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## Chapter 3: Results from the Partnering for Care Project





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Health care for participants in HIV/AIDS clinical trials comes in two general forms: direct and indirect. Direct health care comes from the clinical trial staff, and indirect care comes through referrals based on partnerships with other health facilities, such as clinics and hospitals. The Partnering for Care project found that most HPTN sites use a combination of direct and indirect care.

Specifically, 13 of the 16 sites that responded to the FHI study use referral sites. Moreover, the HPTN sites arranged referrals with one to seven sites — most of them developed through partnerships with other organizations or facilities. In most cases, HPTN sites created referral systems to provide care that was not available through the trial. Some referral sites also provided technical or laboratory support. In addition, some HPTN sites developed partnerships for help with enrolling participants in studies.

The Partnering for Care project found that the balance between direct and indirect care depends on several — often interacting — factors:

- **Public health system constraints.** All HPTN sites work with participants with a range of health care needs. Moreover, the neediest participants were at sites where local health services struggled with long waiting lists and limitations in the level of care. Such constraints must be considered in developing a program of direct and indirect care.

- **Local community values, attitudes, and priorities.** The way people live their lives, interpret their experiences, and envision their collective future needs to be understood and respected. Cultural, historical, and political factors vary; a strategy that is successful in one context might fail in another.
- **Public health attitude.** Clinical trial leadership and staff must recognize the balance between research and health care challenges, meaning that trials must reach scientific goals while handling treatment needs. In many cases, the latter depends on developing partnerships for referrals.
- **Referral follow-up.** Only by following up on referrals can clinical trial staff evaluate the performance and limitations of a referral system. Referral systems can face a variety of challenges, including transportation needs, costs of referrals to both the program and the participants, pharmaceutical shortages, and so on.
- **Physical proximity.** Referral systems prove more effective when developed with nearby resources. By developing partnerships with nearby facilities or by setting up research sites near appropriate facilities, clinical trial staff can keep better track of referral success or failure and develop stronger partnerships with the referral agencies.
- **Capacity building.** The availability of health care resources depends on the research being conducted by a clinical trial, the capabilities of the organization running the research, and the resources available through the trial and local facilities and agencies. Building more capacity for health care depends on assessing these resources for strengths and weaknesses.
- **People living with HIV/AIDS enrolled in research.** Studies focused on participants who are infected with HIV often contain more in-house health care resources for direct care. On the other hand, studies that focus on healthy, uninfected participants often must rely more heavily on referrals to partners.

- **Community engagement.** To better understand the needs of participants, clinical trial leaders and staff and the local community must interact. Such interactions improve problem-solving and enhance the health care provided to participants and the community overall.
- **Partnership-building.** Many of the above factors depend on partnerships, particularly for referral care. Such partnerships develop through contacts of the clinical trial staff, by interactions with the community, and sometimes through unique circumstances that arise during a study.

Although HIV/AIDS clinical trials face a range of health care concerns encountered by participants, the needs often surpass medical issues. For example, the Partnering for Care project also documented a range of psychological and social challenges. Many of the HPTN sites developed systems that specifically addressed such additional needs. For example, in Kampala, Uganda, the MU–JHU team developed a Psychosocial Support Group that helps to meet a wide range of needs. (See box titled “The MU–JHU Psychosocial Support Group.”)

## The MU–JHU Psychosocial Support Group

Agnes Ssendege and other members of the MU–JHU team created the Psychosocial Support Group in 2003. Ssendege was a health visitor — part of a team of nurses and midwives that follows up on trial participants throughout a study.

That support group started when Ssendege arranged a meeting between HIV-positive participants in a trial and a visitor to the research site. The encouraging comments from the participants led Ssendege to see the need for a support group, where participants could share concerns and stories. The leaders of the MU–JHU project agreed, and the support group grew from five couples to 200 members in just one year. Eventually, the MU–JHU team made an official, full-time position for Ssendege as psychosocial coordinator. Ssendege — soon known simply as “Mama Agnes” — was called “one of our angels” by a member of the MU–JHU team.

Today, the Psychosocial Support Group provides many benefits beyond health care for trial participants. For example, one program makes small loans available to members to start businesses. Other programs provide grief counseling to families, skills for making and selling crafts, peers who provide counseling, programs for HIV-positive children, and more. In fact, the Psychosocial Support Group proved so effective that members of the MU–JHU team often volunteer their time to the group, including securing funding from the Doris Duke Foundation for a building for the group.

To meet medical needs and psychological support at HPTN sites — and certainly within any group focused on care related to HIV/AIDS — leaders must overcome one ongoing problem: sustainability. Many health needs, and particularly those of people living with HIV, extend well beyond the life of a clinical trial. To keep participants connected with the necessary care and treatment, clinical trial programs must build partnerships with health care in the local communities.

Some clinical trials have already provided extensive health care for participants. The GCM's *Mapping the Standard of Care at Microbicide Clinical Trial Sites* study, for instance, found that the women in those clinical trials — and even those who screened out — received some effective HIV-prevention services. They also received HIV testing, as well as pre- and post-test counseling. Almost all women screened for trial participation also received STI testing and treatment.

To maintain an effective system of health care for participants in an HIV/AIDS clinical trial, leaders must focus on the list of interacting factors: public health system constraints, public health attitude, stigma and discrimination, referral follow-up, community engagement, and so on. Furthermore, these factors must be considered at stages from trial planning through follow-up after a trial's completion.