

# THE PARTICIPANT

THE PATIENTS' PERSPECTIVE

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## Volunteers say site staff is crucial to involvement

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**S**tudy volunteers have several motivations for participating in clinical trials, but one of the important factors is the warm, professional care and attention they receive from the site staff during the trials.

Those are among the key findings that emerged from three focus groups conducted by Kenneth A. Getz, CISCRP Founder and chairman, and Diane Simmons, President and CEO of CISCRP, in March in Winston Salem, NC. The focus groups are part of an ongoing effort to gather primary research and gain a deeper understanding about study participants.

CISCRP is preparing a White Paper that discusses the focus group findings in more detail, but the preliminary findings are cited below. One very critical factor that played a key role in attracting first-time participants and repeat volunteers emerged:

**The patients' connection with the trials investigator and study staff is crucial in creating a positive experience. This valuable feedback points out that clinicians' efforts toward friendliness and consideration are noticed and appreciated.**

These interactions included a number of areas:

*Personal connection:* Many focus group members noted that their relationship began with an already-established association with someone who either participated in a trial or worked at the trial site.

*Staff was organized, prepared, responsive, and coordinated:* Volunteers commented that the site operation was professional, and they trusted the site staff to take excellent care of them.

"It's just like a doctor's office. I really enjoyed the fact that they followed up and did what they said they were going to do," said one volunteer.

*Staff held volunteers accountable while helping them maintain a positive outlook:* Study participants appreciated that the site staff made sure the volunteers stuck with their regimen and took their health seriously, while keeping them positive and motivated.

"I like the fact that you have to be accountable. It's like having to check in and see what you've been doing and it keeps you on target," said one volunteer. "They made sure I took my health seriously," said another.

*Staff was accessible at scheduled and unscheduled encounters:* The site staff's willingness to accommodate volunteers' schedules made a highly positive impression.

"Lots of times I wanted early morning, like 6:30 or 7:00 a.m. I don't think my staff person was really a morning person, but she came in so I really appreciated that," said one volunteer.

*Warm, positive relationships with the staff and a sense of humor were important:* When asked what they liked best about the clinical trials, a majority mentioned the site staff. One man commented, "You kind of develop a personal relationship with the staff. It's not just about the study." Another volunteer said, "The attitude of the physicians and staff just blew me away."

CISCRP's White Paper also includes information about volunteers' reactions to the consent form; how they evaluate risk; and their likes and dislikes about clinical trials.

CISCRP's focus group findings suggest that there is a huge opportunity for study sites to conduct their own internal assessments of staff behavior and attitudes, and how those can affect their relationship with patients. By conducting such studies, site personnel may gain important insights into ways the staff can contribute to a more positive experience for clinical research volunteers.

To receive a copy of the White Paper when it becomes available, please send an e-mail to: [info@CISCRP.org](mailto:info@CISCRP.org)