

RESEARCH ADVOCACY: The Important Role of Patients

In this PIP Digest, we provide an overview of patient research advocacy and the important role that patients play in the research process.

Key concepts

- The role of patient advocates in research
- Levels of engagement in research by patients

Related PIP Digest

- Research Advocacy: Preparing Your Research Advocate Resume

The Worlds of Patient Advocacy



Research advocacy¹ is but one of the interrelated activities that patients can do to improve patient outcomes in the short- and long-term.

- **Support:** Helping patients with medical visits, accessing support systems, and providing vital information about clinical trials, treatments, and other resources. (This includes providing advice on how to make information and supports more relevant and useful to patients.)
- **Fundraising:** Raising money for medical research and patient support services and helping to advance the public's understanding of science and its vital role in improving the health system and health status of the population.
- **Political advocacy:** Lobbying for legislative changes and overarching policies that benefit patients. This may also include establishing linkages between researchers and policymakers and advocating for more evidence-informed policy making.
- **Watchdog:** Bringing to light system-wide issues that affect health—things like inequities in access to care and treatments, adverse drug events, ethical breaches, environmental and occupational risks, and so on.

¹From <https://www.cancer.net/blog/2019-03/how-patient-advocacy-helps-advance-cancer-research-conversation-collaboration>.

- **Research:** Working directly with researchers and the broader research system to ensure that research is more relevant, timely, and beneficial for a broad range of patients. This includes helping to promote transparency, accelerate the implementation of promising discoveries to the clinic, and ensure that innovations introduced in the health system improve outcomes and quality of life for patients.

The Role of Patients



There are many stakeholders involved in helping to deliver on the benefits of health research.²

But what is the unique value offered by patient research advocates?

"Patients and advocates are able to often look at questions and research problems through a lens...of optimism and hope for better outcomes, and for a brighter future with new options. This optimism and alternative lens is desperately needed in the laboratory, especially during times of fiscal crisis, when so much great research is left unfunded."³

"We must strive to find a balance between funding great science, and funding discovery and questions that are risky, and have the most potential to directly impact the patients that we are ultimately trying to help. The best way to ensure we are asking questions relevant to patients is to ask the patients right from the start!"⁴

Patient research advocates play an important role in helping researchers to deliver the best science to those affected by cancer. They add a human face and sense of urgency to cancer research. Advocates are also well positioned to ask

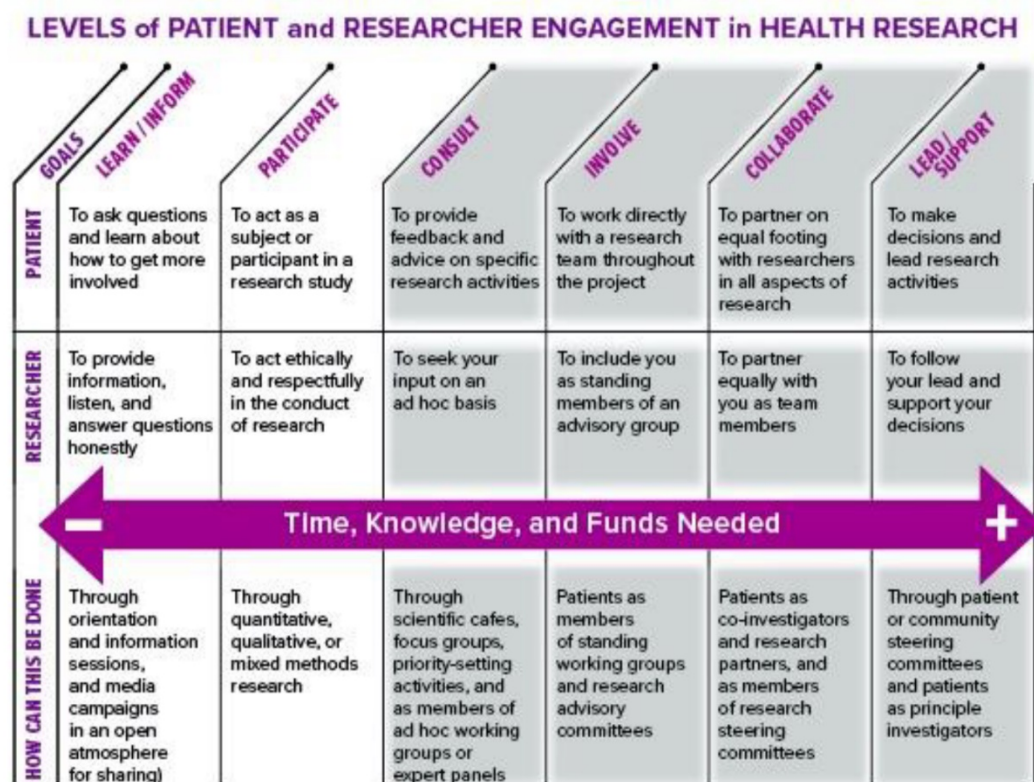
²From: <http://www.cihr-irsc.gc.ca/e/documents/CIHR-strat-plan-eng.pdf>

³Ciccarella A, Staley AC, Franco AT. (2018) Transforming research: engaging patient advocates at all stages of cancer research. *Annals of Translational Medicine*, 6(9):167. <http://atm.amegroups.com/article/view/19388/html>

⁴Ibid.

questions that may be more difficult for professional colleagues to raise. By participating in the development, oversight and dissemination of cancer research, patient research advocates help to advance research progress and improve patient outcomes.

Patient engagement in research goes beyond patients as passive recipients of information or research participants. The shaded sections of the diagram below show the different and increasingly influential roles that patients may assume in a research project. How this can be done varies with the level of engagement and, an important consideration is that as patient engagement increases, more time, knowledge and funding are required to adequately support the process.



Vandall-Walker, 2017

Shaded area indicates the levels that the AbSPORU Patient Engagement Platform focusses on

From: Alberta SPOR Support Unit. *Patient Engagement in Health Research: A How-to-Guide for Patients*. Patient Engagement Platform, May 2018 (Version 8.0).

Effective Patient Research Advocates

Some tips for increasing your effectiveness:

- Remain focused on the impact and significance of the research for patients. Do not pretend to grasp all the details of the science that the researchers are seeking to advance. The reality is that almost no one knows the full details. Everyone is learning all the time.
- Use your life skills and expertise to bring innovative solutions to cancer research problems. In addition to your patient experience, your professional and broader life experience can help to provide diverse insights and enhance the design and execution of a research project.
- Challenge token involvement and don't hesitate to say "no" if you are being asked to do something that you feel is not designed to engage patients in meaningful ways. For example, it is appropriate to refuse to send a letter of support for a research project when you have not an opportunity to be involved.
- Help to facilitate communication and collaboration with advocacy groups, researchers, and health care providers. Patient advocates are often the ones who bring the right people together to make things happen!
- Seek opportunities to interact and change perceptions of trainees and researchers at early points in their careers to change the culture of the value of patient involvement.

Key Initiatives



Announced in 2011, the **Strategy for Patient-Oriented Research (SPOR)** was developed by the Canadian Institutes of Health Research (CIHR) in collaboration with provincial/territorial governments, health charities, academic healthcare organizations, faculties of medicine and industry. The strategy represented a fundamental shift in the focus of applied medical research — to one focused on better outcomes for the patient. A Patient Engagement Framework is available at <https://cihr-irsc.gc.ca/e/48413.html>. Additional resources are available from the SPOR units that CIHR supports in all jurisdictions:

- Alberta Strategy for Patient Oriented Research SUPPORT Unit (AbSPORU) - <https://absporu.ca/>
- BC Support Unit - <https://www.bcsupportunit.ca/>
- Centre for Healthcare Innovation (Manitoba Support Unit) - <https://www.chimb.ca/about>
- Maritime SPOR SUPPORT Unit (New Brunswick, Nova Scotia, and Prince Edward Island) - <http://www.spor-maritime-srap.ca/>
- NL SUPPORT (Newfoundland and Labrador) - <http://www.nlsupport.ca/home.aspx>
- Hotìì ts'eeda (Tłìchq Government and Northwest Territories) <https://nwtspor.ca/>
- Ontario SPOR Support Unit - <https://ossu.ca/>
- Unité de soutien SRAP du Québec - <https://unitesoutiensrapqc.ca/>

- Saskatchewan Centre for Patient-Oriented Research (SCPOR) - <https://www.scpor.ca/>

Patient Advisors Network



The **Patient Advisors Network** (PAN) is a network developed by and for patients and caregivers. The group is committed to building a supportive community of practice for likeminded people to promote the involvement of patient advisors and improve healthcare for Canadians. See <https://www.patientadvisors.ca/>.



The **Patient-Centered Outcomes Research Institute** (PCORI) is a US-based organization with the mandate to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make better-informed health decisions. The organization is involved in building an evidence base of effective ways to conduct research on patient-centred outcomes. In addition, the PCORI website offers a broad repository of resources and online training modules for patients interested in the research process. See <https://www.pcori.org/>.

Research Advocacy Network

The US-based **Research Advocacy Network** (RAN) was formed in 2003 with the goal of helping to bring together participants in the cancer research endeavour and help educate, support, and connect patient advocates with the larger research community. RAN offers a resource-rich website to help advance your knowledge about specific areas of cancer research. See <https://researchadvocacy.org/>.

For more, see:

- Black A et al. (2018). What constitutes meaningful engagement for patients and families as partners on research teams? *Journal of Health Services Research & Policy*, 23(3):158–67. <https://journals.sagepub.com/doi/pdf/10.1177/1355819618762960>
- Perlmutter J, Bell SK, Gwen Darien G. (2013). Cancer Research Advocacy: Past, Present, and Future. *Cancer Research*, 73(15):4611–5. <https://cancerres.aacrjournals.org/content/canres/73/15/4611.full.pdf>
- Perlmutter J, Roach N, Smith ML. (2015). Involving Advocates in Cancer Research. *Seminars in Oncology*, 42(5):681–5. <http://www.masoniccanceralliance.org/Documents/mca/Involving%20Advocates%20in%20Cancer%20Research.pdf>
- Salamone JM et al. (2018). Promoting Scientist–Advocate Collaborations in Cancer Research: Why and How. *Cancer Research*, 78(20):5723–8. <https://cancerres.aacrjournals.org/content/canres/78/20/5723.full.pdf>

There are a great many videos available on YouTube that cover the topic of patient engagement in research. These are varying lengths and have different focuses and you may want to check them out at your leisure. The couple listed below, although a few years old, are very succinct and focus on the main “whys” of patient engagement in research.

- HealthOutcomesStrats. *Patient Engagement in Research*. (YouTube) June 5, 2015 [2:14 minutes]
<https://www.youtube.com/watch?v=4SOK8CA6mQk>
- National Cancer Institute. *Research Advocacy 101: Research Advocates Improve Cancer Care at NCI*. (YouTube) November 20, 2014 [1:00 minute] <https://www.youtube.com/watch?v=5SUPqVnfdg>
- St. Baldwin's Foundation. *Patient Advocates – A Dream Team Video* (YouTube) August 13, 2020 [5:18 minutes]
https://www.youtube.com/watch?time_continue=3&v=RNeVC1m12DQ&feature=emb_logo

Reviewer: Patrick J. Sullivan
Last revised : 2020-Sept-16