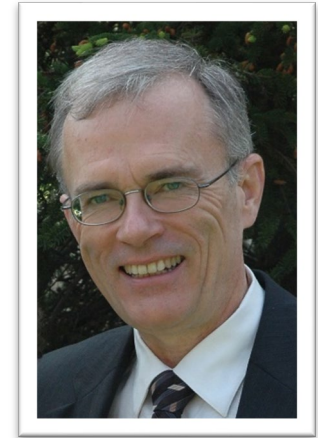


Interview with

**David McMullen**

## **2023 CCRA Awardee for Exceptional Leadership in Patient Involvement in Cancer Research**



**Given your long-term involvement as a patient research advocate, how has the needle moved in Canada in terms of patient engagement in cancer research?**

Firstly, thank you so much for inviting me to take part in this interview and, of course, for the award. I'm just so humbled and immensely grateful for this wonderful honour. I know there are many other patient leaders in Canada who make tremendous contributions to cancer research. But regarding your question, the needle has really moved a lot, is still moving, and will move further!

Thank goodness for researchers, for without them I would have been gone a long time ago with my disease. But it is impossible for researchers to fully appreciate the needs of patients and their families without having input from patients with lived experience.

In the last 12 years that I've had cancer, we have increasingly recognized and implemented patient engagement in research. Research funding agencies such as the CIHR, PCORI in the US, and the NIHR in the UK, are some examples where increasingly patient engagement is a requirement. Not-for-profit research organizations too, have increasingly embraced patient engagement in research. An excellent example of this is the Canadian Cancer Trials Group (CCTG), where I am a patient representative. The CCTG has truly embraced patient engagement throughout the whole cycle of clinical trials. Another group in my experience is the Canadian Myeloma Research Group, which has two patients on its board and has an extensive patient database with a patient on the database steering committee. I'm currently that patient.

Pharmaceutical companies are increasingly implementing patient engagement. I have friends very involved as patient partners with a large pharma company exploring ways to increase engagement in research. I believe many large pharma companies have similar initiatives. Patient groups for various types of cancer (for me, it's Myeloma Canada) are running their research grant reviews with at least one patient or family member on the review committee. I have participated in three of these. Patients are also taking part in the development of long-term research strategies.

**What do you feel are the biggest challenges and opportunities for patient engagement in research?**

Again, we've made great progress but there is more to come. The ultimate customers of cancer research are patients and their families. Cancer will at some point in our lives impact essentially

everybody in Canada as either a patient or as family. We as patients, or future patients, need some of us to be our spokespeople in research.

A major challenge as well as an opportunity is education – educating patients to become good patient partners. This takes time and effort. The CCTG does this very well as do some other organizations. Details on how the CCTG does this are available on their public website (<https://www.ctg.queensu.ca/public/patients-families>).

**Given your extensive involvement in support groups, how do they help support patients and facilitate research and knowledge translation?**

Ever since I was diagnosed, I've been involved in myeloma support groups. These are associated with Myeloma Canada. I've been the chair of a large group in Toronto for the past 10 years and helped set up other groups in Southern Ontario. We have two main purposes: one is to provide support – going through a deadly disease experience like myeloma can be very daunting and psychologically challenging. The other purpose is to provide information – about the disease and treatments, and suggestions on asking good questions to health care providers. We also provide information about research advances. This is part of the knowledge translation that we do. We are also fortunate to have in the myeloma medical community some really engaged, knowledgeable specialists, gracious enough to come to our support group meetings and provide the latest about what is happening in myeloma research. We also facilitate knowledge translation ourselves as patients. This knowledge translation, providing information about new developments in research, provides us tremendous hope to live longer and better lives.

Myeloma Canada is a tremendous patient-based organization that provides a lot of resources, including information about recent research findings, research underway, and planned research. This is in addition to advocating for funding research and new treatments.

**What research advances in multiple myeloma give you the most hope?**

Over the last 12 years, there have been tremendous advances, but myeloma, unlike many cancers, is not yet curable. Unfortunately, most patients still die from the disease. But again, there is hope because of the research underway. The biggest hope now is the new and rapidly expanding area of immunotherapy, including cellular therapies. I recently benefited tremendously by participating in a clinical trial with a very new type of CAR T-cell therapy. It was amazingly successful, although for myeloma, CAR T is not a cure. We expect relapse sometime down the road. However, there is much work underway to enhance CAR T-cell and other cellular therapies for myeloma to enable longer remissions and possibly at some point, a cure. This is what gives me the most hope.

**What advice would you give to patients interested in becoming more involved in cancer research?**

Firstly, many cancer types have patient groups associated with that cancer. I mentioned Myeloma Canada for me. I would suggest getting involved with a patient group for your cancer. Many of these organizations support research programs or initiatives and are looking for patient partners. The CCRA has the **Patient Involvement in Cancer Research Program (PIP)**. This excellent and very comprehensive education and engagement program is conducted every other

year for people with all types of cancer, and participants attend the CCRA biannual conference. Details are on the CCRA website. There are other organizations like the Canadian Cancer Survivor Network, which provides education programs for patients and partners with very many cancer-based organizations which fund or conduct research. BioCanRx, in the field of cancer immunotherapies, also greatly incorporates patient engagement. The Canadian Cancer Society has a program called Patient Engagement in Research, including patient partners with lived experience with cancer.