Asking Patients About Their Experiences, Opinions and Needs when Planning Health Services

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ISSUE: Program administrators frequently set about planning programs and services without patient input. Here are three examples demonstrating the importance of including patient input when planning services that affect them.

- **TELEMEDICINE SERVICES**
  - Survey of rural HIV patients to determine interest in use of telemedicine

- **STATEWIDE HIV CARE NEEDS**
  - Comprehensive assessment of HIV care needs around the state

- **WOMEN’S SERVICES**
  - An investigation into how one HIV clinic can best meet the needs of its female patients

THE PATIENT IS THE GUIDE.

What questions do we ask patients in order to inform programs and services?

- How many miles do you travel from your home to come to your HIV appointments?
- Do you have to take time off work to travel to your HIV appointments?
- Do you have a doctor in your local community that you see for non-HIV health issues?
- Would you be interested in having some of your routine HIV appointments done via telemedicine?
- Please check all the HIV services you currently use (from a list).
- Is it easy or hard for you to get the services you need? Why/why not?
- Do you get all the services you need? Why/why not?
- How many people do you know who are HIV-positive and not accessing services? Why do you think they’re not accessing services?
- Studies done with women who have HIV show that a lot of women experience feelings of depression. Have you ever felt that way? If so, how have these feelings affected your life?
- How has having HIV affected how you feel about yourself as a woman?
- How much control do you feel you have over your disease?

LESSONS LEARNED AND OUTCOMES REALIZED THROUGH PATIENT INPUT

- An estimate of costs to travel to the hub clinic (time, mileage, lodging, time away from work)
- Accounting of reasons for missing or cancelling appointments
- Opinions about being able to see their HIV specialist without having to travel
- Fears, barriers and concerns about receiving care from a remote site
- Patient responses to a few questions were counter to what providers reported; prompting a deeper investigation into the matter and a revision of goals and objectives for the Comprehensive Care Plan.
- Information unavailable through other sources: first-hand account of access issues and barriers to care, including both clinical and social services.
- HIV risk assessment and education provided at all clinic visits, as some of the younger women admitted to not using safer sex practices.
- Also, the clinic began holding support groups offsite for women, because many of them didn’t want to attend groups located at the clinic.

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