

Measuring Community Involvement in HIV Prevention Research

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Project Description: The HIV Prevention Trials Network (HPTN), a worldwide collaborative of clinical trials and research sites, has a policy to promote community participation in HIV prevention research. However, quantitative measures have not yet been developed to assess the spectrum of community participation. The few instruments that do exist cater to the perspective of researchers. Through an iterative process we developed a new instrument to measure community involvement.

Strategies employed to develop the instrument included regular discussions with Community Advisory Board (CAB) members, community educators and research staff, as well as informal piloting at research sites and scientific peer review. Community involvement was integral to the synthesis of this questionnaire. The survey divides community participation into seven domains: CAB function, CAB process, Community Representation, Research Team Involvement, Contribution to Research Design and Process, Participation in Resolving Ethical Issues, and Feedback and Research Results to Communities. It examines community participation from two perspectives: factual and subjective.

Involving researchers and community members in the design process produced an instrument that is contextually relevant, conceptually comprehensive, and understandable to all respondents. The participatory process yielded discrete indicators that can be used to prospectively monitor and evaluate community involvement. Furthermore, the collaborative method increases the community and researcher's investment in the evaluation process and respect for the results produced.

Quantitative approaches can be used to monitor ongoing activities at research sites over specific time periods and to facilitate partnerships between communities and researchers. Such measures can also be used to evaluate individual research site performance and to identify technical assistance needs across the entire network.

Project Web Site: www.hptn.org