

**Economic Analysis of the Ryan White Part A Program
A Progress Report**

Prepared for the New York City Department of Health and Mental Health
Bureau of HIV Prevention and Control
Care, Treatment, and Housing Program

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This is the second progress report under the contract between the New York City Department of Health and Mental Hygiene's HIV Care, Treatment, and Housing Program (CTHP) and the Research Foundation of the State University of New York. This report includes the assessment of existing data sources included in the previous report, along with a new section that presents the results of two focus groups with Ryan White contract agency staff.

Project goal: The goal of this project is to develop a methodology for an economic analysis of the Ryan White HIV/AIDS program as administered by CTHP for 9 million people in the New York eligible metropolitan area. To provide a comprehensive care system with a wide array of elements and services, CTHP has over 250 contracts with more than 150 separate agencies. CTHP seeks to identify a methodology that will allow it to make the best use of its limited resources by spending on services that will provide the greatest benefit for its clientele.

Models of economic evaluation: Standard microeconomic costing techniques estimate the cost of programs and compare them with alternative programs or methods for producing comparable benefits. For example, one of the objectives in the most recent Comprehensive Strategic Plan for HIV/AIDS Services is "to decrease visits to emergency departments (ED) by 2011." One way to evaluate the cost-effectiveness of efforts to reach this objective would be to compare the cost of reducing the number of ED visits per 1000 among Ryan White program clients with the cost of reducing ED visits per 1000 among persons with HIV/AIDS who are not receiving Ryan White services. One barrier to such an analysis is the lack of systematic information about patients with HIV/AIDS who are not receiving Ryan White funded services. Without data that would allow for comparisons between patients receiving Ryan White funded services and those who are either not receiving services or receiving services funded by some other program, it is difficult to make claims about the relative cost-effectiveness of the program.

Despite this limitation, it is still possible to conduct an economic evaluation of these services with existing data.

We plan to develop a cost benefit analysis (CBA) methodology that will weigh the costs of Ryan White Part A funded services against their benefits. A hallmark of CBA is that all benefits and all costs are expressed in money terms, and are adjusted for the time value of money, so that all flows of benefits and flows of project costs over time (which tend to occur at different points in time) are expressed on a common basis in terms of their “present value.”

Spending vs. costs: We are developing a methodology that will allow DOHMH to assess whether returns on *spending* are worth the investments in Ryan White Part A services. Although spending is obviously related to the actual costs of providing services, our methodology does not depend on an assessment of the reimbursement rates to contractors or the actual costs of providing these services. In 2005, American Express Tax and Business Services Inc. (TBS) performed a unit-costing analysis that: defined the units of services by the contracting organizations; measured the volume of services provided by the contracting organizations; calculated the global, as well as individual organizational costs by unit of service, for all service types; determined the global and individual contract payments per unit of service for all service types and developed tools to re-run the cost analysis with revised service and volume data. Although these are important questions, they are only indirectly related to the purpose of this project. We are developing a methodology that allows the DOHMH to compare spending on Ryan White Part A services with the economic value associated with the benefits these services produce. If, based on a unit-cost analysis, the department adjusts how much it pays for specific services, this would change the *results* of a cost-benefit and/or cost-effectiveness analysis

(because the payment for services would either increase or decrease as a result), but it would not change the *method* for conducting an economic analysis.

The challenge of measuring benefits: While the amount of money spent by the DOHMH to secure these services is easier to determine in this model, the benefit side is more difficult to determine. During the month of January, we conducted two focus groups with contract agency staff to better understand the benefits associated with Ryan White Part A services. A summary of these conversations and their implications for conducting an economic evaluation of Ryan White Part A services is included in this report. The final report will also address the question of how to place a monetary value of the outcomes that can be measured. This discussion will include our assessment of whether it is possible to place an economic value on broader goals and objectives that are often ignored by economic evaluations. For example, Goal 4 in the *Comprehensive Strategic Plan* is to “Reduce HIV/AIDS health disparities.” Listed under this goal are three objectives: “Objective 4A: To reduce (and then maintain below significance) sociodemographic differences in delayed diagnosis of HIV, by 2012; Objective 4B: To reduce (and then maintain below significance) sociodemographic differences in prompt linkage to HIV/AIDS care following HIV diagnosis, by 2011; Objective 4C: To reduce (and then maintain below significance) sociodemographic differences in retention in primary medical care, by 2011.” Within the limitations that we describe below, it is possible to measure progress on each of these objectives with existing data, but the monetary value of achieving reductions in disparities is less clear. We will provide suggestions for how to conduct such an analysis

Outline of the report: We begin with a review of existing data sources. In particular, we assess whether existing data would allow researchers to estimate the effects of Ryan White services on the outcomes listed in the *Comprehensive Strategic Plan* and the *Ryan White Part A*

Implementation Plan. Next we present the findings from the contract agency focus groups. Finally, we present a brief summary and identify next steps.

Expected Benefits of Ryan White Part A

A requirement of the methodology we hope to develop is the ability to identify and measure the benefits associated with the program. We use, as a starting point for discussing the benefits of the Ryan White Part A program, the *2009-2012 Comprehensive Strategic Plan for HIV/AIDS Services* and the *Ryan White Part A Implementation Plan*. The *Comprehensive Strategic Plan* identifies several goals and objectives for 2009-2012 (see Appendix). The goals include: 1) increasing the number of individuals who are aware of their HIV status; 2) promoting early entry into and continuity of HIV care; 3) Promoting optimal management of HIV infection; 4) reducing HIV/AIDS health disparities; and 5) ensuring that the EMA has a robust plan for the cost-efficient delivery of quality Part A services. The *Implementation Plan* lists 12 service priorities with goals, objectives, outcomes and indicators for each service priority area. In the next section, we review the degree to which existing data sources can be used to monitor these goals, objectives, outcomes and indicators.

Estimating QALYs produced by Ryan White Part A: As the preceding discussion indicates, for several of the services provided under Ryan White Part A, the *Implementation Plan* suggests CD4 counts as an outcome measure. In addition to being an important clinical outcome measure that provides information about the progress of HIV, CD4 counts are useful for conducting an economic evaluation because there is a relationship between CD4 count and Quality Adjusted Life Years (QALYs). It is also possible to calculate QALYs with survey data that include age, gender, race/ethnicity, education level, and health status.

QALYs are a widely used measure of health status that attempt to capture quality, as well as length, of life. A QALY is a measure of that combines information about mortality and illness. Each year lived in perfect health is assigned a value of 1.0 and death is assigned a value of 0. Researchers then use data from surveys to weight of quality of life for different states of ill health. If a person has a permanent condition, the weight established for that state of health (established by health surveys) is multiplied by the time spent in that state.¹ If, however, a person suffers from a temporary state of ill health followed by a return to full health, the quality-adjustment weight is multiplied by the time in the state. “As a result, an intervention that generates four additional years in a health state valued at 0.75 will generate one more QALY than an intervention that generates four additional years in a health state valued at 0.5.”¹

QALYs have been critiqued, however, on a number of ethical grounds. For example, critics argue that QALYs are biased against persons with disabilities because the measure suggests that their lives are worth less than the lives of persons without these conditions. The application of QALYs in policy has also been criticized for focusing on the maximization of total QALYs “without consideration of their distribution.”² For example, it may be possible to increase the total number of QALYs in a population even though some groups within that population are not doing very well. If an economic analysis focuses exclusively on maximizing QALYs, it may ignore health disparities.

Although imperfect, QALYs are useful because, unlike life expectancy or mortality rates, they attempt to incorporate morbidity and they are used frequently in economic evaluations of health care interventions. Cost-effectiveness analyses compare the relative efficiency of two or

¹ The Panel on Cost-Effectiveness in Health Medicine (PCEHM), organized by the US Public Health Service, recommended establishing a national catalogue of preference weights that could be used by cost-effectiveness researchers. The catalogue, which was completed in 2006, was built from a sample that represents the U.S. population. Standard QALY values can be accessed at: <http://www.ohsu.edu/epc/mdm/calculator.htm>.

more interventions by comparing the price of producing a QALY. Cost-benefit analyses specify the economic value of a QALY and recommend adoption of interventions if their cost is below this cut-off point.³ Several previous examinations of the cost-effectiveness of HIV/AIDS prevention and treatment used cost per QALY. In these studies, QALYs were estimated from CD4 counts.⁴ An economic evaluation of Ryan White Part A services could first examine the relationship between these services and CD4 count using the AIDS Institute Reporting System (AIRS) and/or the Community Health Advisory & Information Network (CHAIN) study, and use this to estimate the relationship between services and QALYs. QALYs are only one way to assess the benefits associated Ryan White Part A services and should not substitute for other benefits that we may identify in our subsequent analysis. Nevertheless, it is useful to assess the program using this measure as part of a more comprehensive economic analysis.

Data sources

The at least four potential sources of information that could be used as part of an economic evaluation of Ryan White Part A services: New York City HIV/AIDS Surveillance statistics; AIRS; the CHAIN study; Service Category Scorecards prepared by the Analysis and Reporting Unit of HIV Care Services, a program of Public Health Solutions; and the 2009 Consumer Focus Groups conducted by the Care, Treatment and Housing Program. In this section, we review the features of each dataset and discuss their strengths and limitations.

NEW YORK CITY HIV/AIDS ANNUAL SURVEILLANCE STATISTICS: New York City collects data on the number of reported HIV/AIDS diagnoses, persons living with HIV/AIDS and deaths among persons living with HIV/AIDS, by age, gender, ethnicity, race, transmission risk and neighborhood of residence. This database does not provide any information

about Ryan White funded services, but it may be possible to use these data to conduct an aggregate analysis of spending on HIV/AIDS. This approach would be consistent with some recent economic evaluations of national health spending in Europe and the U.S.

During the past decade, a number of studies investigating the relationship between health and wealth examined the relationship between health spending at the national level and measures of economic growth. For example, three studies that use health expenditures as a share of GDP as proxies for health find a statistically significant impact of health expenditures on economic growth and on income levels.⁵ Beraldo and colleagues found that spending on health explained a larger share (between 16 and 27 %) of economic growth rates than expenditures on education (around 3 %). Similarly, McKee and colleagues compared the economic value of changes “avoidable mortality,” a measure that captures deaths before the age of 75 due to conditions for which there are effective medical treatments with changes in expenditure on healthcare (e.g. breast cancer, colon cancer)⁶ to changes in health care expenditures in several European countries (France, Italy, Spain, Sweden, and the UK). They find returns to health expenditures between about 50 and 270 percent. Furthermore, they argue that their study may underestimate the returns on health spending because they consider only reductions in avoidable mortality, but do not measure improvements in quality of life.⁷

To conduct an equivalent analysis, researchers could compare changes in the economic value of health improvements (reductions in the number of persons diagnosed with and/or dying from HIV/AIDS) measured by the epidemiological data with total expenditures on Ryan White Part A services.

One obvious limitation to this approach is the inability, using these data alone, to establish a causal relationship between spending on HIV/AIDS and the health outcomes

measured in this dataset. It is even difficult to establish more than a tenuous correlation between Ryan White Part A spending and these measures of health because the dataset does not identify individuals by program. Decreases in number of people with HIV/AIDS or CD4 levels may be correlated positively with Ryan White Part A funding -- and the economic value of these outcomes may exceed Ryan White Part A expenditures -- but it would be risky to draw any conclusions about the economic value of these services based on this analysis.

AIDS INSTITUTE REPORTING SYSTEM (AIRS): AIRS is the data collection system used by all Ryan White Part A contractors and some prevention contractors. It provides information about: 1) patient demographics; 2) various outcomes (viral load...etc.) that are identified in the *Comprehensive Strategic Plan*; 3) services received by clients and; 4) some information about where and when they received these services.

In theory AIRS should permit comparisons on outcomes by periods of continuous enrollment, but the ability to link multiple years of AIRS data is limited because the client identifiers in the database are unstable. As a result, the department is only able to analyze outcomes associated with individual services among individuals enrolled during a given program year. They are not, however, able to analyze the possibility of lagged effects. For example, if a person receives supportive counseling and family stabilization services, the indirect health benefits of such services may not be measurable for several years. If the database is unable to track unique clients over time, it is impossible to capture these longer term benefits. If any Ryan White Part A services produce longer term benefits for clients, this would bias the results of an economic evaluation because the analysis would include all of the costs associated with such services, but it would not include the benefits that accrue after the year in which the services were provided.

For the same reasons, it is also difficult to use the AIRS system to identify all of the services received by a unique individual. They are working to improve the database so that they will be able to identify the impact of specific combinations of services, but to date, they have focused on reporting outcomes by HRSA service category. Until the database is improved, it is not possible to investigate potential interactions among services. By using AIRS, it is possible to examine the correlation between individual service categories and a host of outcomes, controlling for some cofounders (age, gender), but estimating the effect of services on outcomes is limited. The value of core medical service may be enhanced when people also receive supportive services, such as housing or medical transportation, but if researchers are unable to identify all of the services a unique individual is receiving, it is not possible to capture these important interactions.

The AIRS system is able to provide some information about the organization that delivered each service. If clients are referred for non-Ryan White funded services, the information about these services and the organizations that provide them are limited.

Despite its current limitations, the AIRS database would allow us to estimate the cost per person associated with producing the outcomes specified in the Comprehensive Strategic Plan and the Implementation Plan. Even without conducting longitudinal analysis by linking individual level data over time, it will be possible to estimate the relative efficiency of Ryan White Part A services over time. Using the formula in the existing literature, it will also be possible to estimate the QALYs associated with each Ryan White Part A service category.

CHAIN: CHAIN is New York Eligible Metropolitan Area's longitudinal survey of HIV-positive individuals. It was started in 1994 by researchers at Columbia University's Joseph L. Mailman School of Public Health. It includes five waves of data on a cohort recruited in 2002.

The CHAIN survey includes data on: (1) need for health and social services, (2) access, utilization and satisfaction with health and social services, (3) sociodemographic characteristics, (4) housing and other aspects of living situation; (5) sex and drug risk behaviors; (6) informal caregiving from friends, family and volunteers, and (7) their quality of life with respect to health status and psychological and social functioning. In more recent years, the survey has also included questions about the use of antiretroviral therapies, specific medical care services, and viral load levels, among others.⁸ As we suggest above, these variables are sufficient to generate QALY estimates for the persons included in the CHAIN survey, so this database would allow researchers to calculate an aggregate measure of health status that is used commonly in economic evaluations.

The CHAIN database allows us to overcome some of the limitations associated with AIRS, but introduces others. Because CHAIN is a survey of people receiving HIV/AIDS services, it provides information about all of the services that an individual receives, so it should be possible to examine the relationship among these services and how this may affect outcomes.

Unfortunately, CHAIN is not restricted to Ryan White Part A clients. The target population of the survey is the same population served by the Ryan White Part A program, and it is also possible to identify the individuals in the survey that are likely to be in the program by reviewing the services they are receiving. Although CHAIN allows researchers to estimate the effects of particular services on health outcomes, the ability of researchers to use these data to comment specifically on the impact of the Ryan White program is limited.

Another limitation of CHAIN is that it does not provide any information about the sites delivering services. In addition to identifying the aggregate economic return on spending for Ryan White Part A services, it would be useful to know whether it is more cost effective to

provide services in particular settings. Do hospitals deliver certain services more cost-effectively than community-based organizations or vice versa? CHAIN does not allow researchers to address these questions.

Like AIRS, it should be possible to conduct longitudinal analysis with the CHAIN data. Some longitudinal analysis using CHAIN is currently being conducted by researchers at Columbia. If these efforts are successful, it may be possible to examine lagged relationships between services (or combinations of services) and outcomes. CHAIN also includes questions about CD4, so these data can be used to estimate QALYs -- and the relationship between services and QALYs.

NYC RYAN WHITE PART A SERVICE CATEGORY SCORECARDS 2006-2008:

The scorecard reports created by Public Health Solutions for DOHMH provide a summary of the NYC Eligible Metropolitan Area (EMA) level service categories. They provide information about the funds and services provided to the HIV population and the demographics of clients who received services. Based on feedback from the Needs Assessment Committee of the Planning Council, the Scorecards include data on various populations that the Committee felt was several underserved in NYC: young men who have sex with men (MSM) of color, lesbian, gay, bisexual and transgender (LGBT) individuals, women of color and young women of color, immigrants, and individuals over age 50.

These scorecards are useful for providing information about spending for each category of Ryan White Part A services. Because the scorecards provide information about the number of clients served by category for each year between 2006 and 2008, it is possible to conduct an analysis of the cost per client served during this time period. It is not possible, with these data, to

link particular services, or combinations of services, to outcomes. Nor is it possible to compare the cost per clients served among contractors.

2009 CONSUMER FOCUS GROUPS: This study is based on 12 two hour focus groups with 125 HIV-related consumers from 38 different agencies in New York City. Before each focus group, the participants were asked to complete an individual survey in which they were asked how important or useful each Ryan White fundable service is to the average person living with HIV in New York for: 1) accessing HIV primary care and 2) remaining in HIV primary care. The survey also captured information about their satisfaction with each core and supportive service they had used in New York. The subsequent focus group conversations identified three major domains of factors that are perceived to influence access to and maintenance in HIV-related primary care: Consumer-centered factors; systemic factors; and specific services & elements of service delivery.

Although the study is based on a small sample, it provides useful qualitative data for confirming the importance of services from the perspectives of clients. These findings can be used in conjunction with a quantitative analysis using the AIRS and/or CHAIN data to identify the benefits associated with each Ryan White fundable service. It is also useful for explaining the value of services for which it is difficult to identify a measurable outcome. For example, clients identified the process of “coming to terms” with their diagnosis and “taking control” of their health as important factors. It seems plausible that counseling services funded by Ryan White help clients with this process of “becoming a patient,” but this could not be measured with existing data. Several insights from the consumer focus groups were echoed during our conversations with contract agency staff. In particular, the contract agency staff emphasized the importance of developing a relationship with their clients. According the contract agency staff,

these relationships are important for helping clients “come to terms” with their HIV status and for linking clients to services that will help them “take control” of their lives and their health.

2010 CONTRACT AGENCY FOCUS GROUPS: We conducted two, two- hour focus groups with nine contract agency staff. Two of the participants worked for community based organizations without co-located medical facilities; two worked for community based organizations with co-located medical facilities; one person worked for a Federally Qualified Health Center (FQHC); and four worked for hospital-based programs. Five of the respondents have worked in an organization that provides HIV services for more than 10 years; four have worked in an organization that provides HIV services for 5-10 years.

The focus group protocol and survey were adapted from the material developed by DOHMH for the 2009 consumer focus groups. We eliminated questions from the 2009 protocol and survey related to the personal experiences of clients with Ryan White services. For the focus group protocol, we added questions about contractor perceptions about: 1) the interactions among services; 2) other benefits, beyond facilitating access to care, associated with Ryan White services; and 3) how to best to measure the benefits associated with Ryan White services. The 2009 consumer focus group guide (Appendix 2), the 2010 contractor focus group guide (Appendix 3), the 2010 contract agency staff survey instrument (Appendix 4) and the 2010 contract agency staff survey initial results (Appendix 5) are attached as appendices to this report.

Importance of Ryan White Part A services: The staff had a difficult time ranking Ryan White services. The relative importance of each service, they argued, depends a great deal on the specific needs of the client. For example, one participant explained that her clients’ needs were shaped by their role as parent. As she put it, “[my] clients [are] dealing with needs of children as well as themselves, so navigating housing and other services important. They need to deal with

issues of children and other factors that affect their ability to take care of themselves -- parenting and disclosure of illness, relationship advice and relationship counseling.”

Despite the reluctance to “rank” services, all of the participants agreed that both medical and non-medical case management is essential for their clients. These services help to connect people with medical care and remain in medical care. The first connection most people have after learning about their HIV status is with a case manager. The relationship they establish with this person is important. The case manager is able to assess the needs of their client and translate the crisis at door into actual services – medical, housing, food and a host of other needs.

Mental health services and the AIDS Drug Assistance Program (ADAP) were both identified as “essential” for accessing and/or remaining in HIV primary care by nearly all of the participants. Nevertheless, the participants thought it would be a mistake to focus on medical services and neglect supportive services. As one participant put it, “if you cannot provide support services, our clients can’t get through to the medical side.” Another explained that, “supportive services are essential to get patients to the medical side. Patients don’t have a relationship with the doctor [but] support services and the relationship clients establish with a case worker or social worker is helpful and supports medical piece.”

A special challenge identified by the participants in our focus groups is the need for coordinating the work of different case managers working in different settings. Clients often establish a relationship with their initial case manager, but they must work with a different case manager every time they go to a new organization for a different service. This can become confusing for the patients and the case managers. One participant argued that this was an important reason for the so-location of services. At the same time, some participants suggested that hospitals are not conducive to support services because they are too big and bureaucratic.

This suggests that the effectiveness with which Ryan White Part A services are provided could depend on the location of services.

Housing and legal were also identified as important because, for those who need them, they address a crisis. Housing, in particular, was identified as an essential service for accessing and remaining in HIV primary care.

During the group discussions, the participants emphasized the value of support groups. These are extraordinarily popular, especially when they include snacks. The issue of snacks and other food came up frequently. The ability of agencies to provide hot food and a food pantry are crucial and, during the recent recession, contractors have noticed an increase in the number of people using food pantry services. Some people, they claim, are now bringing families in to receive food. A number of contractors complained that budget cuts made it difficult for them to provide snacks during support group meetings. This is a problem because limiting the ability of organizations to attract people into support groups could translate into a more limited ability to link people with medical and other services they need. These comments point to the need to evaluate services for different subsets of Ryan White Part A clients. Services that may not appear to be cost effective in the aggregate may be for subsets of the population.

Despite the value placed on supportive services by the contractors with whom we met, they claim they have been forced to reduce the availability of these services. One person said that, “the planning council reduced funding for supportive services from 50% of our budget to 25%, so things had to be cut...People value complementary services and alternative medicine, and they make people’s lives better, but the drugs are more important.”

Measurement and reporting: The focus group participants categorized existing measurement activities as “counting units and getting paid.” They argued that it would be better

to identify a range of outcome measures that they could track, at the individual level, over time. They identified a number of outcomes that they would like to track over time. These include: whether clients visit doctors regularly; adherence to treatment; and substance use. Each of the participants expressed frustration over how to find a more effective way to use data that is already gathered. One focus group participant argued that, “we need to get 5 items on housing, 5 on viral load, five on something else—so we know something about progress of patients.” They also indicated that it would be helpful if DOHMH could provide summaries of the data they collect from Ryan White contractors. A few people during our second focus group suggested that it might be helpful to see the outcomes for their agency in contrast to other agencies providing the same services. Although they recognized that these comparisons could be misleading without some form of “risk adjustment,” they still thought it would be useful to review them.

The participants also emphasized the importance of time frame when estimating the impact of these services on outcomes. Several participants claimed that the relationship between services and outcomes could only be understood through a longitudinal analysis. As one person explained, “a medical model -- diagnose, treat, discharge --is inappropriate for the care of HIV patients. Because clients progress at different levels, it is important to look at trends to understand the overall impact of the program.”

The primary care status measures that are currently reported to DOHMH are important, but these measures do not capture the social programs that keep people connected to care. According to the focus group participants, their clients face instabilities in life that can undermine everything, but it is difficult to capture how these things affect the use of medical care or the primary care indicators. Problems with housing, substance abuse, and relationships, among others, often have a profound impact on the health of their clients and their ability and willingness to

seek HIV primary care. There is a complex process that occurs before they get primary care status measure. The relationships that are built between clients and case manager are important. The connection with staff members is what determines if clients are going to get into the system.

All of the focus group participants told us that their organizations hold monthly case conferences during which they review what is happening with each client. The participants claimed that their understanding of the relationships among services was enhanced by the conversations that take place during these case conferences. They find these narratives invaluable for understanding client needs and assessing the value of services, but they were not certain these could be quantified for the purposes of reporting. Capturing positive changes in a patient's life can be important. If people are in bad shape, small improvements can mean a lot, so it is important to use qualitative measures that capture these subtle changes.

Beyond figuring out how to capture information from case conferences, the participants were very concerned about the burden this might impose on their agencies. They were unanimous in their opposition to the development of new reporting requirements. The contractors all believe that they are already asked to measure too much and do not have the resources to generate additional reports.

Summary

To conduct an economic evaluation of Ryan White Part A services, it is crucial to first estimate the benefits of these services. For our initial assessment, we focused narrowly on the clinical outcomes specified in the *Comprehensive Strategic Plan and Implementation Plan*. The primary sources of information are limited because it is difficult to conduct longitudinal analysis and difficult to examine the relationship among different services. One of the major sources of

data is not limited to Ryan White Part A clients. The 2009 focus groups with clients and the 2010 focus groups with contract staff reinforce the significance of these limitations and suggest that findings from existing data must be interpreted cautiously.

The focus groups highlight a number of services that provide essential, but indirect benefits. It is difficult to assess their value unless we have the capacity to look at whole individuals over time, particularly since one of the goals of Ryan White is to help people remain in HIV primary care. Developing a database with more reliable unique patient identifiers that will allow DOHMH to conduct longitudinal analysis and examine potential interactions among service categories is an important longer-term goal. Until such a database is constructed, however, it is possible to produce initial estimates and develop a reasonable strategy for conducting an economic evaluation of these services. Together, the existing sources of data can be used to estimate costs per QALY associated with each service and all of the Ryan White Part A services in the aggregate. It may also be possible to conduct a cost-effectiveness analysis in which we compare costs per QALY over time. We will present our recommendations for how to do so in our final report.

Appendix 1: Comprehensive Strategic Plan Goals

To advance further toward the EMA's vision of an ideal HIV/AIDS care system, the comprehensive plan sets forth the following goals and objectives for 2009-2012.

Goal 1: Increase the number of individuals who are aware of their HIV status.

Objective 1A: To increase the number of individuals receiving voluntary HIV rapid testing across health care and social support service provider settings, by 2010.

Objective 1B: To decrease delayed diagnosis of HIV, by 2012.

Goal 2: Promote early entry into and continuity of HIV care.

Objective 2A: To increase the number of newly diagnosed individuals who enter into primary care within three months of HIV diagnosis, by 2011.

Objective 2B: To increase retention in HIV care and treatment, by 2011.

Objective 2C: To decrease visits to emergency departments (ED) 4, by 2011.

Goal 3: Promote optimal management of HIV infection.

Objective 3A: To improve medication adherence to a rate of 95%, by 2011.

Objective 3B: To increase viral suppression, by 2011.

Objective 3C: To improve immunological health (e.g., CD4 count) 5, by 2011.

Objective 3D: To decrease HIV-related hospitalizations⁶, of PLWHA by 2011.

Goal 4: Reduce HIV/AIDS health disparities.

Objective 4A: To reduce (and then maintain below significance) sociodemographic differences in delayed diagnosis of HIV, by 2012.

Objective 4B: To reduce (and then maintain below significance) sociodemographic differences in prompt linkage to HIV/AIDS care following HIV diagnosis, by 2011.

Objective 4C: To reduce (and then maintain below significance) sociodemographic differences in retention in primary medical care⁷, by 2011.

3 Non-retention (or "a gap") in primary care is defined in the text below in terms of a four-month or longer period without care. However, because a six-month standard (for minimum frequency of primary care) has also been recognized recently by both the NYC DOHMH and the NYS DOH, retention-in-care analyses will also be run using the standard of one visit at least every six months.

4 Where the data source (e.g., MMP or Medicaid) permits analyses by reason for visit, these indicators will also be monitored specifically with regard to HIV-related (vs. all-type) ED visits.

5 In addition to examining immunological health in terms of stable or improving CD4 counts, the grantee will specifically look at those MCM clients and PLWHA overall whose CD4 counts remain >200 or improve to >200.

6 Where the data source (e.g., MMP or Medicaid) permits analyses by reason for hospital admission, these indicators will also be monitored specifically with regard to HIV-related (vs. all-type) hospitalizations.

11

7 Non-retention (or "a gap") in primary care is defined in the text below in terms of a four-month or longer period without care. However, because a six-month standard (for minimum frequency

of primary care) has also been recognized recently by both the NYC DOHMH and the NYS DOH, retention-related disparity analyses will also be run using the standard of one visit at least every six months.

Goal 5: Ensure that the EMA has a robust plan for the cost-efficient delivery of quality Part A services.

Objective 5A: To develop a set of criteria for planning and evaluating Part A services with regard to cost-efficiency and quality, by 2011.

Appendix 2

2009 DRAFT CONSUMER FOCUS GROUP GUIDE

(adapted from 2008 Consumer Focus Group guide and Planning Council Consumer Committee input)

Pre-focus group activities: participants will complete the quantitative survey and eat lunch/dinner.

Notes to facilitator: An examination of consumer perspectives on Health Resources and Services Administration (HRSA) Ryan White service categories represents an opportunity to assess and improve HIV/AIDS care, treatment, and housing services in the New York City (NYC) Eligible Metropolitan Area (EMA). The purpose of the focus group is to elicit consumer opinions regarding the utility, priority, impact, accessibility, and quality of Ryan White Part A services.

Food/Nutrition, Outreach Services, Home Care, and Housing Services will be re-bid shortly. NYCDOHMH is interested in consumer feedback on these services, in particular, since there is the opportunity to alter deliverables/service models for these categories.

Intro: Re-state purpose of the focus group, how/why these participants were invited, the understanding that participants speak from their personal experiences, the protection of privacy of participants, and the structure of the focus group interview guide and the similarities/differences between discussion groups and focus groups. Remind all present that the group is being audio-taped for transcription and later review/analysis of responses. The facilitators should define terms. For example, “services” refer here to Care, Treatment, and Housing services (funded under Ryan White Part A, formerly called Title I), and *discussion will be focused on New York City* or specific areas within New York City.

This is also a time to lay out some ground rules or expectations – for example, participants should:

1. Use their first name only or use a nickname/pseudonym if they feel at all uncomfortable using their first name and having it on tape;
2. Refer to other participants *without* mentioning names *or* using only the first names or nicknames those others have chosen to use for the group (rather than forgetfully calling out someone else’s real or full name);
3. Respect all other participants and allow everyone his/her own perspective and voice;
4. Respect the moderator if he/she says it is time for the group to move to the next question;
5. Be clear when they are speaking for anyone other than themselves (e.g., people they know or the larger NYC PLWHA population);
6. Ask questions whenever something is unclear.

Icebreaker: Go around the room and everyone state their first name (or what they would like to be called during the group) and their favorite type of candy.

Section 1: Assessment of Services on Relevance to HIV Primary Care Utilization and Consumer Needs

1. Thinking about the services you have used in New York City, how helpful/useful/ important is a particular service for you to *access* HIV-related primary care? Why?

Instructions: *Go through each service category. Identify the different criteria participants are using to determine usefulness or importance for access to care, draw out places where (and reasons why) participants see the actual service as delivered as different from the intent of that service category.*

Probing questions: *1) Which service categories were most important for you to access care? 2) What motivated you to seek out HIV medical care? 3) Were there any barriers for you to access HIV-related primary care? (If so, what got in the way?) 4) Are there any services that are not covered under Ryan White Part A that you think would better enable you to access HIV primary care?*

2. Thinking about the services you have used in New York City, how helpful/useful/ important is a particular service for you to *remain in* HIV-related primary care? Why?

Instructions: *Go through each service category. Identify the different criteria participants are using to determine usefulness or importance for retention in care, draw out places where (and reasons why) participants see the actual service as delivered as different from the intent of that service category.*

Probing questions: *1) Since you started care, what has been your biggest challenge in keeping it up? 2) What services have you needed or used to maintain your medical care regimen? 3) If you stopped going for HIV care in the past, what caused you to stop? 4) What helped you get re-connected to care? 5) Are there any services that are not covered under Ryan White Part A that you think would better enable you to stay connected to HIV primary care?*

3. Which services did you want to use in New York City but couldn't? Why?

Instructions: *Refer to the list of all services. Determine which services participants think are rarely available or hard to access. Determine if any services are becoming harder to get and why. If services are not accessed, but are needed, which of these gaps should be prioritized in the planning of Ryan White Part A spending? Determine which gaps may have more to do with accessibility or quality, and could be addressed in some other way (e.g., selection of funded contractors, quality improvement activities, provider training requirements or other requirements that the NYC DOHMH could set to make sure that services are delivered according to the levels and intent of their funding and according to specific standards of care).*

Probing questions: *1) Which services would you use if you had the opportunity? 2) Have you tried to access a particular service and been unable to use that service? Which ones? What happened? 3) What about HIV-related services that you do not see on this list – were there any that you wanted to use but couldn't find or couldn't access in New York? Why and which ones?*

4. How well do these Ryan White Part A services meet your needs?

Instructions: Go through each service category. Identify criteria for “meeting needs” and ways in which meeting needs overall may differ from serving primarily to increase access to or engagement in HIV-related primary care. Ask participants to clarify what they think of as “need,” and whether need is based on expected health outcomes/benefits of the service and their importance to survival, uniqueness of the service in addressing issues that are not addressed by other services, and/or client expectations for and interest in the service.]

Probing questions: 1) What is your biggest service need that has been met? 2) What is your biggest service need that has not been met? 3) Which services do you think have the most lasting effect on HIV-related care and health outcomes? Why?

Section 2: Satisfaction with and Quality of Part A (Title I) Services

Instructions: Facilitator to determine what participants think determines their satisfaction with care – what are the factors behind satisfaction or dissatisfaction? What are the providers doing right or wrong, or is it partly just in the nature of the service or the expectations surrounding it (e.g., meals are a generally positive experience, but dental visits are not)? What aspects of HIV services can be made more satisfying, or at least agreeable, to clients? How? Also, discuss what is affected **by** satisfaction with care (utilization, outcomes?), and how.

Are there opinions in the group as to where satisfaction should count more, and where it should count less (in planning for how to divide Ryan White funding between service types), or should it be weighed equally for all types of services? Where in particular (if it varies by service type) do participants think that increased satisfaction would cause consumers to use more of the services they need? Where in particular would increased client satisfaction improve the impact/outcomes of those services, not just through utilization rates (any examples?)?

Housing has been suggested repeatedly by NYC consumers as a key topic. Consider probing about HIV-related housing services, where they are failing, and how they could be improved.

1. What services in New York City are you most satisfied with? Why?

Probing questions: 1) What has been your best or most encouraging experience with HIV-related services? 2) Which services do you think have made the most positive impact on your HIV related care and health outcomes? Why?

2. What services in New York City are you least satisfied with? Why?

Probing questions: 1) What has been your most frustrating or disappointing experience with your HIV-related services? Why? 2) Does (dis)satisfaction sometimes have to do with an experience of stigma and/or providers (consciously or not) making you feel stigmatized? 3) Which services (in terms of how they were actually delivered) have made the most negative impact on your HIV related care and health outcomes? Why?

3. Are there other ways in which the quality of HIV-related services can be improved in New York City? How?

Probing questions: 1) What factors should be considered in judging the quality of a service? 2) Do you consider stigma to be a service quality issue? (If yes, how?) Is this true for some types of services or some types of providers more than for others?

Section 3: Geography and Specific Populations

1. In your experiences with seeking and using HIV-related services in New York, do you feel like you are treated differently because of some aspect of yourself (for example, being a member or being *seen* as a member of a particular group? Please describe your experience and how you explain it.

Instructions: Facilitator to determine if there are any specific populations that are underrepresented in the available/funded HIV related services.

Probing questions: 1) Do you represent a particular population or group that you think may not be getting adequate levels of service? 2) How can these gaps best be addressed? 3) What are the barriers to access that might remain even with increased funding targeting those under-served groups or populations?

2. What HIV services do you receive in your neighborhood? What HIV services are needed in your neighborhood? Why?

Instructions: Facilitator to determine if participants receive care in their neighborhood or if participants are unsatisfied with the services in their neighborhood and have to travel to receive adequate care. Do any participants indicate that they travel out of neighborhood for HIV services for other reasons (e.g., privacy and lower chance of running into neighbors/acquaintances)?

Probing questions: 1) What improvements are needed to improve services in your neighborhood? Why? 2) Are there any other factors that affect your ease or comfort in accessing services in your own neighborhood?

Section 4: Other Health Concerns (i.e., “It’s Not All Just About Living with HIV!”)

1. What is your most important health concern other than HIV?

Instructions: Consider mental health and emotional health as well as physical health. Consider social functioning as well as basic physical functioning.

Probing questions: 1) What are some of your other health related challenges? 2) Are the other health concerns related to the HIV in some way? How? 3) Do you think the other health concerns relate to other factors such as age or gender? 4) Are these other health concerns more serious or important to you at times, compared to the HIV?

2. How do you deal with that concern at the same time as managing your HIV?

Probing questions: 1) How do non-HIV conditions make it more or less difficult to cope with HIV? 2) Does care for these other conditions tend to get in the way of care for HIV, or vice-versa? 3) How do you prioritize these different needs and the different parts of your health care?

3. How satisfied are you with the medical care you are receiving for your other health concern(s)?

Probing questions: 1) What is/was your experience accessing care for other health concerns? 2) Do you have any challenges remaining in care for your other health concerns?

4. Do your health care providers work at coordinating the care for your different needs? If so, how?

Probing questions: 1) Do you have a health care provider who you are working with for other chronic or serious conditions aside from HIV? Is it the same provider as your HIV care provider? If it is a different provider, do you think your other health care provider and your HIV care provider coordinate your care in any way? How well is this working? 2) Are there communication gaps or other gaps? If so, where are the gaps?

Section 5: Participating in Improvement and Planning

1. When you have a concern about the delivery of HIV/AIDS care and supportive services in New York City, what do you think of as your options for making that concern known/heard (what actions do you think you could take)?

Probing questions: 1) Before now, have you ever made your voice heard about the delivery of HIV/AIDS care and support services? 2) What was that experience like? What happened as a result? Were there repercussions, or did you feel things changed for the better? 3) Would you do it again? If not (or for those participants who haven't taken such an action before), what would you think of doing now, in a situation where you had a problem with your services or with the larger picture of HIV services in New York City?

2. Have you ever had the experience of serving on a consumer advisory board ("CAB") or consumer advisory group ("CAG") of an HIV-services-providing agency in New York City?

Probing questions: 1) Can you talk about that experience? 2) Do you feel like you have been able to improve services at that agency, through your CAB /CAG participation? 3) Has your experience been disappointing or frustrating? Why? 4) How could CABs or CAGs work better in NYC?

3. What do you know about the HIV Health and Human Services Planning Council of New York (which we can call "the Planning Council" for short)? Is there anything in particular you would want the Planning Council to be doing to improve HIV services and care for you?

Probing questions: 1) Do you know about the Planning Council and its role in deciding priorities for Care, Treatment, and Housing (Ryan White Part A) service delivery? 2) What do

people think the Planning Council does now, and what do they think it should do, to ensure that PLWHA in NYC can get the kinds of care/services they need?

Conclusion

1. Are there other things you would like to discuss?

Instruction: *Facilitator to thank the participants for their thoughts and time, encourage people to take home any leftover food, etc.*

Appendix 3

2010 DRAFT CONTRACTOR FOCUS GROUP GUIDE

(adapted from 2009 Consumer Focus Group guide)

Pre-focus group activities: participants will complete the quantitative survey and eat lunch.

Self-Introductions and Warm up (15 minutes)

1. What is a focus group? What will be discussed this afternoon.
2. How focus groups work:
 - interested in your viewpoints, you represent other contractors who provide Ryan White Part A services who may have views just like you
 - research project, not selling anything, just want your perceptions
 - talk to each other, not just to us
 - no right or wrong answers, OK to differ, if your opinion is different we want to hear it
 - honest answers
 - everyone talks, no hand-raising
3. Recording, assurance of privacy
4. Role of the moderator:
 - put out issues/subject areas
 - facilitate the discussion, get everyone to talk to each other, hear from everyone
5. Develop Ground Rules
 - confidentiality
 - no talking more than 1 at a time
 - respecting everyone's viewpoint, etc.
6. Self-introductions/icebreaker: First person, tell us your name, and pick a word that describes something about you (e.g., funny, brave, strong, etc.). Next person has to tell us their name, their word, and the first person's word. Basically, last person introduces themselves and lists off everyone's words (group help completely encouraged!).

Section 1: Assessment of Services

1. Thinking about the services your organization provides in New York City, how helpful/useful/important is a particular service for your clients? Why?

Instructions: Go through each service category. Identify the different criteria participants are using to determine usefulness or importance for access to care, draw out places where (and

reasons why) participants see the actual service as delivered as different from the intent of that service category.

Probing questions: 1) Which Ryan White Part A services are most important for helping your clients access HIV care? 2) Beyond their impact on access to care, do these service categories provide additional benefits to your clients? 3) Are there any services that are not covered under Ryan White Part A that you think would better enable your clients to access HIV primary care?

Section 2: Satisfaction with and Quality of Part A (Title I) Services

Instructions: Facilitator to determine what participants think determines their client's satisfaction with care – what are the factors behind satisfaction or dissatisfaction? What are the providers doing right or wrong, or is it partly just in the nature of the service or the expectations surrounding it (e.g., meals are a generally positive experience, but dental visits are not)? What aspects of HIV services can be made more satisfying, or at least agreeable, to clients? How? Also, discuss what is affected **by** satisfaction with care (utilization, outcomes?), and how.

Are there opinions in the group as to where satisfaction should count more, and where it should count less (in planning for how to divide Ryan White funding between service types), or should it be weighed equally for all types of services? Where in particular (if it varies by service type) do participants think that increased satisfaction would cause consumers to use more of the services they need? Where in particular would increased client satisfaction improve the impact/outcomes of those services, not just through utilization rates (any examples?)?

Housing has been suggested repeatedly by NYC consumers as a key topic. Consider probing about HIV-related housing services, where they are failing, and how they could be improved.

1. What services in New York City are your clients most satisfied with? Why?

Probing question: 1) Which services do you think have made the most positive impact on HIV related care and health outcomes? Why?

2. What services in New York City are your clients least satisfied with? Why?

Probing question: 1) Does (dis)satisfaction sometimes have to do with an experience of stigma?

3. What factors should be considered in judging the quality of a service?

Probing question: 1) Do you consider stigma to be a service quality issue? (If yes, how?) Is this true for some types of services or some types of providers more than for others?

Section 3: The relationships among services

1. Are there important relationships among services that we should understand?

Probing questions: 1) *Is the value of a particular Ryan White Part A service ever dependent on the availability of another Ryan White Part A service?* 2) *Is the value of a Ryan White Part A service ever dependent on the availability of a non-Ryan White Part A service?*

Conclusion

1. Are there other things you would like to discuss?

Instruction: *Facilitator to thank the participants for their thoughts and time, encourage people to take home any leftover food, etc.*

2010 CONTRACTOR FOCUS GROUP DEMOGRAPHIC & ASSESSMENT OF SERVICES
SURVEY

Thank you for participating in the 2010 Contractor Focus Group Project. The New York City Department of Health and Mental Hygiene is interested in hearing from the organizations that provide Ryan White Part A services regarding value, priority, impact, and assessment of Ryan White Part A services.

Please tell us a little about yourself..

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

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

3) Do you identify yourself as man or as a woman?

- Man
- Woman

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

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

5) 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: _____)

10) How long (in months) have you been working for an organization that provides Ryan White funded HIV care, treatment, or housing services? (1 year = 12 months, 4 weeks = 1 month) _____ months.

For the next few questions, we would like you to think about the average person living with HIV/AIDS in New York 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” using the separate check box to the right of each category. Please see example below.**

Core Service Category	Not Very Important	Somewhat Important	Essential	<i>Check only if response applies to your answer</i>
<i>Example: Oral Health Care</i>	✓			I don't have an opinion <input type="checkbox"/>
<i>Example: Home Health Care</i>			✓	<input checked="" type="checkbox"/>

Access to HIV Primary Care (Core Services)

Core Service Category	Not Very Important	Somewhat Important	Essential	<i>Check only if response applies to your answer</i>
Outpatient /Ambulatory Health Services (<i>services from a doctor in an outpatient setting like a clinic or medical office</i>)				I don't have an opinion <input type="checkbox"/>
AIDS Drug Assistance Program (ADAP) Treatments (<i>assistance with</i>				<input type="checkbox"/>

<i>medications for people with limited or no medical insurance)</i>			
AIDS Pharmaceutical Assistance (local) (<i>local pharmacy assistance with medications</i>)			

Access to HIV Primary Care (Core Services) continued

Check only if response applies to your answer

I don't have an opinion

Core Service Category Not Very Important Somewhat Important Essential

Oral Health Care (<i>dental care</i>)			
Early Intervention Services (<i>HIV testing & counseling</i>)			
Health Insurance Premium & Cost Sharing Assistance (<i>financial assistance in form of premium payments, co-pays</i>)			
Home Health Care (<i>medical services in the home offered by licensed health care worker</i>)			
Home and Community-based Health Services (<i>home health aides</i>)			
Hospice Services (<i>end of life care in a residential setting</i>)			
Mental Health Services (<i>psychological and psychiatric treatment and counseling</i>)			
Medical Nutrition Therapy (<i>nutrition services provided</i>)			

<i>by a dietician)</i>			
Medical Case Management (including Treatment Adherence) <i>(coordination of medical care)</i>			
Outpatient Substance Abuse Services <i>(substance abuse services provided in an outpatient setting)</i>			

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

I don't have an opinion

Core Service Category Not Very Important Somewhat Important Essential

<i>Example: Oral Health Care</i>	✓		
<i>Example: Home Health Care</i>			✓

Again, for these questions, we would like you to think about the average person living with HIV/AIDS in New York 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" using the separate check boxes to the right of each category. Please see example below.

Check only if response applies to your answer

I don't have an opinion

Support Service Category Not Very Important Somewhat Important Essential

<i>Example: Child Care Services</i>			✓
<i>Example: Outreach Services</i>			

Check only if response applies to your answer

Access to HIV Primary Care (Support Services)

I don't have
an opinion

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>)			

Check only if response applies to your answer

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

I don't have
an opinion

Support Service Category Not Very Important Somewhat Important Essential

Housing Services (<i>temporary or transitional housing assistance</i>)				<input type="checkbox"/>
Legal Services (<i>power of attorney, DNR orders</i>)				<input type="checkbox"/>
Linguistics Services (<i>translation services</i>)				<input type="checkbox"/>
Medical Transportation Services (<i>pick-up service or voucher for transportation</i>)				<input type="checkbox"/>
Outreach Services (<i>finding people with unknown HIV status or to connect people to HIV services</i>)				<input type="checkbox"/>
Psychosocial Support Services (<i>support groups</i>)				<input type="checkbox"/>
Referral for Health Care/Supportive Services (<i>connecting client to services in person or by calling</i>)				<input type="checkbox"/>
Rehabilitation Services (<i>physical or occupational therapy, low-vision training</i>)				<input type="checkbox"/>
Respite Care (<i>relief to the primary caregiver of client living with HIV/AIDS</i>)				<input type="checkbox"/>

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>)			

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 don't have an opinion

<i>Example: Child Care Services</i>			✓	<input type="checkbox"/>
<i>Example: Outreach Services</i>				<input checked="" 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” using the separate check box 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 don't have an opinion

<i>Example: Oral Health Care</i>			✓
<i>Example: Home Health Care</i>	✓		



Check only if response applies to your answer

Remaining in HIV Primary Care (Core Services)

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

Outpatient /Ambulatory Health Services (<i>services from a doctor in an outpatient setting like a clinic or medical office</i>)				<input type="checkbox"/>
AIDS Drug Assistance Program (ADAP) Treatments (<i>NY State assistance for medications for people with limited or no medical insurance</i>)				<input type="checkbox"/>
AIDS Pharmaceutical Assistance (local) (<i>local pharmacy assistance with medications</i>)				<input type="checkbox"/>

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

Check only if response applies to your answer

Core Service Category Not Very Important Somewhat Important Essential

I don't have an opinion

Oral Health Care (<i>dental care</i>)				<input type="checkbox"/>
Early Intervention Services (<i>HIV testing & counseling</i>)				<input type="checkbox"/>

Health Insurance Premium & Cost Sharing Assistance <i>(financial assistance in form of premium payments, co-pays)</i>			
Home Health Care <i>(medical services in the home offered by licensed health care worker)</i>			
Home and Community-based Health Services <i>(home health aides)</i>			
Hospice Services <i>(end of life care in a residential setting)</i>			
Mental Health Services <i>(psychological and psychiatric treatment and counseling)</i>			
Medical Nutrition Therapy <i>(nutrition services provided by a dietician)</i>			
Medical Case Management (including Treatment Adherence) <i>(coordination of medical care)</i>			
Outpatient Substance Abuse Services <i>(substance abuse services provided in an outpatient setting)</i>			



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

I don't have an opinion

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

-
-

For these questions, we would like you to keep thinking about the average person living with HIV/AIDS in New York 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” using the separate check box 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 don’t have an opinion
<i>Example: Child Care Services</i>			✓	<input type="checkbox"/>
<i>Example: Outreach Services</i>		✓		<input checked="" type="checkbox"/>

Check only if response applies to your answer

Remaining in HIV Primary Care (Support Services)

Support Service Category	Not Very Important	Somewhat Important	Essential	I don’t have an opinion
Non-medical Case Management (<i>support in obtaining services like legal and financial assistance</i>)				<input type="checkbox"/>
Child Care Services (<i>child care services while at treatment related appointments</i>)				<input type="checkbox"/>
Emergency Financial Assistance (<i>emergency assistance for short term</i>)				<input type="checkbox"/>

<i>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>			



Check only if response applies to your answer

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

I don't have
an opinion

Support Service Category Not Very Important Somewhat Important Essential

Housing Services <i>(temporary or transitional housing assistance)</i>				<input type="checkbox"/>
Legal Services <i>(power of attorney, DNR orders)</i>				<input type="checkbox"/>
Linguistics Services <i>(translation services)</i>				<input type="checkbox"/>
Medical Transportation Services <i>(pick-up service or voucher for transportation)</i>				<input type="checkbox"/>
Outreach Services <i>(finding people with unknown HIV status or to connect people to HIV services)</i>				<input type="checkbox"/>
Psychosocial Support Services <i>(support groups)</i>				<input type="checkbox"/>
Referral for Health Care/Supportive Services <i>(connecting client to services in person or by calling)</i>				<input type="checkbox"/>
Rehabilitation Services <i>(physical or occupational therapy, low-vision training)</i>				<input type="checkbox"/>

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>)			

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>Example: Child Care Services</i>			✓
<i>Example: Outreach Services</i>		✓	

Appendix 5

2010 Contract Agency Survey: Initial Results

(Number of contract agency staff, out of 9, listing the service as essential)

I. Three most essential Ryan White Part A core services for accessing HIV primary care

1. *Mental Health Services (psychological and psychiatric treatment and counseling) (7)*
2. *Medical Case Management (including Treatment Adherence) (coordination of medical care) (6)*
3. *AIDS Drug Assistance Program (ADAP) Treatments (assistance with medications for people with limited or no medical insurance) (5)*

II. Three most essential Ryan White Part A supportive services for accessing HIV primary care

1. *Housing Services (temporary or transitional housing assistance) (8)*
2. *Non-medical Case Management (support in obtaining services like legal and financial assistance) (6)*
3. *Medical Transportation Services (pick-up service or voucher for transportation) (3)*

III. Three most essential Ryan White Part A core services for remaining in HIV primary care

1. *Mental Health Services (psychological and psychiatric treatment and counseling) (8)*
2. *Medical Case Management (including Treatment Adherence) (coordination of medical care) (7)*
3. *AIDS Drug Assistance Program (ADAP) Treatments (NY State assistance for medications for people with limited or no medical insurance) (6)*

IV. Three most essential Ryan White Part A supportive services for remaining in HIV primary care

1. *Housing Services (temporary or transitional housing assistance) (7)*
2. *Non-medical Case Management (support in obtaining services like legal and financial assistance) (7)*
3. *Psychosocial Support Services (support groups) (4)*

References

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