

Integrating the Patient Voice in Health Research: The What, Why and How

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Part of the AllerGen webinar series: Knowledge Translation for Research Success

Colleen McGavin delivered a webinar in AllerGen's Knowledge Translation (KT) for Research Success series on March 8, 2017, discussing what patient engagement is, why it's important and how BC's Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit is working to "get it right." The main messages from this webinar and a hyperlinked index to the presentation are provided below.

THE WHAT

patient engagement: meaningful and active collaboration with patients in research governance and priority-setting, and in the conduct of research and/or knowledge translation

patient-oriented research: research that 1) aims to improve healthcare systems and practices; 2) is conducted in partnership with and by patients, researchers, healthcare providers and health system decision-makers; and that 3) focuses on priorities that matter to patients, whether the priorities come directly from patients, or from the research community with the endorsement of patients.

THE WHY

Why patient engagement? *The moral argument:* patients have a right to be involved in publicly-funded endeavors that affect them personally. *The relevance argument:* as knowledge users, patients know what matters to them and which treatments and therapies are most likely to be acceptable to them—so their involvement in research better guarantees that the findings will impact policy and practice change. *The quality argument:* patients bring a unique perspective that complements scientific and academic expertise.

Having a patient at the table changes the entire conversation. A patient presence reminds others what health research is ultimately all about, keeping the discussions patient-centred rather than system-centred. Patients may be freer to think creatively and challenge assumptions, as they are not peers or employees of the researchers, nor are they obliged to represent institutional views. Many researchers find that engaging patients in research makes them better communicators; it gives them an opportunity to hone their knowledge translation

skills and gain practice at making their results understandable and usable to knowledge users.

Patients can contribute to all phases of the research lifecycle. In the design phase, patients can co-develop the patient recruitment strategy, and review and comment on proposed questionnaires and data collection methods. For the grant proposal, patients can define outcome measures of importance to all patients, like quality of life. In preparing for study implementation, patients can help develop patient information and consent forms. During data collection, patients can conduct peer-to-peer interviews and focus groups. For data analysis, you can consult with patients to see if they interpret data in the same way as the researchers. When disseminating research results, patients can co-author manuscripts and newsletters, identify other information outlets, and jointly present the findings with researchers at conferences. During implementation, patient involvement can increase the likelihood of uptake by adding validity to the findings.

THE HOW

Bring patients in early, preferably before the research question has even been identified. Be certain to involve patients in the development of the research proposal, to make sure that the question is clear and the outcomes resonate with the patient partners.

Be clear about roles, responsibilities and levels of engagement. Are you involving patient partners merely to consult with, or to play a more collaborative role? What exactly are you asking them to do? If you are not sure of what the patient role will be, be honest about that from the outset.

Develop a patient engagement plan. Ask yourself the following: What role(s) do you envision for patients in this project? How will you create a safe and welcoming environment to interact in? How will you ensure that your patient partners feel confident in their roles? Will you provide orientation, training and/or mentorship? Have you budgeted for patient engagement? How will you evaluate whether it made a difference?

Be realistic with patient partners, and stay in contact. Make sure they are aware of your project's timelines, and that there can be stretches of time when it appears that nothing is happening. Keep the patient partners informed about progress. For example, if you're waiting many weeks for ethics approval, inform them so that they do not lose interest or feel that they have been dropped from the project.

Keep the lines of communication open, and always invite feedback from patient partners around how the collaboration is working for them and how you might do things differently.

Plan for the resources you will need. Give some thought as to how you will budget for even small costs, like parking, mileage and coffee, and so on, for patient partners who most often are volunteers. It's important to support them and show your appreciation.

Get ethics approval where needed. When patients become part of the research team, helping to shape the direction of the research lifecycle, it is not necessary to get ethics approval for their involvement. But if you need to get data from a larger group of patients with lived experience, through surveys or focus groups, for example, you will need ethics approval.

Only do it if you believe in it. If there is not true buy-in to the idea of patient engagement, if you are doing it because you have to—perhaps to apply for a grant, though you don't actually believe in it—this will be a barrier to success. On the other hand, if you really buy in to the idea on a gut level, but you have no idea about how to go about doing it, you *can* make it work. If you keep an open attitude, are prepared to commit some time and energy, and maintain open communication with your patient partners, you will overcome the hurdles you encounter along the way.

RESOURCES

[Patient Engagement Framework](#): a SPOR/CIHR living document outlining goals and opportunities.

[Is it worth it?](#) *Patient and public views on the impact of their involvement in health research and its assessment* (paper).

[Roles for Patients](#): an overview of the roles patients might play in research

[BC SPOR SUPPORT Unit resources](#): a variety of resources to support researchers planning to engage patients in their work.

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Available for this webinar: [slides \(in PDF\)](#) | [video recording](#)

Colleen McGavin is the Patient Engagement Lead for BC’s Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit. Particular areas of interest to Colleen include: patient-centered care, patient engagement, patient-reported outcome and experience measures and patient-oriented health research.