



NATIONAL HEALTH COUNCIL

Meaningful Patient Engagement in Health Care Delivery
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Background

As stakeholders across the health care ecosystem embrace patient centeredness and integrate the patient voice into their processes, decisions, and organizations, meaningful patient engagement has become increasingly important. The National Health Council (NHC) has played a vital role in the field of patient engagement within drug development, quality measurement, health care policy, and research.^{1,2,3,4,5} Nationally, programs like the Food and Drug Administration's (FDA) Patient-Focused Drug Development Initiative have helped bring the patient voice into the development of new drugs.⁶

While many organizations (e.g., PCORI, AHRQ, NIH, FDA, and pharmaceutical companies) are working to incorporate patient engagement into research settings, this type of work is less apparent in health care delivery settings. Thus, *our objective for this project was to identify examples of patient engagement in health care delivery and the impact it is making on patient care and outcomes.*

Methods

During 2017, a search was conducted to identify examples of patient engagement in improving, changing, or implementing programs or services in a health care delivery setting. For the purposes of this project, meaningful "patient engagement" in health care delivery required that patients be involved in the process (e.g., true co-development of initiatives or projects) — not merely others making decisions for patients with patients in mind. That is, patients had to be actively involved throughout the process. There were three criteria required for a prospective case to be selected as an example:

1. Patient-generated: The idea for the service/intervention was generated from patient suggestions (e.g., patient helped identify and articulate a problem, gap, or information need);
2. Co-development/creation: Patients provided input on how the service best be delivered or the approach to the intervention;

3. The impact of the engagement on processes or outcomes had to be described in the example (e.g., once implemented, the service shortened wait times and improved patient satisfaction with care).

A range of sources were utilized in this search:

1. Published literature searched through the use of Google Scholar and PubMed;
2. Center for Medicare and Medicaid Innovation (CMMI) website Innovation Models, specifically service delivery models;⁷
3. Google searches for terms related to patient engagement: “patient engagement” AND “health care delivery” and also these terms within the sites of specific delivery systems; and
4. Convenience reports found in the media, noted by staff members during the course of their routine work.

Results

Thousands of candidate examples were identified that included the terms “patient-centric” and/or “engagement” in health care delivery. But ultimately, upon close examination, they were excluded because they did not include meaningful patient engagement as we defined it. For example, many reported clear goals to increase patient engagement in their own care or gave patients an opportunity to voice their opinions, needs or preferences. But there was no evidence the information was used to make any changes, intervene, or add new programs.

Unfortunately, there were only a few examples of health care systems actively engaging patients in decision-making processes, and they relied on an increasingly popular way for health care systems to engage their patients, through patient and family advisory councils (PFACs). Through PFACs, hospital staffs work with patients to gather information about what matters most to them in their system or organization. Patients can drive change by sharing their perspective and advising on key decisions. Two key examples were found using Google search.

Key examples:

Beth Israel Deaconess Medical Center has three PFACs in addition to its hospital-wide PFAC. The Intensive Care Unit (ICU) PFAC was very active in 2017. As mentioned in the 2017 Annual Report,⁸ patient advisors focused mainly on the topic of patient transition out of the ICU. They spoke with ICU leaders and informed them of the often difficult transition from a place where patients feel comfortable and know the routine to a new floor with new staff. They suggested the use of volunteers, and through a collaboration with multiple departments, the PFAC developed the ICU Transition Guide Program. Program volunteers are trained to help patients and their families navigate through the process, from setting expectations before the transition to becoming comfortable in their new room. One ICU PFAC advisor helped to develop the training program and participates in leading the training sessions.⁸

The PFAC at Milford Regional Medical Center (MRMC) breaks into subcommittees each year to focus on main topic areas. One notable accomplishment of MRMC’s PFAC was the work of the “Medication Reconciliation” sub-committee in 2016. As mentioned in the PFAC Annual Report,⁹ the subcommittee was formed by multiple patient and family advisors who sought to

educate community members on the importance of keeping up-to-date lists of medications. The subcommittee created various materials for patients to use, including “My Medication Record,”¹⁰ which is available on the medical center’s website in English, Spanish, and Portuguese. PFAC members distributed pill organizers and medication cards to residents of senior centers in the area, and appeared on various television programs to share medication information.⁹ In this example, the patient and family advisors had an idea and the hospital staff collaborated with them and provided resources to follow through.

Notably, these were the strongest examples found. However, neither annual report mentioned any positive or negative outcomes or impacts of the programs the PFACs worked on. This information was also not available through Google search or on each medical center’s website. Without an understanding of the outcomes, it is impossible to know whether the engagement was impactful.

Discussion

It is remarkable that while thousands of examples are found that refer to patient engagement in health care delivery, no examples could be identified where true patient engagement (e.g., in the form of co-development) and resulting impact (process or outcomes) could be identified. A few instances of meaningful engagement could be found and, in both of the cases, patients were able to share concerns and ideas and take action through the use of a PFAC. No clear examples of patient engagement were identified without the use of a PFAC in any health care organization.

It is important to note that the term patient engagement gets used in two very different ways when it comes to the area of health care delivery. The two uses of the term are: 1. patient engagement in their own care, and 2. patient engagement as we defined it, engagement in identifying and/or developing care delivery structure or process (e.g., co-development). This is obviously different from other sectors such as research, drug development, or policy where the use of the term, patient engagement, is narrower but has the ultimate goal of providing evidence patients can use in their decision making.

In health care delivery, there is a great deal of emphasis on patient engagement in his/her own health care decision making upfront. Numerous programs have been developed to try to improve patient engagement in their own care, such as various shared decision-making tools. Mayo Clinic’s Shared Decision Making National Resource Center¹¹ provides decision-making aids for the use of health care providers treating specific conditions or symptoms. Aids available from the National Resource Center include Chest Pain Choice,¹² Depression Medication Choice,¹³ and Head CT Choice Decision Aid.¹⁴ These informative aids help patients understand their options and work with their provider to choose the best treatment option for their specific needs. Interestingly, CMMI developed the Shared Decision Making (SDM) Model¹⁵ in early 2017, but ultimately cancelled the program due to lack of interest from Accountable Care Organizations. This suggests that while these tools are gaining in popularity in health care delivery, there is still a reluctance by patients to participate.

However, it is somewhat ironic that these efforts are often designed and implemented without any patient input, drawing the distinction between something being done FOR or TO patients, rather than WITH patients. Thus, a problem we may have unveiled is that the health care delivery community needs to better understand the role of patient engagement in the identification and development of structure and processes for health care delivery programs and services to improve the uptake and success of programs intended to improve patient engagement in their own health care.

It also may be that we could not find examples where organizations have meaningfully engaged the patient community and have created successful programs because they are not publishing or communicating about these programs. It may be the organizations are not academically oriented; thus, publication in professional or peer-reviewed journals is of low priority. Or, it could be that they consider their work proprietary and do not want to share the information with competitors. However, we do not believe that these reasons completely account for why examples are rare.

Lastly, we began this project as a minimal effort to identify case examples, not understanding how difficult the effort would be. We did not begin with a standardized search protocol and did not uniformly track the thousands of cases we reviewed or the reason for rejection for each. In the next few months, we will repeat our efforts with a formal protocol and tracking system and will be able to provide a more formal assessment.

Conclusion

There is evidence that health care providers and organizations understand the importance of patient centricity and engagement, but there are few examples where patients have been meaningfully engaged in a service, program, intervention, or other activity to improve health care delivery. Patient and Family Advisory Councils remain strong catalysts for meaningful patient engagement, but there is an absence of information on patients being involved in health delivery decision-making outside of a PFAC structure. If such examples exist, they are not easily accessible to the public or for replication by others. As the health care ecosystem continues to focus on partnering with and listening to patients, successful instances of patient engagement should be widely available for shared learning and dissemination.

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