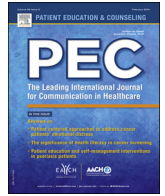




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Short communication

The citizen scientist: Community-academic partnerships through Translational Advisory Boards

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ABSTRACT

Objective: To describe the effectiveness of engaging patient partners as “citizen scientists” in the research process to boost patient centered outcomes research in underrepresented populations.

Methods: Translational Advisory Boards in South Texas have effectively collaborated with University researchers to develop community-based patient centered research. Here we describe innovative approaches in research to engage patients and offer practical methods to enhance partnerships between patients and researchers to facilitate patient engagement.

Results: Three health issues identified by the TABs were diabetes, obesity and teen pregnancy. Examples of other community inspired research topics include air and water quality, methicillin-resistant staphylococcus aureus, intimate partner violence, chronic pain, and human papilloma virus and hepatitis C vaccinations.

Conclusion: Patient engagement of underrepresented populations is inverse to the vast disparities they experience. In order to adequately address our nation's deficits in providing equitable healthcare, we must fully integrate disparate partners into the research process. By engaging community champions, academic health centers can fully integrate meaningful interventions on topics of interest to the catchment area in which they serve.

Practice implications: These lessons can be used in developing local and regional collaborations across the country to boost active participation of patient stakeholder in PCOR to reduce healthcare disparities and improve our healthcare systems.

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1. Introduction

Equitable partnerships between scientists and community members is required in order to make substantial changes in the way we implement the scientific method. In the field of medical and healthcare research, engagement of patients and other stakeholders into the research process provides a significant opportunity for research to be directly study what matters most to patients. Over the past decade, the concept of engaging “citizen scientists” has been advanced through the Patient Protection and Affordable Care Act which congressional mandated the creation of the Patient Centered Outcomes Research Institute (PCORI) [1,2].

Specifically, PCORI was created with the purpose to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions through research, evidence synthesis and dissemination of research findings [2]. Engagement of “citizen scientist” into medical research has its inherent benefits [3], however, much work needs to be done to continue to build capacity within the scientific community to enthusiastically engage with stakeholders. To effectively translate scientific discoveries to the healthcare consumer, we must actively engage with stakeholders in all stages of research; from conception to dissemination.

Recently, our PCORI funded conference, the 2015 Summer Institute: Engaging patients and professionals to advance clinical excellence, hosted a panel of citizen scientists from South Texas that (1) described innovative approaches in research to engage patients to advance clinical excellence, and (2) offer practical

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methods to enhance partnerships between patients and researchers to facilitate patient engagement in PCOR. This panel, titled “Citizen Scientists: Translational Advisory Board Patient Representative Panel” presented insightful evidence on the benefits and effectiveness of stakeholder engagement in community health research. In efforts to increase reach of our conference content, we present an overview of the session with examples and lessons learned that were presented by two Translational Advisory Board (TAB) representatives. Video archive of the Citizen Scientist Panel can be accessed by following this link: <http://bit.ly/SIProceedings>.

2. Methods

2.1. Structure of Translational Advisory Boards

Translational Advisory Boards (TABs) are an evolution of Area Health Education Center (AHEC) Boards, groups which have historically worked to develop community-academic partnerships throughout South Texas. A TAB is comprised of community members who are committed to improving the health of their community, and who, through active involvement in community-based participatory research (CBPR), will bring research partnerships and findings from “bench to bedside to community”. The overall mission of the TABs is to serve as a representative body to improve community health through the facilitation of community-based participatory research and educational outreach activities in partnership with the University of Texas Health Science Center at San Antonio (UTHSCSA).

2.2. Forming the Translational Advisory Boards

TABs were brought to South Texas communities by the South Central AHEC and UTHSCSA Institute to Integrate Medicine and Science (IIMS), a department funded by the National Institute of Health (NIH) through a Clinical & Translational Science Award. One self-nominated community champion from each of the 5 counties surrounding San Antonio took the lead in developing the TABs in collaboration with UTHSCSA. Each champion held several orientation meetings that were held with the Community Engagement Research Team at UTHSCSA to recruit 5–7 community representatives that will comprise the TAB.

3. Results

Developing a successful collaborations between our academic health center and the citizen scientists in the community takes time and major efforts. Each TAB’s first activity after an orientation meeting was to brainstorm the health priorities of their county and the top priority topic would guide their development based on the Principles of CBPR. Each TAB group brainstormed topics and listed them; it was agreed that even when they found the top priority of the community, no other topics would fall off the list so that there could be a dissemination of the topics to researchers, county government and other community stakeholders. Assessment of priorities took several via surveys and group interviews. Not surprisingly, the big three health issues identified by the 5 TABs were diabetes, obesity and teen pregnancy. Based on this information, AHEC staff approached researchers at UTHSCSA to assess their interest to present their research at a TAB meeting to see if there was interest in working together on grants. Since that initial startup phase, the counties have expanded their interests because more researchers have approached the TABs about interests that have arisen since the inception of the group. Examples of other community inspired research topics include air

and water quality, methicillin-resistant staphylococcus aureus, intimate partner violence, chronic pain, and human papilloma virus and hepatitis C vaccinations.

3.1. Thoughts from the citizen scientist in Winter Garden, TX

Health is seen as a right we have had to fight for in the winter garden area south of San Antonio and along the border area. We still struggle to keep access open through the Affordable Care Act implementation and the education of our communities on multiple areas regarding human rights. There is a lot of awareness from the policy makers that education, environment and social determinants affect health, yet we continue to see the reliance on a single scope approach to diagnostic and treatment of illness. The entire causes of poor health are never completely addressed by the health care industry.

It is important for people to understand the struggles we have experienced in the Winter Garden region due to mistrust based on ethnicity and how civic engagement helped us to win some status in political life for the first time. Awareness of where we stand in society is important but more important is to engage to change our situation.

Understanding the disparities in the way we think about health and doing something about it from the patient perspective is also important. That is why the engagement of collaborative interventions between those affected by the lack of good health and research are important.

Collaboration is hard amongst the established health care industry and the people who are treated as “patients” whom considered subjects in the system. So, the change must come slowly by bringing awareness and consciousness about the things that do work to improve holistic health in a rural community.

The continuity of grass root efforts need to be supported by academia as research questions are developed around people centered approaches to empower patients to reach physical, economic and emotional health through institutional change.

3.2. Citizen scientist: Frio County, TX

Since 2009, there has been a quiet revolution going in our rural community of Frio County, Texas. Every month since 2009 we have met with our affiliated UTHSCSA agency, the South Central AHEC, to build an infrastructure of community health improvement in spite of our very low income, under resourced environment. This initiative was due to leaders of the CTSA at UTHSCSA/IIMS who worked with us to build resources that otherwise we would not have had and would have built a sustaining effort as we currently enjoy. We are not stakeholders in our community; that puts too much pressure on us because we aren’t elected or chosen by any group to represent them. But we want to be good citizens to contribute to science, so we call ourselves “citizen scientists”.

So how did we get started as a Citizen Science group? Well, our UTHSCSA partner met with a small group of us to discuss the opportunity to form a community group that would work with them on translational science. We brainstormed a list of others who would have interest, set a date to meet and met to discuss the opportunity. We were first struck by the fact that those we invited were not all health professionals. Numbering 37 participants, we had school teachers, extension agents, pastors, real estate agents, police officers, farmers/ranchers, retired people and local business people (tow truck driver, school bus drivers, restaurant workers etc.) in addition to doctors, nurses, social workers and PAs. We met around a meal that the UTHSCSA provided and our first meeting was a facilitated meeting which kept us on track. It lasted 2 h, but we stayed past our time because we all knew each other; many of the original group have dropped out for a number of reasons, but

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