September 2016

Dear Provider:

The AIDS Institute recently issued a series of data briefs highlighting key findings from the State’s HIV Partner Services Data to Care programming. Data briefs were created for New York State (excluding New York City) and the following five regions: Capital District; Central New York; Long Island; Lower Hudson; and Western New York. Patient demographics, reasons for being out-of-care, and re-linkage to care status are displayed on the enclosed briefs and can be found on the New York Links website.

The briefs highlight locally relevant information regarding the reasons HIV positive persons report being out of care and the outcomes of Partner Services (PS) staff efforts to identify, locate, and re-engage persons in HIV medical care. Active engagement in HIV-related medical care is imperative to improve the health of persons living with diagnosed HIV infection (PLWDHI) and prevent the spread of the disease. Collaboration between medical providers, community based organizations and County and State Partner Services staff is essential to the re-linkage and retention of PLWDHI in HIV-related medical care. We recommend using the information in the enclosed briefs as a platform to begin or continue regional or localized planning discussions to aid in the re-linkage of individuals to care.

The AIDS Institute greatly appreciates your efforts in this regard. Should you have any questions regarding this correspondence, please email ps@health.ny.gov and a NYSDOH staff will return your message.

Sincerely,

James M. Tesoriero, Ph.D.
Director, Division of HIV/STD Epidemiology, Evaluation and Partner Services
NYS Department of Health, AIDS Institute

cc: Johanne E. Morne, Director, AIDS Institute
Reasons for being out-of-care among persons living with diagnosed HIV-infection (PLWDHI)*

New York State (Excluding NYC) Data Brief | September 2013-March 2016

New York State Department of Health (NYSDOH) uses Data to Care, a CDC endorsed High-Impact Prevention strategy, to locate PLWDHI and re-engage them in HIV-related medical care. The Expanded Partner Services (ExPS) strategy and High Impact Care and Prevention Project (HICAPP), use HIV surveillance data to identify HIV infected individuals who appear to be out-of-care. The majority of PLWDHI are considered out-of-care if no viral load, CD4 or genotype labs were reported to NYSDOH in the previous 13 to 24 months. PLWDHI identified as being out-of-care, are assigned to State and County Partner Services (PS) staff, who identify, locate, and interview these individuals with the specific objectives of re-engaging them in medical care. During the interview process, patients are asked their reasons for being out-of-care, and offered comprehensive partner notification/testing services, inclusive of: linkage to medical care; referrals for identified supportive services; risk reduction counseling; HIV and STI testing; and safer sex supplies.

Purpose of Data to Care

- Identify PLWDHI who are suspected to be out-of-care
- Relink PLWDHI who are confirmed to be out of care to HIV-related medical care, supportive services, and notify and test named partners
- Improve HIV outcomes along the continuum of care for people living with HIV

Data to Care Methodology

- Use routinely collected HIV surveillance data (and for HICAPP, select partnering health center data) to identify PLWDHI who appear to be out-of-care
- County and state health department PS staff locate, interview, and offer assistance to re-link PLWDHI (who are confirmed to be out of care) to HIV-related medical care, supportive services, and notify and test named partners
- PS staff contact the patient’s last known HIV medical provider to verify care status prior to patient contact
- At the time of the interview with PS staff, patients were asked for their reason(s) for being out of care

As a result of AIDS Institute Partner Services Data to Care activities in NYS (excluding NYC) from September 2013 through March 2016, 78.80% (409/519) of patients were re-linked to HIV medical care.

*This analysis was made possible through the support of the Centers for Disease Control and Prevention: PS14-1410 Secretary’s Minority AIDS Initiative Funding to Increase HIV Prevention and Care Service Delivery among Health Centers Serving High HIV Prevalence Jurisdictions; PS 12-1201 Comprehensive HIV Prevention Program for Health Departments; and PS 13-1302 National HIV Surveillance System.
## Patient Responses to Reason Out of Care Question (N=519)\(^1,2\)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day-to-Day Responsibilities</td>
<td>37.1%</td>
</tr>
<tr>
<td>Felt Healthy</td>
<td>36.0%</td>
</tr>
<tr>
<td>Insurance Issues</td>
<td>23.8%</td>
</tr>
<tr>
<td>Work Obligation/School</td>
<td>19.2%</td>
</tr>
<tr>
<td>Refused/Disinterested in Care</td>
<td>16.5%</td>
</tr>
<tr>
<td>Felt Depressed/Stigmatized</td>
<td>13.2%</td>
</tr>
<tr>
<td>Family Commitments/Issues</td>
<td>11.7%</td>
</tr>
<tr>
<td>Lack of Transportation</td>
<td>10.7%</td>
</tr>
<tr>
<td>Issues with Provider</td>
<td>10.0%</td>
</tr>
<tr>
<td>Inconvenient Appointment Times</td>
<td>9.4%</td>
</tr>
<tr>
<td>Issues with Healthcare Workers</td>
<td>7.8%</td>
</tr>
<tr>
<td>Behavioral Health Issues</td>
<td>7.0%</td>
</tr>
<tr>
<td>Forgot About Appointment</td>
<td>6.7%</td>
</tr>
<tr>
<td>Lack of Stable Housing</td>
<td>4.6%</td>
</tr>
<tr>
<td>Adverse Effects of HIV Meds</td>
<td>4.2%</td>
</tr>
<tr>
<td>Does Not Think HIV Positive</td>
<td>3.8%</td>
</tr>
<tr>
<td>Other Health Related Issues</td>
<td>3.4%</td>
</tr>
<tr>
<td>Language Barrier</td>
<td>2.1%</td>
</tr>
<tr>
<td>No Child Care</td>
<td>2.1%</td>
</tr>
</tbody>
</table>

1 Among those confirmed as being out of care (N=698), 538 patients agreed to be interviewed by PS staff. Among those 538 patients, patients were removed from analysis if they refused to answer, did not give a reason why they were out of care, claimed they were in care or reported they were incarcerated. A total of 19 cases met this criteria. Respondents could provide more than one response, therefore percentages do not add up to 100%.

2 28.9% (N=150) of patients provided an open-ended response and they were analyzed and recoded into one of the 19 categories above.

## Other Reasons Out of Care (N=150)\(^3\)

- Unsatisfied
- Religious
- Disagreement
- School/Detached
- Expensive
- Mailing
- Confidentiality
- Work
- Cost
- MISTREATED
- OUT OF TOWN
- Multivitamins
- Blinding
- Surgery
- IVDU
- AGORAPHOBIA
- ALTERNATIVE APPROACH
- Worried
- Sex Work
- CARETAKER

3 28.90% (N=150) of patients provided an open-ended response to their reason out of care.

## Patient Demographics (N=519)

### Age
- 16% 18-24
- 24% 25-34
- 35% 35-44
- 18% 45-54
- 6% 55+

### Gender
- 38% Males
- 61% Females
- 1% Transgender

### Race/Ethnicity
- 47% Black
- 27% White
- 12% Hispanic
- 8% Asian
- 2% Other/Unknown
- 4% Missing
Reasons for being out-of-care among persons living with diagnosed HIV-infection (PLWDHI)*

New York State Department of Health (NYSDOH) uses Data to Care, a CDC endorsed High-Impact Prevention strategy, to locate PLWDHI and re-engage them in HIV-related medical care. The Expanded Partner Services (ExPS) strategy and High Impact Care and Prevention Project (HICAPP), use HIV surveillance data to identify HIV infected individuals who appear to be out-of-care. The majority of PLWDHI are considered out-of-care if no viral load, CD4 or genotype labs were reported to NYSDOH in the previous 13 to 24 months. PLWDHI identified as being out-of-care, are assigned to State and County Partner Services (PS) staff, who identify, locate, and interview these individuals with the specific objectives of re-engaging them in medical care. During the interview process, patients are asked their reasons for being out-of-care, and offered comprehensive partner notification/testing services, inclusive of: linkage to medical care; referrals for identified supportive services; risk reduction counseling; HIV and STI testing; and safer sex supplies.

Purpose of Data to Care

- Identify PLWDHI who are suspected to be out-of-care
- Relink PLWDHI who are confirmed to be out of care to HIV-related medical care, supportive services, and notify and test named partners
- Improve HIV outcomes along the continuum of care for people living with HIV

Data to Care Methodology

- Use routinely collected HIV surveillance data (and for HICAPP, select partnering health center data) to identify PLWDHI who appear to be out-of-care
- County and state health department PS staff locate, interview, and offer assistance to re-link PLWDHI (who are confirmed to be out of care) to HIV-related medical care, supportive services, and notify and test named partners
- PS staff contact the patient’s last known HIV medical provider to verify care status prior to patient contact
- At the time of the interview with PS staff, patients were asked for their reason(s) for being out of care

![Map of New York State with Albany highlighted]

As a result of AIDS Institute Partner Services Data to Care activities in the Capital District from September 2013 through March 2016, 87.50% (35/40) of patients were re-linked to HIV medical care.

Most Common Patient Response to Reasons Out of Care Question

<table>
<thead>
<tr>
<th>Reason</th>
<th>Response Percentage</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day-to-Day Responsibilities (N=22)</td>
<td>55.0%</td>
<td>3 patients</td>
</tr>
<tr>
<td>Felt Healthy (N=16)</td>
<td>40.0%</td>
<td></td>
</tr>
<tr>
<td>Refused/Disinterested in care (N=15)</td>
<td>37.5%</td>
<td></td>
</tr>
</tbody>
</table>

*This analysis was made possible through the support of the Centers for Disease Control and Prevention; PS14-1410 Secretary’s Minority AIDS Initiative Funding to Increase HIV Prevention and Care Service Delivery among Health Centers Serving High HIV Prevalence Jurisdictions; PS 12-1201 Comprehensive HIV Prevention Program for Health Departments; and PS 13-1302 National HIV Surveillance System.
Patient Responses to Reason Out of Care Question (N=40)  

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day-to-Day Responsibilities</td>
<td>55.0%</td>
</tr>
<tr>
<td>Felt Healthy</td>
<td>39.0%</td>
</tr>
<tr>
<td>Refused/Disinterested in Care</td>
<td>37.5%</td>
</tr>
<tr>
<td>Work Obligation/School</td>
<td>30.0%</td>
</tr>
<tr>
<td>Issues with Provider</td>
<td>27.5%</td>
</tr>
<tr>
<td>Insurance Issues</td>
<td>25.0%</td>
</tr>
<tr>
<td>Lack of Transportation</td>
<td>22.5%</td>
</tr>
<tr>
<td>Inconvenient Appointment Times</td>
<td>22.5%</td>
</tr>
<tr>
<td>Family Commitments/Issues</td>
<td>15.0%</td>
</tr>
<tr>
<td>Felt Depressed/Stigmatized</td>
<td>15.0%</td>
</tr>
<tr>
<td>Issues with Healthcare Workers</td>
<td>12.5%</td>
</tr>
<tr>
<td>Adverse Effects of HIV Meds</td>
<td>12.5%</td>
</tr>
<tr>
<td>Lack of Stable Housing</td>
<td>10.0%</td>
</tr>
<tr>
<td>Does Not Think HIV Positive</td>
<td>10.0%</td>
</tr>
<tr>
<td>Forgot About Appointment</td>
<td>7.5%</td>
</tr>
<tr>
<td>Behavioral Health Issues</td>
<td>7.5%</td>
</tr>
<tr>
<td>Other Health Related Issues</td>
<td>2.5%</td>
</tr>
<tr>
<td>Language Barrier</td>
<td>2.5%</td>
</tr>
</tbody>
</table>

1 Among those confirmed as being out of care (N=53), 42 patients agreed to be interviewed by PS staff. Among those 42 patients, patients were removed from analysis if they refused to answer, did not give a reason why they were out of care, claimed they were in care or reported they were incarcerated. A total of 2 cases met this criteria. Respondents could provide more than one response, therefore percentages do not add up to 100%.

2 42.5% (N=17) of patients provided an open-ended response and they were analyzed and recoded into one of the 18 categories above.

Other Reasons Out of Care (N=17)

- Provider Left Practice
- Case Worker
- Active IV Drug Use (IDU)
- Unimportant Past Medical Bills
- Homeless
- High Medical Costs
- Pain Management
- Insurance
- Out of Town
- Domestic Violence
- Cost of Medication
- Fear of Needles
- Feels Better with Juicing
- Too Many Providers
- No Connection with Provider
- Blood Draw

3 42.5% (N=17) of patients provided an open ended response to their reason out of care.

Patient Demographics (N=40)

- Age:
  - 18-24: 25%
  - 25-34: 35%
  - 35-44: 28%
  - 45-54: 7%
  - 55+: 10%

- Gender:
  - Females: 35%
  - Males: 65%

- Race/Ethnicity:
  - White: 28%
  - Black: 25%
  - Hispanic: 18%
  - Other: 12%
  - Asian: 7%
  - Unknown: 10%
**Reasons for being out-of-care among persons living with diagnosed HIV-infection (PLWDHI)**

Central NY Region Data Brief | September 2013-March 2016

New York State Department of Health (NYSDOH) uses Data to Care, a CDC endorsed High-Impact Prevention strategy, to locate PLWDHI and re-engage them in HIV-related medical care. The Expanded Partner Services (ExPS) strategy and High Impact Care and Prevention Project (HICAPP), use HIV surveillance data to identify HIV infected individuals who appear to be out-of-care. The majority of PLWDHI are considered out-of-care if no viral load, CD4 or genotype labs were reported to NYSDOH in the previous 13 to 24 months. PLWDHI identified as being out-of-care, are assigned to State and County Partner Services (PS) staff, who identify, locate, and interview these individuals with the specific objectives of re-engaging them in medical care. During the interview process, patients are asked their reasons for being out-of-care, and offered comprehensive partner notification/testing services, inclusive of: linkage to medical care; referrals for identified supportive services; risk reduction counseling; HIV and STI testing; and safer sex supplies.

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**Purpose of Data to Care**

- Identify PLWDHI who are suspected to be out-of-care
- Relink PLWDHI who are confirmed to be out of care to HIV-related medical care, supportive services, and notify and test named partners
- Improve HIV outcomes along the continuum of care for people living with HIV

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**Data to Care Methodology**

- Use routinely collected HIV surveillance data (and for HICAPP, select partnering health center data) to identify PLWDHI who appear to be out-of-care
- County and state health department PS staff locate, interview, and offer assistance to re-link PLWDHI (who are confirmed to be out of care) to HIV-related medical care, supportive services, and notify and test named partners
- PS staff contact the patient's last known HIV medical provider to verify care status prior to patient contact
- At the time of the interview with PS staff, patients were asked for their reason(s) for being out of care

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**Most Common Patient Response to Reasons Out of Care Question**

- **Day-to-Day Responsibilities** (N=22): 43.1%
- **Refused/Disinterested in Care** (N=16): 31.3%
- **Work Obligation/School** (N=15): 29.4%

**= 3 patients**

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As a result of AIDS Institute Partner Services Data to Care activities in Central NY Region from September 2013 through March 2016, **58.82% (30/51)** of patients were re-linked to HIV medical care.

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*This analysis was made possible through the support of the Centers for Disease Control and Prevention; PS14-1410 Secretory’s Minority AIDS Initiative Funding to Increase HIV Prevention and Care Service Delivery among Health Centers Serving High HIV Prevalence Jurisdictions; PS 12-1201 Comprehensive HIV Prevention Program for Health Departments; and PS 13-1302 National HIV Surveillance System.*
Patient Responses to Reason Out of Care Question (N=51) 

1. Among those confirmed as being out of care (N=68), 52 patients agreed to be interviewed by PS staff. Among those 52 patients, patients were removed from analysis if they refused to answer, did not give a reason why they were out of care, claimed they were in care or reported they were incarcerated. A total of 1 case met this criteria. Respondents could provide more than one response, therefore percentages do not add up to 100%.

2. 35.2% (N=18) of patients provided an open-ended response and they were analyzed and recoded into one of the 19 categories above.

Other Reasons Out of Care (N=18)

3. 35.2% (N=18) of patients provided an open-ended response to their reason out of care.

Patient Demographics (N=51)
New York State Department of Health (NYSDOH) uses Data to Care, a CDC endorsed High-Impact Prevention strategy, to locate PLWDHI and re-engage them in HIV-related medical care. The Expanded Partner Services (ExPS) strategy and High Impact Care and Prevention Project (HICAPP), use HIV surveillance data to identify HIV infected individuals who appear to be out-of-care. The majority of PLWDHI are considered out-of-care if no viral load, CD4 or genotype labs were reported to NYSDOH in the previous 13 to 24 months. PLWDHI identified as being out-of-care, are assigned to State and County Partner Services (PS) staff, who identify, locate, and interview these individuals with the specific objectives of re-engaging them in medical care. During the interview process, patients are asked their reasons for being out-of-care, and offered comprehensive partner notification/testing services, inclusive of: linkage to medical care; referrals for identified supportive services; risk reduction counseling; HIV and STI testing; and safer sex supplies.

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- Identify PLWDHI who are suspected to be out-of-care
- Relink PLWDHI who are confirmed to be out of care to HIV-related medical care, supportive services, and notify and test named partners
- Improve HIV outcomes along the continuum of care for people living with HIV

**Data to Care Methodology**

- Use routinely collected HIV surveillance data (and for HICAPP, select partnering health center data) to identify PLWDHI who appear to be out-of-care
- County and state health department PS staff locate, interview, and offer assistance to re-link PLWDHI (who are confirmed to be out of care) to HIV-related medical care, supportive services, and notify and test named partners
- PS staff contact the patient's last known HIV medical provider to verify care status prior to patient contact
- At the time of the interview with PS staff, patients were asked for their reason(s) for being out of care

**Most Common Patient Response to Reasons Out of Care Question**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day-to-Day Responsibilities</td>
<td>50.0%</td>
</tr>
<tr>
<td>Felt Healthy</td>
<td>41.2%</td>
</tr>
<tr>
<td>Insurance Issues</td>
<td>22.5%</td>
</tr>
</tbody>
</table>

As a result of AIDS Institute Partner Services Data to Care activities on Long Island from September 2013 through March 2016, 87.50% (70/80) of patients were re-linked to HIV medical care.

*This analysis was made possible through the support of the Centers for Disease Control and Prevention; PS14-1410 Secretary’s Minority AIDS Initiative Funding to Increase HIV Prevention and Care Service Delivery among Health Centers Serving High HIV Prevalence Jurisdictions; PS 12-1201 Comprehensive HIV Prevention Program for Health Departments; and PS 13-1302 National HIV Surveillance System.
Patient Responses to Reason Out of Care Question (N=80)\(^1,2\)

- Day-to-Day Responsibilities: 50.0%
- Felt Healthy: 41.2%
- Insurance Issues: 22.5%
- Work Obligation/School: 20.0%
- Inconvenient Appointment Times: 17.5%
- Family Commitments/Issues: 12.5%
- Refused/Disinterested in Care: 10.0%
- Lack of Transportation: 7.5%
- Issues with Healthcare Workers: 6.25%
- Issues with Provider: 6.25%
- Adverse Effects of HIV Meds: 6.25%
- Does Not Think HIV Positive: 5.0%
- Language Barrier: 3.75%
- No Child Care: 2.5%
- Forgot About Appointment: 2.5%
- Felt Depressed/Stigmatized: 2.5%
- Other Health Related Issues: 1.25%
- Lack of Stable Housing: 1.25%

1Among those confirmed as being out of care (N=123), 80 patients agreed to be interviewed by PS staff. Respondents could provide more than one response, therefore percentages do not add up to 100%.

216.24% (N=13) of patients provided an open-ended response and they were analyzed and recoded into one of the 18 categories above.

Other Reasons Out of Care (N=13)\(^3\)

- UNDOCUMENTED
- CAR ACCIDENT
- CO-PAY VERY HIGH
- FEAR OF DISCLOSURE
- FEAR OF NEEDLES
- DID NOT WANT MEDS
- FEARS
- DENIAL
- WANTED A NEW PROVIDER
- DID NOT KNOW WHERE TO GO FOR CARE

316.24% (N=13) of patients provided an open-ended response to their reason out of care.

Patient Demographics (N=80)

- Age:
  - 18-24: 21%
  - 25-34: 32%
  - 35-44: 39%
  - 45-54: 14%
  - 55+: 6%
- Gender:
  - Males: 37%
  - Females: 63%
- Race/Ethnicity:
  - Hispanic: 30%
  - Black: 32%
  - White: 24%
  - Unknown/Missing: 5%
Reasons for being out-of-care among persons living with diagnosed HIV-infection (PLWDHI)*

New York State Department of Health (NYSDOH) uses Data to Care, a CDC endorsed High-Impact Prevention strategy, to locate PLWDHI and re-engage them in HIV-related medical care. The Expanded Partner Services (ExPS) strategy and High Impact Care and Prevention Project (HICAPP), use HIV surveillance data to identify HIV infected individuals who appear to be out-of-care. The majority of PLWDHI are considered out-of-care if no viral load, CD4 or genotype labs were reported to NYSDOH in the previous 13 to 24 months. PLWDHI identified as being out-of-care, are assigned to State and County Partner Services (PS) staff, who identify, locate, and interview these individuals with the specific objectives of re-engaging them in medical care. During the interview process, patients are asked their reasons for being out-of-care, and offered comprehensive partner notification/testing services, inclusive of: linkage to medical care; referrals for identified supportive services; risk reduction counseling; HIV and STI testing; and safer sex supplies.

**Purpose of Data to Care**

- Identify PLWDHI who are suspected to be out-of-care
- Relink PLWDHI who are confirmed to be out of care to HIV-related medical care, supportive services, and notify and test named partners
- Improve HIV outcomes along the continuum of care for people living with HIV

**Data to Care Methodology**

- Use routinely collected HIV surveillance data (and for HICAPP, select partnering health center data) to identify PLWDHI who appear to be out-of-care
- County and state health department PS staff locate, interview, and offer assistance to re-link PLWDHI (who are confirmed to be out of care) to HIV-related medical care, supportive services, and notify and test named partners
- PS staff contact the patient’s last known HIV medical provider to verify care status prior to patient contact
- At the time of the interview with PS staff, patients were asked for their reason(s) for being out of care

**Most Common Patient Response to Reasons Out of Care Question**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt Healthy</td>
<td>41.0%</td>
<td>10 patients</td>
</tr>
<tr>
<td>Insurance Issues</td>
<td>36.4%</td>
<td>10 patients</td>
</tr>
<tr>
<td>Work Obligation/School</td>
<td>17.8%</td>
<td>10 patients</td>
</tr>
</tbody>
</table>

As a result of AIDS Institute Partner Services Data to Care activities in Lower Hudson Region from September 2013 through March 2016, a total of 68.21% (103/151) of patients were re-linked to HIV medical care.

*This analysis was made possible through the support of the Centers for Disease Control and Prevention; PS14-1410 Secretary’s Minority AIDS Initiative Funding to Increase HIV Prevention and Care Service Delivery among Health Centers Serving High HIV Prevalence Jurisdictions; PS 12-1201 Comprehensive HIV Prevention Program for Health Departments; and PS 13-1302 National HIV Surveillance System.
Patient Responses to Reason Out of Care Question (N=151)¹,²

<table>
<thead>
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</tr>
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<tbody>
<tr>
<td>Felt Healthy</td>
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<td>Insurance Issues</td>
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</tr>
<tr>
<td>Work Obligation/School</td>
<td>17.8%</td>
</tr>
<tr>
<td>Day-to-Day Responsibilities</td>
<td>17.2%</td>
</tr>
<tr>
<td>Refused/Disinterested in Care</td>
<td>9.2%</td>
</tr>
<tr>
<td>Family Commitments/Issues</td>
<td>9.2%</td>
</tr>
<tr>
<td>Forgot About Appointment</td>
<td>9.2%</td>
</tr>
<tr>
<td>Issues with Provider</td>
<td>7.2%</td>
</tr>
<tr>
<td>Felt Depressed/Stigmatized</td>
<td>6.6%</td>
</tr>
<tr>
<td>Lack of Transportation</td>
<td>6.6%</td>
</tr>
<tr>
<td>Issues with Healthcare Workers</td>
<td>5.9%</td>
</tr>
<tr>
<td>Inconvenient Appointment Times</td>
<td>3.9%</td>
</tr>
<tr>
<td>Adverse Effects of HIV Meds</td>
<td>3.3%</td>
</tr>
<tr>
<td>Other Health Related Issues</td>
<td>3.3%</td>
</tr>
<tr>
<td>Lack of Stable Housing</td>
<td>2.6%</td>
</tr>
<tr>
<td>Does Not Think HIV Positive</td>
<td>2.6%</td>
</tr>
<tr>
<td>Behavioral Health Issues</td>
<td>1.3%</td>
</tr>
<tr>
<td>Language Barrier</td>
<td>0.6%</td>
</tr>
<tr>
<td>No Child Care</td>
<td>0.6%</td>
</tr>
</tbody>
</table>

¹Among those confirmed as being out of care (N=205), 161 patients agreed to be interviewed by PS staff. Among those 161 patients, patients were removed from analysis if: if they refused to answer, did not give a reason why they were out of care, claimed they were in care or reported they were incarcerated. A total of 10 cases met this criteria. Respondents could provide more than one response, therefore percentages do not add up to 100%.

²30.4% (N=46) of patients provided an open-ended response and they were analyzed and recoded into one of the 19 categories above.

Other Reasons Out of Care (N=46)³

³30.4% (N=46) of patients provided an open ended response to their reason out of care.

Patient Demographics (N=151)
New York State Department of Health (NYSDOH) uses Data to Care, a CDC endorsed High-Impact Prevention strategy, to locate PLWDHI and re-engage them in HIV-related medical care. The Expanded Partner Services (ExPS) strategy and High Impact Care and Prevention Project (HICAPP), use HIV surveillance data to identify HIV infected individuals who appear to be out-of-care. The majority of PLWDHI are considered out-of-care if no viral load, CD4 or genotype labs were reported to NYSDOH in the previous 13 to 24 months. PLWDHI identified as being out-of-care, are assigned to State and County Partner Services (PS) staff, who identify, locate, and interview these individuals with the specific objectives of re-engaging them in medical care. During the interview process, patients are asked their reasons for being out-of-care, and offered comprehensive partner notification/testing services, inclusive of: linkage to medical care; referrals for identified supportive services; risk reduction counseling; HIV and STI testing; and safer sex supplies.

Purpose of Data to Care

- Identify PLWDHI who are suspected to be out-of-care
- Relink PLWDHI who are confirmed to be out of care to HIV-related medical care, supportive services, and notify and test named partners
- Improve HIV outcomes along the continuum of care for people living with HIV

Data to Care Methodology

- Use routinely collected HIV surveillance data (and for HICAPP, select partnering health center data) to identify PLWDHI who appear to be out-of-care
- County and state health department PS staff locate, interview, and offer assistance to re-link PLWDHI (who are confirmed to be out of care) to HIV-related medical care, supportive services, and notify and test named partners
- PS staff contact the patient’s last known HIV medical provider to verify care status prior to patient contact
- At the time of the interview with PS staff, patients were asked for their reason(s) for being out of care

Most Common Patient Response to Reasons Out of Care Question

- Day-to-Day Responsibilities (N=83): 42.1%
- Felt Healthy (N=64): 32.5%
- Felt Depressed/Stigmatized (N=47): 23.9%

As a result of AIDS Institute Partner Services Data to Care activities in Western Region from September 2013 through March 2016, **86.80% (171/197)** of patients were re-linked to HIV medical care.

*This analysis was made possible through the support of the Centers for Disease Control and Prevention; PS14-1410 Secretary’s Minority AIDS Initiative Funding to Increase HIV Prevention and Care Service Delivery among Health Centers Serving High HIV Prevalence Jurisdictions; PS 12-1201 Comprehensive HIV Prevention Program for Health Departments; and PS 13-1302 National HIV Surveillance System.
### Patient Responses to Reason Out of Care Question (N=197)\(^1,2\)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day-to-Day Responsibilities</td>
<td>42.1%</td>
</tr>
<tr>
<td>Felt Healthy</td>
<td>32.5%</td>
</tr>
<tr>
<td>Felt Depressed/Stigmatized</td>
<td>23.9%</td>
</tr>
<tr>
<td>Refused/Disinterested in Care</td>
<td>16.8%</td>
</tr>
<tr>
<td>Insurance Issues</td>
<td>16.8%</td>
</tr>
<tr>
<td>Work Obligation/School</td>
<td>16.2%</td>
</tr>
<tr>
<td>Behavioral Health Issues</td>
<td>15.7%</td>
</tr>
<tr>
<td>Lack of Transportation</td>
<td>11.7%</td>
</tr>
<tr>
<td>Issues with Provider</td>
<td>10.7%</td>
</tr>
<tr>
<td>Family Commitments/Issues</td>
<td>10.7%</td>
</tr>
<tr>
<td>Issues with Healthcare Workers</td>
<td>9.1%</td>
</tr>
<tr>
<td>Inconvenient Appointment Times</td>
<td>7.6%</td>
</tr>
<tr>
<td>Lack of Stable Housing</td>
<td>7.1%</td>
</tr>
<tr>
<td>Forgot About Appointment</td>
<td>5.6%</td>
</tr>
<tr>
<td>Other Health Related Issues</td>
<td>4.1%</td>
</tr>
<tr>
<td>No Child Care</td>
<td>3.0%</td>
</tr>
<tr>
<td>Does Not Think HIV Positive</td>
<td>3.0%</td>
</tr>
<tr>
<td>Adverse Effects of HIV Meds</td>
<td>2.5%</td>
</tr>
<tr>
<td>Language Barrier</td>
<td>2.1%</td>
</tr>
</tbody>
</table>

\(^1\) Among those confirmed as being out of care (N=249), 202 patients agreed to be interviewed by PS staff. Among those 202 patients, patients were removed from analysis if they refused to answer, did not give a reason why they were out of care, claimed they were in care or reported they were incarcerated. A total of 5 cases met this criteria. Respondents could provide more than one response, therefore percentages do not add up to 100%.

\(^2\) 33.5% (N=66) of patients provided an open-ended response and they were analyzed and recoded into one of the 19 categories above.

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### Other Reasons Out of Care (N=66)\(^3\)

- Caretaker
- Agoraphobia
- Refused Medication
- Hepatitis
- Suicide
- Refused School
- Homeless
- Transgender
- Hormones
- Frustrated
- Afraid
- Lost Employment
- Domestic Violence
- Felt Sick
- Surgery
- Travel
- Confidentiality
- Medicaid
- Canceled
- Blind
- Moving

\(^3\) 33.5% (N=66) of patients provided an open-ended response to their reason out of care.

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### Patient Demographics (N=197)

- **Age**:
  - 17% 18-24
  - 31% 25-34
  - 17% 35-44
  - 17% 45-54
  - 29% 55+

- **Gender**:
  - 33% Males
  - 3% Transgender
  - 64% Females

- **Race/Ethnicity**:
  - 32% Black
  - 4% Hispanic
  - 2% Unknown
  - 5% Asian
  - 2% White
  - 2% Missing
  - 55% Unknown