

Connecting orphan patients with family physicians

Differences among Quebec's access registries

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Access to family physicians is a very current and political issue. Close to 16% of Canadians report that they do not have family physicians.¹ Close to 5% report that they have tried unsuccessfully to find family physicians.² The number of orphan patients—patients who do not have family physicians—is a substantial problem. Access registries have been created³ in an attempt to deploy medical resources more efficiently. Three examples of access registries are Health Care Connect in Ontario, Primary Care Initiative in Alberta, and *Guichet d'accès pour la clientèle sans médecin de famille* in Quebec.

What these access registries have in common is the goal of centralizing the search for family physicians. These registries vary widely across Canada. This is particularly true in Quebec, where registry operating procedures follow local guidelines. In this article, we describe Quebec's access registries and explain how inconsistencies in the introduction of these referral mechanisms have led to inconsistencies in service delivery. This, in turn, creates inequalities for patients waiting for a family physician. We will demonstrate that, without clear guidelines, some of Quebec's access registries cannot operate efficiently.

A formula for orphan patients

To promote access to a family physician, the Quebec *Ministère de la Santé et des Services sociaux* (MSSS) and its federation of general practitioners (*Fédération des médecins omnipraticiens du Québec* [FMOQ]) decided jointly in 2008 to introduce 95 access registries for orphan patients. The goal of these registries was to make it easier for people in a given local area to find family physicians, based on a scale of clinical priorities and the availability of physicians. However, the agreement that the MSSS and FMOQ reached contained very little in the way of guidelines for implementation, which gave local officials a lot of latitude for determining how the registries would operate and what resources would be allocated to them. A local medical coordinator is appointed to help with the operation of each registry. This coordinator is a family physician who reports to the local regional department of general medicine. The coordinator is paid for this task. In addition, physicians who agree to accept orphan patients through the registry are entitled to the same financial incentives negotiated on their behalf by the FMOQ. They receive

a lump-sum amount based on the levels of vulnerability of the patients they accept. This amount is \$100 for each nonvulnerable patient and \$200 for each vulnerable patient presenting with 1 of 14 types of vulnerability defined and coded by the Quebec health insurance board (*Régie de l'assurance maladie du Québec*). Examples of vulnerability codes include diabetes, chronic obstructive pulmonary disease, and mental health problems.

In terms of their implementation, the disparities among Quebec's orphan patient access registries are huge. For example, because there are no standard inclusion and exclusion criteria, the profiles of patients who register are not consistent. Some registries only take patients deemed vulnerable and high priority; others register all patients, regardless of their state of health. This disparity in inclusion leads to unequal access. With medical resources in such short supply, how is it possible to provide adequate coverage while giving priority to vulnerable patient populations? And, once a patient's name is added to a centralized list, how is it possible to manage the expectations that registration creates, especially when referral to a family physician for these patients is often an extremely long process?

Another example of divergent practice is the registration of pregnant patients in search of prenatal care. Some orphan patient registries give priority to this patient population; others do not give these requests any sort of priority treatment. Pregnant women require medical follow-up for a short period of time; not all physicians want to treat pregnant patients, much less specialize in this practice. In light of this, should the registries give priority to pregnant women, referring them for effective, albeit often temporary, care? Ideally, pregnant women should be able to find a family physician who will provide them with long-term care and continue to care for their infants.

Divergent practice extends to the roles played by registry nurses as well. For some registries, nurses document the patient's state of health. For others, nurses use collective prescriptions to order diagnostic tests and treatment before a patient is even referred to a family physician. Although this is the exception, some registries have a nurse practitioner who specializes in primary health care and who has a much broader role.

Family physician participation varies among regions. Given that a decreasing number of physicians want to accept new patients, how can we encourage family physicians to participate without overburdening them?


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Increasingly we are seeing “self-referral,” whereby a family physician registers a patient that he or she has already accepted. This practice defeats the purpose of the registry, which is to refer orphan patients in a centralized registry on the basis of clinical priority, defined by a nurse’s assessment of a patient’s state of health. Some registries respond by saying that they need to accept all offers, regardless of how small, including physicians whose only participation in the registry consists of self-referrals. Other registries believe that there should be a more structured approach with family physicians, somewhere between accepting self-referrals and accepting patients through the registry. There are discussions on how to encourage family physicians to accept orphan patients through the access registries. These discussions are based on a review of the ratios of clinical priorities assessed by the nurse or on the ratio of vulnerable patients to nonvulnerable patients. Once again, there is no consensus about the need to encourage voluntary participation, with no administrative constraints, or about the need to establish criteria to structure family physician participation in the registries. We believe that the access registries should have guidelines for family physician participation and that physicians should be asked to accept a minimum number of vulnerable, high-priority patients from the orphan patient access registry.

Some registries are used to manage the patients of physicians who are retiring. Once again, however, strategies for this transition differ. We have seen situations where a family physician who is close to retirement shirks his or her responsibility to provide patients with follow-up care and asks all of them to register. While a registry might provide retiring physicians with a useful way to hand off their patients, we believe that certain minimal steps must be taken by these physicians, as set out in their code of deontology. Referring patients to a colleague is preferable to “unloading” one’s entire practice onto the access registry. Cases in which all of a physician’s patients are referred to a registry should be limited to extenuating circumstances, such as the physician’s death.

Conclusion

Several studies have shown the benefits to patients of

having a family physician—more timely treatment,⁴ more preventive care (eg, blood pressure monitoring, mammograms, Papanicolaou tests), better health outcomes,⁵ and better management of chronic disease.⁶⁻⁸ Various Canadian provinces have introduced access registries for referring orphan patients and managing medical resources more efficiently. We believe that access registries are an excellent strategy for helping patients to find physicians who will provide them with continuity of care; however, the creation of Quebec’s 95 orphan patient access registries has shown that when the guidelines for registry development and operation are not adequate, the result is great disparity of registry operation. The MSSS is planning to release a framework for the access registries in the near future. It is hoped that this framework will provide the access registries with an opportunity to review their operating structure so that service delivery is consistent across Quebec. 

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Competing interests

None declared

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