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Patient-Centered Priorities for Improving Medication Management and Adherence

Carmit K. McMullen, PhD¹, Monika M Safford, MD², Hayden B. Bosworth, PhD³, Shobha Phansalkar, RPh, PhD^{4,5}, Amye Leong, MBA⁶, Maureen B. Fagan, DNP, MHA⁷, Anne Trontell, MD, MPH⁸, Maureen Rumpitz, PhD¹, Meredith L. Vandermeer, MPH¹, the Centers for Education and Research on Therapeutics (CERTs) Patient-Centered Medication Management (PCMM) Workshop Working Group, William B. Brinkman, MD, MEd, MSc⁹, Rebecca Burkholder, JD¹⁰, Lori Frank, PhD¹¹, Kevin Hommel, PhD⁹, Robin Mathews, MD³, Mark C. Hornbrook, PhD¹, Michael Seid, PhD⁹, Michael Fordis, MD¹², Bruce Lambert, PhD¹³, Newell McElwee, PharmD, MSPH¹⁴, and Jasvinder A. Singh, MD, MPH^{2,15}

¹Center for Health Research, Kaiser Permanente Northwest, Portland, OR

²Division of Preventive Medicine, Department of Medicine, University of Alabama at Birmingham, Birmingham, AL

³Duke University, Durham, NC

⁴Partners Healthcare Systems, Inc., Wellesley, MA

⁵Brigham and Women's Hospital and Harvard Medical School, Boston, MA

⁶Healthy Motivation, Santa Barbara, CA

⁷Center for Patients and Families, Brigham and Women's Hospital and Harvard Medical School, Boston, MA

⁸Agency for Health Care Research and Quality, Rockville, MD

⁹Cincinnati Children's Hospital and Medical Center, Cincinnati, OH

¹⁰National Consumers League, Washington, DC

¹¹Patient-Centered Outcomes Research Institute, Washington, DC

¹²Baylor College of Medicine, Houston, TX

¹³Center for Communication and Health, Northwestern University, Chicago, IL

¹⁴Merck & Co., Inc., New York, NY

¹⁵Birmingham Veterans Affairs Medical Center, Birmingham, AL

Abstract

Objective—The Centers for Education and Research on Therapeutics convened a workshop to examine the scientific evidence on medication adherence interventions from the patient-centered

perspective and to explore the potential of patient-centered medication management to improve chronic disease treatment.

Methods—Patients, providers, researchers, and other stakeholders (N=28) identified and prioritized ideas for future research and practice. We analyzed stakeholder voting on priorities and reviewed themes in workshop discussions.

Results—Ten priority areas emerged. Three areas were highly rated by all stakeholder groups: creating tools and systems to facilitate and evaluate patient-centered medication management plans; developing training on patient-centered prescribing for providers; and increasing patients' knowledge about medication management. However, priorities differed across stakeholder groups. Notably, patients prioritized using peer support to improve medication management while researchers did not.

Conclusion—Engaging multiple stakeholders in setting a patient-centered research agenda and broadening the scope of adherence interventions to include other aspects of medication management resulted in priorities outside the traditional scope of adherence research.

Practice Implications—Workshop participants recognized the potential benefits of patient-centered medication management but also identified many challenges to implementation that require additional research and innovation.

1. Introduction

More than half of American adults take at least one prescription drug, and 1 of 10 take five or more [1]. As the U.S. population ages and as the number of individuals with multiple chronic conditions increases [2], poor adherence to medication regimens to treat chronic disease will pose a public health challenge of increasing significance. Optimal use of medications to manage chronic conditions can improve patient outcomes and decrease the costs of health care; however, suboptimal medication adherence is pervasive and results in poor health outcomes. An estimated \$105 – \$290 billion is spent annually in avoidable health care costs related to poor adherence to medication regimens [3–7]. Reasons for low adherence include poor prescribing practices, as well as patient concerns about cost, bothersome side effects, burdensome regimens, absence of chronic disease symptoms, doubts about effectiveness of medications, and low health literacy [8]. Prior work has shown that 20 to 30 percent of prescriptions are never filled. Of those that are filled, about half of medications for chronic disease are not taken as prescribed [9].

The findings on medication adherence are especially disappointing given the vast literature on the topic. Adherence research has largely focused on determinants of successful or unsuccessful medication-taking behavior as well as methods to improve patients' medication taking. Furthermore, previous research has assumed that prescribers' recommendations constitute instructions that patients are simply expected to follow—hence the somewhat paternalistic terms “compliance” and “adherence” that predominate the literature [10]. However, the relatively modest progress on improving medication adherence, despite decades of research on the topic, has led researchers, clinicians, patients and other stakeholders to seek additional perspectives. New opportunities to improve medication management could arise by placing the individual patient in the center of decisions [11–15].

Such patient-centered care “is respectful of and responsive to individual patient preferences, needs, and values, and ensure[s] that patient values guide all clinical decisions.”[16] In the context of medication use, a patient-centered approach suggests that improving medication use is not entirely about getting patients to simply follow a provider’s plan, to take more medicines, or to take their medicines more often [17;18]. Instead, efforts should focus on delivering care in a way that incorporates patient beliefs, preferences, goals, practical realities, and concerns into decisions and practices that support appropriate medication prescribing and use [19].

A growing literature explores tailoring medications to patient goals, as well as using shared decision-making in the context of medication therapy for chronic disease [20] to engage patients in prescribing decisions. Two recent systematic reviews of interventions to improve adherence to medications prescribed for chronic conditions found mixed results [21–23]. The most successful interventions were multi-modal, high-intensity, and personalized. The finding that personalized interventions are more effective suggests that patient-centered care may offer a way to further improve medication management. Additional research is needed to determine whether patient-centered medication management can improve health outcomes and whether such management can be accomplished in ways that are feasible, cost-effective, scalable and sustainable.

The potential for patient-centered approaches to improve medication outcomes for people with chronic illness prompted a diverse group of therapeutics researchers funded by the Agency for Healthcare Research and Quality (AHRQ)—the Centers for Education and Research on Therapeutics (CERTs)—to convene a two-day workshop in October, 2012 to evaluate how medication adherence interventions could be more patient-centered. An early decision was made to engage other key stakeholders to collaboratively identify and prioritize research and practice needs related to medication adherence. Drawing on the scientific literature (Kuntz et al., manuscript submitted for publication along with this manuscript) and their own expertise in health services research, social science, and analytical methods, conference organizers identified a broad scope of activities for consideration that, in addition to medication-taking behavior (the traditional scope of adherence research), included shared decision-making, methods to enhance effective prescribing, and systems for eliciting and acting upon patient feedback about medication taking and treatment goals (see Figure 1). We refer to this set of activities as patient-centered medication management (PCMM). Next, we convened a workshop at which patients, caregivers, providers, product makers, payers, purchasers of health care, research funders, policymakers, and researchers shared their expertise and perspectives, then collectively identified and prioritized knowledge gaps needing further research and action. This paper reports the key priorities nominated by workshop contributors. We also present themes about PCMM that emerged from qualitative analysis of recordings and transcripts from workshop discussions. Finally, we reflect on our process for engaging diverse stakeholders in shaping patient-centered research.

2. Methods

2.1. Goal of the workshop

The goal of the workshop was to identify and prioritize opportunities to advance PCMM by convening diverse stakeholders involved in prescribing and/or medication taking.

2.2. Pre-workshop activities

The workshop was planned by a steering group composed of 11 CERTs investigators who have worked on medication adherence from a variety of scientific perspectives (medicine, pharmacy, informatics, epidemiology, and social science) as well as two patient representatives who have personal and advocacy experience with arthritis and juvenile diabetes. The steering group developed definitions of PCMM and its components, and used PCMM to guide a literature review as well as the workshop's agenda and prioritization process. The steering group also identified potential workshop participants. In alignment with Concannon's (2012) list of key stakeholders for patient-centered outcomes research, the steering group invited 23 thought leaders representing the following constituencies: patients/patient advocates, caregivers, providers, payers, researchers, funders, product makers, policymakers/consumer advocates, and purchasers of health care. We selected individuals who had been nominated by CERTs researchers from across the United States as experts on patient-centered care and medication management. Fifteen attended the workshop or sent an equally knowledgeable colleague from their organization. In addition, 22 CERTs-affiliated researchers participated in the meeting, including 9 steering group members. Table 1 summarizes self-identified primary stakeholder perspectives (e.g., one workshop attendee identified herself primarily as a researcher, but also as a funder and a patient).

2.3. Workshop activities

The workshop combined presentations and group discussions on pre-selected topics, followed by a period of voting to establish research and practice priorities (Figure 2). We modeled the workshop on approaches to consensus building, data collection, and analysis described elsewhere [24–26]. On the first day of the workshop, there were three presentations: 1) a review of the current literature on patient-centered interventions to improve medication management (Kuntz et al., manuscript submitted for publication, in parallel); 2) a review of social science research about the lived experience of chronic illness [19;27–29]; and 3) a discussion by a panel of five patients, caregivers, and patient advocates about how to improve medication management. The presentations were followed by small-group discussions with reports back to the entire group. Small groups designed to achieve diverse stakeholder perspectives were assigned one or two of four PCMM areas, matched to participants' areas of expertise as much as possible: 1) shared decision-making and patient feedback, 2) effective prescribing, and 3) medication-taking behavior. At the end of the day, each group produced a list of research questions or activities in its content area that might advance research and practice related to PCMM.

The following day, conference organizers reviewed the lists, eliminated duplicate items, refined wording and categorized the lists into broad, cross-cutting domains (i.e., methods and measures, policy, and education). Items in each domain were written on large sheets of

paper and were posted around the conference room. Attendees used stickers, with colors indicating their stakeholder perspective, to place a total of 6 votes on the agenda items they prioritized. Nine members of the CERTs coordinating center did not participate in the voting but did participate actively in other aspects of the workshop. Attendees were permitted to vote more than once for a single item to indicate a priority they felt was very important. Day 2 continued with a discussion of the priorities with the most votes overall and differences in stakeholder group priorities. The meeting concluded with each attendee providing his or her “takeaway” messages about the workshop. During the workshop, large-group discussions were tape-recorded, and small-group session recommendations were captured on large sheets of paper.

2.4. Data analysis

2.4.1. Stakeholder voting results—We asked attendees to list their primary perspective as stakeholders, in addition to other perspectives that shaped their contributions to the workshop. For example, someone whose primary contributions reflected the research perspective could acknowledge a secondary perspective as a provider. We tabulated votes according to each voter’s primary stakeholder perspective. We edited the wording of items for clarity and brevity and grouped some very similar items under more general headings. For example, three very specific items relating to the need for more epidemiologic knowledge about long-term medication use were combined under the more general heading of “improve epidemiologic knowledge of long-term medication-taking behavior.”

2.4.2. Theme analysis—We transcribed and analyzed digital recordings. Using a grounded theory approach to theme identification, we created a list of all discussion topics [30]. We reviewed and consolidated the list of topics into more than 100 themes. Each theme was noted as an individual row in a spreadsheet, and the first author led a multidisciplinary team in a virtual card-sort exercise over the course of several webinars. We grouped similar themes and then assigned names to the groups of themes. The sorting process resulted in a three-part taxonomy of considerations for advancing PCMM in research and practice.

3. Results

3.1. Stakeholder voting results

Ten categories of priorities emerged from the workshop. These are listed in Table 2, ranked according to total number of votes for each priority. Table 2 also includes the number of votes for each priority by stakeholder group and a representative selection of items in each category. Table 3 shows the rank order of each priority according to stakeholder group: researchers, patients, and all other stakeholders. We deemed the top four ranked priorities within each group as “high priority.” Accordingly, three priorities were highly rated by all types of stakeholders: 1) creating tools and systems to facilitate and evaluate patient-centered medication management plans; 2) developing patient-centered prescribing curricula for providers (physicians, physician assistants, and nurses); and 3) increasing patient knowledge about medication management to improve health outcomes. Other priorities rated highly were: changing the culture of health care to focus on creating and maintaining health

as opposed to treating disease; defining patient-centered goals and measures; and involving peers, family and social networks in PCMM.

We found notable differences among stakeholder groups. As shown in Table 3, researchers' second-ranked priority—"improve epidemiologic knowledge of long-term medication-taking behavior"—was ranked as relatively unimportant by the other two groups: fifth by patients and seventh by other stakeholders. A group composed mostly of individuals engaged in the business of delivering health care ranked the category "define patient-centered goals and measures" as its third-highest priority. In contrast, patients and researchers ranked this category seventh. Finally, as Table 2 shows, while patients cast 17% of their total votes for efforts to incorporate peers, family, and social networks into medication management efforts, only 4% of researchers cast votes for this category.

3.2. Theme analysis: Workshop discussion topics

Our thematic analysis of transcripts and notes from workshop discussions revealed a wide range of issues to consider in research and implementation of PCMM. We clustered these topics into three overarching themes:

1. What is patient-centered health care?
2. Why is PCMM needed? (See Table 4);
3. How can we develop, evaluate and implement PCMM?

3.2.1. What is patient-centered health care?—Workshop participants, especially patients, emphasized that engaging them in health care (and health care improvement) is a critical component of medication adherence. One patient advocate stated:

“Patient-centeredness means patients have the support to do what we need to do to care for ourselves and use health care as a tool for us to live as well as we can for as long as we can.”

Other patient representatives reported that engagement should involve recognizing patients' expertise, being sensitive to the diversity of patients' preferences, and understanding how outcomes that matter to patients can differ from those that matter to clinicians. In terms of prescribing, participants noted that therapeutic goals should be attainable by patients given their specific circumstances, and that a patient-centered health care system should seek out and actively remove barriers to accessing health care and successful medication-taking. Another discussion topic explored the importance of teaching people how to become informed and engaged patients, perhaps even as part of primary or secondary school education.

3.2.2. Why is PCMM needed?—Extensive discussions highlighted several justifications for a broad, patient-centered approach to medication management: 1) to provide information that makes sense to patients; 2) to enhance patient-provider communication and to build trust; 3) to understand the differences between disease-oriented prescribing and person-oriented prescribing; 4) to create a health care system that is more supportive of patients;

and 5) to better understand and overcome the challenges of evidence-based prescribing. More details about these reasons for PCMM are noted in Table 4.

3.2.3. How can we develop, evaluate, and implement PCMM?—Participants offered several policy-relevant insights to guide implementation of PCMM. First, there is a need to find opportunities for alignment between the often conflicting goals of standardized and personalized health care; finding a balance can be challenging at both the system and provider-patient level. Patient-centered care requires incorporating individual goals and preferences into care, but implementing such variability may burden providers and health systems. Workshop participants recognized the challenge of generalizing individualized patient care on a broader scale. For example, one provider commented:

“Providers in the fee for service world are even just struggling to identify who’s had a recent ER visit, and why [the patient came in]... So for me, as a provider [questions like] how are you doing on your medication today? Are you doing okay? What information do you need from me? How can I help you? Those are things that are not on the trigger list as far as looking at you medically in a patient centered fashion.”

Innovative solutions, including those that make use of information technology and new forms of communication, are needed. Indeed, interventions at the health system or provider level may be as important as those that focus on patients or provider-patient communication. As one participant noted,

“Not everything we discussed as being patient-centered is directly aimed at the patient.” (Researcher)

Participants also emphasized the need to recognize heterogeneity in health care contexts, such as differences between fee-for-service and integrated health systems. Integrated systems that combine medical care, health education, case management, and pharmacy services potentially offer easier entry points to advancing PCMM, but for PCMM to have real impact we will need to test interventions in fee-for-service, mail-order pharmacy, retail pharmacy, and other contexts.

4. Discussion and Conclusion

4.1. Discussion

In an effort to rethink medication taking in the context of chronic disease from a patient-centered perspective, we considered processes outside of the traditional purview of medication adherence, including shared decision-making and incorporation of patient feedback in therapeutic plans, and effective prescribing. Multiple stakeholders gathered to create a research agenda and call for action to advance PCMM.

Priorities that received strong overall endorsements from all stakeholders were: create tools and systems to facilitate and evaluate PCMM plans; develop patient-centered prescribing curricula; and increase patient knowledge about medication management. A majority of the workshop participants deemed the latter two critically important. The suggestion to incorporate patient-centered training into providers’ training and continuing education in

order to enable them to be patient-centered prescribers is consistent with the American Association of Medical Colleges' 2008 recommendation that improvements are necessary to train physicians in safe and effective prescribing practices [31;32]. Consensus on some priorities may be difficult to achieve, as reflected in the differences in prioritization across stakeholder groups. Among stakeholders who were not patients or researchers, the perceived need for tools to identify and measure patient-centered goals may reflect the challenges of implementing customized processes in large-scale health care operations, which are less salient for researchers and patients. Also, while patients and "other" stakeholders prioritized using social networks to advance PCMM, researchers did not rate this area as high priority. This suggests that the promise of interventions that use social networks and peer support represent is being overlooked by researchers. Finally, researchers' second-rated priority, improving epidemiologic knowledge of long-term medication taking behavior, was not highly ranked by other stakeholder groups (Table 3) and may reflect the dominance of quantitative pharmacoepidemiologists among the workshop participants.

The fact that a top priority of researchers was not highly ranked by others illustrates that an agenda that results from engaging multiple stakeholders—and not only patient stakeholders—is likely to differ substantially from an agenda set solely by researchers. The results of this workshop demonstrate a concrete, feasible process for actively engaging patients and non-researcher stakeholders to ensure integration of their needs into research.

Thematic analysis of workshop discussions highlighted: 1) what patient-centered health care is, 2) why PCMM is needed, and 3) how to develop, evaluate, and implement PCMM. Each of these issues is relevant for current policy debates, and workshop discussions emphasized the centrality of medication management for improving health care quality.

Including patients in the pre-workshop planning substantively informed the workshop and also the development of the innovative, expanded PCMM framework that extends beyond patients' medication-taking behavior. Including patients in the planning and conceptualization of priority-setting activities should be replicated in future similar efforts.

Participants made several observations about the workshop process that are worth noting. They recognized the complexity of medication management and the benefits of engaging multiple stakeholders to improve it. Participants were energized by the productive debate and insights they gained because many types of stakeholders were present, and they recognized the strength of the multiple-stakeholder approach. Despite their disciplinary and experiential differences, workshop participants were open to new ways of conceptualizing medication adherence and were able to communicate well in workshop discussions. Participants also affirmed efforts such as those initiated by the Patient-Centered Outcomes Research Institute (PCORI; www.pcori.org) and AHRQ's Effective Healthcare Program (www.effectivehealthcare.ahrq.gov) that are changing the process of determining health policy, quality improvement efforts, and research priorities by including the voices of patients and other stakeholders. Our experience showed that a diverse-stakeholder workshop is both feasible and important. The workshop composition and process could be considered as a model for similar health-related priority setting efforts.

Participants also noted several significant challenges with the workshop process and its results. First, a solid conceptual framework for PCMM is lacking. The proceedings revealed that the framework developed in preparation for the workshop was less than optimal, in part because the boundaries between PCMM activities and their inter-relationships were unclear. For example, the framework did not specify the boundary between shared decision-making and effective prescribing, or show the flow of activities from one PCMM component to the next. Second, multiple stakeholder engagement is resource-intensive. Providers, patients, advocates, and community leaders have limited time, energy, and financial resources to dedicate to agenda-setting activities. Third, patients' expertise needs to be recognized in discussions and processes that have traditionally been limited to clinical and scientific experts. Neglecting the value of patient experiences and expertise in all phases of research can result in failure to identify and advance patient-centered research. Fourth, progress can be slow. Participants in our workshop reflected on the high energy generated by a presentation that questioned the validity of medication adherence as a concept and shared social science approaches to medication taking and their direct relevance to patient experience. But they also observed that when it was time to generate research questions, participants retreated to more familiar territory. At the end of the conference, many participants were somewhat disappointed by the "mainstream" research questions that were generated in the prioritization exercise. This was a very important outcome of the workshop — the recognition of how challenging it will be to move away from familiar and comfortable paradigms toward new ways of conceptualizing, researching and delivering health care.

4.1.1. Limitations—The workshop outcomes suggest areas for future research and action, but they represent only a first step in reframing medication adherence so that it is patient-centered. The workshop attendees raised many questions and suggested activities that were not fully formulated. Further work will be required to delineate, generate consensus and add specificity to the issues raised and to take appropriate next steps. The guiding framework we developed to describe PCMM will also need refinement.

It should be noted that, while we aimed to represent the viewpoints of diverse stakeholders in our work, we found it difficult to find payers who were available to attend the workshop, and some representatives of funding agencies were precluded from participating due to government travel restrictions. In addition to patients or patient advocates, we also would have benefited from including additional consumer advocates, who aim to ensure a fair health-care marketplace, transparency of information, product safety and other consumer protections, rather than having direct experience with a disease or condition, per se. Both patient advocate and consumer advocate perspectives are valuable and needed, and probably should be distinguished rather than collapsed into one category. Methodologically, the workshop's process was less formal than a traditional Delphi approach to drawing consensus, which could have generated different results. A different set of stakeholders could have also reached different conclusions. Further efforts to elicit perspectives from these constituencies would be warranted.

4.2. Policy Implications

Our results have implications for policy efforts to address a significant public health problem: poor medication adherence in the context of chronic disease treatment. There are currently a number of policy initiatives aimed at improving adherence. These include: Medicare star ratings, patient-centered medical homes, meaningful use of health information technology (HIT), medication therapy management, and risk-sharing incentives by accountable care organizations (ACOs). None of these initiatives, with the exception of the patient-centered medical home, puts patient-centered care at the core.

There are a number of adherence-oriented coalitions, campaigns, and research groups—NIH Adherence Research Network [33], the National Consumers League Script Your Future campaign [34], the Medication Adherence Alliance [35], the National Council on Patient Information and Education (NCPPIE) [36], nonprofits such as NEHI [37], the Office of the Surgeon General [38], and Prescriptions for a Healthy America [39]. Only some of these groups were represented at the workshop (National Consumers League, Medication Adherence Alliance). To follow up on the workshop recommendations, the CERTs sponsored a meeting in Rockville, MD, in March 2014. More than 60 diverse stakeholders (including most of the national medication adherence initiatives listed above, as well as patients and researchers) attended the two-day meeting to discuss patient-centered approaches to appropriate medication use. Specific topics ranged from the role of health information technology to health literacy. The goals of the meeting were to: foster a patient-centered perspective on medication use; share perspectives on needed innovations in terms of policy, intervention, and research, as well as available resources; identify key priorities for action; and determine interest in continued collaboration. A number of these initiatives incorporate patient perspectives in their efforts, and our process and findings suggest promising areas of continued policy and advocacy work.

4.3. Conclusion

The priorities and considerations identified in our multi-stakeholder workshop, as well as the process we used for engaging multiple stakeholders' perspectives, suggest a roadmap for multiple stakeholders to engage, educate, and support patients in addressing chronic disease management.

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Patient-Centered Medication Management (PCMM)

Shared decision-making & patient feedback

- Process resulting in decisions made collaboratively by providers and patients, informed by the best evidence available, and weighted according to the specific characteristics and values of the patient. The goal of shared decision-making in medication management is to attain concordance, or equal buy-in, between provider and patient in regard to treatment goals and plan.
- Ongoing decision-making is facilitated by the patient's ability to communicate with the provider as unanticipated barriers or new questions about their treatment regimen arise. Feedback is followed by an efficient process to modify the treatment plan if needed.

Effective prescribing

- Process by which a provider selects the best medication regimen for accomplishing clinical and patient-centered goals after weighing shared decision making information. Effective prescribing also results in patient understanding of how, when, and why the medication is to be taken.

Medication taking behavior

- Healthcare system processes and designs that help patients with their medication taking behavior at home, including strategies such as reminders and automated refills. This medicine-taking behavior is what has traditionally been viewed as "adherence."

Figure 1.

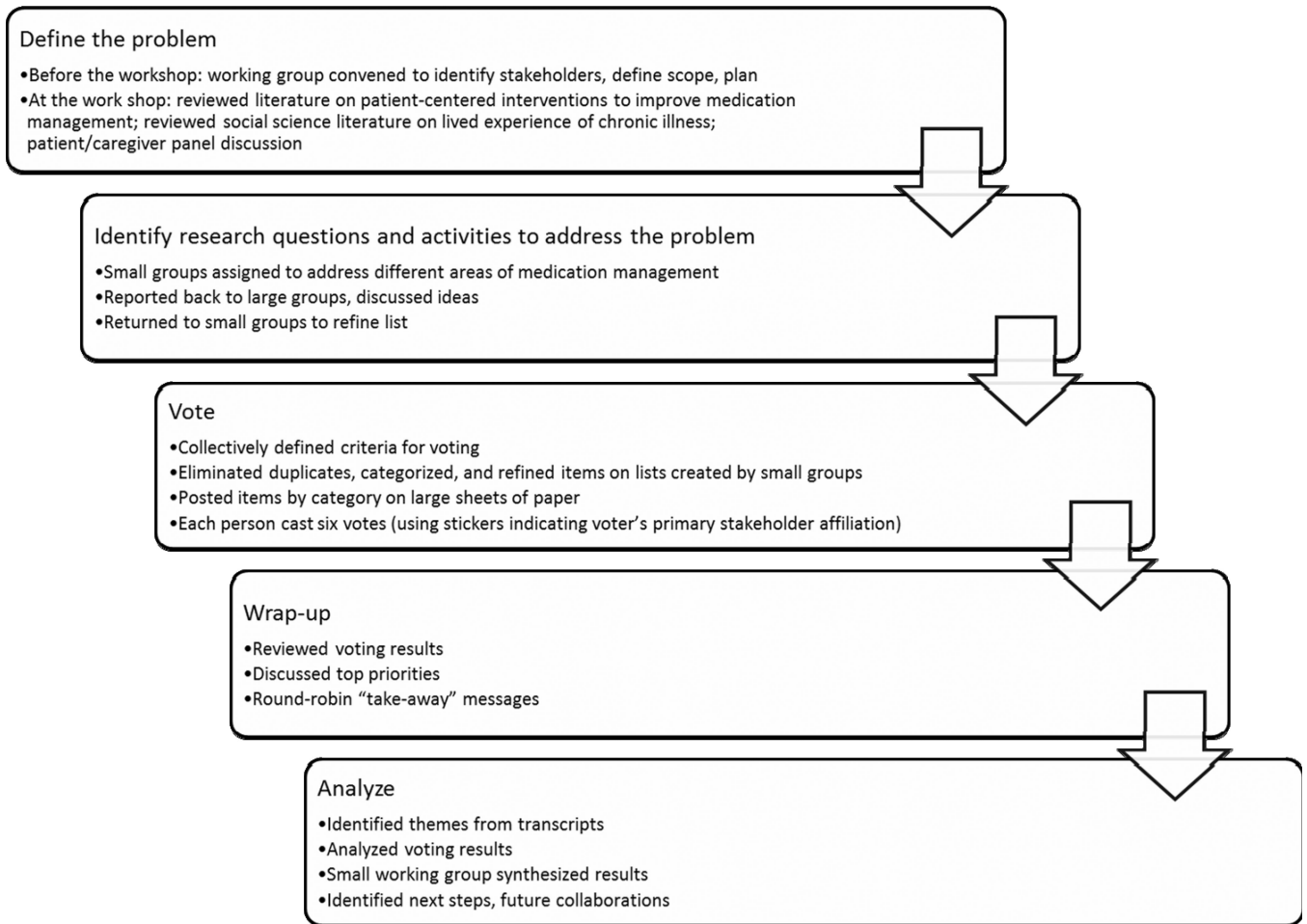


Figure 2.

Table 1

Primary Stakeholder Group Represented by Workshop Participants

Stakeholder Category	Primary Perspective (n=28 [*])
Patient/Patient Advocate ¹	5
Payer ²	1
Policy Maker ³	2
Product Maker ⁴	2
Provider ⁵	3
Researcher ⁶	13
Funder ⁷	2

* Does not include 9 Steering Group members from Center for Health Research, Kaiser Permanente Northwest (8) and Baylor College of Medicine (1)

¹ – Three patients/patient advocates, two caregivers

² – Aetna, Inc.

³ – AARP; National Consumers League

⁴ – Surescripts; Merck & Co., Inc.

⁵ – Brigham & Women's Hospital; Duke Cardiology; Group Health Cooperative

⁶ – Partners Healthcare; Indiana University School of Medicine; Cincinnati Children's Hospital Medical Center (2); Department of Veterans Affairs; Duke University School of Medicine; Northwestern University; Rutgers University (2); University of Alabama at Birmingham (2); University of North Carolina at Chapel Hill; University of Illinois at Chicago

⁷ – Patient-Centered Outcomes Research Institute; Agency for Healthcare Research and Quality

Table 2

Vote Totals for Research Questions and Actions to Advance Patient-Centered Medication Management, by Self-Identified Stakeholder Group (see Table 1). (Each participant had six votes)

Category and illustrative research questions included within each category:	Total (N=168) n (%)	Researchers (N=78) n (%)	Patients (N=30) n (%)	Others (N=60) n (%)
Create Tools and Systems to Facilitate and Evaluate Patient-Centered Medication Plans <ul style="list-style-type: none"> Can these be tailored to the patient and/or to likely barriers to a medication plans' success? How can we overcome barriers to having meaningful conversations between patients and providers about how to manage the expected and unexpected challenges to successful medication management? How can we enable ongoing re-evaluation of a decision's effectiveness and alignment with changing patient values and preferences? How can we assess the effectiveness of prescriptions? By measuring adherence, clinical outcomes (or both)? How can we incorporate outcomes that are developed by a provider and patient based upon shared decisions and explicit desired outcomes? 	38 (22.6)	21 (26.9)	5 (16.7)	12 (20.0)
Develop Patient-Centered Prescribing Curricula <ul style="list-style-type: none"> What are the competencies for providers to improve effective patient-centered prescribing? How do we involve patients in the development of a provider curriculum and competency assessment? 	24 (14.3)	9 (11.5)	6 (20.0)	9 (15.0)
Increase Patient Knowledge about Medication Management to Improve Health Outcomes <ul style="list-style-type: none"> Does patient understanding of medications, risks and benefits, and treatment choices lead to better outcomes? Can we use direct-to-consumer advertising to empower patients about effective self-management of medications or to engage in more productive clinical communications? What are the competencies for chronically ill patients that will give them the ability to use medicine as a tool to take care of themselves? 	22 (13.1)	10 (12.8)	6 (20.0)	6 (10.0)
Improve Epidemiology of Long-term Medication-taking Behavior <ul style="list-style-type: none"> What is the trajectory of chronic medication-taking behavior and what factors affect the trajectory over a period of time? What are the risks and benefits of medications in patients on multiple medications, or with multiple concurrent conditions? 	20 (11.9)	12 (15.4)	3 (10.0)	5 (8.3)
Patient-Centered Medication Management Requires Change in the Culture of Health Care <ul style="list-style-type: none"> How does one change culture from providing care to patients to creating health with patients? 	17 (10.2)	8 (10.3)	3 (10.0)	6 (10.0)
Define Patient-Centered Goals and Measures in Research and Practice <ul style="list-style-type: none"> What are the outcomes of prescribing that matter to patients, and can we identify goals and measures of medication self-management that most patients agree upon? Can we identify and incentivize medication management measures and outcomes that are important for both health systems and patients? 	14 (8.3)	5 (6.4)	1 (3.3)	8 (13.3)

Category and illustrative research questions included within each category:	Total (N=168) n (%)	Researchers (N=78) n (%)	Patients (N=30) n (%)	Others (N=60) n (%)
<ul style="list-style-type: none"> How do we engage patients in creating research methods and outcomes that are patient-centered (in light of differing definitions of patient-centered research)? 				
Involve Peers, Family and Social Networks in the Solution <ul style="list-style-type: none"> Do online support communities work for impacting medication adherence? What are the best practices for incorporating peers and lay expertise into shared decision- making about medications and prescribing? 	14 (8.3)	3 (3.9)	5 (16.7)	6 (10.0)
Incorporate Patient Feedback into Medication Management <ul style="list-style-type: none"> What points or processes in the existing health care system offer opportunities for patient feedback on their medication-taking experience and help meet agreed-upon goals? 	10 (6.0)	6 (7.7)	1 (3.3)	3 (5.0)
Incorporate the Patient Experience of Medications into Research and Practice <ul style="list-style-type: none"> How do burden of disease and burden of care impact patient preferences and values and sense of self? 	4 (2.4)	3 (3.9)	0 (0)	1 (1.7)
Target Interventions by Prioritizing Populations and Allocating Resources <ul style="list-style-type: none"> How do we prioritize who should benefit from effective medication-taking interventions, which are multi-faceted and resource intensive? Can research help to identify highest risk patients using existing data systems? 	3 (1.8)	1 (1.3)	0 (0)	2 (3.3)
Other	2 (1.2)	0 (0)	0 (0)	2 (3.3)

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Table 3

Rank Order of Voting by Stakeholder Category (Researchers, Patients, and Other Stakeholders). Shaded cells show top 4 priorities for each group.

	Researchers	Patients	Other Stakeholders*
Create Tools and Systems to Facilitate and Evaluate Patient-Centered Medication Plans	1	3 (tie)	1
Develop Patient-Centered Prescribing Curricula	4	1 (tie)	2
Increase Patient Knowledge about Medication Management to Improve Health Outcomes	3	1 (tie)	4 (tie)
Improve Epidemiology of Long-term Medication-taking Behavior	2	5 (tie)	7
Patient-Centered Medication Management Requires Change in the Culture of Health Care	5	5 (tie)	4 (tie)
Define Patient-centered Goals and Measures in Research and Practice	7	7 (tie)	3
Involve Peers, Family, and Social Networks in the Solution	8 (tie)	3 (tie)	4 (tie)
Incorporate Patient Feedback into Medication Management	6	7 (tie)	8
Incorporate the Patient Experience of Medications into Research and Practice	8 (tie)		10
Target Interventions by Prioritizing Populations and Allocating Resources	10		9

*Two votes could not be categorized.

Table 4

Why Patient-Centered Medication Management is Needed: Themes from Workshop Discussions

Providing information that makes sense to patients
<p>“Give patients a fighting chance: talk to them; inform them.” (Patient advocate)</p>
<ul style="list-style-type: none"> • Risk information is not easily understood and patients do not make decisions using statistics. • Teach patients about psychosocial impacts of illness so they can be prepared for/manage them. • Use peer navigators as translators in health care interactions. • Look to successful technologies, social networks, and online communities. • Involve nurses and care teams more.
Enhancing patient/provider communication and building trust
<p>“When providers connect with patients, magic happens. But this happens when the patient stays for a long time and there is time to get to know the patient.” (Patient advocate)</p>
<ul style="list-style-type: none"> • Patient/doctor relationships do not have automatic built-in trust. This trust evolves, in part, through empathy and compassion. • Fragmented care and communication gaps frustrate and confuse patients and caregivers. • We should encourage relational, not transactional interactions in health care? • Patients and families should feel like they are really a part of the decisions being made. • Can providers learn to assess and incorporate patients’ and family members’ values in practice?
Prescribing to treat a whole person, not a disease
<p>“I could not do any of the things I used to ... as a young adult. The symptoms of my disease affected my identity.” (Patient advocate)</p> <p>“I think I take [my medicines] because of my loss of identity. If I take my meds, I look a little less like a patient.” (Patient advocate)</p>
<ul style="list-style-type: none"> • Symptoms and management of disease affect a patient's sense of personal identity. • Textbook examples of disease do not represent patients’ experience. • When unable to identify with a disease, patients may deny the disease and/or treatment. • Patients will take medications if doing so reinforces their sense of personal identity. We need to measure the lived experience of illness and suffering as well as we measure diagnoses and symptoms.
Creating a health care system that is more supportive of patients
<p>“Thousands of dollars’ worth of drugs and procedures that took hundreds of thousands of dollars of medical personnel to administer to me and the whole thing, the entire enterprise, rested on a skinny scared adolescent. ... I was just in awe how much responsibility is now “ours” in order to make our care successful.” (Patient advocate)</p>
<ul style="list-style-type: none"> • Patients are wholly responsible for managing their medications outside of hospital settings, and this can be overwhelming to patients. • Health system processes do not account for variability in patient experiences/preferences. • How can we make system changes so that more clinicians can practice patient-centered care?
Understanding the challenges of evidence-based prescribing
<p>“A peer has experience with medication, so you trust that. Much more than you would the provider ... who is basing the info on literature and statistics.” (Patient advocate)</p>

- Patients experiment with their medications but this is not studied.
- Need evidence about the effectiveness of different prescribing practices.
- Need standardized measures of adherence.
- Medical school curricula do not train physicians adequately in how to prescribe drugs.
- Need better evidence/guidelines to help reduce polypharmacy.
- Research on patients is prolific; research on prescribers is lacking.

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