



**Réseau-1 Québec**

## Reflections on primary care during the pandemic

December 2020


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These essays are part of a series of [reflections on primary care during the pandemic](https://reseau1quebec.ca/nouveautes/covid-19/) published by Réseau-1 Québec. They are available online at <https://reseau1quebec.ca/nouveautes/covid-19/>.



*Reflections of a patient-partner on her experience in this time of pandemic*  
*An essay by Marie-Dominique Poirier published on March 26<sup>th</sup>, 2020*

Right now, because of my relatively weak immune system I've had to stay at home since March 12<sup>th</sup>!

I could easily cut myself off from everything that's happening. If I didn't read the newspaper or listen to the news, I would be in my own little cocoon. But no, I can't do that, I'm worried about the people around me....

I'm a patient-partner on several committees in my CIUSSS, including the one on infection prevention and control. So I stand with these teams of caregivers and managers, who have been thinking for several years about the possibility of what is now happening to us, hoping all the while that it would never happen. I'm thinking of all the maintenance and disinfection teams who work tirelessly to keep hospitals and CHSLDs in impeccable condition. Their task was already heavy, and they're being asked to do even more, these people who are our first line of defense against COVID-19.

I'm also the patient co-lead of a research project that, of course, is now on hold. I've been able to be a part of teams of nurses and social workers and to see their work up close. I've witnessed their dedication, their professionalism, and especially their immense workload. For the past two weeks, they've been asked to do even more, to forget themselves and devote all of their attention to a population at risk. They, too, have family, relatives, friends... and the fear of transmitting this virus is surely always on their minds. In spite of everything, they are here for us.

I'm involved in a community organization and see the anxiety of all those who feel isolated, not only physically but psychologically. For many, the health care system helped to overcome this isolation, but now I believe it is our collective responsibility to take care of this vulnerable population.

I also have a family. My spouse works and is in contact with a lot of people. He, too, could get COVID. My child no longer goes to school, no longer works, no longer has a social life; it's difficult. At 20 years old you're full of life, you have lots of dreams, but now everything is on hold.... My parents stay at home, they do their duty as good citizens, but if it lasts a long time, it

will become difficult for them, as it will be for all these people who feel like hostages in their own homes.

Then there are also all those who show up for all of us. They work in grocery stores, pharmacies, shops, and the food industry. They are police officers, paramedics, daycare workers. They also work in both levels of government. We have a responsibility to protect them. They are essential to our survival.

I've decided to do my duty as a human being. Of course, I support all these people who are important to me, but I also act, to the extent that I can.

I'm staying in contact with my parents, my family, my friends. Long live the telephone and the Internet! I've taken on a commitment to contact people I don't know who need to talk, even with someone they don't know! I take care of my husband, who takes such good care of me!

But most of all, I stay away from other people to protect myself... but especially to protect us all!

I'd like to close with a word of thanks to everyone on the front line:

*I want to thank you all for everything you're doing for us, users of the health care system. It's a difficult situation for you. You're being asked to devote yourselves to us... Please keep some time and energy for yourselves and your families. That's important, too! Take care of yourselves, not just of us. See you soon, I hope!*

[Marie-Dominique Poirier](#), Patient-partner, member of Réseau-1 Québec

*Primary care, a public priority even in a time of crisis*  
*An essay by Yves Couturier and Catherine Hudon published on April 27<sup>th</sup>, 2020*

The COVID-19 crisis has reminded the general public of the relevance of public health and shown that, from the government's perspective, the hospital remains the central institution of the health and social services system. The focus on hospitals and intensive care services at the beginning of the pandemic has unfortunately delayed preparedness in other sectors, which partly explains the profound crisis currently ravaging long-term care hospitals (CHSLDs) and, to a lesser extent for now, home care services. What does this portend for primary care services in the aftermath of the pandemic?

A strong primary care system (medical clinics, community groups, emergency departments, Info-santé, etc.) has and will continue to respond quickly to the ongoing needs of the population before, during, and after the pandemic, just as it is responding to the ongoing needs of the majority of people affected by COVID-19.

The smoke and mirrors of media reports exposed the confusion in public opinion regarding primary care or front-line services. Microbiologists and other respirologists have been called the front line, while the actual front line has not received as much attention, except for public information lines (811), ad hoc screening clinics, and emergency departments. It goes without saying that hospitals, specialists, and emergency physicians are among the most vital players in such a context. There is no question of minimizing their importance. It is equally obvious that the primary care system is not set up to receive a mass of contagious or potentially contagious people. Still, to be effective, public health, the 811 service, screening clinics, and emergency departments depend on primary care, primary medical care in particular, which plays a crucial role. The overall effectiveness of the health and social services system in general, and the fight against COVID in particular, depends on it. Thus, the imperative of adapting and enhancing the front line's capacity to meet the challenges of the next phase of endemicity is key to a sustainable strategy against COVID-19.

Public policies relating to emergency or pandemic measures should be reviewed to better foresee what conditions will ensure that primary care remains central, so it can continue to play an indispensable role in caring for the most vulnerable clientele, in terms of not only physical and mental health, but also social issues. A number of conditions are required for primary care to play this role fully.

In a pandemic, and then an endemic context, i.e., after a gradual return to normal life but with SARS-COV-2 still present, these include:

- Making protective equipment and other resources needed for primary care management of the illness available in sufficient quantities, at all stages of the pandemic.
- Continuing to act on both the chronic conditions that were present prior to COVID-19 and their psychosocial effects on patients.
- Maintaining continuity of care for the entire population.
- Anticipating and managing the significant reverberations that will affect, over a long period of time, those clienteles whose follow-up has been delayed or altered.
- Ensuring that decision-making units during the crisis include expert primary care and chronic disease counsellors at all levels.
- Providing specialist and managerial support for front-line clinicians' decisions when necessary.
- Developing and supporting a good-quality, sustainable teleconsultation strategy.
- Planning the contributions of all community resources.

To support the hospital's essential, acute care role in the context of a pandemic, it is imperative to continue developing a health and social services system in which primary care ensures access to and continuity of services for the most vulnerable people in times of crisis, whether in the community, at home, or in medical clinics. Primary care must remain a public priority; even more so in these difficult pandemic times.

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*This essay was [reproduced in l'Actualité](#), May 29, 2020.*

As primary care physicians and community practitioners, we are first hand witnesses of the covid crisis and its impact on our communities. The pandemic wave is just hitting Canada and we have benefited from the experience of other countries to implement early measures of containment, preparation, and care management. As elsewhere, we are uncertain about the outcomes for our patients, our communities, our colleagues, our families, and ourselves. But as we navigate the changing landscape of community care in downtown Montreal, we are observing the most rapid and profound healthcare transformation of our entire careers. This crisis is changing our teams, our relationships, and ourselves.

### **Teams are changing**

Our spirit has switched from “me, myself and my patients”, to “we’re all in this together.” Within a week, primary care practice has changed from exclusive face-to-face meetings to about 95% phone consultations. Accessibility—an intractable problem of [Canadian primary care reforms over the past 20 years](#)—has markedly increased within a few days. The “bureaucratically frozen public health system” we thought we inhabited has unfrozen and massive improvement has been achieved without adding a single professional. Hierarchies have been shaken and we have mobilized the intelligence and creativity of our full team in transforming the way we work together. A team which includes receptionists, cleaning staff, equipment suppliers, and managers as well as hands on health professionals.

We have rapidly adopted “new” technologies (ie. phone, emails, and internet) for prescriptions, document exchange and video-conferences. We are questioning the value of every diagnostic test, referral, and treatment, asking ourselves if our interventions do more harm than good (ex. balancing the risk of in-hospital investigation for chest pain in people at high-risk of covid complications, given local epidemic data of the day). We are also increasing capacity by postponing a number of screening tests and chronic care follow-up, all of which needs to be carefully balanced in order to [minimize indirect pandemic impacts on other major health conditions](#). And we are sharing uncertainty collectively rather than individually. As one of our colleagues said: “We don’t always know where we are going, but we are going together.”

### **Relationships and collaborations are changing**

We are realizing that patients, citizens and community members can be trusted as caregivers. Mothers and fathers have become our eyes and ears when assessing a child’s illness over the phone. The majority of our patients with COVID (and other conditions) are caring for themselves, by themselves, at home, with help from neighbours, family and friends. We have

been impressed by how resilient many of our patients are. They are embracing change, offering constructive suggestions, mobilizing their knowledge and inner resources to adapt to the crisis, showing appreciation of the and reassurance of being remaining connected with a trusted team of health professionals who know them. [Experienced patient partners](#) working closely with our primary care team coach and support other patients to help them find practical solutions to their new life.

Collaborators on paper have become real partners, as community organizations and health professionals seek joint solutions to common practical challenges. We see narrow professional roles and silos suddenly giving way and new ways of working adopted. Volunteers from all ages (kids, teenagers, adults and seniors) are [reducing the health impacts of social isolation](#) by maintaining contact with people confined at home. Community organizations, peer-support workers, social care and volunteers are acknowledged as key players to address the huge needs for psychosocial, material, food and economic support. Local initiatives with the health care system and municipalities are being invented to respond to the needs of the most vulnerable individuals in our communities (eg. turning old buildings into individual rooms for home isolation of homeless people). Professional turf wars have been abandoned, as we realize our inter-dependence with colleagues working in the intensive care units, hospitals, emergency rooms, other primary care clinics, home care, long-term care, palliative care, public health, not-for-profit community organizations and informal social support networks.

### **Changing ourselves**

[Society is no more divided into healthcare workers and others](#). We suddenly realize the common vulnerability. We are all at risk of illness and death. We are deeply reminded of our own interdependence and personal need for support. We are deeply shaken in our professional limits, facing a disease for which no specific treatment yet exists. We have reintegrated within the community we serve; reciprocally acting as care-givers and care-receivers. We are grateful to the teenagers delivering food to our parents, the neighbours giving us lasagna and a smile after a long day of work, the child care workers helping with our kids.

And we are more intensely aware of our privileges. We are all in the same boat, but not all of us have access to lifeboats. “Health inequalities” and “social determinants of health” have turned from abstract concepts to real patients, friends and community members who have fallen ill, have lost their jobs, are unable to pay for rent or groceries, are living alone, or cannot implement “home isolation” because they have no home, living in crowded shelters or in the streets.

These lived experiences mobilize the health professional in us, caring for one patient at time, but also the human beings in us, caring about each other in connection with our communities. Communities that have always been there, sometimes without our awareness, but that [we see and value more clearly now](#).



## Witnesses and actors of a history in writing

This is not a movie we are watching on TV but a history we are writing together. We are at a crossroad that could tear us apart or make us stronger as teams, health systems, and communities. What we are witnessing at the moment is being written, imprinted, in our experience and memory. Who knows which turn we will take next, and which of these changes will last. But these choices are likely to shape our individual and collective future.

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## The health of primary care after the pandemic

*An essay by Jean Rochon published on May 11<sup>th</sup>, 2020*

Crises reveal both strengths and weaknesses. The French philosopher and sociologist Edgar Morin summarized the consequences clearly: "A crisis generates three different scenarios, but

only the third should be encouraged: the desire to return to the world as it was, an escape into anything at all, and the emergence of new learning.”

It is crucial that we seize this opportunity, as another much more insidious and devastating crisis is unfolding because of the burden of chronic conditions and social inequalities in health. These also pose a threat to the economy and to social peace.

The crisis provoked by the COVID-19 pandemic has reminded us that complex situations require solutions validated by facts and science. It has also shown us the importance of having a broader conception of primary care, or the front line, in order to contain the emerging crisis.

### **Evolution of the front line**

Fifty years ago, when the health and social services system was created, primary care was supposed to consist of family physicians and local health service centres (CLSCs), which would be the entry point to multidisciplinary team services for the treatment of individuals’ health problems, referral to specialized services when required, and a coordinated overall response to individuals’ needs. The rapid aging of the population and the rise in chronic conditions prompted the development of other services such as home care, adapted housing, and long-term care.

Over the following decades, the development of knowledge on the determinants of health demonstrated that three-quarters of a population’s health problems are influenced by environmental conditions, the quality of living environments, and healthy lifestyles. Research has shown that resulting chronic conditions can be prevented through a population-based approach that emphasizes disease prevention and health promotion through coordinated and integrated interventions. We now know that massive and sustained interventions starting in the first years of life, and timely responses to problems as they arise, can improve the life course of individuals and the health of the population.

Primary care can no longer be managed as simply the base level of a system whose resources are primarily invested in hospitals that provide specialized and superspecialized services. It needs to be conceptualized as a system in itself, serving a population in a given territory. This system is responsible for implementing government policies and programs at the local and regional levels by coordinating comprehensive and continuous services. The range of primary care services includes prevention and health promotion interventions within the provincial public health program, general health services, social services, community pharmacies, home care services, support for informal caregivers, housing adapted to support mobility and autonomy, and long-term care. The primary care system should refer patients to specialized services while providing support and care management over the medium and long term.

### **A new front line**

From this standpoint, the primary care system should be conceived of as a consortium of public, socio-economic, and community partners, as well as citizens engaged in the community. This system is based on stakeholders' geographic proximity and shared dynamics rather than on administrative boundaries. The territory constitutes a locus of network interaction and interdependencies among partners. Boundaries can shift depending on the deployment of activities. The consortium's governance must make it possible to move from a sectoral, top-down approach to one that is territorial and interactive. It is the foundation for decentralizing decision-making and implementation powers to the local and regional levels.

Coordinating the consortium implies recognizing the partners' specific responsibilities and expertise and identifying common problems. Its aim must be to develop objectives and actions collectively, and to seek solutions to common problems through collaborative means. As such, it needs to support the pooling of ways and means, as well as new resource allocation. The coordination of services and interventions ensures a smooth and harmonious process. In the Quebec context, the CLSC appears to be the entity that is qualified to undertake this coordination.

Individually, partners remain responsible and accountable for the outcomes of their specific activities. Together, they must aim for a collective impact on the health and well-being of the territory's population. To this end, they require:

- A shared action plan with concerted actions;
- A common evaluation framework that involves sharing information;
- Complementarity in their activities;
- Ongoing communication based on a relationship of trust among the partners and with the community;
- A method and the means for monitoring and for data collection;
- A competent and dedicated team.

Funding for the consortium and its partners should be multi-year, in three to five year cycles, to ensure sustainability. Financial and technical support should promote the development of workers' competencies and foster innovation to ensure continuous adaptation and improvement in response to changing needs, opportunities, and outcomes.


### **Perspective**

The deployment of a primary care system as outlined above is a major undertaking, but several experiences in Quebec and elsewhere have established foundations on which we could build. It would be risky to focus only on a few isolated parts of the consortium concept, such as family medicine groups (FMGs) or seniors' residences. As with a chain, the system will only be as strong as its weakest link.

Another concern is the competition for available resources that can be expected after the crisis, including the risk of austerity policies due to short-term pressures. Yet investing in health promotion, disease prevention, and front-line services will have a significant positive economic impact in the medium to long term. However, we have both the means and the capacity to pursue a sustainable development path to meet the needs of the population today and to protect the future for generations to come.

This will require foresight and political will.

**Jean Rochon**, Professor Emeritus, Université Laval, former Quebec Minister of Health and Social Services (1994–1998)



## Home care: More funding needed, but especially under a new model

*An essay by Réjean Hébert published on May 19<sup>th</sup>, 2020*

The Covid-19 crisis, with its fatal impacts on vulnerable seniors, impels us to rethink our model of services in support of functional disabilities. The Canadian health care system and the Canada Health Act have put hospitals at the heart of the health response. While this orientation was

warranted in the last century to meet the needs of a younger population, it is much less valid today as an older population faces chronic conditions and disabilities. In this essay, I will explain why institutionalisation and group housing became the preferred models in Canada. I will then show that home care is the appropriate approach for addressing the current and future needs of older adults facing a loss of autonomy. Finally, I will propose an efficient and more appropriate method of financing home care: autonomy insurance.

In Canada and Quebec, the proportion of older adults living in residences that provide care services is higher than in other industrialized countries. Long-term care accommodation rates are 5.7% and 5.9% for people aged 65 and over in Canada and Quebec, respectively, compared to the OECD average of 4.7% [1]. But it is in seniors' residences (SRs), where more than 100,000 seniors live (7%), that Quebec stands out. More than half of all spots in SRs in Canada are in Quebec. Nearly 20% of people over age 75 in Quebec have chosen to live this collective lifestyle, which means that seniors are concentrated in a certain autarky and in a self-exclusionary way from other social groups [2]. These seniors of the so-called "silent" generation are looking for security and access to services, as needed. Their children, from the baby boom generation, have also seen SRs as a practical solution to ensure their parents' support and security. While residences were struggling to fulfill their mandate prior to the crisis, it is now clear that in light of the Covid-19 outbreaks and the widespread containment measures that were imposed in these settings, this mandate is no more than an illusion.

The popularity of collective housing stems from the inability of society and the health care system to provide the home care services needed in the event of functional decline. The absence of adequate home care has put increased pressure on long-term care institutions (CHSLD), and a lucrative market of non-licensed private CHSLDs and seniors' residences has developed in an anarchistic manner, with no state control. But the seniors of today and tomorrow would prefer to continue living at home, provided they can have access to sufficient and good-quality services in the event of any functional decline. This requires a change in how we view autonomy support services: rather than moving people to residences that meet their needs, it would be better to adapt and develop home care services that allow them to live where they have chosen to age.

Home care represents only 14% of public funding for long-term care in Quebec and Canada. All other OECD countries devote a larger share of their long-term care public funding to home care, even reaching as high as 73% in Denmark [3]. The low investment in home care here can be explained by the logic of our funding model; the Canadian health care system essentially covers medical and hospital care. This means that accommodation provided in long-term care institutions is covered by the public health insurance plan, whereas home care is funded at the margin, at the discretion of each province. As such, it is understandable that the institutional solution would take precedence.

But investing more in home care will not be enough to effect significant change. A longitudinal study looking at the services used by all Sherbrooke seniors from 2011 to 2015 showed a significant progressive decrease in home care services over this period: from 200,000 visits per year in 2011 to less than 60,000 in 2015. This decrease was particularly significant among people receiving a higher intensity of services. This phenomenon was all the more troubling given that the 2013–2014 budget included an additional investment of \$110 million for home care, a 20% increase in the base budget. Clearly, this increase did not lead to improved services. Instead, institutions reallocated funds according to their priorities. At that time, CLSC home care services were managed under the same budget as hospital and residential services. So hospitals received these additional investments. It is easy to imagine that, with the 2015 reform in Quebec, which created large regional institutions including rehabilitation and youth services, the situation will not improve and that the recent investments in home care will not translate into additional services for home care users. For the management of the current superstructures, the temptation is too strong to reorganize revenue sharing to cover the rising costs of regular hospital care.

So, we need to move away from the current institution-based funding model. Rather, the new funding model for long-term care should be based on the needs of individuals. This is the principle of public long-term care insurance that has been implemented in many countries over the past 20 years, including in Japan, France, and most continental European countries [4]. In these insurance systems, the person's needs are assessed using a disability measurement tool. An allocation is determined based on level of need. This allocation is used to pay for public or private services chosen by the person or their family in accordance with the intervention plan developed by a health professional, often a case manager. Some countries even allow a cheque to be issued directly to the person, who can then arrange for the needed services. Provider quality is ensured through a mechanism of accreditation, and service quality is evaluated by the case manager. These insurance plans are usually funded on a “pay-as-you-go” basis through employer–employee contributions, annuity tax, income tax, or other specific forms of revenue (such as electricity fees or the abolition of a statutory holiday).

This is what was proposed by the autonomy insurance plan in Quebec in 2013, when I was a minister in the government. In fact, Quebec has several elements already in place that would facilitate rapid implementation of this important reform: an assessment tool already widely used for all persons requiring home or residence-based services (the Multiclientele Assessment Tool [OEMC], which includes the Functional Autonomy Measurement System [SMAF]); a classification system consisting of 14 standard disability profiles (Profiles Iso-SMAF), used to translate needs into the necessary resources and allocations; case managers already deployed as part of the integration of services following the PRISMA project; computer tools to support the development of intervention plans and service allocation; and an efficient management body that is already keen on this type of funding model, the Régie de l'assurance-maladie du Québec [5].

Following the publication of a white paper [6] that was well received by all stakeholders, a bill was tabled in the National Assembly in December 2013. It was never adopted due to the hasty election call and the loss of power by the Marois government. The bill was not taken up by subsequent governments. The project may be dead, but the idea is not, and the elements that that would make it possible are still present. It is all the more relevant today in light of the Covid-19 crisis.

Our seniors deserve to age at home with the services they need. If the funding and organization of services is adapted to 21st century realities, Canadians and Quebecers will choose to age at home and will resist the siren calls of residences and other places of institutionalized social exclusion.


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## References :

- [1] OECD. Health at a Glance 2019: OECD Indicators. [https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance\\_19991312](https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance_19991312)
- [2] Hébert, R. 2006. Les vieux se cachent pour mourir. [//www.ledevoir.com/opinion/idees/464685/les-vieux-se-cachent-pour-mourir](http://www.ledevoir.com/opinion/idees/464685/les-vieux-se-cachent-pour-mourir)
- [3] Huber, M., Rodrigues, R., Hoffmann, F., Gasior, K., & Marin, B. 2009. Facts and Figures on Long-Term Care. Europe and North America. Vienna: European Centre for Social Welfare Policy and Research.
- [4] Hébert, R. 2012. L'assurance autonomie: une innovation essentielle pour répondre aux défis du vieillissement. *Revue canadienne sur le vieillissement*, 31(1):1-11.
- [5] Hébert, R., Gervais, P., Labrecque, S., & Bellefleur, R. 2016. L'assurance-autonomie au Québec : une réforme inachevée. *Health Reform Observer – Observatoire des Réformes de santé*, 4(1):Article 1. doi: [dx.doi.org/10.13162/hro-ors.v4i1i.2737](https://doi.org/10.13162/hro-ors.v4i1i.2737)

[6] Hébert, R. 2013. L'autonomie pour tous: livre blanc sur la création d'une assurance autonomie. [//www.assnat.qc.ca/fr/travaux-parlementaires/commissions/csss/mandats/Mandat-24161/index.html](http://www.assnat.qc.ca/fr/travaux-parlementaires/commissions/csss/mandats/Mandat-24161/index.html)



Supporting the next generation and rethinking tomorrow's research in the context of research "covidification"

*An essay by the Young Leaders Committee in Patient-Oriented Research (POR) published on May 25<sup>th</sup>, 2020*



## **The “covidification” of research**

The COVID-19 pandemic has shone the collective spotlight on health research. The media report daily on scientific advances supporting the fight against COVID-19: epidemiological data, clinical trials of treatments, vaccine development, etc. Many members of the scientific community in Quebec, Canada, and internationally have mobilized to address the emerging issues of this COVID-19 crisis, to such an extent that we are witnessing a rapid “covidification” of research: major investments in research on COVID-19 (e.g. pharmaceutical, basic science, specialized medicine), the creation of networks and platforms for sharing research on COVID-19, the suspension of several non-COVID-19 research activities, the cancellation or postponement of funding competitions for non-COVID-19 studies, and the reorientation of many research teams towards COVID-19.

This “covidification” of research reflects an intention to answer pressing questions in the fight against COVID-19, but it also poses certain risks. Of course, research on epidemiology, vaccines, and treatments for COVID-19 is essential. However, it is also crucial to address issues of health service organization, quality of care, health equity, and the social aspects of this crisis. We need to avoid an “over-covidification” of research; let’s not forget that the non-COVID issues still affect patients and many challenges in our health systems have been amplified by this health crisis. Moreover, neglected or postponed health care and the delays in management of patients’ health problems will bring new challenges.

## **The importance of patient-oriented research**

In this context, patient-oriented research (POR) is once again critically important. The upheavals we are experiencing underscore the need to produce knowledge that addresses people’s concerns. POR can produce evidence on health care services and policies oriented towards improving the health and well-being of populations and health professionals. Yet POR, which involves a strong collaborative process, is on shaky ground. During the pandemic, we need to make sure patients, health professionals, and decision-makers can continue to participate safely, and significantly, in order to ensure the production of meaningful and relevant evidence. In our post-COVID society, it will be more important than ever to maintain strong links with patient-partners so that work currently on hold can resume and adapt to the emerging challenges facing patients and the health system.

### ***What is POR?***

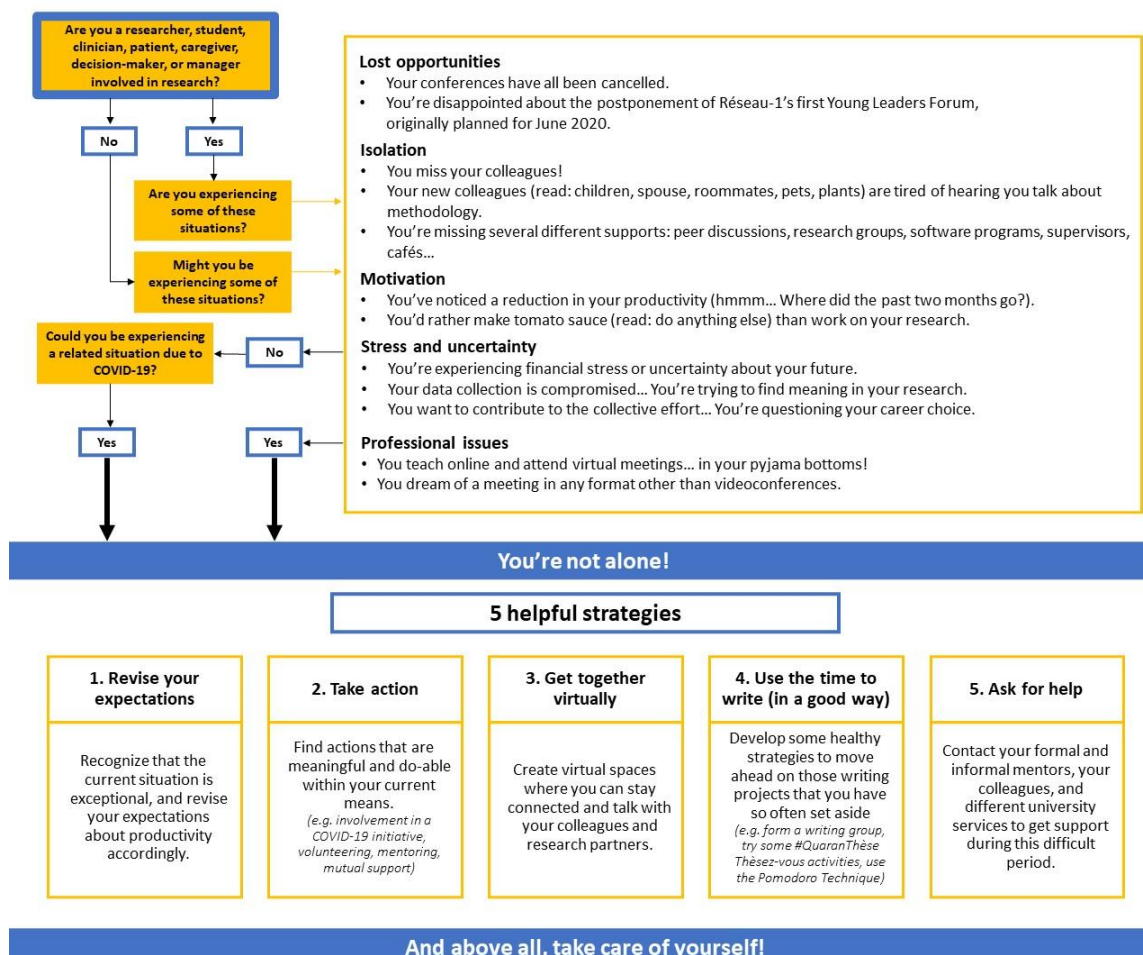
*Patient-oriented research (POR) mobilizes patients and multidisciplinary partners, focuses on priorities established by patients, and improves patient outcomes. POR aims to apply knowledge to improve health systems and health care.*

## **Issues for the next generation of researchers**

As early career researchers and student-researchers, this “covidification” of research has hit us head-on, and we are dealing with inevitable collateral effects (see our algorithm below). A loss of motivation and uncertainty about this situation have strained our capacity to be resilient and to adapt. Here are some examples of what we are experiencing: reduced job prospects and job insecurity in research; uncertain thesis defenses in formats that don’t do justice to the scope of the work and don’t allow for celebration commensurate with the effort; unreliable research funding due to the cancellation of various competitions; difficulties reconciling pro-COVID-19 research with our own research programs in a coherent manner; excessive project delays caused by the interruption of data collection; reduced ability to maintain links with patient-partners and other collaborators; the cancellation of networking events that are so valuable for our career advancement; a heavy workload generated by the move to online coursework; work–family balance issues related to working from home and the closure of schools and daycare centres; etc.

The next generation of researchers does not necessarily have the same resources and networks as experienced researchers to cope with these challenges. This situation contributes to a certain precariousness and can make research students and young researchers vulnerable.

## Are you suffering from the collateral repercussions of COVID-19 on your research?



## Supporting the next generation of researchers

These upheavals contribute to weakening the next generation of researchers. Without additional support, there is a risk our generation of young researchers will crumble. Research supervisors, more experienced researchers, universities, research networks, and funding agencies all have a role to play in supporting the next generation of researchers, particularly in the current context.

It is crucial that student-researchers and early career researchers are afforded the support, flexibility, and understanding they need. Resources must be made available to us to carry out our work and plan our early career paths: more frequent follow-ups; formal and informal mentoring; support in reorienting our projects and data collection; setting priorities with regards to our objectives; flexibility in deadlines for grant and scholarship applications; consideration of work–family balance in scientific production; extension of grants and funding; etc. The creation of virtual spaces to facilitate collaboration, mutual aid, and networking can also strengthen a sense of belonging and reduce isolation. Innovative ways must be found to enable the next generation of

researchers to attend training sessions, gain experience, demonstrate leadership, and engage in research. For example, the next generation can become involved in COVID-19 grant applications and projects if they are given opportunities by more experienced researchers or if their participation is encouraged by research networks and funding agencies. Granting agencies and universities could also be encouraged to show flexibility and support in maintaining and creating strategies to support the next generation of researchers in the short, medium, and long terms (e.g. competitions, funding, sponsorships, virtual events, mentoring, productivity support, career planning support).

### **An opportunity to rethink the research of tomorrow**

As young POR researchers, we often experience discomfort and frustration with more traditional research structures and approaches that seem old-fashioned and partially out of step with the needs and realities of patients and health systems. We dream of research that is more agile, innovative, and interdisciplinary, conducted in collaboration with all holders of knowledge and experience (patients, clinicians, communities, managers, decision-makers, and researchers); research that is applied in real time to solve emerging problems, and where our performance as researchers is measured by the impact of our contributions and not just by the number of lines in our CVs. In short, “[Research 3.0](#)”, as Réseau-1 would describe it.

Amongst ourselves, we sometimes question our career choice: will research enable us to make a significant contribution to improving the health system and the well-being of populations? If the major research upheavals of recent months have proven one thing to us, it is that research can change, adapt to emerging needs, and be agile. This gives us renewed hope in research and its mission. Let’s take advantage of this crisis to rethink research, to innovate, and to make lasting changes that will maintain this agility and renewed relevance of research. We, the next generation of patient-oriented researchers, are ready to take on this challenge. Let’s not forget: we are not alone. We are part of a strong research community that is more important now than ever!

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**On behalf of the Young Leaders Committee in POR**, *a community of young researchers and research students supporting the scientific community and its members, whose mission is to promote the next generation of POR leaders by supporting POR capacity building, networking and mentorship, scientific production, and POR knowledge transfer, as well as collaboration among its members.*

## Leadership in the context of a pandemic: What are the lessons for front-line care and services?

*An essay by Jean-Louis Denis, Nancy Côté and Catherine Régis published on September 2<sup>nd</sup>, 2020*

Since March, a major health crisis has disrupted the daily lives of Quebec citizens. For many, watching the regular press briefings by political leaders is essential to better understand the government's orientations and their implications. The current pandemic offers a unique opportunity to learn about leadership in a crisis context, and to reflect on the role that primary care leaders can play as well as on the resources needed to deal with this crisis. Here we examine the lessons we can draw from this experience in preparation for future crises.

In this respect, primary care has a key role to play, but for it to be able to exercise its role fully, certain conditions are necessary.

Recent data published on the Santé-Montréal website

(<https://santemontreal.qc.ca/en/public/coronavirus-covid-19/situation-of-the-coronavirus-covid-19-in-montreal/survey-of-the-health/>) reveal the existence of inequalities in relation to the pandemic, particularly between men and women and in racialized populations. It has long been known that health is not only a question of access to care and services; it is intimately linked to living conditions that provide more or less access to the economic, social, and cultural capital through which individuals can benefit from environmental resources (education, a social network, financial resources, etc.) that enable them to develop and be healthy. While public health can sound the alarm about the importance of addressing people's living conditions, it must nevertheless be supported by a strong primary care network to be able to act on them. Primary care services are clearly only one part of the possible response, but they play an important role in mitigating health risks during a pandemic, particularly for certain segments of the population.

Let's return to the matter of leadership. In extreme situations, leadership that is concentrated at the top will only run out of steam (Hannah et al., 2009) given the complexity of the issues and their unpredictability in times of a pandemic; the need for a diversity of levers and expertise to protect health is undeniable. The government or health system must be able to mobilize actors at lower levels of governance, such as the regional or community levels. This leadership also has to decisively transcend a series of boundaries between sectors, social groups, professions, and fields of knowledge (Ospina et al., 2020). These areas of intervention need both a diversified leadership that adapts to challenges as they arise, and evolves with the pandemic, and sufficient resources to intervene effectively. Primary care refers to a more comprehensive model that is not confined to a medicalized conception of service provision, though it may include it. That medicalized approach, being essentially oriented towards access to a family doctor or to an interprofessional team that is often limited and based on exclusively clinical expertise, is

insufficient to carry out effective targeted interventions and to respond adequately to the needs of populations considered vulnerable (Ouimet et al., 2015; Levesque et al., 2012).

Moreover, the knowledge and expertise required to support the development of a primary care model that can respond adequately to the challenges presented by the pandemic are extensive. They span social epidemiology, sociology, anthropology, behavioural and organizational sciences, and economics, to name just a few. Public authorities must be willing to mobilize this knowledge, sensitively and at the right time, to support and equip local authorities, such as primary care, the local service networks (RLS), and the community, in deploying their services and interventions. Collaboration between these different sectors is only possible if there is an integrative and diversified leadership that enables interventions to be thought out in their entirety (Crosby & Bryson, 2010).

This call for integrative and diversified leadership implies, first of all, giving greater scope to the leaders of health care institutions, whose role must not be limited to carrying out the directives of central government. Here we refer not only to senior management, but also to other stakeholders who exercise informal leadership, as well as to middle managers, who can provide the necessary relay between the strategic heads of organizations and the professionals and stakeholders directly involved in the delivery of care and services. It also involves creating more substantial bridges than currently exist between public health, health care system resources, and academic communities that could potentially engage in collaborative and innovative intervention approaches. This means, as well, that primary care would become a true experimental laboratory for reflection and action to promote population health.

Numerous initiatives have been implemented here and there by front-line, primary care managers and clinicians to adapt service provision to the crisis context and adequately support their teams. For example, in several family medicine groups (FMGs), the roles of professionals, such as clinical nurses, pharmacists, and administrative personnel, have been redefined to optimize their scope of practice and to foster more collaborative teamwork. Some middle managers have used technology to hold more frequent team meetings, which has allowed them to stay in close contact with their teams, be more responsive to difficulties encountered in the field, and be able to recalibrate quickly, as the crisis gave some of them more decision-making latitude. These few examples demonstrate enthusiasm and a willingness to act, but their impact will remain limited unless they are integrated into a more ambitious plan devoted to pursuing equity. This presupposes a willingness and an ability on the part of current political, administrative, and clinical leaders to collaborate with new actors, who are essential intermediaries not only in the development of communities and an enhanced primary care offer, but also in terms of ensuring more extensive knowledge mobilization. This willingness must also translate, in the long term, into sufficient resources to support a goal as ambitious as working to reduce health inequities in the context of a pandemic.

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## References:

Crosby, B. C., & Bryson, J. M. (2010). Integrative leadership and the creation and maintenance of cross-sector collaborations. *The Leadership Quarterly*, 21(2), 211-230.

Ford-Gilboe, M., Wathen, C. N., Varcoe, C., Herbert, C., Jackson, B. E., Lavoie, J. G., ... & Wong, S. T. (2018). How equity-oriented health care affects health: Key mechanisms and implications for primary health care practice and policy. *The Milbank Quarterly*, 96(4), 635-671.

Hannah, S. T., Uhl-Bein, M., Avolio, B. J. & Cavarretta, F. (2009). A framework for examining leadership in extreme contexts. *The Leadership Quarterly*, 20(6): 897-919.

Levesque, J. F., Pineault, R., Hamel, M., Roberge, D., Kapetanakis, C., Simard, B., & Prud'homme, A. (2012). Emerging organisational models of primary healthcare and unmet needs for care: Insights from a population-based survey in Quebec province. *BMC Family Practice*, 13(1), 66.

Ospina, S. M., Foldy, E. G., Faurhurst, G. T. & Jackson, B. (2020). Collective dimensions of leadership: Connecting theory and method. *Human Relations*, 73(4), 441-463.

Quimet, M. J., Pineault, R., Prud'homme, A., Provost, S., Fournier, M., & Levesque, J. F. (2015). The impact of primary healthcare reform on equity of utilization of services in the province of Quebec: A 2003–2010 follow-up. *International Journal for Equity in Health*, 14(1), 139.



## COVID-19, telemedicine, and humanistic medicine: Back to the future?

*An essay by Marie-Dominique Beaulieu published on September 24<sup>th</sup>, 2020*

It's still too early to measure all the impacts of the unprecedented crisis we are experiencing. But one thing is certain, if we accept the reports coming from the front lines: clinical practice will no longer be the same. The transition to telemedicine, which took literally two weeks, will finally bring us, by all accounts, into the 21<sup>st</sup> century and make it possible to deploy connected health care and a variety of telediagnostic platforms. We are finally entering the modern era. We are also beginning to see the collateral damage of remote practice: missed diagnoses, segments of the population falling below the radar. Here I offer a few thoughts on what I know best—family medicine—but I believe they are applicable to primary care clinical practice in general.

### **Telemedicine and connected health, for what objectives and what types of decisions?**

Clinicians paid on a contract or salary basis have long known that many small problems could, in fact, be solved remotely. It's a bit ironic that people are only discovering this now. I used to end every consultation day with a half-hour of returning calls to manage minor problems for patients I knew well. But I would have gotten into a lot of trouble, even with patients I knew well, without all the information that an in-person visit provides—gait, gestures, facial expressions, moments of silence—from the greeting in the waiting room to the good-bye with the hand on the doorknob, and the “By the way, doctor, for a while now I’ve been having this chest pain when walking.” To explain the craze for telemedicine—which by the way is mostly audio (over the phone) rather than “tele-” (video)—we hear all sorts of things, such as this poorly understood quote that “80% of diagnoses are based on history,” invoked to assert that the phone is sufficient in the majority of cases. This is a mistaken understanding of the clinical process, so well described by Epstein 40 years ago. While it's still true that 80% of the clinical process is based on history, most often it takes a physical examination and sometimes a few laboratory tests to capture the missing 20% in order to arrive at the right diagnosis. Of course, connected objects and tools derived from artificial intelligence will make us even more efficient at a distance. But the intellectual task required for the clinical process is excessively demanding and complex. It calls for acquiring several types of information and “processing” them—in the computing sense of the term—and then linking this information with scientific knowledge obtained from research to decide on the most probable diagnosis or prognosis and the treatment most likely to be effective. This involves not only identifying symptoms but also

understanding the person and their context. Symptoms are more of a narrative than a precise set of data.

Telemedicine, connected objects, and diagnostic applications derived from artificial intelligence (AI) will be particularly useful for facilitating the monitoring of known problems, reducing diagnostic and therapeutic uncertainty, and bringing certain medical advances to more remote areas. But these advances will not relegate the medical visit to the back burner anytime soon. In fact, according to Eric Topol in his essay “Deep Medicine,” the main benefit of these advances should be to make healthcare more humane than ever by freeing up healthcare professionals to focus on what is essential to the practice of “good medicine”: listening, understanding the whole person, and being compassionate.

### **Reducing inequalities: access to primary care services as a factor in equity**

COVID-19 also exposed the weak links in our health care system. One of these was the inability to lessen the impact of health inequalities. More than ever, COVID revealed and deepened inequalities. Inequalities in disease severity accentuated by the dangerous mix of co-morbidity, poverty, and precarious living conditions. Inequalities in access to non-COVID related care and the resurgence of diseases responsive to prevention and early treatment. Access to primary care services is a protective factor against health inequalities. Unfortunately, in Canada and in Quebec, there is strong evidence that less advantaged people have more difficulty accessing a family physician and that lower socio-economic status, older age, ethnic origin, and being female are more frequently associated with poorer quality preventive and curative services. As it is, many clienteles are unable to breach the fortresses that medical offices and health care institutions have sadly become. While the use of telemedicine will certainly help reduce certain geographic inequalities in access, there is a danger that this mode of practice will deepen inequalities by reducing access, already difficult, for the homeless, persons with mental health and addiction problems, the elderly, the less educated, and recent immigrants. It will take creative thinking to reach out to these people where they live, on the street, in their homes, and to find ways to make our practice environments welcoming to them. COVID-19 has already shown how courageous and inventive front-line practitioners can be. Some striking examples of this are projects supported by Réseau-1 (<https://reseau1quebec.ca/projets/projets-sur-la-covid-19/>) and the Foundation for the Advancement of Family Medicine (<https://fafm.cfpc.ca/fr/programme-sci-covid-phaseone/>).

### **Learning by doing: The importance of research in primary care**

Paradoxically, the technological advances promoted by COVID-19 could have a deleterious impact if not used wisely, both clinically and in terms of problems they could create of unequal access to front-line services. So we need to learn from these practice transformations, in order to identify those that really add value and those that cause us to backslide. When I completed my master’s degree in epidemiology, my research director, Ms. Jacqueline Fabia, a great

epidemiologist, gave me this advice, the importance of which I was slow to realize: “Keep good records. Important discoveries come from careful observation of practice. Your records are a mine of information.” Careful observation is also about measuring the impact of COVID and our new clinical and organizational practices from the patients’ perspective.

No, clinical practice should not continue as it was, and there must be no going back once the pandemic is over. But to truly move forward and take advantage of this unprecedented crisis, we need to return to the art of clinical practice and the value of research rooted in practice. This is the only way to learn “while building the plane.” *Back to the Future*.

[Marie-Dominique Beaulieu](#), C.Q., M.D.,CMFC, M.Sc., FCMF, Professor Emeritus, Department of Family Medicine and Emergency Medicine, Université de Montréal

## COVID-19: Lessons and directions for the future of our healthcare system

*An essay by Howard Bergman published on October 5<sup>th</sup>, 2020*

*"It was the best of times, it was the worst of times, ... it was the spring of hope, it was the winter of despair." – Charles Dickens, Tale of 2 Cities*

Although we are still very much in the centre of the storm of the pandemic, it is important to begin a reflection on what we can learn about the foundations of our healthcare system from a policy perspective.

The COVID-19 pandemic has demonstrated a great deal that is positive about our healthcare system. Governments and political parties have generally put aside differences. Decisions are based on the best available public health counsel. Healthcare workers have responded with determination and self-sacrifice. Innovations are now rapidly being implemented. The population has generally followed the advice and the instructions from political and health authorities.

The most important factor is that Canada has a universal, single-payer healthcare system that is based on the notion that health is a social and societal value and not a market commodity. Each province is essentially one healthcare system capable of mobilizing human and physical resources. Canada has both excellent primary and specialty/hospital care with clearly delineated responsibilities.

Yet not all is perfect. The initial strategy to protect the hospital system has been successful. But it is the deplorable situation of older persons in nursing homes (NH) and residences that has been the most striking.

It is tragic but not surprising that the vast majority of deaths are found in very vulnerable older persons in NH and residences. However, it is heartbreaking to witness older people living and dying in unacceptable conditions, cut off from their families, cared for by poorly protected, overwhelmed and under-resourced staff.

This devastating pandemic has evolved very rapidly and there is little precedent on which to make key decisions. However, there are structural factors that help explain why we have generally succeeded in controlling the crisis in hospitals but much less so in other parts of the healthcare system.

Our healthcare system is less universal and comprehensive than it should be. While hospital and medical services are covered with no out-of-pocket payment, community and institutional long-term care (LTC) can be described as simultaneously both universal and selective with both public coverage and private payment with ambiguous public/private relationship.

The present crisis demonstrates the impact of policies adopted by successive governments over many years.

Budgetary planning is based on having just enough human and material resources, with no reserve or margin for maneuver. For example, hospital beds are always filled beyond 100% capacity. The impact of sub-optimal financing is felt most in LTC institutions, many with obsolete buildings, where reduction of services has led to pathetic debates about a second bath per week.

The rapidly increasing number of COVID-19 cases in Montreal's poorest neighbourhoods brings to mind the recent 30% cut in Quebec's public health budget.

Successive governments decided that efficiency required very strong centralization and top-down micro-management. In most provinces, essentially all healthcare boards have been abolished with massive mergers resulting in the disengagement and a loss of sense of belonging by communities and staff. This has led to the inability to adapt to local needs and to react to crises.

After the pandemic, the population will expect that we draw the valuable lessons learned. Key issues include:

- Healthcare expenses promoting high quality care and robust public health are investments contributing to both the well-being of the population and the growth and protection of the economy.
- Homecare and LTC, as well as community services such as dentistry, rehabilitation, psychology and social services are as integral a part of public healthcare as medical and hospital services.
- A strong healthcare system is anchored in local governance with population and community engagement.

The COVID-19 crisis has provided us with a unique opportunity to organise serious and transparent public discussion on the foundations of our healthcare system. There are no simple solutions. But we can work towards changing the paradigm.

[Howard Bergman](#), MD, FCFP, FRCPC, FCAHS, Professor of Family Medicine, McGill University; member of the Clair Commission (2000); author of the Quebec Alzheimer Plan (2009).

## Picking one's battles: COVID-19 and I

*An essay by Martin Fortin published on November 3<sup>rd</sup>, 2020*

Last March, the province was put on pause. Everything stopped. Everything, that is, except the health care system, which went into crisis management mode. The microscopic enemy triggered panic among the population and all involved in the health care system. We've never seen anything like it!

In primary care, practitioners were thrown into a state of chaos. Lots of questions and few answers. Mandatory reorganization: everyone in protection mode. Protecting others. Patients. The most vulnerable. Protecting ourselves from others, too, with our own vulnerabilities. We witnessed unprecedented situations: non-emergency surgeries cancelled, specialist physicians unable to practice, outpatient consultations stopped, activities jettisoned, massive reassignment of staff, most research activities halted. And all of this while the community was suffering through major turmoil with closures of businesses, schools, and regions.

In our health care organizations, everyone had to give thought to what they would do to redefine themselves. What role to play? Nothing was dictated. We had to build the plane and fly at the same time. As a researcher and family medicine clinician, I was faced with a choice: what part of the plane could I help build?

The colleagues in my family medicine group (FMG) were pioneers in applying the measures prescribed by the authorities. Champions. We banded together. Everything was reorganized. In this chaotic turmoil, as a researcher nearing the end of my career, I suddenly felt very useless. Protected by colleagues because of my age and hamstrung in my research, it was unthinkable to me that I would not contribute to the collective effort.

The call from public health was timely. Outbreaks were happening; professionals from all sectors had just been repatriated to public health. A medical team was needed to assist with epidemiological investigations. I jumped right in.

First, we had to learn the National Institute of Public Health's interim recommendations (*interim*, as it turned out, was the key word) for community cases, for health care workers, for seniors' residences, for CHSLDs. We also had to become familiar with the legal context: emergency measures, public safety, the powers of the public health department, quarantine law. Then juggling with risk management and its consequences. Quite a change for a clinician accustomed to treating patients individually, and for a researcher focused on patients with

multiple chronic conditions! All this can be learned quickly when you accept that what's true today may not apply tomorrow! After all, we're building the plane!

From one day to the next, we found ourselves part of a relatively eclectic medical team: family doctors, emergency doctors, surgeons, specialists, professionals of all disciplines. All loaned to public health for different reasons and working for the same cause: the protection of patients and the community.

With the arrival of summer, we entered a lull. Activities were gradually resumed in a redefined way, that became, little by little, our new normal. In the clinic: teleconsultation, limited time allotted for face-to-face visits, distancing, protective equipment. In research, slow resumption of activities. Back to ethics committees with requests for modifications to protocols, consent, procedures. We had to adapt to a new reality in the field. COVID-19 was here, we couldn't ignore it.

And the lull was short-lived. With the arrival of fall, Quebec deployed its system of color codes, no doubt inspired by the season, and regions that started out green transitioned to yellow, then orange, then red, at different rates. What does winter have in store for us?

Our governments have invested generously to help the population get through this. As have our research funding agencies. Several funding opportunities have been created to generate knowledge. We need to understand this virus, how it's transmitted, what destroys it, what activates it, what reactions it causes in animals, in humans. We also need to understand the crisis we're experiencing, its impact on the population, on children, on seniors, on the most vulnerable. In short, we have everything to learn. For many researchers whose work was on hold, this was an ideal opportunity to help answer these questions. Bravo, and thank you for putting your own research agenda aside and working for this cause that affects us all!

For my part, I made the choice to hold down the fort. I didn't apply to any funding program. That wasn't the call I felt. I stayed in the here and now, in crisis management. The crisis called out to me as a researcher, caregiver, and first responder, as well as to my fears; I needed to help make a difference by acting swiftly, I needed to attend to my own fears. Our surest defense at this time is to control spread, which involves rapid identification of cases and contacts, their stratification, and isolation. At first glance, this sounds simple, but implementation of these measures can be very demanding. Data collection is required, which has certain obvious constraints, and personalized analysis in real time. Each situation has to be assessed in its entirety. And you really have to play detective to identify the source, formulate hypotheses, and then try to validate them. In short, there are many elements that correspond to the skills required in research. So for me, it made sense. And finding in the public health team, however eclectic it may be, the same values that I expect from my research collaborators motivated me to come on board. Caring, vigilance, rigour, adaptability, resilience, these are all attributes that I have found in my colleagues—physicians, nurses, kinesiologists, nutritionists, dental hygienists,



occupational therapists—all working with a single goal: to help curb the spread of the invisible enemy using a transdisciplinary approach; a concept I learned in research but that I'm truly experiencing in public health!

As of October 22, a PubMed search identified 66,496 articles on COVID-19. My contribution to this research was nil. As of October 22, the Saguenay Lac-St-Jean region had 891 cases of Covid-19, including 290 active cases, and 1,229 people were in isolation at the time of writing, or about 0.5% of the population. All our efforts are aimed at keeping these figures as low as possible. It may be that I'm disappointing my university by not participating in the research effort, but I've decided instead to fight for my community. In my dual role as researcher and clinician, choosing my battles comes down to a question of emotions, which reason alone cannot explain, but to which I'm happy to respond.

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## Confinement chronicle

*An essay by Karina Prévost published on December 3<sup>rd</sup>, 2020*

For several years now, I've been a patient-partner for my own care. This has been important because, as someone living with cystic fibrosis, I've learned more about my disease and have been able to talk about it with my health care team. All my life, I've been sailing on this big cruise ship that is the health care system. I have experienced some important failures as well as great successes, including my successful bilateral lung transplant six years ago. I've always received the highest quality care in a system that is often out of breath and travelling at top speed. I'm very grateful to all health care staff.

I wanted to do something to express my thanks, but I didn't know if there was anything I could do. For a long time I had been carrying around a large "backpack" where I had stashed my experiences of receiving care and living with a chronic condition, but I could never figure out if this backpack had a purpose to serve. I talked about it with one of my doctors and a door was kindly opened for me. That's how I became a patient-partner.

For the past several years I've been collaborating with the [SPOR Pan-Canadian Primary and Integrated Health Care Innovations Network](#) (PIHCI Network), of which Réseau-1 is the Quebec member. As part of this network, I'm one of the Quebec representatives on the [Pan-Canadian Patient Council](#). Every month, for a little over two years now, I've been meeting with about ten colleagues from every province in the country. We get together to talk about best practices in patient partnership across the country. We talk a lot. This networking is rewarding because it breaks down some barriers. It helps us to better understand the partnership realities of each province and, at the same time, to work collaboratively.

One thing is for sure, the atmosphere is definitely dynamic and there is no shortage of projects!

At the end of last winter, things were going along well, and then came March 23rd. Quebec was put on hold and a series of similar measures were deployed in all Canadian provinces. Despite all the turmoil created by the pandemic, we continued our activities. And it was my involvement as a patient-partner on the Pan-Canadian Patient Council that enabled me to get through the first wave without sinking. It was thanks to the strength of the group that we got through it.

Our March meeting, which had been scheduled for some time, went ahead as planned. However, as we went around the table at the beginning, several of us had to admit we weren't doing well: anxiety, stress, trouble concentrating, things were not looking good. We had a thousand and one questions on our minds, and no answers. It was very scary! That day, when it

was my turn to speak, I burst into tears and said, “I’m afraid of dying. I’m afraid I won’t be able to receive care.” I had become obsessed with the issue of “non-Covid” patients, an issue that still worries me just as much, I have to say.

As a group, despite our individual difficulties, we decided to continue our activities, if only to overcome our isolation, among other things. From this common decision, an interesting proposal arose: what if we saw each other more often? We accepted the idea with great enthusiasm.

While we each experience the pandemic in our own way, no one should have to spend every day coping with this kind of obstacle in fear, isolation, and without resources. We increased the pace of our meetings to twice a month. The meetings were more informal so we could support and encourage each other. These meetings became a beacon in the fog that had invaded my daily life since the start of the pandemic. They helped me to regain confidence in my abilities and to feel less alone with my “covidian” worries. Eventually, I was able to tap into my “backpack of experiential knowledge” where I found resilience and a great capacity to adapt, which have helped me to live better since then.

This summer, the patient-partners in that group participated in [the PIHCl Network webinars](#), and we had the privilege of hosting one: [\*Rendre l’invisible visible: le pouvoir des partenariats entre les patients et leur communauté\*](#) (“Making the invisible visible: the power of partnerships between patients and their communities”). We’re also planning to produce podcasts in the near future, where we will discuss patient partnership based on each individual’s experiences. Our meetings have gone back to a regular schedule, and we’re doing well despite the second wave now surging across the country.

Sometimes, when I’m asked what it’s like to live with illness, I like to use the image of a house of cards. Through the winds of adversity, I’ve had to deal with some really surprising things to be able to move on more effectively. I’ve rebuilt certain aspects of my life. I’ve gone through a lot of grief and major changes. It is a complex life that has become meaningful through happiness, resilience, and above all, tenacity. Always remember that when a patient-partner speaks to you in the context of a patient partnership, it’s done in a spirit of openness, generosity, and often because he or she considers it to be an important added value in the broader picture of the health care system.

Recently, I’ve had conversations with patient-partners who tell me they’ve had no news of the research teams they were involved with. Some even said they felt abandoned, as if their contribution didn’t really count. Times are hard for everyone; a short follow-up, a callback, a little “hello” can make a difference in a situation where many patient-partners have been isolated for several months and are going through difficult times.

Even though I present my own opinion in this essay, I'm speaking here as a patient-partner member of the Pan-Canadian Patient Council. Everything I've said above are purely my own thoughts. Don't worry, I don't pretend to speak for all patients. I want to make it clear that I'll be here, once the pandemic is over, ready to help you, to collaborate in sharing my experiential knowledge, which I hope will continue to contribute to the enrichment of primary care. My wish for us all is that whatever we learn from this will be used to improve the quality of patient care.

Having said that, I can also tell you that, after eight months of confinement, I'm really looking forward to seeing you for "real". There is a light at the end of this long tunnel—it's called 2021.

[Karina Prévost](#), Patient-partner, member of Réseau-1 Québec

## *Infodemic and pandemic: scientific evidence in a time of uncertainty*

*An essay by Jean-Frederic Levesques published on January 18<sup>th</sup>, 2021*

### **Pandemic – emergence of uncertainty**

Early January 2020. A feeling of uncertainty emerged with the initial news of the infection. SARS-CoV-2? A new Acute Respiratory Syndrome? The conference calls started quickly. In Australia, China is nearby. On several dimensions: geographic, economic, social. Prior to the pandemic, China accounted for one-third of all exports and more than 45,000 international students at Australian universities.

An outbreak of respiratory syndromes in Wuhan quickly became a major concern in the Southern hemisphere. On February 1, our borders were closed to China and by mid-March also to Iran, Italy, and South Korea. By March 21, the borders were completely closed for what would turn out to be the majority of 2020, and they remain closed at the beginning of 2021. There is still no travel abroad for Australians unless they obtain a travel permit, and those are rare.

On March 22, as a core measure in the implementation of pandemic response structures, I was given the mandate to set up a critical intelligence unit to support our public policies and services for managing the SARS-CoV-2 pandemic. This decision was based on the realization that the decisions to be made over the next several months would require critical appraisal, by a team with sophisticated capacities for knowledge synthesis, data analysis, and mobilization of clinical expertise. On March 26, the COVID-19 Critical Intelligence Unit launched its activities [<https://aci.health.nsw.gov.au/covid-19/critical-intelligence-unit>].

### **Big evidence – volume, velocity, variety, and veracity**

As with the concept of *big data*, the pandemic has generated what might be called *big evidence*. In terms of **volume**, more than 100,000 scientific articles (about 4% of the global scientific output for 2020) have been published [Else 2020]. In terms of **velocity**, more than 30,000 articles were published in pre-publication, many of them first on the newswires, and the intervals between studies and publication have shrunk, especially for articles about the pandemic. In terms of **variety**, the nature of the articles published has changed over the course of the pandemic, with articles on modeling and diagnosing dominating early on and those on public health interventions and mental health prevailing more recently. Science (and pseudoscience) has permeated social networks. Finally, in terms of **veracity**, scientific retractions have also been in the news, and numerous polarized opinions and conspiracy theories have emerged, while studies providing contextualized insights remain scarce. More recently, such conclusions relating to vaccine studies have also been the subject of debate.

This pace, cadence, and complexity created significant challenges for decision-making at both the clinical and public policy levels. The role of the unit we established was to conduct, in an unbiased

manner, various rapid knowledge syntheses and to mobilize tacit knowledge that could support decision-making. We established a rapid synthesis team (whose reports were produced in under 24 hours early in the pandemic), an empirical data team (which produced a digital dashboard that was updated daily and various weekly reports), a clinical intelligence group (that included various academic clinicians), and a research intelligence group (that coordinated research activities in care and services and public health) [Levesque et al. 2020].

Fundamentally, the unit's guiding principles are: transparency of information sources, sufficiency in extraction and analysis, triangulation of types of evidence, and transposition to the real-world context. In such a context, the unit's products had to be fast (often produced in less than 24 hours), fairly exhaustive without being overly so, brief and clear, and focused on the evidence and not on the detail. A continuing challenge is to produce advisories that differentiate between the absence of evidence, evidence of the absence of evidence, evidence of evidence, and the transposition of evidence to address the questions formulated by decision-makers.

### ***Uncertainty as a platform for change – clinical decision-making and public policy***

In essence, the pandemic created a paradoxical situation for evidence-based decision-making. First, the scientific evidence was sparse at the beginning of the pandemic and many decisions had to be made in a context of uncertainty. Then, another type of uncertainty was created by the sheer size of the scientific corpus and the fact that the science was emerging at a rapid pace and soon produced a situation in which evidence was contradictory. The evidence changed over time and varied greatly from one context to another.

Because the pandemic is a dynamic phenomenon, with different countries being at different epidemic stages, and with pandemic control measures also varying between contexts, a range of contradictory results have emerged. For example, mask use appears to be effective in some places but not in others, epidemic curves suggest that factors of infection transmission are highly variable, and the indirect effects of the pandemic have not been experienced to the same extent everywhere. This is not to mention the variability in approaches adopted for clinical management of confirmed cases and other patients.

Another emerging paradox has to do with uncertainty and the impact of research on clinical and policy decisions. Even if the quality of scientific output is still tenuous in many respects, it does not take much to influence decision making. While strong systematic reviews usually have difficulty penetrating the clinical sector and the public health planning and policy-making arena in normal times, in this time of pandemic the appetite for evidence, however weak, has increased. Combined with good mechanisms for communication with various clinical groups, ranging from primary care to emergency care, community services, and clinical specialties, the reviews and syntheses produced during the pandemic have been translated rapidly into clinical and organizational practice guidelines, within days to weeks (see Communities of Practice website: <https://aci.health.nsw.gov.au/covid-19/communities-of-practice>).

### **Research and scientific dissemination in real time**

The pandemic has not only influenced how research has been used in planning the response at the population or system level. It has also created a natural experiment environment in which

research has been integrated into clinical care delivery and management of the population response. Multiple cohort studies have emerged, real-time research has been funded, and innovative data collection methods have created a variety of real-time living research laboratories. Primary care electronic medical records have become accessible via rapid retrieval systems to monitor the situation in near real time, using primary care as a sentinel.

The health care system has undergone rapid transformation, particularly with respect to the halting of elective procedures, a drastic reduction in discretionary demand for care, the use of information technology for remote care, and the reorganization of care processes and patient trajectories. In such a turbulent context, capturing the transformation by collecting experiential data has served to complement the more formal mechanisms of care and services research.

In terms of individual clinical care delivery, various electronic instruments have been implemented to capture and circulate information related to COVID-19 cases, creating an opportunity to study this cohort beyond ongoing clinical trials. Many clinicians have also had questions from their patients about the pandemic and have drawn on the daily work of the Critical Intelligence Unit to answer them, despite the uncertainty. Discussions about science and evidence, uncertainty, and debates around thorny issues have thus become more prominent in the clinical space.

Regarding decision-makers, supporting a response that is proportional to the risk and to the emergence of evidence has meant putting in place tools for communicating and disseminating scientific evidence. The need to integrate different forms of knowledge and discuss the strength of scientific evidence has become part of public policy-makers' daily routine.

### **A new research paradigm?**

The pandemic has created a distinctive environment for research and knowledge transfer that would be difficult to generate under normal circumstances. The sense of urgency, the emotion, and the complexity of the situation are, in themselves, unique. Still, we need to learn from this experience and influence how we fund, plan, and conduct research for the later phases of the pandemic and whatever comes next. Several researchers crossed the threshold between research and activism during the pandemic. Many researchers became *pan-experts* or *omni-experts*, invited to provide insights into many subjects that extended well beyond the boundaries of their research expertise. It is essential that we put in place sustained and rigorous mechanisms for carrying out such roles. Structuring research and scientific dissemination activities within the time horizons of both the clinician and the decision-maker is possible—the pandemic has thrust us into it!

Perhaps the issue is no longer simply “how to disseminate”, but also “how to do research in a real-world context.” Translating the opportunities created by the pandemic, a common enemy that has captured everyone's attention for months, will not be easy when suddenly everyone—researchers, clinicians and decision-makers—will be refocusing their attention on a myriad of areas of interest. The notion of debate and of integrating knowledge to respond to complex issues is an avenue that our Critical Intelligence Unit is exploring for transposing a structure erected during an emergency into a permanent structure incorporating the same ingredients and methods

in a peri-pandemic context. The challenge is before us. One year later, uncertainty is still omnipresent on several fronts.

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#### **Références:**

Else, H. How a torrent of COVID science changed research publishing — in seven charts. *Nature* 588, 553 (2020). <https://www.nature.com/articles/d41586-020-03564-y>

Levesque, J-F., Sutherland, K., Watson, D.E., Currow, D.C., Bolevich, Z., Koff, E. *Learning Systems in Times of Crisis: the Covid-19 Critical Intelligence Unit in New South Wales, Australia*. November 23, 2020. <https://catalyst.nejm.org/doi/full/10.1056/CAT.20.0542>