Antiretroviral therapy (ART) patients surveyed were most likely to switch between health sectors when making decisions about where to receive HIV testing, initial HIV care, and ART initiation. Treatment pathways stabilized after ART initiation, but many respondents switched to a different sector for treatment of opportunistic infections.

As the global HIV response continues to make progress, two key challenges persist: expanding HIV prevention, testing, care, and treatment services; and implementing a well-developed continuum of response to coordinate the long-term provision of a full range of services to address the multiple health needs of people living with HIV and AIDS. Rather than relying solely on the public sector to provide HIV services, many countries are leveraging resources from the commercial and NGO sectors to increase treatment coverage and access.

Providing HIV services across multiple sectors brings new challenges. People receiving ART from one provider may choose to access HIV and non-HIV care from multiple providers in other sectors—public, commercial, or NGO—at different times during their illness. It is critical to ensure treatment continuity to promote positive outcomes. To inform the development of systems that promote effective coordination of care, SHOPS conducted a study to better understand HIV patients’ health care-seeking behavior throughout their treatment.

**Methods**

SHOPS conducted a retrospective survey of 1,470 respondents receiving ART at 16 public, commercial, and NGO facilities and collected data in four Ugandan districts (Gulu, Jinja, Kampala, and Mbarara) from August 2013 to May 2014. Based on a pathways to HIV care framework (Figure 1), the survey focused on capturing when and where the respondents received key HIV services from the time of their HIV diagnosis through ART. Respondents were asked what factors influenced their choice of facility for each service and if they were treated for opportunistic infections at different facilities from where they received ART.

**Key Findings**

- Switching between sectors—public, commercial, and NGO—was substantial when respondents were deciding where to receive care after learning of their HIV-positive status.
- Patients’ treatment pathways tended to stabilize after ART initiation.
- Proximity to a health facility, expected quality of service, and wait time most prominently influenced choice of facility for ART.
- One third of respondents switched from their regular ART provider to a facility in a different sector to be treated for opportunistic infections.
- Ten percent of respondents reported that they knew at least one person who had obtained ARVs from more than one facility at the same time.
Switching between sectors—public, commercial, and NGO—was substantial when respondents were deciding where to receive care after learning of their HIV-positive status.

Switching between the public, commercial, and NGO sectors was more common in the early stages of the HIV continuum of care than in the later stages. As shown in Table 1, between testing HIV positive for the first time and ART initiation, 74 percent of patients who were tested for HIV in the public sector did not switch sectors for ART initiation, but the other 26 percent did switch, to either NGO (18 percent) or commercial (8 percent) sectors. Similarly, 22 percent of patients who were tested in the NGO sector switched to the public or commercial sector for ART initiation, and 30 percent of patients tested in the commercial sector switched to another sector for ART initiation. The most common switching pattern observed was from patients tested for HIV in the public sector switching to the NGO sector for initial HIV care and ART initiation.

### Table 1. Distribution of respondents by sector where they obtained HIV testing and ART initiation

<table>
<thead>
<tr>
<th>HIV test</th>
<th>ART initiation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Public</td>
</tr>
<tr>
<td>Public</td>
<td>74%</td>
</tr>
<tr>
<td>NGO</td>
<td>10%</td>
</tr>
<tr>
<td>Commercial</td>
<td>16%</td>
</tr>
</tbody>
</table>
Patients’ treatment pathways tended to stabilize after ART initiation.
In contrast to the switching behavior observed during the early stages of the HIV continuum of care, the data in Table 2 indicate very little movement of respondents between sectors after ART initiation. Among those who started ART in public facilities, 1 percent had switched to NGO facilities by the time of their most recent antiretroviral (ARV) prescription, and 5 percent had switched to a commercial facility. For respondents who started ART in NGO or commercial facilities, the magnitude of switching between ART initiation and most recent ARV prescription was even lower (less than 2 percent).

Proximity to a health facility, expected quality of service, and wait time most prominently influenced choice of facility for ART.
Three factors primarily influenced choice of facility for ART initiation and for access to ongoing ART: geography (i.e., proximity to a health facility); expected quality of service; and wait time (particularly for respondents at commercial facilities). Provider recommendation and referral to a specific facility was also an important reason cited by patients for choice of facility for ART initiation.

One third of respondents switched from their regular ART provider to a facility in a different sector to be treated for opportunistic infections.
Thirty-five percent of respondents had been treated for at least one opportunistic infection (including skin infections, STDs, chronic diarrhea, tuberculosis, chest infections, and meningitis) since they started ARV treatment. Among those respondents, 22 percent obtained treatment for the opportunistic infection at a health facility in a different sector than the one in which they were receiving ARV treatment at the time of the infection. The most common pattern observed for this type of concurrent care was of patients receiving ART at NGO facilities while being treated for the opportunistic infection at commercial facilities.

Ten percent of respondents reported that they knew at least one person who had obtained ARVs from more than one facility at the same time.
When asked why someone might do this, the most commonly cited reasons were “to sell them later for a profit” (mentioned by 34 percent of respondents), followed by “to avoid ARV stock outs” and “to obtain medication for an HIV-positive relative or friend” (24 and 18 percent, respectively).

### Table 2. Distribution of respondents by sector where they obtained ART initiation and last ARV prescription

<table>
<thead>
<tr>
<th>ARV initiation</th>
<th>Public</th>
<th>NGO</th>
<th>Commercial</th>
<th>Total</th>
<th>n=1,339</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public</td>
<td>94%</td>
<td>1%</td>
<td>5%</td>
<td>100%</td>
<td>594</td>
</tr>
<tr>
<td>NGO</td>
<td>0%</td>
<td>99%</td>
<td>1%</td>
<td>100%</td>
<td>445</td>
</tr>
<tr>
<td>Commercial</td>
<td>2%</td>
<td>0%</td>
<td>98%</td>
<td>100%</td>
<td>300</td>
</tr>
</tbody>
</table>
**Policy Implications**

Respondents’ switching between health sectors during the early phases of the HIV continuum of care suggests that after diagnosis, patient health care-seeking behavior may focus on finding the most convenient or preferable source of long-term HIV care and ART. Although this does not necessarily translate into worse patient outcomes, it is of potential concern if patients who self-refer—or switch—between providers do so without effective coordination.

Uganda uses the district health information system (DHIS II) software, which collects only aggregate data, not patient-level data. To improve coordination referral between facilities, one possible solution is that the Ugandan Ministry of Health, private provider networks, and donor partners develop a system to access patient medical records (including for HIV). Similar systems have been attempted in other settings, such as the SmartCare electronic health records system in Zambia or the Millennium Challenge Corporation’s investment in Lesotho’s electronic medical records system. As described in Uganda’s National Priority Action Plan (2011–2013), the government has prioritized operationalizing the system for unique patient identifiers to enable patient tracking within and across sites. However, this system has not been implemented due to resource and logistical constraints. While such a solution would lead to better coordination of care, this approach could involve the creation of a parallel system, which would be costly. One alternative may be to examine existing stand-alone systems of collecting patient-level data that are already being used by the public, commercial, and NGO sectors.

The SHOPS study found significant patient movement for concurrent opportunistic infection treatment. This indicates the need for a strong focus on strengthening referral and communication mechanisms for ART patients who require treatment for opportunistic infections and to address other primary health care needs. Sites dedicated to ART should be encouraged to identify nearby points of opportunistic infection and primary health care service delivery, where referral and follow-up for concurrent health needs can be systematically coordinated. These efforts could be initiated at the facility level, or they could be explored as part of formal public-private collaboration fora. Such referral relationships can enhance patient flexibility and safety in moving between facilities and sectors for multiple health needs.

**Full Report**


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