



Partnering With Patients, Families, and Communities

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BACKGROUND AND OBJECTIVES: Collaborating with patients, families, and communities is a core principle of family medicine. However, the health care system in the United States has grown increasingly complex, fragmented, and difficult to navigate. This system, focused on disease-specific care delivered by specialists, often treats patients as the objects of care rather than as partners in care. Family Medicine for America's Health (FMAHealth) offers an opportunity to challenge the status quo in collaborative care through enhanced patient outreach and community engagement. With a central focus on improving health and achieving the Triple Aim, the FMAHealth initiative recognizes that successful transformation of the US health care system requires collaborative partnerships between clinicians, patients, families, and communities. Patient and population-level outcomes can be improved through shared decision making; application of new technology; and authentic partnerships with patient, families, and communities. Broader collaboration in practice transformation, research, and policymaking can lead to identification of common goals and mutually embraced transformation. The discipline of family medicine aspires to encourage patients, families, and communities to demand change as consumers, as citizens, and as voters.

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The health care system in the United States ranks lowest among other industrialized nations despite the highest per capita expenditures.¹ Improving the health care system requires balancing the interests of patients, providers, and payers in order to achieve the Triple Aim of better health, better health care, and lower costs.² In pursuit of the Triple Aim, Family Medicine for America's Health (FMAHealth) is dedicated to transforming the family medicine discipline through reformed payment policies, work force development and education, adoption of ever-evolving technologies,

and practice improvement including the patient-centered medical home (PCMH). FMAHealth acknowledges that truly transformative changes in the health care system can only occur if patients, families, and communities are embraced as partners and collaborators in care.

The discipline of family medicine is uniquely positioned to provide leadership for this transformation because of its commitment to care for families over the lifespan providing support as they navigate the broader health care system and tap into community-based resources. These trusted long-term

relationships serve as a foundation for partnerships that inform and mobilize health care improvement and transformation. Indeed, collaborating with patients, families, and communities is a core principle of family medicine. The very origins of the discipline, the 1967 Folsom Report³ describes the need for a "community of solution" to meet health challenges. One of the tasks put before the Folsom Group was to propose a more comprehensive means of providing health care. The Folsom Group envisioned a problem and its solution existing within a unique geographic, social, and political context and noted that the work of defining problems and finding solutions requires coordination, communication, and, fundamentally, collaboration within the community.

However, in the ensuing decades since the Folsom Report, the health care system in the United States has drifted far from "communities of solution"⁴ and grown increasingly

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complex, fragmented, and difficult to navigate.⁵ In general, it has evolved into a bureaucratic orthodoxy with an expert-driven model of care that is focused on illness and delivered largely through episodic visits in outpatient practices and hospital settings.⁶ Supported by professional authority and narrow definitions of health and health care, this system sees patients as receivers of care rather than as essential partners.⁷ This paradigm limits active partnerships with all patients and families and is especially limiting for those with little or no capacity to make their own choices such as children.⁸ Particularly at risk are populations that already face challenges due to limited health literacy, low self-efficacy, challenges with English proficiency, or those confronted with financial, social/political, or geographic barriers to care.⁹⁻¹²

Despite the challenging structure of the health care system, it is increasingly evident that patient, family, and community partnerships are critical elements in improving and managing the health of individuals and populations. In their 2001 report, *Crossing the Quality Chasm*, the Institute of Medicine underscored the importance of system change that included engaging the patient as a primary source of control over their own health care.⁷ More recently, Carman and colleagues proposed a framework for examining patient and family engagement,¹³ which views engagement as a continuum from consultation to full collaborative partnership. Patients who are empowered to actively participate in the process of their own care have better outcomes.¹⁴⁻¹⁶ Patients with chronic conditions particularly benefit due to greater treatment adherence, self-care, and scheduling of appropriate follow-up care.^{17,18} There is also increasing evidence that the PCMH offers great promise for improving patient and community engagement. However, while the PCMH model has spurred advanced practice transformations in some settings over the decade since

it was proposed as part of the Future of Family Medicine initiative,¹⁹ patient, family, and community engagement in the processes of care have generally been minimal.²⁰ There have been some inroads with patient advisory councils, shared decision making, and community-health system partnerships, but these have been exceptions and exemplars, rather than widely accessible standards of care.

There are many reasons for this limited progress. For example, even with increased focus on patient engagement in decision making, it is difficult for patients and families to make informed decisions about their care as they rarely have access to understandable and comparable data, health care records are often difficult to access and interpret, and the medical literature is both vast and ever-expanding. There are also few incentives for providers and health systems to invest in meaningful patient engagement that would accelerate transformation efforts.

The FMAHealth initiative offers an opportunity to realize the potential and the power of effective, proactive patient, family, and community partnerships. This initiative is an opportunity to push engagement from consultation toward partnership at the level of the encounter, as well as the design of care and policy. FMAHealth also provides the opportunity to expand the focus of engagement from the patient outward to the family and the community. Core campaign elements include Patient Engagement to increase collaboration between patients and providers as well as Community Engagement to identify strategies to transform primary care. This paper describes the current state and future vision of key initiatives in patient and community collaboration: shared decision making; patient, family, and community health education; technology; practice transformation; research; and policy. We seek to provide a vision and call to action to go beyond talking about engagement as a buzzword, moving toward meaningful

partnerships with patients, families, and communities. To this end, several areas of engagement can be considered:

Shared Decision Making

Shared decision making is a key component of patient and family engagement and is critical to the FMAHealth objective of ensuring personal relationships between clinicians and patients and families. Such a personal relationship has always been a core attribute of both family medicine and the PCMH model. Built upon mutual respect and trust, these partnerships require two-way communication resulting in decisions made with patients as opposed to decisions made for patients. In the framework suggested by Carman and colleagues,¹³ shared decision making requires not only sufficient knowledge of the medical condition or procedure but also an understanding of the context, values and beliefs, and goals and preferences of the patient, their family, and community.

Shared decision making in the literature often focuses on a specific disease such as cardiovascular disease or chronic obstructive pulmonary disease (COPD) and generally incorporates condition-specific decision aids to facilitate discussion.²¹⁻²³ These complex patients often rely on their families, communities, and other supports to facilitate daily activities and disease management decisions. Disease-specific outcomes, such as change in expiratory volume for a patient with COPD, may not be meaningful to the patient directly. The patient and family may have greater interest in improving independent functioning, pursuing activities, increasing self-care, or deciding where or when they will accept interventions.

It is also important to understand the extent to which patients and families want to be involved in medical decisions and when. While higher educational attainment or increased health literacy is associated with enthusiasm for involvement,^{24,25} interest in involvement appears to

vary widely by patient characteristics and circumstances.²⁶ For example, patients who are interested in discussing weight loss strategies may not be interested in debating treatments for acute asthma events. However, in complex treatment discussions the use of decision aids has shown consistent effectiveness in increasing patient involvement.²⁷

What is missing from our health care system is a comprehensive approach for decision making that embraces the patient and family at all stages of health. Optimally, the process brings together the needs and values of all involved or affected by the decision. Such broad involvement may seem difficult or impractical, but understanding the context in greater detail can better inform the decision. Engaging patients and families at the point of care can be a pivotal part of this process, enabling capture of patient information that is important but not necessarily disease related, such as caregiver contacts, social background, values, and beliefs. Critical to this process is redirecting the decision dialogue toward eliciting the patient's and family's goals and preferences beyond the context of a specific illness or injury.

In ambulatory practices, patients and families can be offered the opportunity to communicate their priorities for a clinic visit, thus creating an opportunity for partnership. At the Humboldt Open Door Clinic in California, patient and family advisors designed a form to help patients organize their thoughts before a clinic visit. In hospital settings, daily rounds are often the time care planning decisions are made.²⁸ At The Christ Hospital in Cincinnati, OH, the Patient and Family Advisory Council partnered with a family medicine geriatrician and guided the development and evaluation of an Acute Care for the Elderly (ACE) unit and the implementation and evaluation of family-centered rounds.²⁹ Policies and practices of the unit and the approach to teaching rounds are modeled on partnerships

and encourage the participation of patients and families in decision making.

An unintended result of increased shared decision making is the potential for increased burden placed on the clinician with limited time. Indeed, the clinician's perception of time pressure is often a barrier to shared decision making.^{30,31} Such a concern is understandable given the emphasis that the current health care system places on short encounters and increased relative value units (RVUs).

In contrast, an emerging model of primary care—Direct Primary Care (DPC)—has the potential to increase patient engagement and improve shared decision making while avoiding the time constraints found in traditional delivery systems. Bypassing third party payment systems, DPC directly contracts with patients, often resulting in smaller patient panels and more time available to discuss treatment options.

Patient, Family, and Community Health Education

Health education can enhance patient, family, and community engagement by increasing understanding of conditions and treatments and can contribute to reductions in health disparities, a core strategy of FMA-Health. The point of care, when caregivers, patients, and sometimes family caregivers meet, offers an opportunity to share useful educational information with patients and families in both static and dynamic ways. Commonly, printed materials serve the function of providing patients and families with information—general or condition-specific—that is designed to be accessible to a broad range of readers. Interactions with clinic staff offer opportunities to clarify or complement static information, and the clinician encounter provides an opportunity to transform the information into usable knowledge relevant to the patient and family. During this process the patient and family must be encouraged to ask questions and express confusion

or lack of understanding. Incumbent upon the provider is the guarantee that transformation occurs. Only through a dynamic exchange between all parties can comprehension be assured.

Group visits are another opportunity for useful information sharing between patients and families in a peer-support process. Group visits offer the opportunity for dynamic interaction and discussion with others who may share similar conditions and with the care team. These visits can also be a time-efficient way for clinicians and other staff to share more in-depth information, stories, and care plans with patients and families and to elicit insights from the group.

Events outside of the clinic setting offer clinicians the opportunity to understand the needs and health of the communities within which they practice and serve as forums for patient, family, and community education. Through such events, both public health needs and health care delivery can be evaluated and addressed in the manner of community-oriented primary care, which emphasizes health promotion and prevention.^{32,33} Community venues such as schools, colleges, health fairs, and other community events provide settings accessible to broad audiences. In such an environment, clinicians can gain insight into patients' or families' perspectives about health-promoting activities or their experiences living with a chronic condition. While questions and comments in such settings can lead to dialogue, it can be difficult to address the concerns of all participants.

Focus groups, study groups, or support groups and patient and family advisory councils—patient and family advisors serving on quality improvement committees—can lead to productive conversations even among and between groups with very different opinions.³⁴ Patient and family advisory councils can also participate in the design of health care delivery.³⁵ Such councils provide the opportunity for direct feedback

from patients, families, and communities, encourage dialogue between providers and patients, promote greater understanding of community context, and foster collaboration with the community. Whether in large public forums or smaller groups, sufficient time must be allowed for adequate communication of information.

The broad availability of electronic media also provides a means of reaching many patients, whether by text, email, web sites, or insertion of health messages such as public service announcements into popular entertainment. Web sites can behave like large public forums, extending the broadcast range of broad content that can be drilled into by interested parties.³⁶ One obvious benefit of electronic and on-line platforms is the connection of individuals or groups that share common concerns despite relative remoteness. One challenge faced by web-based systems is getting the right traffic to the right page. The vast sea of information can make it difficult for a message to reach its intended audience and vice versa.

Additionally, the availability of disparate sources of information can create confusion as to the validity of the content. Even trusted sources can contribute to confusion when different professional organizations publish material that is contradictory or inconsistent. For example, the guidelines on mammography screening from the US Preventive Services Task Force³⁷ differ somewhat from those of the American Cancer Society.³⁸ A critical patient-centered activity for clinicians is to provide expert opinion on matters of controversy and help the patient interpret conflicting information from trusted sources.

Education efforts to improve the knowledge and skills for developing effective partnerships must also be incorporated into faculty development and in the training of physicians and inter-professional teams.³⁹ Students in health professions and residents should be prepared to

enter into partnerships with their patients, families, and communities and must be supplied with the tools to do so. The development of these tools should incorporate stakeholder input from the beginning to assure adequate coverage of concepts and concerns.

Technology

Another core strategy of the FMA-Health initiative is improved patient, family, and community engagement through incorporation of available technology beyond didactic information distribution. Directed forms of information exchange such as email and telemedicine consultation have great potential to enhance patient, family, and community engagement. Specific questions can be addressed, issues clarified, and engagement encouraged in a timely fashion, without a trip to the clinic. In addition, directly disseminating information through voice and text messages can lead to improvements in processes of care, positive behavioral changes, greater disease management, and enhanced quality of life.⁴⁰ Similarly, direct communication through secure email exchanges has been associated with improved effectiveness of care.⁴¹

Access to medical records via patient portals can keep patients and families informed and can be linked to resources for clarification. These portals can provide easy-to-navigate access to comprehensible patient data in their own language. Access to electronic health records and the ability to connect with care providers can also result in reductions in office visits and phone calls to providers.⁴² It is important to note that the impact of patient portals on outcomes may be dependent on the patient's or family's health literacy, education, and technological prowess.⁴³ Moreover, patient engagement through use of electronic health records can go beyond one-way transmissions of information. It may be reasonable for patients and their representatives to have the opportunity to add notes to their records and have a process to correct errors.⁴⁴

Other delivery systems such as social networks can further encourage engagement through direct campaigns addressing specific health concerns. Social networks can facilitate rapid dissemination of health information and increase social support and self-empowerment.⁴⁵⁻⁵⁰ There is some indication that social media can be effectively deployed to assist in improving health behaviors.⁵¹ Such exchanges may also facilitate improved disease self-management.⁵²

Patient, family, and community engagement can also be enhanced through the incorporation of big data. In this context big data does not refer to the analysis of extracted data from large data warehouses such as Medicare claims. Rather, it refers to the manipulation and use of information from multiple sources, individuals, and groups with the aim of improving health care. Such data could include information regarding health care utilization, transportation, the built environment, and resource availability at the population level combined in real time with individual level data such as heart rate, blood pressure, hemoglobin A1c, and other markers of health. This kind of combined big data, presented in useful ways, can provide immediate feedback to patients regarding their health, environment, and their interaction. Communities can also use big data to become learning systems for health.⁵³

Partnering With Patients and Families in Practice and System Transformation

Achieving the Triple Aim goal of a better health care experience requires practice and system transformation. Supported by the core strategies of FMAHealth, lasting transformation requires engaging patients and families in practice and system redesign from the beginning stages and at high levels, such as executive committees, to ensure the commonality and acceptance of goals and processes, as well as metrics for evaluating success. Early

and sustained relationships establish trust and credibility,^{54,55} important contributors to the transactional costs of goal attainment.⁵⁶⁻⁵⁸ Without high levels of trust, lasting improvement will be elusive. The inclusion of patient and consumer stakeholder groups in the process is beneficial in establishing priorities and recommendations,⁵⁹⁻⁶¹ and the early involvement of patients and families helps align common goals. Unfortunately, it is difficult to measure the extent to which stakeholders—patients, families, and communities—are actually involved and their input used.^{60,62,63} In this regard, it is important for the process to be well documented and transparent to prevent relationships from becoming purely transactional and to avoid the “inclusion of the patient and family”—another box to check. Following this approach, Maine Quality Counts supported primary care practices across the state of Maine in practice transformation and provided resources and support for the involvement of patients and family advisors from the beginning of the initiative.⁶⁴ Patients, families, and communities can also be engaged in determining and prioritizing the needs and payer coverage of local services.^{59-61,65-68}

Research

Research, including needs assessment and achievement evaluation, is an ongoing process and is critical to the FMAHealth goal of continued evolution of the PCMH. Engaging patients and families in research activities makes the results more relevant to local needs. Community-based participatory research (CBPR), action research, practice-based research, and user-centered design are examples of scientific fields that use many techniques to incorporate the research subjects into the science and is cognizant of context.⁶⁹⁻⁷⁷ Examples of this participatory approach include the Patient Centered Outcomes Research Institute, which involves patients, providers, researchers, and policy

makers in identifying priority research areas, as well as reviewing and awarding research funding.⁷⁸ Another example is the Colorado Clinical and Translational Sciences Institute, which employed a participatory process to engage local communities in research. A Community Advisory Council participated in all aspects of the research process, including research ideas, funding requests, research design, quantitative and qualitative analysis, interpretation of results, and dissemination of findings.⁷⁹

Policy

Patients, families, and communities also have the opportunity to engage in health care transformation at the policy level. To some extent, such involvement is invited by policy makers and the policy process through public comment and is somewhat entrenched due to the long history of open democratic process.⁶⁶ However, in order to ensure that patient and family priorities with respect to practice transformation are reflected at community, state, and federal policy levels, it is important that consumers make their voice heard as a political constituency. Activities include local canvassing and lobbying efforts as well as supporting the election of candidates at all levels of governance who advocate the goals outlined by FMAHealth.

Engagement at the policy level can be seen in CareOregon, a Medicaid managed care organization, which works closely with its member advisors to make policy changes within their organization and to influence statewide policy reforms,⁸⁰ including a change in dental coverage in Medicaid plans.⁸¹ Through conversations with the Oregon legislature, CareOregon influenced the establishment of Community Advisory Councils and the mandate to include Medicaid beneficiaries in the creation and ongoing operations of Coordinated Care Organizations. In addition, a CareOregon advisor serves on the Medicaid Advisory

Committee that makes health care policy recommendations.⁸²

The FMAHealth campaign highlights the role of family medicine in meeting the challenge of the Triple Aim. FMAHealth engages local stakeholders to showcase collaborations that have been effective and to explore strategies to expand primary care and promote health through partnerships.

Call to Action

The complexity and scale of the health care system in the United States has resulted in fragmented, expensive, and often ineffective care.⁷ Patients, families, and communities have become de-personified commodities, caught in a tug-of-war between providers and payers. The failings of the current system have prompted repeated calls for transformation, urging a re-focus on the primacy of the patient in patient care.^{7,10,13} Unfortunately, the inertia of the current system has left it with limited adaptive agility, limiting its ability to respond to patient, family, and community needs.

In other industries, lack of responsiveness to the needs and values of customers has had disastrous results. For most of the 20th century, Eastman Kodak and Sears Roebuck and Company were pioneers, innovators, market leaders, and style makers. Eastman Kodak invented the digital camera in the 1970s but failed to recognize the value of digital images to consumers and embrace this disruptive technology.⁸³ Sears Roebuck and Company, once the largest retailer in the United States, did not respond to the shifting needs and demographics of consumers by altering its business model and building on its strengths.⁸⁴ Both companies failed to adapt to consumers' changing needs by providing products and services accordingly and now seem destined to be footnotes in history.

Despite immense inertia, the health care system in the United States can transform and deliver the Triple Aim of better health, better health care experiences, and

lower costs. Achieving these goals requires the discipline of family medicine to prioritize patient, family, and community engagement across the engagement continuum from consultation to partnership and shared leadership at the direct care, organizational, and policy level. The list of opportunities for enhancing engagement is ever growing and includes increased use of shared decision making; patient, family, and community education and outreach; adoption of emerging and maturing technologies; and patient and family involvement in research, practice transformation, and policy change. While the starting point and focus area will vary across practices, change must begin with a greater understanding of patient, family, and community expectations of family medicine as well as their perceptions of what family medicine is promising as a discipline.

FMAHealth provides an opportunity to articulate and implement mechanisms for sustained patient and family voices in health care delivery, health policy, and politics. As a discipline, family medicine must encourage patients, families, and communities to demand change as consumers, as citizens, and as voters by fully partnering with them to accelerate transformation. Ongoing and sustained partnerships are central to the ability of family medicine to address the Triple Aim, as well as our likelihood to exist and thrive in the changing health care arena. We must, as a discipline, act in concert and in full collaboration with patients, families, and communities as if the future of health and wellness of the American people depends upon it. This call to action for partnering with patients is an imperative and a road we must travel together.

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References

- Davis K, Stremikis K, Squires D, Schoen C. *Mirror, mirror on the wall: how the performance of the US health care system compares internationally*. New York: The Commonwealth Fund, 2014.
- Berwick DM, Nolan TW, Whittington J. *The Triple Aim: care, health, and cost*. *Health Aff (Millwood)* 2008;27(3):759-69.
- The National Commission on Community Health Services. *Health is a community affair—Report of the National Commission on Community Health Services (NCCHS)*. Cambridge, MA: Harvard University Press, 1967.
- The Folsom Group. *Communities of solution: The Folsom Report revisited*. *Ann Fam Med* 2012;10(3):250-60.
- American Hospital Association and Picker Institute. *Eye on Patients: A Report from the American Hospital Association and the Picker Institute*. Washington, DC: American Hospital Association, 1997.
- Stephens GG. Family medicine as counterculture. *Fam Med* 1979;11(5):14-18.
- Institute of Medicine Committee on Quality of Health Care in America. *Crossing the quality chasm: a new health system for the 21st century*. Washington, DC: National Academy Press, 2001.
- Institute for Patient and Family-Centered Care. *Patient- and family-centered care and the pediatrician's role*. *Pediatrics* 2012;129(2):394-404.
- DuBard CA, Gizlice Z. Language spoken and differences in health status, access to care, and receipt of preventive services among US Hispanics. *Am J Public Health* 2008;98(11):2021-8.
- Bennett IM, Chen J, Soroui JS, White S. The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. *Ann Fam Med* 2009;7(3):204-11.
- Baker DW, Parker RM, Williams MV, et al. The health care experience of patients with low literacy. *Arch Fam Med* 1996;5(6):329-34.
- Fiscella K, Franks P, Doeschner MP, Saver BG. Disparities in health care by race, ethnicity, and language among the insured: findings from a national sample. *Med Care* 2002;40(1):52-9.
- Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)* 2013;32(2):223-31.
- Katon W, Von Korff M, Lin E, et al. Collaborative management to achieve treatment guidelines: impact on depression in primary care. *JAMA* 1995;273(13):1026-31.
- Robinson JH, Callister LC, Berry JA, Dearing KA. Patient centered care and adherence: definitions and applications to improve outcomes. *J Am Acad Nurse Pract* 2008;20(12):600-7.
- Greene J, Hibbard J. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med* 2012;27(5):520-6.
- Mosen DM, Schmittiel J, Hibbard J, Sobel D, Remmers C, Bellows J. Is patient activation associated with outcomes of care for adults with chronic conditions? *J Ambul Care Manage* 2007;30(1):21-9.
- Rask KJ, Ziemer DC, Kohler SA, Hawley JN, Arinde FJ, Barnes CS. Patient activation is associated with healthy behaviors and ease in managing diabetes in an indigent population. *Diabetes Educ* 2009;35(4):622-30.
- Future of Family Medicine Project Leadership Committee. *The Future of Family Medicine: a collaborative project of the family medicine community*. *Ann Fam Med* 2004;2(suppl 1):S3-S32.
- Homer C, Baron R. How to scale up primary care transformation: what we know and what we need to know? *J Gen Intern Med* 2010;25(6):625-9.
- Krones T, Keller H, Sönnichsen A, et al. Absolute cardiovascular disease risk and shared decision making in primary care: a randomized controlled trial. *Ann Fam Med* 2008;6(3):218-27.
- Akl EA, Grant BJ, Guyatt GH, Montori VM, Schünemann HJ. A decision aid for COPD patients considering inhaled steroid therapy: development and before and after pilot testing. *BMC Med Inform Decis Mak* 2007 May 15;7:12.
- Dales RE, O'Connor A, Hebert P, Sullivan K, McKim D, Llewellyn-Thomas H. Intubation and mechanical ventilation for COPD: development of an instrument to elicit patient preferences. *Chest* 1999;116(3):792-800.
- Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. *J Gen Intern Med* 2005;20(6):531-5.
- Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy. *J Gen Intern Med* 1989;4(1):23-30.
- Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? *Med Care* 2000;38(3):335-41.
- O'Connor AM, Bennett CL, Stacey D, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2009 Jul 8;(3):CD001431.
- Molofsky J. Patient voice: involving patients and families in improving care. *Transforming health through the patient experience*. Burbank, CA: California HealthCare Foundation, 2011.
- AHRQ Health Care Innovations Exchange. Patient- and family-centered care: approaches for children and seniors. 2014. <https://innovations.ahrq.gov/events/2014/07/patient-and-family-centered-care-approaches-children-and-seniors>. Accessed March 10, 2015.
- Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Educ Couns* 2008;73(3):526-35.
- Friedberg MW, Van Busum K, Wexler R, Bowen M, Schneider EC. A demonstration of shared decision making in primary care highlights barriers to adoption and potential remedies. *Health Aff (Millwood)* 2013;32(2):268-75.

32. Mullan F, Epstein L. Community-oriented primary care: new relevance in a changing world. *Am J Public Health* 2002;92(11):1748-55.
33. Tollman S. Community oriented primary care: origins, evolution, applications. *Soc Sci Med* 1991;32(6):633-42.
34. Hodgetts K, Hiller J, Street J, et al. Disinvestment policy and the public funding of assisted reproductive technologies: outcomes of deliberative engagements with three key stakeholder groups. *BMC Health Serv Res* 2014 May 5;14:204.
35. Webster PD, Johnson BH. Developing and sustaining a patient and family advisory council. Bethesda MD: Institute for Family-Centered Care, 2000.
36. Mittler JN, Volmar KM, Shaw BW, Christianson JB, Scanlon DP. Using websites to engage consumers in managing their health and healthcare. *Am J Manag Care* 2012;18(6 Suppl):S177-S184.
37. US Preventive Services Task Force. Screening for breast cancer: US Preventive Services Task Force Recommendations. *Ann Intern Med* 2009;151(10):I-44.
38. American Cancer Society. Breast cancer prevention and early detection. 2014. <http://www.cancer.org/cancer/breastcancer/moreinformation/breastcancerearlydetection/breast-cancer-early-detection-acs-recs>. Accessed December 2014.
39. Josiah Macy Jr. Foundation. Partnering with patients, families, and communities: an urgent imperative for health care. Arlington, VA: Josiah Macy Jr. Foundation, 2014.
40. Krishna S, Boren SA, Balas EA. Healthcare via cell phones: a systematic review. *Telemed J E Health* 2009;15(3):231-40.
41. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at Kaiser Permanente through e-mail between physicians and patients. *Health Aff (Millwood)* 2010;29(7):1370-5.
42. Zhou YY, Garrido T, Chin HL, Wiesenthal AM, Liang LL. Patient access to an electronic health record with secure messaging: impact on primary care utilization. *Am J Manag Care* 2007;13(7):418-24.
43. Goldzweig CL, Orshansky G, Paige NM, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Ann Intern Med* 2013;159(10):677-87.
44. Hartzler A, McCarty CA, Rasmussen LV, et al. Stakeholder engagement: a key component of integrating genomic information into electronic health records. *Genet Med* 2013;15(10):792-801.
45. Hawn C. Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. *Health Aff (Millwood)* 2009;28(2):361-8.
46. Cobb NK, Graham AL, Abrams DB. Social network structure of a large online community for smoking cessation. *Am J Public Health* 2010;100(7):1282-9.
47. Greene J, Choudhry N, Kilabuk E, Shrank W. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *J Gen Intern Med* 2011;26(3):287-92.
48. Wangberg SC, Andreassen HK, Prokosch H-U, Santana SMV, Sørensen T, Chronaki CE. Relations between internet use, socio-economic status (SES), social support and subjective health. *Health Promot Int* 2008;23(1):70-7.
49. Idriss SZ, Kvedar JC, Watson AJ. The role of online support communities: benefits of expanded social networks to patients with psoriasis. *Arch Dermatol* 2009;145(1):46-51.
50. van Uden-Kraan CF, Drossaert CHC, Taal E, Seydel ER, van de Laar MAFJ. Participation in online patient support groups endorses patients' empowerment. *Patient Educ Couns* 2009;74(1):61-9.
51. Laranjo L, Arguel A, Neves AL, et al. The influence of social networking sites on health behavior change: a systematic review and meta-analysis. *J Am Med Inform Assoc* 2014;22(1):243-56.
52. Frost JH, Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. *J Med Internet Res* 2008 Jul-Sep; 10(3):e15.
53. Institute of Medicine Roundtable on Evidence-Based Medicine. *The Learning Healthcare System*. Washington, DC: National Academies Press, 2007.
54. O'Haire C, McPheeters M, Nakamoto E, et al. Engaging stakeholders to identify and prioritize future research needs. Rockville, MD: Agency for Healthcare Research and Quality, 2011.
55. Guise J-M, O'Haire C, McPheeters M, et al. A practice-based tool for engaging stakeholders in future research: a synthesis of current practices. *J Clin Epidemiol* 2013;66(6):666-74.
56. Lewicki RJ, McAllister DJ, Bies RJ. Trust and distrust: new relationships and realities. *Acad Manage Rev* 1998;23(3):438-58.
57. Kramer RM, Cook KS. Trust and distrust in organizations. New York: Russell Sage Foundation, 2004.
58. Fukuyama F. Trust: the social virtues and the creation of prosperity. New York: Free Press, 1995.
59. Klein G, Gold LS, Sullivan SD, et al. Prioritizing comparative effectiveness research for cancer diagnostics using a regional stakeholder approach. *J Comp Eff Res* 2012;1(3):241-55.
60. Rosenberg-Yunger ZR, Thorsteinsdóttir H, Daar AS, Martin DK. Stakeholder involvement in expensive drug recommendation decisions: an international perspective. *Health Policy* 2012;105(2):226-35.
61. Watt AM, Hiller JE, Braunack-Mayer AJ, et al. The ASTUTE Health Study Protocol: Deliberative stakeholder engagements to inform implementation approaches to healthcare disinvestment. *Implement Sci* 2012;7:101.
62. Nitsch M, Waldherr K, Denk E, Griebler U, Marent B, Forster R. Participation by different stakeholders in participatory evaluation of health promotion: a literature review. *Eval Program Plann* 2013;40(0):42-54.
63. Han E, Scholle SH, Morton S, Bechtel C, Kessler R. Survey shows that fewer than a third of patient-centered medical home practices engage patients in quality improvement. *Health Aff (Millwood)* 2013;32(2):368-75.
64. Roseman D, Osborne-Stafnes J, Amy CH, Boslaugh S, Slate-Miller K. Early lessons from four "aligning forces for quality" communities bolster the case for patient-centered care. *Health Aff (Millwood)* 2013;32(2):232-41.
65. Krska J, Mackridge AJ. Involving the public and other stakeholders in development and evaluation of a community pharmacy alcohol screening and brief advice service. *Public Health* 2014;128(4):309-16.
66. Timotijevic L, Raats MM, Barnett J, et al. From micronutrient recommendations to policy: consumer and stakeholder involvement. *Eur J Clin Nutr* 2010;64:S31-S37.
67. Gold R, Whitlock EP, Patnode CD, McGinnis PS, Buckley DI, Morris C. Prioritizing research needs based on a systematic evidence review: a pilot process for engaging stakeholders. *Health Expect* 2013;16(4):10.1111/j.1369-7625.2011.00716.x.
68. Lobb R, Colditz GA. Implementation science and its application to population health. *Annu Rev Public Health* 2013;34(1):235-51.
69. Mikesell L, Bromley E, Khodyakov D. Ethical community-engaged research: a literature review. *Am J Public Health* 2013;103(12):e7-e14.
70. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health* 1998;19(1):173-202.
71. Malterud K. Action research—a strategy for evaluation of medical interventions. *Fam Pract* 1995;12(4):476-81.
72. Hart E, Bond M. Making sense of action research through the use of a typology. *J Adv Nurs* 1996;23(1):152-9.
73. Westfall JM, Mold J, Fagnan L. Practice-based research—"blue highways" on the NIH roadmap. *JAMA* 2007;297(4):403-6.
74. Hartung DM, Guise J-M, Fagnan LJ, Davis MM, Stange KC. Role of practice-based research networks in comparative effectiveness research. *J Comp Eff Res* 2012;1(1):45-55.
75. Mold JW, Peterson KA. Primary care practice-based research networks: working at the interface between research and quality improvement. *Ann Fam Med* 2005;3(suppl 1):S12-S20.
76. Hoffman A, Montgomery R, Aubry W, Tunis SR. How best to engage patients, doctors, and other stakeholders in designing comparative effectiveness studies. *Health Aff (Millwood)* 2010;29(10):1834-41.
77. Angier H, Wiggins N, Gregg J, Gold R, DeVoe J. Increasing the relevance of research to underserved communities: lessons learned from a retreat to engage community health workers with researchers. *J Health Care Poor Underserved* 2013;24(2):840-9.
78. Frank L, Basch E, Selby JV. The PCORI perspective on patient-centered outcomes research. *JAMA* 2014;312(15):1513-14.
79. Westfall JM, Nearing K, Felzien M, et al. Researching together: a CTSA partnership of academicians and communities for translation. *Clin Transl Sci* 2013;6(5):356-62.
80. Klein S, McCarthy D. *CareOregon: transforming the role of a Medicaid health plan from payer to partner*. New York: Commonwealth Fund, 2010.

81. Medicaid Advisory Committee. Oral health and the Oregon Health Plan. Office for Oregon Health Policy and Research, 2009.
82. Health System Transformation Team. Coordinated Care Organizations (CCO): Strawperson Summary: Oregon Health Authority, 2011.
83. Bower JL, Christensen CM. Disruptive technologies: catching the wave. Harvard Business Review Video, 1995.
84. Raff D, Temin P. Sears, Roebuck in the twentieth century: competition, complementarities, and the problem of wasting assets. Learning by doing in markets, firms, and countries. University of Chicago Press, 1999:219-52.