Why should you get involved in health research?

Darlene Gallant
I’m optimistic that every patient can find the right place to get involved; a place where patients are the focus and are seriously heard. This can be challenging, but there is a lot of good work out there being done. It's about working together with people who share a common goal that focuses on the collective good for patients in Alberta.

Family Member, Wife of Patient

Neil Durrant
I continue to be involved with the PE Platform to ensure that changes in health research benefit patients and not just administrators/researchers - we need to see a direct patient benefit from research. I am concerned by the amount of money being spent in the healthcare industry; there are steps we can take by being engaged in research to ensure effective health care for the general population. I push for patient engagement to start happening earlier in the process, in the hopes that their involvement is no longer an afterthought in research work.

Patient Engagement Platform Advisory Council (PEPAC) Member

Jessica Havens
Very rarely are youth talked to as though our opinions count; that our lived experience is just as legitimate as the experiences of adults. Patient engagement in research, and in all aspects of healthcare, is key because there are never one-size-fits-all questions or answers. Healthcare should be constantly ongoing, evolving, and improving, and that cannot happen without the involvement of patients and family members who are willing to let researchers learn from patients' personal experiences. Getting involved means that together we are turning both good and bad experiences into learning experiences for all Albertans to benefit from.

Child and Youth Advisory Council (CAYAC) Member
Patient Engagement Platform Advisory Council (PEPAC) Member

Nicole Olivier
I [realize] how complementary patient engagement [is] to the project. The contributions that have been made by patients to our project have expanded the limits of our research comfort zone to include ethics and marketing. Who better to help us determine if our project mattered to patients than by patients themselves?

BedMed Study Coordinator
The Patient Engagement Platform is:
- a small team
- involved in the Canadian Strategy for Patient-Oriented Research (SPOR) initiative
- helping influence active, meaningful patient engagement in health research in Alberta.

“Patient” is an overarching term inclusive of people with a personal experience of a health condition (including caregivers, family, and friends).

Patient engagement includes patients working with researchers in all stages of health research, from the choice of research project, through to collecting data and the sharing of study results.

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The Patient/Family Registry
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