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Into Practice

Methods for engaging stakeholders in comparative effectiveness research: A patient-centered approach to improving diabetes care



Julie A. Schmittiel^{a,*}, Jay Desai^b, Emily B. Schroeder^c, Andrea R. Paolino^c, Gregory A. Nichols^d, Jean M. Lawrence^e, Patrick J. O'Connor^b, Kris A. Ohnsorg^b, Katherine M. Newton^f, John F. Steiner^c

^a Division of Research, Kaiser Permanente Northern California, 2000 Broadway, Oakland, CA 94612, USA

^b HealthPartners Institute for Education and Research, Minneapolis, MN, USA

^c Kaiser Permanente Colorado Institute for Health Research, Denver, CO, USA

^d Kaiser Permanente Center for Health Research, Portland, OR, USA

^e Department of Research & Evaluation, Kaiser Permanente Southern California, Pasadena, CA, USA

^f Group Health Research Institute, Seattle, WA, USA

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ABSTRACT / IMPLEMENTATION LESSONS

- Engaging stakeholders in the research process has the potential to improve quality of care and the patient care experience.
- Online patient community surveys can elicit important topic areas for comparative effectiveness research.
- Stakeholder meetings with substantial patient representation, as well as representation from health care delivery systems and research funding agencies, are a valuable tool for selecting and refining pilot research and quality improvement projects.
- Giving patient stakeholders a deciding vote in selecting pilot research topics helps ensure their 'voice' is heard.
- Researchers and health care leaders should continue to develop best-practices and strategies for increasing patient involvement in comparative effectiveness and delivery science research.

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1. Background

Diabetes mellitus is a chronic health condition affecting more than 29 million people in the United States.¹ Diabetes has a profound negative impact on patient clinical outcomes and quality of life, and is costly to individual patients, their families, and society at large.^{2,3,4,5,6,7} Diabetes poses enormous challenges for both individuals with diabetes and the health care system. Individuals and their caregivers must manage diet, exercise, medications, and self-monitoring on a daily basis.⁸ In turn, the health care system must coordinate the efforts of multiple clinical disciplines to support patients and prevent serious and costly complications.

Comparative effectiveness research (CER) has the potential to improve the effectiveness and safety of diabetes care. The key goals of CER are to enhance the ability of patients, providers, delivery systems, and policy-makers to make evidence-based health care decisions, and to improve health care delivery and

outcomes.⁹ Patient-centered outcomes research (PCOR) is a type of CER that places a strong emphasis on input from a wide variety of health care stakeholders, especially patients, into research design, conduct, analysis, and translation.¹⁰ Many experts have suggested that PCOR's emphasis on stakeholder input into the research process makes research more robust and relevant, and increases the wide-scale implementation of evidence-based findings into health care practice.^{10,11} The creation of the Patient Centered Outcomes Research Institute (PCORI) through the passage of the Affordable Care Act (ACA) in 2010 underscores the commitment of policy makers to involve patient stakeholders in PCOR,¹⁰ and PCORI's "Methodology Standards" specifically require that investigators provide evidence of patient involvement in creating research questions and appropriate study designs.¹²

Despite the call for increasing the involvement of patients and other stakeholders in the research process, there are very few specific guidelines or strategies for health care researchers developing plans to actively engage stakeholders in the research design process. Methods and best-practices for obtaining stakeholder guidance on shaping critical CER questions for improving patient

* Corresponding author. Tel.: +1 510 891 3872; fax: +1 510 891 3606.

E-mail address: Julie.A.Schmittiel@kp.org (J.A. Schmittiel).

care, particularly for diabetes and other chronic conditions, are largely unknown.¹³ The purpose of this paper is to outline an evidence-based process for seeking input from patients and other stakeholders in shaping critical CER questions for diabetes. This process may provide a useful, replicable template for other researchers seeking to engage stakeholders in the CER design and implementation process.

2. Organizational context

The SURveillance PREvention and ManagEment of Diabetes Mellitus (SUPREME-DM) network was funded by the Agency for Health Care Research and Quality (AHRQ) from 2010 to 2013 through AHRQ's "PROspective Outcome Systems using Patient-specific Electronic data to Compare Tests and therapies (PRO-SPECT)" initiative to develop and enhance CER data infrastructure and methods. The aims of the original SUPREME-DM study were to develop a multi-site data resource and investigator network for conducting high quality CER in diabetes,¹⁴ and to leverage this data resource to conduct surveillance and CER studies. SUPREME-DM studies include efforts to better define the incidence and prevalence of diabetes in adults and youth,^{15,16,17,18} assess temporal trends in diabetes complications, evaluate patterns of prescription medication use, initiation, intensification,^{19,20,21} describe racial and ethnic disparities in care, evaluate quality measures,²² examine pediatric diabetes care transitions, and advance CER methods for diabetes studies.^{23,24,25,26} SUPREME-DM also conducted an observational CER study comparing the effectiveness of different counseling and referral strategies for women with gestational diabetes mellitus (GDM), and a cluster randomized CER trial of telephone outreach to improve adherence to newly-prescribed diabetes medications.

The SUPREME-DM CER data resource for conducting these studies is known as the DataLink, which includes a defined population of almost 1.3 million patients with diabetes across 11 HMO Research Network (HMORN) integrated health care delivery systems in the US.¹⁴ The DataLink is a robust, geographically distributed research resource that combines patient demographic, health care utilization, diagnosis, procedure, medication, and laboratory data from EHR and other clinical and administrative databases. While the DataLink leverages diverse clinical data sources to advance CER in diabetes care and prevention, it currently includes few patient-reported outcomes (e.g. self-reported depression or diabetes distress measures are not available), and the studies conducted as part of the original SUPREME-DM grant were designed and implemented without input from stakeholders outside of the research team.

3. Personal context

Kaiser Permanente (KP) Colorado is the lead site for the SUPREME-DM study, with John Steiner, MD, MPH, Senior Director of the KP Colorado Institute for Health Research, serving as Principal Investigator, and Andrea Paolino, MA, serving as the study's senior project manager. Dr. Steiner and Ms. Paolino worked closely with a subset of original SUPREME-DM research team members across 6 sites (Jay Desai, PhD, Emily Schroeder, MD PhD, Katherine Newton PhD, Jean Lawrence ScD MPH MSSA, Gregory Nichols PhD, Patrick O'Connor, MD MPH, and Julie Schmittiel PhD) to develop and implement a strategy to enhance SUPREME-DM's capabilities to conduct patient-centered CER in diabetes.

4. Challenge/problem

In 2013, AHRQ released a "limited competition" Funding Opportunity Announcement (FOA) for grantees from PROSPECT and other large, AHRQ-funded CER research grants. This "Enhancing Investments in Comparative Effectiveness Research Resources" FOA called for proposals to use a stakeholder engagement process to "(1) understand stakeholder needs in order to develop new comparative effectiveness research questions for which future research could fill important knowledge gaps and generate critical insights on the clinical effectiveness and comparative clinical effectiveness of health care interventions; (2) enhance the current data infrastructure and move toward sustainability through developing the ability to address these additional stakeholder-relevant questions." The proposals were designed to fund primary data collection (including stakeholder input) and exploratory pilot projects, and were required to have a full project timeline no longer than 18 months.

Upon receiving an award through this mechanism in September 2013, our first challenge was to develop a stakeholder engagement process that would provide meaningful insight into the key patient-centered questions for diabetes CER. Our second challenge was to use this information to develop CER/PCOR pilot projects that would help enhance the SUPREME DM DataLink's usefulness for conducting patient-centered research, and facilitate the DataLink's long-term sustainability. We set out to create a strategy to include patients in outlining critical needs in CER/PCOR that was innovative, comprehensive, meaningful, and fast, and that would provide a template for patient stakeholder engagement that could be used by the SUPREME-DM research team and others in future research.

5. Solution

We developed a 5-step approach to engaging a diverse set of stakeholders to help us identify and prioritize CER questions that are most relevant to diabetes care and prevention, and guide the enhancement of the infrastructure and sustainability of the DataLink: a diagram outlining these steps is included as Fig. 1. This participatory research-based process¹¹ was modeled on five key principles of engaging a wide range of stakeholders in CER: ensuring balance among stakeholders; helping stakeholders understand their role in the process; providing neutral, expert facilitators for key discussions, and engaging participants throughout the research process.²⁷ In addition, we sought to combine both qualitative and quantitative methods to gather stakeholder input.¹³ Our first step was to develop and administer an internet-based survey of

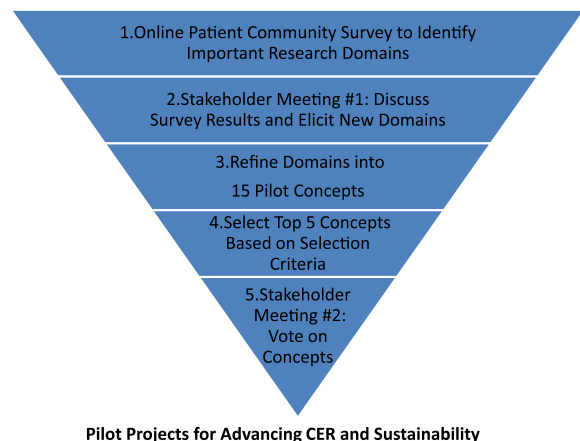


Fig. 1. Five step process to design pilots for diabetes CER/PCOR research.

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