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The power of patient ownership: The path from engagement to equity

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Abstract

Understanding patient engagement from the lens of a person who is suffering, who is in pain and anguish, who is wracked with fear of the impact of this pain on their body, their family, their career, and their mortality, is a complex undertaking. The authors provide an important patient perspective in acknowledging and highlighting efforts to shift the conversation on experience from one about patients and families to one with patients and families. They challenge us to consider the power that can be found in creating ownership for patients and suggest it may be the one true path to moving beyond a mindset of engagement to real equity in healthcare.

Keywords

Patient engagement, patient and family advisors, patient and family advisory councils, ownership

Note

Zal Press is Co-Chair of The Beryl Institute Global Patient and Family Advisory Council and Executive Director of Patient Commando Productions, a producer of accredited patient experience programming for health care professionals. Dawn Richards is a science and patient consultant. She is Vice President of the Canadian Arthritis Patient Alliance, the first patient advisor of the Canadian Medical Association's Wait Time Alliance, a member of the Institute Advisory Board and Ethics Committee of the Institute of Musculoskeletal Health and Arthritis (CIHR), and a Patient Panel Reviewer of the British Medical Journal (BMJ).

Understanding patient engagement from the lens of a person who is suffering, who is in pain and anguish, who is wracked with fear of the impact of this pain on their body, their family, their career, and their mortality, is a complex undertaking.

It was 2 1/2 years ago that Leonard Kish published his now famous blog¹ proclaiming patient engagement as the blockbuster drug of the century. While we still await wide scale adoption of this new drug, the equivalent of clinical trials around the world are starting to prove the value of patient engagement as a method to re-imagine not only how healthcare is delivered, but is re-imagining who actually owns healthcare. In our view, this is the most relevant conversation of our time.

Patients around the world have been demonstrating their eagerness to engage with healthcare systems as active members of patient and family advisory councils in hospitals, long term care, mental health, and specialty delivery organizations. They are advising on strategy, governance, care delivery, practice guidelines and participating in experience-based design. They are advisors and lay representatives in research. Some are developing capacity as competent researchers in their own right. Professional education has patients involved at many

levels, including faculty recruitment. From all of this, one would begin to think that patients are everywhere.

It is important, however, to temper this enthusiasm with a reality check. While inroads are being made, there's a long and winding road ahead. Research by Barbara Lewis of Joan's Family Bill of Rights, highlights that 60% of hospitals in the United States² do not have a Patient and Family Advisory Council (PFAC). Nevertheless, this also represents a great opportunity for groundbreaking initiatives that can inform transformation on a global scale.

Patients and professional education

- The University of Manchester's Medical School has created the Doubleday Centre for Patient Experience that will fully integrate the experiences of patients, their families and carers into the undergraduate program, including patients on panels assessing student applications, creating course materials and allowing students to work with patients and be assessed by them from the first year of study.³
- In April 2014, The Josiah Macy Jr. Foundation brought together the worlds of health professions education, healthcare delivery, and patient and community advocacy as a direct response to the principle that patients, families, and communities

must be engaged at each step in the process of linking education and practice redesign.⁴

Patients and Research

- The "European Patients' Academy on Therapeutic Innovation" (EUPATI), will "increase the capacities and capabilities of well-informed patients and patient organisations to be effective advocates and advisors in medicines research, e.g. in clinical trials, with regulatory authorities and in ethics committees."⁵
- The Patient and Community Engagement Research Program (PACER) in the University of Calgary Faculty of Medicine trains Patient Engagement Researchers (PERs) who are actual patients and family members enabled with the capacity to design and conduct health research, using methods of qualitative inquiry. Their mission is to transform the role of patients through engagement research.

Patients and Policy

In Canada, the Province of Ontario's Minister of Health Dr. Eric Hoskins has made the principle of "Putting Patients First" the core element driving healthcare policy. He claims that a focus on patient engagement is taking hold and that healthcare leaders need to empower patient decision making through education and knowledge translation.

To that end, an important program delivering care focused on the most complex needs patients, the 5% who consume over 70% of system resources hired an Expert Patient Advisor, a person chosen specifically for the depth of lived illness experience, to lead its community engagement strategy.

Patients and Health Service Delivery

- In New Zealand, Ko Awatea has a mandate to lead an innovative approach to achieving sustainable, high-quality healthcare services locally, nationally and across the Asia-Pacific region. Critical to its approach is a dedication to community engagement⁶, which empowers its constituency with capacities and resources through leadership development. Community engagement is the tool to shift care to a more holistic approach, from intervention to prevention.
- In Alaska the Southcentral Foundation's "Nuka Model" raises the bar of engagement to a new level. Every one of their 150,000 clients is served and referred to as "Customer-Owners".

"In our process redesign, we transferred control of the system to the people who are receiving the services and are using the expertise of our professionals to help them make

decisions", says Southcentral's April Kyle. "That is a very different mindset than just being a customer, or patient. The Nuka system of care transcends the organizational boundaries because it includes our community, our partners, our stakeholders – all those things, all together."⁷

While these examples demonstrate great advances in this 21st century, there are still systemic challenges obstructing true engagement. Cathy Fooks, CEO of The Change Foundation, an independent Canadian health policy think tank, declared in March at their Capstone Summit "There will be sceptics and they will be loud". She also advised to "Focus on the early adopters and support them" as a key strategy to overcome inherent organizational obstacles to engagement.

Healthcare leaders such as Jason Wolf, President of The Beryl Institute, tell us that true cultural transformation needs to start with a demonstrated and relentless commitment from the top echelons of an organization. The army of citizens, patients, families, and caregivers is ready to embrace a meaningful demonstration from the very top to the principles espoused in the partnership with patients. We have seen how effective this can be with only these few examples.

It has been offered by Dr. Rita Charon, Executive Director of the Program in Narrative Medicine at Columbia University, that patients own their stories.⁸ While patients generally come into the therapeutic relationship with only their pain and their personal story of suffering, activated patient engagement demonstrates an ownership model beyond the story. By implication we are suggesting that patient engagement is evolving into a phase where patients are taking ownership not only of their own health, but also exerting their influence as the real owners of the system that is serving them.

Can Kish's blockbuster drug of patient engagement be indicated for a broader range of treatment? Patient ownership needs to be understood on a personal, organizational, systemic, and economic perspective. Extrapolating this potential into the future, the traction gained from the patient engagement movement will result in a re-imagining of healthcare from a new model of ownership, one that is unrecognizable from the one we now know and that reflects the vision of Buckminster Fuller:

"You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete."

Patients from around the world are doing just that. A glimpse into the Kish/Fuller future expresses the concept of ownership in new ways, not the least of which includes patients in the C-Suites of all stakeholders in the care

continuum where they will leverage their influence and expertise into an authentic ownership stake, to create a more sustainable and compassionate healthcare reality.

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