>(pick-up service or voucher for transportation)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Outreach Services <i>(finding people with unknown HIV status or to connect people to HIV services)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Psychosocial Support Services <i>(support groups)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Referral for Health Care/Supportive Services <i>(connecting client to services in person or by calling)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Rehabilitation Services <i>(physical or occupational therapy, low-vision training)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Respite Care <i>(relief to the primary caregiver of client living with HIV/AIDS)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Residential Substance Abuse Services <i>(substance abuse treatment in a residential setting)</i>				<input type="checkbox"/>	<input type="checkbox"/>
Treatment Adherence Counseling <i>(counseling by non-medical professionals to ensure adherence to treatment regimen)</i>				<input type="checkbox"/>	<input type="checkbox"/>

18) On the chart above (pages 9 and 10), please *circle the three (3) most important* Support Services for the average person with HIV/AIDS in New York to *remain in* HIV primary care. Please see below for an example.

Check only if response applies to your answer

Support Service Category	Not Very Important	Somewhat Important	Essential	I don't have an opinion	I have an opinion, but based solely on personal experience
<i>Example: Child Care Services</i>			✓	<input type="checkbox"/>	<input type="checkbox"/>
<i>Example: Outreach Services</i>		✓		<input type="checkbox"/>	<input checked="" type="checkbox"/>

Finally, we would like to hear about your own experience (rather than the average person living with HIV/AIDS in New York). The last questions are about your levels of satisfaction with the Core and Support HIV related care services you have received in New York. We will start with the Core services and then ask about Support services.

19) From ***your own*** experience with the following Core services, please indicate if you are *Not Very Satisfied, Somewhat Satisfied, Very Satisfied, or N/A (did not use this service)* for each service category. Please see example below.

Core Service Category	Not Very Satisfied	Somewhat Satisfied	Very Satisfied	N/A (didn't use this service)
<i>Example: Oral Health Care</i>			✓	
<i>Example: Home Health Care</i>				✓

Satisfaction (Core Services)

Core Service Category	Not Very Satisfied	Somewhat Satisfied	Very Satisfied	N/A (didn't use this service)
Outpatient /Ambulatory Health Services (e.g. services from your doctor in an outpatient setting like a clinic or medical office)				
AIDS Drug Assistance Program (ADAP) Treatments (e.g. NY State assistance for medications for people with limited or no medical insurance)				
AIDS Pharmaceutical Assistance (local) (e.g. local pharmacy assistance with medications)				
Oral Health Care (e.g. dental care)				
Early Intervention Services (e.g. HIV testing & counseling)				
Health Insurance Premium & Cost Sharing Assistance (e.g. assistance to ensure consistent health insurances coverage)				
Home Health Care (e.g. services such as intravenous and aerosolized treatment provided in the home by licensed health care workers)				

Satisfaction (Core Services) continued...

Core Service Category	Not Very Satisfied	Somewhat Satisfied	Very Satisfied	N/A (didn't use this service)
Home and Community-based Health Services (e.g. home health aides)				
Hospice Services (nursing home or hospice services for terminal clients)				
Mental Health Services (e.g. mental health services provided to those with a diagnosed mental illness)				
Medical Nutrition Therapy (services provided by a dietitian outside of a primary care visit)				
Medical Case Management (including Treatment Adherence) (e.g. coordination of medical care)				
Outpatient Substance Abuse Services (substance abuse services provided in an outpatient setting)				

20) On the chart above (pages 11 and 12), please circle the top three (3) Core services *you* are most satisfied with. Please see below for an example.

Core Service Category	Not Very Satisfied	Somewhat Satisfied	Very Satisfied	N/A (didn't use this service)
<i>Example: Oral Health Care</i>			✓	
<i>Example: Home Health Care</i>				✓

This last question is about your own levels of satisfaction with HIV related Support services you have received in New York.

21) From ***your own*** experience with the following Support services, please indicate if you are *Not Very Satisfied, Somewhat Satisfied, Very Satisfied, or N/A (did not use this service)* for each service category. Please see example below.

Support Service Category	Not Very Satisfied	Somewhat Satisfied	Very Satisfied	N/A (didn't use this service)
<i>Example: Child Care Services</i>	✓			
<i>Example: Outreach Services</i>			✓	

Satisfaction (Support Services)

Support Service Category	Not Very Satisfied	Somewhat Satisfied	Very Satisfied	N/A (didn't use this service)
Non-medical Case Management (e.g. support in obtaining non medical services like legal assistance)				
Child Care Services (e.g. child care services while at treatment related appointments)				
Emergency Financial Assistance (emergency assistance for short term expenses like a utility bill)				
Food Bank/Home-Delivered Meals (e.g. food or vouchers to purchase food)				
Health Education/Risk Reduction (e.g. HIV transmission education)				
Housing Services (e.g. temporary or transitional housing assistance)				
Legal Services (e.g. power of attorney, discrimination litigation)				
Linguistics Services (e.g. translation services)				
Medical Transportation Services (e.g. pick-up service or voucher for transportation)				
Outreach Services (e.g. service to identify people with unknown HIV status or to connect people to HIV services)				

Satisfaction (Support Services) continued...

Support Service Category	Not Very Satisfied	Somewhat Satisfied	Very Satisfied	N/A (didn't use this service)
Psychosocial Support Services (e.g. support groups)				
Referral for Health Care/Supportive Services (e.g. connecting client to services by calling or writing a letter)				
Rehabilitation Services (e.g. physical or occupational therapy, low-vision training)				
Respite Care (e.g. services to relieve the primary care giver of client living with HIV/AIDS)				
Residential Substance Abuse Services (substance abuse treatment in a residential setting)				
Treatment Adherence Counseling (counseling by non-medical professionals to ensure adherence to treatment regimen)				

22) On the chart above (pages 13 and 14), please circle the top three (3) Support services *you* are most satisfied with. Please see below for an example.

Support Service Category	Not Very Satisfied	Somewhat Satisfied	Very Satisfied	N/A (didn't use this service)
Example: Child Care Services	✓			
Example: Outreach Services			○ ✓	

Thank you so much for your time. The focus group will begin shortly.