Public Deliberations About Patient Centered Outcomes Research Priorities

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Building on a decade of experience engaging the public in deliberations about health-related priorities, we propose to develop and evaluate a mechanism to engage communities, particularly minority and underserved communities, in informed deliberations about patient centered outcomes research priorities.

In partnership with the Urban Research Center, drawing upon relationships with research institutions and funders, and with support from the National Institutes on Aging (1R01AG040138-01), we are in the process of modifying the simulation exercise, CHAT, to engage communities in deliberations about health research priorities. The Re-CHAT exercise will be informative, understandable and meaningful to nonscientists, will include a range of spending options, feedback and iterative decision making processes, and will be thoroughly pretested. The exercise is being designed such that results will be meaningful and relevant for leaders at research institutions and funders. Re-CHAT software includes the ability to modify content to meet a variety of prioritization needs. In this project, we will:

1. Develop content for a prioritization exercise for patient-centered outcomes research (PCOR) priorities. We will develop, in consultation with patient advocates, community leaders, outcomes researchers and funders, content specific to PCOR priority setting, including options from which to choose, information and education about PCOR, tailored feedback on choices, and relative costs. Content will be translated into Spanish.

2. Evaluate a deliberative exercise designed to engage minority and underserved communities in setting PCOR priorities. Evaluation of community engagement using mixed methods will examine how participants view the experience, and the effect of participation on participants' knowledge and attitudes toward PCOR. We will convene 12 groups of 9-15 persons (N=144) to participate in PCOR priority-setting deliberations, oversampling minority and underserved communities and those with experience of a chronic or serious illness in the family. Recruitment will balance urban, suburban, rural and remote rural settings, gender and age. Data collected during participation (most of which will use laptops or tablets) will include validated measures of procedural fairness, willingness to abide by the group's decisions, trust in research.

RELEVANCE

While substantial progress has occurred recognizing community expertise in research, and involving communities in decisions about research aims and methods, community influence on research priorities remains limited. Building on experience with developing, testing and using the award-winning CHAT (Choosing Healthplans All Together) tool, and propelled by a current project that is developing and evaluating a tool to engage minority and underserved communities in setting priorities for clinical and translational research, we plan to develop and test a method to engage the public and patients in deliberations about patient-centered outcomes research (PCOR) priorities. The proposed study expands public input on research priorities beyond the limited settings of advisory boards and disease advocates in which much public engagement currently functions and contribute to a more just and equitable system of PCOR. Importantly, by evaluating the tool this project will also add to the body of knowledge about methods, processes and outcomes of community engagement.