Patient and Researcher Engagement in Health Research: A Parent’s Perspective

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There is a growing body of evidence in support of more active engagement of patients in health research, beyond the traditional role of a subject or participant, which has led to the realization that their perspectives are a critical component of effective health research.1,2 This importance has recently been acknowledged in a number of countries, including the United Kingdom, the United States, and Canada. For example, the Canadian Institutes of Health Research has established the Strategy for Patient-Oriented Research, a coalition of federal, provincial, and territorial partners all dedicated to supporting researchers in integrating patients into all phases of research to better inform practice for improved patient outcomes. Researchers in integrating patients as partners all dedicated to supporting researchers in integrating patients into all phases of research to better inform practice for improved patient outcomes. The partners include a mix of stakeholders, such as patients (ie, parents, caregivers, family, and public members), researchers, health professionals, and policy makers, among others. Patient-oriented research is defined in the Strategy for Patient-Oriented Research initiative as a continuum of research conducted by multidisciplinary teams who engage patients as partners, focus on patient-identified priorities, and improve patient outcomes through knowledge translation into practice.3–5

THE ELECTRONIC MEDICAL RECORD LETTERS STUDY
Patient and researcher engagement occurs when patients meaningfully and actively engage in governance, priority setting, and the conduct of research for mutual benefit.3 The Electronic Medical Record (EMR) Letters Study provides an example of such a partnership, in which parents are involved in an advisory capacity on the research team.

The purpose of the EMR Letters Study is to examine parents’ perceptions about a letter received at the end of their visit with a pediatric pulmonologist. The letter provides a summary of information of their child’s condition (eg, asthma), past medical history, findings from a physical examination, and recommendations about tests and treatments. We wanted to determine if parents found the information in the letter useful, if it accurately reflected their child’s condition and treatment plan, and if they shared this information with others involved in the care of their child.

PARENT ENGAGEMENT IN THE EMR LETTERS STUDY
To better ensure that the study processes and the survey tool were informed by parents’ voices, we engaged with parents at the outset of this study. An advisory panel of parents was established through word-of-mouth. We attempted to enroll parents who shared similar characteristics to potential EMR Letters Study participants (eg, young parents who previously attended specialty clinics) but who were not part of the EMR Letters Study sample. Roles and expectations of panel members were mutually


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defined and included working with researchers to: (1) develop the study questionnaire, (2) interpret results from analysis, and (3) disseminate findings to members of the public and/or health professionals.

Although in this article we briefly outline the process of the EMR Letters Study, our main goal is to document 1 parent’s compelling, personal, and initial impression about engaging in this study as a member of the panel. Additionally, Ms Saunders’ unsolicited letter is situated within a sample of current literature about patient engagement in health research.

PARENT’S LETTER

When I was first offered the opportunity to be a part of the advisory panel of parents for the EMR Letters Study, I was excited and a little confused. I have no research or health care background and was completely unaware that patient-oriented research was a thing. So, as you can imagine I struggled to understand how I could add value to the study; I struggled to understand how I was supposed to contribute as a non–health care professional.

Walking into the first meeting, I was beyond nervous. My mind was racing with worry: How will I contribute? Will my voice go unheard because I am not a health care professional? Will I be judged for my lack of knowledge? However, upon arrival, I was relieved from my worries as I was greeted warmly by the team. Despite the differences in status (as society defines them), I felt equal to the doctor, to the PhD holders, to the very experienced research investigators. The social barriers that I would have expected to encounter were nonexistent in that room. My personal experiences were met with genuine care and interest by the team members, and my suggestions were implemented and built upon. It was a true demonstration of the power of collaboration and an amazing first experience for me in an advisory capacity.

After the briefing on the study, the answer to the question of how can I add value to the study was clear: my voice as a parent is how I add value. As a parent of 2 very young children, 1 of whom has been diagnosed with asthma, I am a key stakeholder in the management of their health care, and my voice matters. My voice is the voice of my children who are not old enough to manage their own health care. My voice is responsible for initiating health care and questioning and understanding information as it is received regarding my children’s health. As a parent, I am responsible for making the best decisions possible regarding my children’s health. If my voice is not heard, is dismissed, or if I do not understand what is communicated to me in a health care setting, then the ability for me to make informed decisions that directly impact my children’s health care is hindered.

Being a part of the EMR Letters Study makes my voice louder. It allows my voice to transcend the ears of my children’s health care providers to ears that would otherwise never hear it, ears that have the means to create change in the delivery and management of health care. Knowing that my voice is heard and can make a difference is very empowering. Being a part of the EMR Letters Study has opened my eyes to the importance of patient engagement as a critical component of health research and health care in general.

The 1 thing that stood out in my mind was how little involvement I have had in the management and delivery of my health care. It made me realize that aside from the communication occurring in the doctor’s office at my visits, I have little information regarding my health. I have never seen my medical records and certainly do not remember everything that has been communicated to me over the years about my health. This was a concerning realization: I, a patient, a key stakeholder in my health care, am not often in the loop regarding the management and delivery of the care I receive. This gap needs to be addressed through patient engagement initiatives. Engaging patients as key stakeholders in our health care system in an empowering and inclusive manner can make a difference. I believe that the key to a sustainable and effective health care system does not exist without patient engagement.

DISCUSSION

Ms Saunders’ perspective suggests that parents can and want to provide their voices in the conduct of research that may have relevance for them and for their children.6,7 Ms Saunders felt empowered by the prospect of her voice becoming “louder” and more heard, so as to potentially make a difference in research as well as in health care management and health outcomes.

Ms Saunders also shares how she can provide input as a “key stakeholder” through her participation on the panel in the EMR Letters Study to make a difference in children’s health. This highlights the range of parents’ experiences and how they can provide a variety of perspectives, each of which can influence both the research process and the outcomes. Parent and researcher levels of engagement can be described and depicted schematically (see Fig 1), whereby engagement can vary depending on the goals, knowledge, time commitment, experiences, and resources of both parents and researchers.

This schematic can serve as a guide for parents and researchers to situate themselves in whatever research project they are choosing to engage. Any level of engagement...
will require dialogue and agreement between parents and researchers about the engagement activities, and each level is of value to the research process. As the level of engagement increases from left to right, the time commitment and knowledge required by both researchers and parents increases. In the EMR Letters Study, parents and researchers are engaged at the “Involve” level as shown in Fig 1.

We acknowledge that there are inherent drawbacks and challenges for both parents and researchers, such as the amount of effort required, the varying and fluctuating levels of commitment, and the research and engagement knowledge needed to engage meaningfully, as well as the lack of time and money. Added to these challenges are the voluntary nature of the parent’s role, the numerous delays that commonly occur during research, and the slow translation of knowledge into practice, which can result in parents losing interest.

In a review of studies by the US Patient-Centered Outcomes Research Institute initiative, the authors found that common challenges experienced by all stakeholders (inclusive of patients) were lack of time (46%) and lack of knowledge about research (30%); common challenges experienced by researchers were difficulty finding patients and other stakeholders to engage with (27%), lack of time (27%), resources (24%), knowledge and experience in engagement (22%). Furthermore, in a recent systematic review about patient engagement in health research, additional barriers, such as discontinuation among patients, patient frustration with length of training and orientation, transportation for and frequency of meetings, and lack of funding to facilitate patient engagement, were identified. Most poignantly, a shared concern between patients and researchers was the potential for patients’ engagement in research to become devalued and tokenistic.

An interesting topic for further research would be to study the role and experiences of parents appointed to institutional ethics review boards.

In the EMR Letters Study, we experienced challenges related to recruiting parent advisory panel members, scheduling meetings, and staying connected during delays inherent in the research process. Priorities ebbed and flowed, which now and then placed demands on panel members at times that were in conflict with their other priorities. For example, of the 7 parents who initially agreed to participate, only 5 were free to join the panel’s first meeting. Fewer parents participated in the interim analysis meeting, during which we obtained both oral and written feedback about the proposed survey for the study. Despite these challenges, parent involvement led to survey tool refinement that better ensured that we asked the right questions in the right way to elicit participants’ feedback. We made amendments to a few sections in the survey that...
were duplicated or that did not align clearly with the original purpose of the study. When we shared these amendments with the parent advisory panel members for further input, all were in support, reporting that they felt their input had been considered and validated. This 2-way dialogue and the trusting and respectful relationships that have been developed between the parents and researchers in the EMR Letters Study reinforce the bidirectional and reciprocal nature of parent and researcher engagement as depicted in the schematic illustrated in Fig 1.

CONCLUSIONS

The movement toward engaging patients and researchers more actively and broadly in health research is gaining impetus in the United States and Canada, led by the pioneering initiatives undertaken in the United Kingdom over the last 2 decades. Engaging with patients from the outset can help with the generation of new and innovative questions, ideas, and approaches, potentially resulting in research outcomes more relevant to patients, thereby enacting a patient-oriented research agenda.

We close with words shared from Ms Saunders:

“I leave you with a quote from Dr Thompson H. Boyd (MD, physician liaison at Hahnemann University Hospital in Philadelphia):

“There should be the thought of accountability and expectations on behalf of the patient… The patient has to be a contributing member of the care team, not just a bystander.”

I do not want to be a bystander in my health care or in health research. Give patients a voice and a chance to contribute. Thank You.”

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