

# Thinking like a rebel

Listening to patients,  
partnering with disease,  
finding the inspiration in suffering

Story by Sarah de Leeuw

Some where deep inside Philippe Karazivan lives a committed critical nonconformist.



Patient advocate  
Vincent Dumez,  
Codirector of the  
Office of Collaboration  
and Patient Partnership

La traduction en français de cet article se trouve à [www.cfp.ca](http://www.cfp.ca) dans la table des matières du numéro de mai 2017 à la page e291.

The walls of Dr Karazivan's office at the University of Montreal in Quebec, where he shares a research and education leadership role with patient-advocate Vincent Dumez and where they are working on the Patient as Partner project<sup>1,2</sup> and preparing to launch the first ever master's degree in research for patients in 2018, are festooned with rebel imagery.

A life-sized image of gun-slingin' cowboy Clint Eastwood, rollie bitten between pinched fighting lips in *The Good, The Bad and The Ugly*. A collection of Bob Dylan lyrics from the poet's early days of writing back against authoritarianism. Karazivan applauds Dylan's recent Nobel Prize win and speaks plainly about being utterly moved by Patti Smith's subsequent performance of "A Hard Rain's A-Gonna Fall" at the gala awards evening, replete with her now famous voice-quavering mistake.

Karazivan, in other words, is genuinely, fully, sincerely on the side of the outlaw, the broken one, the underdog, the little guy, the person who might have failed a time or two, the one among us who hasn't been heard and has suffered, the artist, the one who's just been told the way it's gonna be. These beliefs extend to a life's work of putting patients' perspectives at the heart of understanding medicine and health care practices.

"Let me give you an example. I was working with a resident. The resident came to me and told me about an interaction with a patient. The patient had come in and said he was experiencing a lot of lower back pain. He was asking for a doctor's authorization to take 3 weeks off from work. The resident said they performed an exam but could not decide conclusively what kind of pain the patient was in. 'So,' said the resident proudly, 'I signed for 2 weeks off. Not a day more!' I asked the resident, what is the difference to you between 2 weeks and 3 weeks? If a patient says they are in pain, why don't we just believe them? What are we guarding against?"

That question of guarding *against* something, that question of not intrinsically believing a patient, of thinking clinical or physician opinion is worth more than a patient's word or experience, really riles Dr Karazivan.

"Who is winning by not granting a patient 3 weeks off work if that's what he's asking for? Is the patient winning? No. Is the physician winning? No. The only person who is winning is the guy's boss at work. Is that who we are working for? Shouldn't we be working for the patient? Every day we seem to be living in fear about being manipulated by patients—but what about being manipulated by systemic power and inequities, what about capitalism? For me, the job of a physician is to be on the side of our patient."



PHOTO Dr Karazivan in his office at the University of Montreal.

## COVER STORY

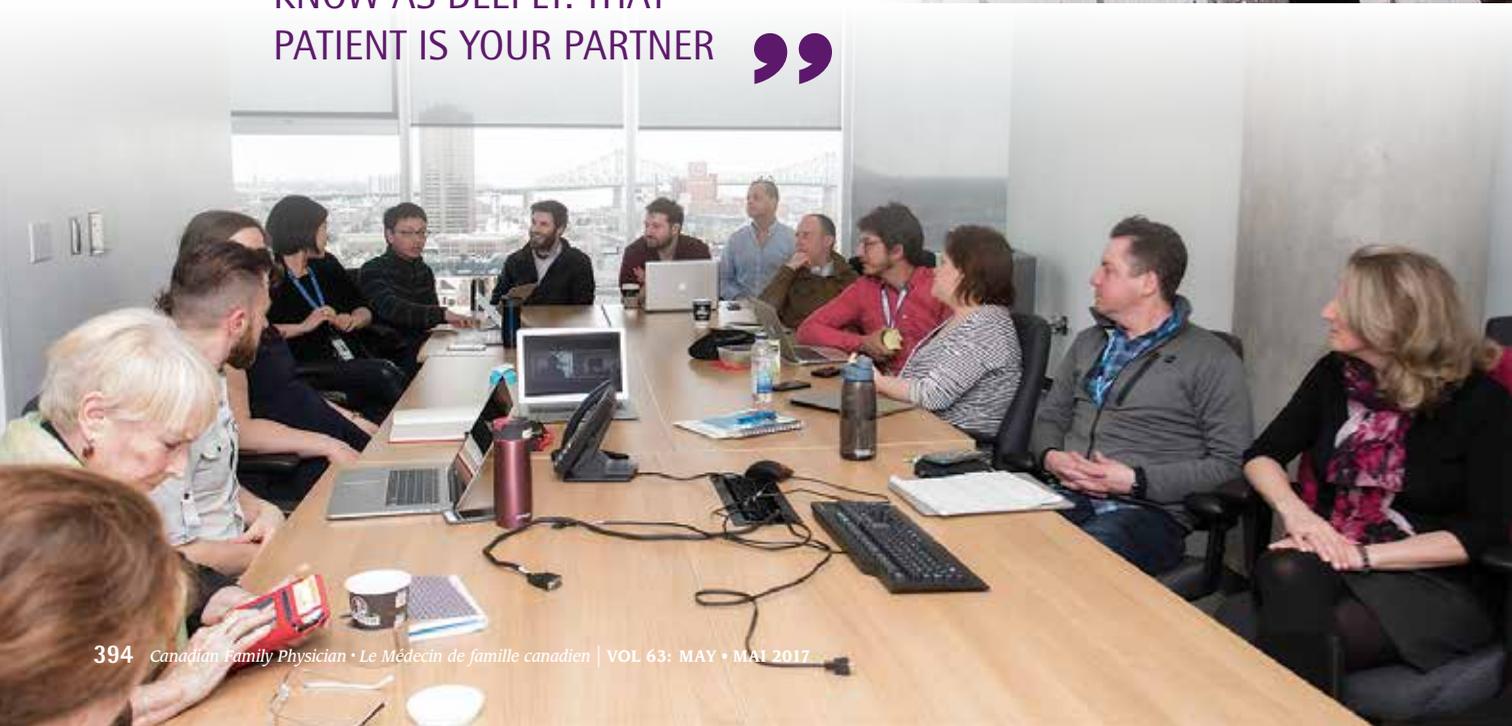
Other examples of physician scepticism about patients also anger Dr Karazivan: “Be truthful. We all have this prejudice that when a patient goes on the Internet, they will go to the worst sites, get the worst information, and draw the worst conclusions. Now imagine rethinking that. Imagine a mother who brings in her 4-year-old son who has a fever. That mother will have put her hand on her son’s head so many times. Maybe she will have called her own mother, and she will have learned something. Then maybe she will call the pharmacist, and she will have learned something more. Then maybe she will go onto the Internet. And she will have learned something. All the time she will be watching her son, caring for her son. She will have been the coordinator of her son’s care. But in the 15 minutes she spends with the doctor, we will deny her all that knowledge. And mostly she will just leave, with some antibiotics, feeling guilty she didn’t come in sooner. That’s crazy.”

Part of the solution, Karazivan believes, is integrating patients as mentors to undergraduate medical students, a project he’s been working on for years. “When you talk to patients living with disease, they don’t talk about living in a lesser state. It’s a new form of normal. And it often creates in them new possibilities that can only happen in their new state. We have to understand that patients know things about their disease that no physician can ever know as deeply. That patient is your partner.”

Another part of the solution, believes Karazivan, is breaking down elitist ideals about medicine having a monopoly on knowledge: “Other forms of knowledge exist and we need to accept, recognize, value, teach, consider them.” Karazivan is proud when he proclaims “I read more philosophy, anthropology, sociology literature than I do literature from medicine. What I love about medicine is the *social* science, not only the medical science.” This



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philosophical bent leads Karazivan to suspect that much of the scepticism about patients is rooted in physician (and broader societal) contempt for disease, suffering, and illness—all the things patients ultimately embody when they are visiting a physician.

“Disease is always seen as something less. But being ill, being sick, that creates possibilities. What examples of beautiful art or music do we have that isn’t somehow created by those who are ill? Think about the beauty that has always come from suffering. Now think about how we talk about mental illness in patients. The goal is to make them ‘better,’ to ‘make them full citizens.’ But now think about how doctors talk about that as opposed to how patients talk about that. When asked about making people with mental illness into ‘full citizens,’ professionals talk about making sure they vote, that they ‘function’—very boring stuff. What do the patients want? They want, in their own words, to be able to give back to society. They speak about altruism. Now. Who is it we should be listening to?”

There is something deeply personal in Karazivan’s commitment to those on the margins, to voices too easily trodden over or upon: “I have a bizarre reaction to authority. My parents are Armenian from Syria, so the first language at home was Arabic. But I was born in Montreal. And I don’t speak Armenian. I’m a minority in a minority.”

So it’s from a place of living on the outside that Dr Philippe Karazivan thinks about medicine, thinks about how to make it better in partnership with those who live the suffering. “If you want to make any concept, any norm, any law *better*, we have to see what’s outside of it. We have to see something different.”

“You’re not alive,” summarizes Karazivan and speaking like a true rebel, “if you’re not transgressing. And remember, if we think disease is a transgression, maybe those who live with it are the most fully alive among us.”

**Dr Karazivan** is a family physician, teacher, and researcher at the University of Montreal in Quebec and Codirector of the Office of Collaboration and Patient Partnership (DCPP) within the Faculty of Medicine. The DCPP is codirected by a patient (**Vincent Dumez**) and a physician (**Dr Karazivan**) and it brings patients and their specific expertise into the medical school where they can mobilize their competencies to help students develop theirs. They coordinate more than 300 patients for the DCPP who are not only active members of their own health care team but are also involved in research and provide valuable training to health science students.

#### References

1. Karazivan P, Dumez V, Flora L, Pomey MP, Del Grande C, Ghadiri DP, et al. The patient-as-partner approach in health care: a conceptual framework for a necessary transition. *Acad Med* 2015;90(4):437-41.
2. Pomey MP, Ghadiri DP, Karazivan P, Fernandez N, Clavel N. Patients as partners: a qualitative study of patients’ engagement in their health care. *PLoS One* 2015;10(4):e0122499.

**The Cover Project** The Faces of Family Medicine project has evolved from individual faces of family medicine in Canada to portraits of physicians and communities across the country grappling with some of the inequities and challenges pervading society. It is our hope that over time this collection of covers and stories will help us to enhance our relationships with our patients in our own communities.

**PHOTOS LEFT (Top)** Stepping out for lunch and **(bottom)** meeting to discuss the design and the curriculum of the new master’s degree for patients on patient partnership.

**PHOTOS RIGHT (Top)** Dr Karazivan at the fish market and with Lam Kiet, the owner of one of his favorite Vietnamese restaurants (Cristal No 41). **(Right)** A rebel with a cause. Dr Karazivan standing against the art piece “Jardins et jardiniers du monde” by Michel Goulet in the Centre de recherche du Centre hospitalier de l’Université de Montréal.

**PHOTOGRAPHER** Andrée Lanthier, Longueuil, Que