

My evolution to becoming a Patient Partner / Advisor

David Wells

Background

I grew up in Montreal. Since 1956 I have lived in the Maritimes, except for four years as a student at UBC. Since 1965 I have bounced back and forth between Dartmouth and Fredericton.

My day jobs have involved three careers. Fifteen years as an engineer at the Bedford Institute of Oceanography; twenty years as an engineering professor at UNB; and the last twenty-two years and counting as a marine science professor at the University of Southern Mississippi. Along the way I collected degrees in physics, engineering physics, nuclear physics, and satellite geodesy.

I met my wife Solveig in 1963 when we were both UBC students. We have three children: Corey the carpenter, who lives in Creston BC, now 52 years old; Tara the graphic artist, who lives in Sackville NB, now 50 years old; and Trevor the electrician, now 38 years old, who lives with me in Fredericton.

Path as a patient partner

My path has gone through four stages:

- 1 - **Oblivious** acceptance of healthcare as it is;
- 2 - **Engagement** in support my wife's many health challenges in the decade 2003-2013;
- 3 - **Activation** to work on improvement of the healthcare system for the benefit of all
- 4 - **Collaboration**, mainly my involvement in **patient-oriented research**

Obliviousness: For the first 40 years of our marriage, my wife and I took our health, healthcare and the healthcare system for granted. We trusted our superb family physician, Dr. Gordon Plummer for 37 years until his retirement. He capably addressed any health issues that came up. In the 1990s I was diagnosed with several mostly lifestyle-derived health issues: obesity; Type 2 diabetes; hypertension; dyslipidemia; sleep apnea; and sarcoidosis. But these pale in comparison with the health issues my wife faced between 2003 and 2013.

Engagement: Our family journey towards patient engagement began in 2003 when our dentist noticed a lesion under Solveig's tongue that had persisted since her previous appointment. It was squamous cell carcinoma. Now health and healthcare became a

family priority. We became engaged (me mostly as Solveig's caregiver and patient advisor).

Solveig had four more cancer diagnoses: 2007 another mouth cancer; 2008 adenocarcinoma in her left lung; 2011 malignant mediastinal lymph node; and 2013 another lymph node in her neck. She underwent three surgeries; two sessions of radiation therapy; three sessions of chemotherapy; and 40 days of hyperbaric oxygen therapy. In March 2013 plaque broke loose and blocked her intestinal blood supply. She passed away 10 days later on March 22, 2013. I still miss her every day.

During this decade I supported her by becoming as informed as possible about her diagnoses and treatments. I subscribed to the Canadian Medical Association Journal, and the Journal of the American Medical Society. When chemotherapy was first recommended I joined the American Society for Clinical Oncology and read about a comparison of cisplatin to carboplatin (the options her oncologist was considering for her chemotherapy). When hyperbaric oxygen treatments were recommended to halt the decay of her mandible (due to chemotherapy), I joined the Underwater and Hyperbaric Medical Society and read Paul Harch's book "The Oxygen Revolution." Solveig received her 40 days of hyperbaric oxygen treatments in Paul's clinic in New Orleans. When there was some question about the staging of Solveig's cancer, I browsed the American Joint Committee on Cancer's staging manual to best understand the factors involved.

I also read three excellent sources that helped me understand the many dimensions of patient engagement:

- 1 - Dave's deBronkart's book "Let patients help! A patient engagement handbook - how doctors, nurses, patients and caregivers can partner for better care."
- 2 - Planetree's "The putting patients first Field Guide: Global lessons in designing and implementing patient-centered care"
- 3 - The February 2013 issue of Health Affairs on the topic "New era in patient engagement" - 30 articles on many aspects of implementing patient centered services.

I have distilled what I learned down to two axioms (self-evident truths)

- 1 - Appropriate care implies patient-centric care.
- 2 - Evidence shows engaged patients have improved outcomes.

Activation: The Institute for Healthcare Improvement defines patient **engagement** as *Engagement is concerned with one's own and one's own family's health and healthcare.*

Judith Hibbard (at University of Oregon Medical School) defines patient **activation** as

An activated patient takes on roles that benefit other patients, and the healthcare system itself.

Surgical Wait Times: My introduction to patient activation occurred in 2005, when Solveig's right hip required replacement, and we were warned the wait time might be over a year. I discovered the 2005 Chaoulli / Zeloitis Supreme Court decision, the Western Canada Wait Time Alliance, and CMA's annual Taming of the Queue conference (a year later I became a member of the steering committee for this conference); realized that Saskatchewan's province-wide surgical registry was a good solution, and impetuously said so to someone in the NB Department of Health.

The reaction was immediate and scary. I received a phone call within an hour asking me to come down to the Department of Health, because they had found my email "intriguing". I feared I had condemned my wife to the longest possible wait time, but decided to do what I could to repair the damage. At this meeting I was surrounded by health bureaucrats who asked me questions like "How do you know so much about surgical wait times?" and "How did you know that our plan was to copy the Saskatchewan solution?" Finally I asked "Why am I here?" They explained that they were ready to announce their surgical wait reduction strategy but there was one hold-up. The strategy was to be overseen by the "New Brunswick Surgical Care Network Advisory Committee" and they had appointed all members except the Chair. They had decided the chair HAD to be a patient. But they had no idea where to find the appropriate patient - until my email arrived. I protested that I was NOT their guy because I am unilingual in a bilingual province; because I spent 50% of my time in Mississippi teaching; and most importantly because I knew absolutely nothing about health care. They immediately replied with one word "Details".

It took me three months to resign from a bunch of international committees that took up a lot of my time. I learned much later that it took the minister of health three months to become convinced that I was not an political opposition plant. He was finally convinced when he learned that I had edited the first textbook on GPS, and he scheduled a private one-on-one dinner together with me. He wanted to know why his GPS receiver did not always work when he went hunting. I was able to explain. Health care and surgical wait times were also briefly mentioned.

But best of all was that my wife's orthopedic surgeon had put her at the top of his cancellation list, and a cancellation came up after just a two-month wait.

It took us six years, with help from Peter Glynn who co-chaired the Saskatchewan Surgical Care Network, and with Lise Daigle and Kathy Bell from the Department of

Health sitting at my side at each meeting, explaining healthcare issues I was just learning about. (Kathy is now Director of Primary Health Care, Chronic Disease, and Family Practice with the NS Health Authority in Cape Breton). Our most positive statistics were that introducing the wait time registry initially reduced surgical wait times by between 50% and 70%, although they remain longer than Canadian benchmarks. Today (before the pandemic) for all surgeries, 50% are completed within 89 days, 90% within 337 days. For cancer surgeries these are 22 days and 90 days respectively. Public access to current NB wait times is available at the website we designed: Surgerynewbrunswick.ca

Primary Care: In 2012 -2013 I served as the patient partner on the NB Primary Health Steering Committee, chaired by Dr. Aurel Schofield of Université de Moncton. Our primary achievement was creating Guidelines for Family Health Teams in NB, which was adopted when Family Medicine New Brunswick was announced in June 2017, as part of a four year physician services master agreement between the province and the NB Medical Society.

Finally Collaboration: I joined Patients for Patient Safety Canada in 2012. I became a patient partner with Maritime SPOR Support Unit (MSSU) in 2013. Through MSSU, in 2018 I was contacted by Diabetes Action Canada, a national SPOR network, and that has since been where most of my patient oriented research activities are occurring. I sit on several DAC committees (Postdoctoral Fellowship Selection Panel; Research Governing Committee; Collective Patient Circle; Operations and Management Committee; Strategic Planning Committee), and am listed as a patient partner on three CIHR Catalyst grants, one with Monica Parry from U of T, one with Holly Witteman at Laval, and one with Shelley Doucet at UNB. In 2019 I sat the examinations and qualified as a Certified Professional in Healthcare Information and Management Systems (CPHIMS-CA).

Patient / Investigator decision aids: Under Monica Parry's leadership, I was a member of a twelve-person team that developed two patient partner and investigator decision aids for Clinical Trials Ontario.

<https://www.ctontario.ca/patients-public/resources-for-engaging-patients/decision-aids-for-patient-partner-engagement-with-clinical-trials/>

A peer-reviewed paper describing these aids is available at <https://link.springer.com/article/10.1007%2Fs40271-020-00460-5>

A 45-minute explanation of these decision aids were developed is available at <https://youtu.be/H3XlchDrz2E>

Do's and Don'ts: Four of us, all experienced patient partners, began meeting informally in 2019 to discuss what advice we would give to investigators about incorporating patients into their medical research projects. After 28 revisions, our list of 10 Do's and Don'ts were adopted by Diabetes Action Canada, turned into an infographic, and translated into French. We are in the process of preparing a paper to be submitted for peer review in an appropriate medical journal. They are available at <https://diabetesaction.ca/patient-engagement-resources/>

Patient-oriented-research training: I attended three of the CIHR-designed three-module SPOR training courses

In March 2017, from MSSU, held at UNB

In August 2018, from SCPOR, in Saskatoon

In July 2019, from MSSU again, in Halifax

I have been a co-presenter of abbreviated versions of the SPOR training courses, so far a dozen times: in March 2019, with Monica Parry, to a workshop held by Clinical Trials Ontario (CTO) for representatives from eighteen national chronic disease associations: on October 29, and November 19, 23 and 25, with Monica Parry and Dawn Richards from CTO, introducing the decision aids mentioned above: monthly from November 2020 to May 2021, for MSSU with Yvonne Hanson, and then Caroline José, and I'm scheduled to participate on future courses monthly from September 2021 to March 2022.

Benefits of being a patient partner: Two things:

1 - Learning what complex, hard to manage, imperfect but wonderful systems we have for health care in Canada

2 - Meeting and getting to know the many exceptional individuals who have dedicated their lives to the delivery of health care to Canadians. Our family physician, Dr. Gordon Plummer, always scheduled my appointments as his last of the day so we could talk about health care issues after dealing with my own health concerns. More recently the people I have been working with at PFPSC, MSSU and DAC. Despite the risk of zoom fatigue, zoom calls have allowed us all to stay in touch on a frequent basis.

Challenges of being a patient partner: Pre-pandemic that was mostly frequent travel and the stresses that presents. In 2019 I attended 13 health-related conferences across Canada, as well as regularly commuting to Mississippi to teach. That really wore me out. After all, I will be 82 years old in June. This also cost me a lot since I mostly was paying my own way.

The pandemic lock-down and isolation policies have had a **positive** benefit for me. I can now sit in my basement specially-designed Zoom Studio and meet with the world. I'm eating better. I'm sleeping better. But I'm still not getting enough exercise.

My initial challenge was not knowing much about health care and the health care system. Over the years I have learned a lot from the SPOR projects I am involved with, from both patient partners and health professionals on the several committees I serve on, and from the conferences I have attended. And from the six JAMA emails I still receive each day, as well as a number of healthcare related podcasts.

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