

# The Importance of Patient Engagement to Improve Healthcare Research and Safety

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## INTRODUCTION

In healthcare the term expert often refers to medical professionals and researchers. In the last 10-15 years another expert has been recognized and that person is the patient. As is stated by the Canadian Strategy for Patient-Oriented Research, “patients bring the perspective as ‘experts’ from their unique experience and knowledge gained through living with a condition or illness.”<sup>[1]</sup> The term patient includes individuals with personal experience of a health issue, informal caregivers including family and friends, patient representatives including advocates or advocacy organizations.<sup>[2,3]</sup>

In 2003 I was 43 and in the second year of my pediatric residency when I was diagnosed with metastatic colon cancer. I ultimately had two recurrences and became no evidence of disease in May 2006. As a result of surviving, I made a commitment to help others by becoming a patient advocate which has evolved over the years in me becoming an engaged patient.

The term “patient engagement” has changed through the years. In the early days of patient engagement patient stakeholders were commonly relegated to narrow or short-term project roles and passive endorsements limiting opportunities to impact project outcomes, these included focus groups, interviews, and advisory panels.<sup>[4,5]</sup> Engagement has evolved from passive endorsement and agreement to reshaping or coproducing research, many projects have included more collaborative approaches and have prominently noted patients and caregivers as contributors.<sup>[5]</sup>

In recent years new definitions of patient engagement have been adopted, one of the more recent and comprehensive definitions is:<sup>[3]</sup>

The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided

by patients’ contributions as partners, recognizing their specific experiences, values, and expertise.

This editorial will look at a brief history of patient engagement, recent definitions, the benefits and challenges of engaging patients and some guidelines.<sup>[6]</sup> Patient engagement in research is actively being pursued in Canada, the UK, the US, Asia and Latin America and Europe (Figure 1).<sup>[2,3,7]</sup>

Many studies have inappropriately used other terms interchangeably with the term patient engagement. This was substantiated by a literature analysis by one group that demonstrated a clear distinction between the terms “patient-centered” and “patient engagement.” “Patient-centered” was more focused on the healthcare setting in a patient-provider context. Whereas “patient engagement” was most strongly associated with an active, involved process. They found evidence of comprehensive engagement at all levels of research as opposed to in the healthcare setting.<sup>[3]</sup>

Engagement is meant to ensure the project is not only relevant but valuable to the end users. There is broad agreement that patient engagement should be meaningful, impactful, and measurable although the means to do this are inconsistent.<sup>[3]</sup> Patients should be involved in the research project from conception to dissemination of the results including bench research to clinical trials.<sup>[1]</sup> Patients are no longer just passengers in decisions that they will ultimately be affected by.

My advocacy began rather informally by attending meetings, speaking with patients and being in chat rooms. From there I started reviewing grants and being on panels at American Society of Clinical Oncology (ASCO) and the National Cancer Institute (NCI) among others. In 2018 I was approached about being a patient advocate on an international grant through Cancer Research United Kingdom (CRUK). I assumed that it would be like my previous experiences, but it was not.

		INCREASING IMPACT ON THE DECISION				
		INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL		To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC		We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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**Figure 1.** IAP2 Spectrum of Public Participation. IAP2’s Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public’s role in any public participation process. The Spectrum is used internationally, and it is found public participation plans around the world.

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Our grant was funded in 2019 for 5 years and I am a co-investigator. My responsibilities have included recruiting international research/patient advocates, writing a budget and a section of the grant presenting at annual meetings and reviews, writing abstracts and posters, and launching a public facing website.

The first year I recruited 11 advocates with different levels of experience, all were enthusiastic about the project. Some of the advocates were “trained” through a research program, some were working as patient navigators and others had founded non-profits. All were survivors and some were in treatment.

The advocates have been involved in all levels of the grant including basic cancer research, participating, and presenting during team meetings, and giving input during topic meetings. The advocates have had an impact on the design of clinical trials, design of patient/public handouts and a lay video on the microbiome. The most challenging aspect of engaging our patient advocates was the lack of knowledge of basic cancer research, but with our engaged patients and researchers it has evolved over time. The advocates are an integral component of all the projects and the entire team functions as a collective.

### BENEFITS OF PATIENT ENGAGEMENT IN RESEARCH

It has been reported in several studies that patient engagement “provided valuable contributions to research feasibility, acceptability, rigor, and relevance.”<sup>[5]</sup>

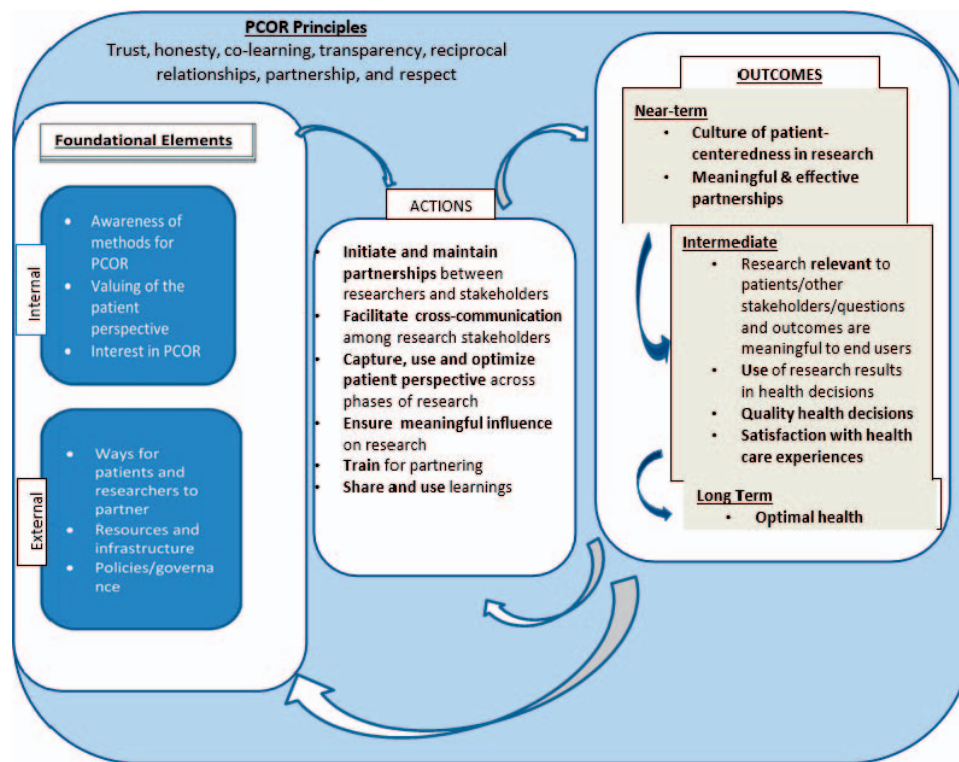
Engaging patients in research can increase its quality and, as healthcare providers integrate it into care, the quality of care will increase.<sup>[1]</sup> Engagement can lead to more relevant research by aligning patients and clinicians needs.<sup>[5]</sup> Engagement enables mutual learning, and the building of new skills, knowledge and skills by patients increased understanding of basic science research and the broadening of researcher’s perspectives including an understanding of what is important to patients.<sup>[7]</sup>

“I cannot overstate the importance of patient advocates and incorporating their perspectives and priorities in this process our patient advocates contributed significantly towards the design of our diet and lifestyle questionnaire and stool collection kits, ensuring that the language was lay friendly and easy to understand and that the process of filling out the questionnaire and collecting samples was as simple as possible.” —Dr. Kimmie Ng.<sup>[8]</sup>

It has been seen that patient engagement has led to an increase in trainee recruitment and retention as trainees have a greater appreciation and new motivation of the purpose and impact of their research.<sup>[3,5]</sup>

Another example:<sup>[5]</sup>

“In one project studying stroke patients described how patient partners helped refocus research aims, saying: ‘We knew regaining functional status was an important component of recovery, but we did not realize how much depression, anxiety, and fatigue weighed on many stroke survivors’ minds. So, we revisited our aims, overhauled our data collection plan, and our results demonstrate that engaging patients in preclinical research is feasible and



**Figure 2.** Conceptual model of patient-centered outcomes research.

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may enhance research conduct in unique ways. Our results should encourage preclinical researchers and patient partners to establish new collaborations.”

## CHALLENGES OF PATIENT ENGAGEMENT IN RESEARCH

A theme in the research is the paucity of data specific to patient engagement and the vague descriptions of engagement methods including lack of reporting the impact on the project<sup>[4]</sup> time and resources, including recruitment and retention<sup>[1]</sup> and a lack of a clear definition of patient engagement.<sup>[4]</sup> The ability of the research/clinicians to effectively communicate in lay language can lead to frustration for all involved. The ability to incorporate the time and resources required for meaningful engagement including financial compensation of the patients.<sup>[3,9]</sup> Another challenge is engaging a small group of patients which could decrease diversity and be seen as tokenism.

## SUMMARY

Patient engagement in research is an avenue for patient-centered and democratic healthcare solutions. Patient engagement has been incorporated and required, in research, by international funding agencies.<sup>[9]</sup> An excellent example is the Patient-Centered Outcomes

Research Institute (PCORI) in the United States, which requires engagement from patients in study design, conduct, and dissemination (Figure 2).

“PCORI has funded hundreds of projects that operationalized engagement in different ways, ranging from community forums to advisory panels and patient coinvestigators. PCORI’s requirements and general guidance about the purpose and principles of engagement provide a shared context for studying the contributions of engagement on a larger scale than has been done before. Furthermore, PCORI was created to fund comparative effectiveness research that compares the benefits and harms of clinical interventions in real-world settings, so engaging people who will receive those interventions is particularly salient.”<sup>[5]</sup>

Although challenges are recognized, the end results of engaging patients as partners outweigh the challenges. The principles of “reciprocal relationships, co-learning, partnership, trust, transparency, and honesty”<sup>[2]</sup> are essential characteristics of patient engagement in research and healthcare in general. Some of these challenges can be alleviated by adopting a global definition of patient engagement, addressing the issue of training, having consensus on guidelines for patient engagement and how to formally document and share the experiences to enable comparisons between methods and conduct<sup>[10]</sup>, ultimately resulting in a measurable parameter.

## References

1. Fergusson D, Monfaredi Z, Pussegoda K, et al. The prevalence of patient engagement in published trials: a systematic review. *Res Involv Engagem.* 2018;22:17.
2. Anderson M, Kimberly MK. On the path to a science of patient input. *Sci Transl Med.* 2016;8:336ps11-ps11.
3. Harrington RL, Hanna ML, Oehrlein EM, et al. Defining Patient Engagement in Research: Results of a Systematic Review and Analysis: Report of the ISPOR Patient-Centered Special Interest Group. *Value Health.* 2020;23:677–688.
4. Enzinger AC, Wind JK, Frank E, et al. A stakeholder-driven approach to improve the informed consent process for palliative chemotherapy. *Patient Educ Couns.* 2017;100:1527–36.
5. Forsythe LP, Carman KL, Szydowski V, et al. Patient engagement in research: early findings from the patient-centered outcomes research institute. *Health Aff (Millwood)* 2019;38:359–67.
6. IAP2 Spectrum of Public Participation. International Association for Public Participation website. Published 2018. Accessed Apr 5, 2022. [cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum\\_8.5x11\\_Print.pdf](http://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf)
7. Fox G, Fergusson DA, Daham Z, et al. Patient engagement in preclinical laboratory research: A scoping review, *eBioMedicine* 2021;70:103484.
8. Kimmie Ng and Candace Henley celebrate the value of the patient advocacy voice in cancer research #IWD2021. Cancer Grand Challenges website. Cancer Research UK, National Cancer Institute. Published Mar 11, 2021. Accessed Apr 5, 2022. [cancergrandchallenges.org/news/kimmie-ng-and-candace-henley-celebrate-value-patient-advocacy-voice-cancer-research-iwd2021](http://cancergrandchallenges.org/news/kimmie-ng-and-candace-henley-celebrate-value-patient-advocacy-voice-cancer-research-iwd2021)
9. Bombak AE, Hanson HM. A Critical Discussion of Patient Engagement in Research. *J Patient Cent Res Rev.* 2017 Jan 31;4:39–41.
10. Kirwan JR, de Wit M, Frank L, et al. Emerging Guidelines for Patient Engagement in Research. *Value Health.* 2017;20:481–486
11. Frank, L., Forsythe, L., Ellis, L. et al. Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute. *Qual Life Res* 2015;24:1033–1041.