Creating Survey Questions to Measure Important Aspects of Health for People Living with HIV

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What was the research about?

Understanding which aspects of health and wellness are most important to patients living with HIV can help clinics improve care. Clinics often have patients complete surveys about their health and wellness. This study created new sets of survey questions for people living with HIV.

This study had two parts. In the first part, the research team asked patients living with HIV and their clinicians, such as doctors and nurses, what health and wellness topics they found important. In the second part, the team created sets of survey questions for two topics: domestic violence and social support. The team then asked patients living with HIV to answer the questions.

What were the results?

The research team found that patients living with HIV and their clinicians ranked different topics as most important. Patients highly ranked HIV stigma and social support. In contrast, clinicians highly ranked drug, alcohol, and tobacco use. Patients and clinicians agreed on the importance of some topics. These topics were depression, taking medicine as directed, HIV symptoms, and sex behaviors that increase risk for HIV transmission.

Of 1,000 patients who responded to the domestic violence questions

- 9 percent said they felt controlled by a partner in the past year

- 5 percent said they were afraid of harm from a partner
- 4 percent said a partner physically harmed them
- 3 percent said a partner forced or pressured them to have sex

Of patients who responded to the social support questions, patients with less social support reported higher levels of depression and lower quality of life than patients with more social support did.

Who was in the study?

The first part of the study included 206 patients living with HIV and 17 clinicians. The patients and clinicians were from five HIV clinics across the country. In the second part of the study, more than 1,000 patients filled out the domestic violence questions, and 680 patients filled out the social support questions. These patients were from six HIV clinics across the country.

What did the research team do?

The research team convened a patient advisory board to help guide the study. The board included three patients receiving care from clinics at the University of Washington.

In the first part of the study, the research team asked patients and clinicians to rank health topics in order of importance. The team then held 11 group discussions

with other patients. These patients also ranked the topics.

In the second part of the study, the team created survey questions for two topics. The patient advisory board had suggested domestic violence because it is common and harmful. Patients in the group discussions had rated social support as highly important.

The research team looked through existing health surveys to find questions about domestic violence. The team then asked patients to read the questions to see if they understood them as intended. Next, the team changed or removed questions that weren't clear.

To develop questions about social support, the team used a similar process. The team found so many questions from existing health surveys that they needed to shorten the list. The team used questions that research studies had linked to patient health and a group of patients had rated as most important.

The team then asked patients living with HIV from across the United States to fill out surveys during routine healthcare visits. The surveys included the domestic violence and social support questions and other questions about the patients' health.

What were the limits of the study?

The study included patients and clinicians from HIV specialty clinics only. Results may differ for patients and clinicians from other settings, such as primary care practices.

Future research could use the survey questions from this study to see how domestic violence and social support affect patient health.

How can people use the results?

Clinicians and patients can use the survey questions about domestic violence and social support to help understand the needs of patients living with HIV.

To learn more about this project, visit www.pcori.org/Crane122.