



STUDY SERIES

June 2020



PATIENT AND FAMILY ENGAGEMENT IN PRIMARY CARE:

Building effective patient and family advisory councils in three Ontario communities



ABOUT THE CHANGE FOUNDATION

The Change Foundation is an independent health policy think tank that works to inform positive change in Ontario's healthcare system. With a firm commitment to engaging the voices of patients, family caregivers and health and community care providers, the Foundation explores contemporary healthcare issues through different projects and partnerships to evolve our healthcare system in Ontario and beyond. Created in 1995 through an endowment from the Ontario Hospital Association, the Foundation is dedicated to enhancing patient and caregiver experiences and Ontario's quality of health care.

Acknowledgements

To encourage unfettered discussion, we promised not to name the many patients, family members and staff we interviewed for these three case studies. Unfortunately, that leaves us unable to thank by name the people who made time in their busy days to help us in this work: to all of you, our deepest gratitude for your generosity in sharing your experience and insights with us.

We also received help from several people we did not interview. Thanks, therefore, are due to people who shared their knowledge of patient engagement in primary care, providing us with the essential background we needed to plan the series. We also thank those in Peterborough, Toronto and Orangeville who organized meetings and interviews for us and reviewed and advised us on various drafts.

The Change Foundation contracted Jane Coutts to undertake the interviews, background research and analysis, and the writing of this case study. Jane is a talented writer and editor with 15 years experience as a journalist, including 10 years at the *Globe and Mail*, five of them as the health policy reporter. We are indebted to Jane for presenting this case study on patient-and family-centred primary care in clear and powerful language.

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MESSAGE FROM THE PRESIDENT AND CEO



When The Change Foundation started working in patient engagement in 2010, it was a bit of an uphill battle. But over time, including the patient voice has become more commonplace. There have been legislative requirements for patient and family engagement, a growing number of patient and family advisory councils, and individual patients and family members serving on committees, helping to orient new staff and educate health practitioners. There are also a number of other mechanisms increasingly being used to bring the voice of patients and families into the healthcare discussion — online forums, kiosks in hospitals, survey panels. At the national level, patient and family-centred care has even found its way into Accreditation Canada’s quality standards.

Notwithstanding the impact that the pandemic has had on the relationship between patients, caregivers and the healthcare system, many organizations have embraced the approach and have seen the benefits of meaningful engagement and partnership.

At The Change Foundation, we believe listening, engaging and working with patients and families is fundamental to improving, redesigning and reimagining Ontario’s healthcare system. We also know there are many ways to engage with patients and their families, and while some basic ideas and approaches will inevitably be similar, each team needs to tailor things to work within their own environment. For that reason, this report profiles three Family Health Teams (FHTs) which serve populations with varying needs.

Similar to the approach we took for the first report in this case studies series: *Achieving True Partnerships: Three case studies of patient and family-centred pediatric care in Ontario*, we selected three FHTs that work closely with patient and caregiver advisors in interesting ways. We visited each site, and did confidential interviews with a mix of patients, staff and care providers to gather stories, ideas and experiences that could benefit other primary care organizations. Although we had an interview guide, we tailored the questions for each site and interview. We only asked interviewees about areas they were qualified to talk about and gave everyone the right to decline to answer any questions. The completed case studies have been reviewed by those who were interviewed.

Unfortunately, all the information collected, and interviews conducted with the three Family Health Teams, were completed prior to the breakout of the COVID-19 pandemic. That means the case studies don’t reflect the new and changing realities that came into place very quickly following the announcement of the pandemic in March 2020.

However, as we redefine healthcare in a post-pandemic environment, we believe that patient and caregiver engagement will be more important than ever. We hope these case studies will serve as a source of inspiration for the future.

Cathy Fooks
President and CEO

the suggestion there might be a role for patients in advising physicians on what patients needed and how it might best be done would have seemed absurd



EXECUTIVE SUMMARY

Every day in Ontario, 160,000 patients are seen by family doctors — in patients’ homes, family doctors’ offices, retirement homes, long-term care facilities, in hospices, emergency rooms, and in hospitals.¹ Primary care is where we turn for everything from preventive vaccines and screening tests to ongoing monitoring and management of chronic conditions.

For most Canadians, until quite recently, primary care was a personal relationship between themselves and a single doctor. It wasn’t just a business arrangement, but it wasn’t quite a partnership, either. The suggestion there might be a role for patients in advising physicians on what patients needed and how it might best be done would have seemed absurd. But that’s changing.

Hospitals have been working for some years on patient engagement — that is, partnering with patients to benefit from their experience, knowledge and perspective, in everything from planning treatments to designing and delivering services.² That concept has been slow to expand into primary care, but now it has arrived.

Any effort to engage patients and families in shaping health care shares some basic challenges: finding the right people to be volunteers, finding the most useful things for volunteers to do and finding the best ways for them to do those useful things. But hospitals have traditionally connected with the community through their boards, fundraising drives and use of volunteers to help patients, families and visitors. That’s established them in the public mind as a place where patients and their families can be involved. Going further by involving them in meaningful ways shaping hospital operations, while a big step, was seen by many as a natural evolution. It took a while, but the idea began to be discussed in primary care organizations as well. Some moved on their own to integrate patient partners into aspects of their work and then, in 2017, Ontario’s Ministry of Health and Long-Term Care called on all Family Health Teams (FHTs) to make the shift. For example, the funding agreement between FHTs and the Ministry requires the FHT to “have a process in place to ensure patient and community input into its planning and priorities.”³

We looked at three Family Health Teams for these case studies. The first is the Peterborough Family Health Team, which was one of the pioneers of advisory councils. Peterborough is a city of just more than 80,000 people about 125 kilometres northeast of Toronto. Because the

1. Based on 2018-2019 OHIP (Ontario Hospital Insurance Plan) billing data.

2. Based on: Baker, B., Cene, C. et al (2013 May) Patient and Family Engagement: PFCMH Research Agenda, quoted in Institute for Patient- and Family-Centered Care, “Patient and Family Engagement Strategies,” downloaded from www.ipfcc.org/bestpractices/engagement-strategies-and-definitions.pdf November 26, 2018.

3. Ministry of Health and Long-Term Care and FHT Agreement, Schedule A: Service Plan, Item 5: Service Delivery and Planning.

Family Health Teams

Family Health Teams (FHTs) are teams of healthcare professionals that work together to provide comprehensive primary health care to the patients in their communities. The composition and service provided by these teams vary depending on community needs. Teams include multiple physicians as well as several interprofessional healthcare providers (IHPs) such as, but not limited to, nurse practitioners, nurses, social workers, dietitians, respiratory therapists and pharmacists. FHTs were introduced in Ontario in 2005 and now there are 187 FHTs, with over 3 million Ontarians receiving care from these teams (see: <http://www.health.gov.on.ca/en/pro/programs/fht>).

FHTs incorporate physicians in two ways: one model is known as community FHTs (cFHTs) where the physicians are paid through a blended salary model (there are 25 of these in the province); the other more typical model is affiliated physician groups with Family Health Organizations (FHOs), Family Health Networks (FHNs) or a Rural Northern Physician Group Agreement (RNPGA). These affiliations to physician groups allow patients extended-hours access to healthcare from other physicians in the FHO or FHN, or by interprofessional healthcare providers, outside of their family physician's regular office hours.

FHNs and FHOs are made up of three or more physicians and are compensated primarily through capitation payments, but also receive fee-for-service payments. The physicians are also eligible for specific bonuses and premiums based on patient enrolment. The FHT is a not-for-profit organization, governed by a skills-based board of directors, and fully funded by the Ministry of Health. FHTs work in partnership with their affiliated physician groups and provide interprofessional healthcare services to all the rostered and affiliated patients within the clinical practice and within the community.

FHT also serves surrounding Peterborough County, the team has a total of 111,000 patients on its roster and a budget of \$11.2 million. There is an estimated 8,000 residents who don't have a primary care provider locally; the team has opened two nurse-led clinics to serve them and summer residents from nearby cottage country, with one of the clinics providing virtual care. Efforts to create its patient council have been carefully thought out and focused on balanced representation.

Our second case study focuses on St. Michael's Academic Family Health Team, which in keeping with its affiliation to the University of Toronto, pursued a research-based approach to build patient engagement. The team serves 46,000 people in a catchment area that encompasses both the city's poorest neighbourhoods and some of its wealthiest. Forty per cent of its patients were born outside of Canada and 8% have immigrated in the past

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10 years. Just over a third of patients own their homes, 5% are “marginally housed” and 30% live below the low-income cut off. Involving members of vulnerable communities and trying to ensure an equal voice to all have been among the challenges it has worked on.

The third case study is the Dufferin Area Family Health Team, just northwest of the Greater Toronto Area. It serves some 48,000 patients, who are spread over several communities including former small towns that are transforming into suburbs — some with a high percentage of visible minorities, others not — as well as rural residents who may struggle to make ends meet. As a result, accurate representation of the population has been a concern.

We distilled key lessons from each case study — many over-lap, some are unique to the organization. For this summary, we’ve refined them even further, into twenty key lessons in five categories.

Launching

1. Don’t start engagement projects if you don’t have the resources or the intention of following through.
2. Successful patient advisory councils are strongly supported by organization management.
3. Having a skilled staff facilitator is essential.
4. Share your successes — with team members who may be having doubts about partnering with patients, and with patient advisors, who need to know their work is having an impact.

Recruiting

5. Finding volunteers isn’t easy — invest the time and money to do it properly, use multiple media to reach people and ask all providers and staff to approach good candidates directly.
6. Recruit a mix of people — age, race, gender, economic status — and focus on giving vulnerable groups a voice.
7. Use a formal application process, with interviews, to build an effective group.
8. Prepare volunteers with training on issues, meeting procedures and speaking and working in groups.

Operating

9. Be clear on the goal of your engagement project and on the roles and expectations for everyone involved.
10. Prepare for all meetings by giving patient advisors the education and information they need to contribute effectively to the discussion.
11. Help your physicians learn to communicate more clearly with patients. No jargon!

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12. Let the patient advisory council set its own agenda — they're the experts on what matters to your patients.
13. Make sure your advisors have interesting, meaningful work to pursue; don't let your council slide into tokenism.

Relationships

14. It takes time to build trust with patient advisors and resources to ensure they can work effectively; when they see their ideas adopted, commitment becomes a bond.
15. Prepare physicians, other providers and staff to be receptive, to accept patients as experts in their own lives and to cede some power to build patient-centred care.
16. Real partnership with patients requires understanding processes may be slower and results may not be what you expected or hoped.

Sustaining

17. Keep in touch, and report promptly on what recommendations are being acted on, or to explain why they can't be done.
18. Share your successes — with team members who may be having doubts about partnering with patients, and with patient advisors, who need to know their work is having an impact.
19. Remember not everyone wants to sit around a board table. Let individual advisors “land where they're comfy” — they'll be most engaged when they care deeply about a project they're working on.
20. Invite advisors to act as ambassadors for the health team: they can be great at informing the public about your services.

**primary care
is where we turn
for everything
from preventive
vaccines and
screening tests
to ongoing
monitoring and
management of
chronic conditions**

**there's a difference between
patients who complain, and
patients who want to make
the system better**



PATIENT AND FAMILY ENGAGEMENT AT THE PETERBOROUGH FAMILY HEALTH TEAM

Despite the close and continuing relationships

between patients and their primary care providers, formally involving patients and their families as partners in health care is rare in the primary care world. The Peterborough Family Health Team (PFHT) is working on changing that. Its Patient and Family Advisory Council was launched in October of 2017 and is cautiously learning the ropes of introducing the patient and family voice to primary care practice in the city and county that surrounds it.



Geography: **Peterborough**
patients rostered or served within the community: **111,063**
of affiliated physicians: **91**
of IHPs: **82**
of sites: **multiple**
<https://www.peterboroughfht.com>

Peterborough is a city of just more than 80,000 people about 125 kilometres northeast of Toronto. Because the Family Health Team also serves surrounding Peterborough County, the team has a total of 111,000 patients on its roster and a budget of \$11.2 million. There is an estimated 8,000 residents who don't have a primary care provider locally; the team has opened two nurse-led clinics to serve them and summer residents from nearby cottage country, with one of the clinics providing virtual care.

Peterborough's FHT had been in existence almost a decade when two key employees, the medical director and the executive director, moved on within a couple of months of each other in early 2014. There was no succession plan, and the board found itself struggling with questions about its purpose, "other than just grinding out more care," as one member put it. Members felt too focused on operational issues and not enough on strategy and policy — what the board member called "the whole vision thing" was lacking. As well, there was a growing feeling in the province that FHT boards composed entirely of physicians had inherent conflicts of interest.

"We started hearing about patient and family advisory councils that are out there, and I loved that idea of the patient voice."

[Staff member]

When the next executive director took over, a strategic planning exercise was launched; there hadn't been one for years. The work began with far-reaching consultations. Out of that process came the realization the all-physician board was missing important skills, particularly legal and financial expertise. But there was one more outside expert they wanted to hear from: a patient. "There had never been any patient involvement in anything we had done," one staff member said. "Once you see that and you pay attention, you begin to

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recognize how much you're missing. Even the brochures we give people — they make sense to us, but do they make sense to them?"

The idea of a patient and family advisory council was born. Increasingly common in hospitals and other health-related institutions, they are rare in primary care. The idea was well-received by the board, and in addition to two public representatives chosen for their legal and financial knowledge, the new board structure called for a representative from the Patient and Family Advisory Council to hold a non-voting seat on the board. (That didn't last: even before a patient representative was appointed, the board had voted to make it a full voting position. "If you're really going to engage people, they should have power," a board member said).

"I think there's an opportunity to develop a sense of ownership for health care in the patient; I don't know if our system necessarily always nurtures that." *[Patient council member]*

The first board meeting with the two public representatives was in September 2016. Shortly after, the work to create the advisory council began.

Recruiting for balance

Creation of the advisory council was carefully controlled by the executive director, beginning with "a whole bunch of research." There is limited information, however, about patient engagement in primary care; Peterborough tried to extract details from material written for and about hospital advisory councils and got the terms of reference for the South East Toronto Family Health Team's Patient and Family Advisory Council.

Goals for the make-up of the council were set: a balance of men and women, a range of ages, and a representative from each of the five family health organizations (essentially primary care group offices) that make up the Peterborough Family Health Team. According to the 2006 census, Peterborough's population was almost 95% white. An indigenous representative was added to the council in 2018.

Seeking the broadest representation possible, the team used multiple channels to get the word out about the council. As well as printing traditional brochures ("Be the Change"), staff used Facebook and other social media. But, in an effort to find the most effective patient representatives they could, they also asked physicians and interprofessional healthcare providers to encourage patients they thought would make effective spokespeople to apply.

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“There’s a difference between patients who complain, and patients who want to make the system better,” the board member said. What you don’t want, a staff member said, is “negative nellys.” As it turned out, older people (mostly seniors) responded to the brochures. Younger people were much less responsive, and where they were, it was mostly young mothers, recruited through social media. Young men, who don’t much use healthcare services, were noticeably absent.

Patients and family members who did step forward were given application forms, which asked why they wanted to be part of the council, what they might bring to it and what their experiences with health care were. They were then interviewed by a panel. They were being rated for their own suitability, of course, but also in the interest of creating the most diverse, yet balanced, board possible. About 12 — double what was needed — were interviewed.

“So refreshing to have patients who are keen and engaged and passionate, and then you combine that with the passion of PFAC to want to do this and the energy was fantastic.” *[Staff member]*

The team, anxious not to lose the interest of people rejected for the council, intended to use them in other advisory roles that might arise — but that’s “been a fall down,” in the words of one staff member.

Members of the advisory council interviewed for this study all thought the process to create the council had been excellent. “It was weird having to do, essentially, a job interview,” one council member said. “I haven’t done that for about 30 years. But I think it’s a good thing.” Another said “I thought they were quite conscientious about who they selected. When it came to the interview, I knew they were trying to choose the right mix of patients and it wasn’t about me necessarily, it was about finding the right mix of patients who could reflect on their experiences.”

Interestingly, while one member of the council had applied because of a sense people tend to become invisible as they age, feeling they needed a voice to speak for them, another had volunteered out of a concern Peterborough’s demographics (the city promotes itself as a great place to retire) would lead to the health system focusing too heavily on seniors, at the expense of young families.

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Another member of the committee, who has drawn heavily on a variety of Peterborough FHT programs during long years of chronic pain, disability and emotional trauma, said “I thought it was a wonderful way to give back to my community because all those programs were no charge. For someone like me who lives on a disability pension, it was life-changing, and I wanted to be part of the process for other people.”

That member also thought a position on the committee would be a chance to encourage physicians to offer more holistic care that would acknowledge the effect of chronic pain and disability on thought and emotion: “Bringing a patient’s perspective, I’m hoping that impacts more on offering total mind-body care rather than just the specific complaint.”

Finding the patient voice the board needed to hear

Although the first meeting of the Patient and Family Advisory Council (PFAC) took place in October 2017, it was almost a full year before one of its members was appointed to the Family Health Team’s board of directors. The same careful thought that went into recruiting members for the council was applied to choosing a board member.

The Peterborough team did extensive consultations before moving to a mixed governance board – and based on informal discussions before those consultations began, the basic premise was that physicians would still be a majority. But, with that assured, there was little resistance to the idea of a patient representative. “I can’t think of any concrete examples of where I felt the patient voice was lacking,” the board member said. “I mean, physicians are paternalistic by nature, we thought what we were doing was right. But sometimes considerations come up that we haven’t thought about, and that’s what was lacking, and we did recognize that it was.”

Meanwhile, after the members of the advisory council and staff spent some months getting to know each other, the question of who would be the best board representative was always hovering. “The wrong person can be very disruptive to a board, and our board is really making great progress towards being a true strategic board,” one staff member said. The characteristics of a good patient representative were discussed – it had to be someone who would not be intimidated, who would be able to contradict physicians, who had the confidence to speak openly and honestly and who would naturally have a problem-solving attitude.

Two of the six members of the council were nominated and interviewed by the board chair and another board member. The selected candidate had several meetings to get briefed on serving on a board. Interviewed not long after first attending a board meeting, the member had felt well-received, but not said anything.

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HAVING A PATIENT AND FAMILY ADVISORY COUNCIL MEMBER ON THE BOARD:

“It gives this group a little more validity. It gives us a voice on the board. And you’re talking doctors. These are very smart people... I think they are willing to sit down and listen to different opinions and different voices.” *[Patient council member]*

“I can open professionals’ eyes to how it feels to be a patient... I understand what it’s like to be so confused about everything everybody is telling you is wrong with you when it’s all different. Everybody tells you something different and every time you think, OK, I’ll just do what this person tells me to do and I will feel better. I can be a voice to explain to the board that when a person’s not well, they can lose their total sense of self. Most of us do. It’s a struggle not to become your disability.” *[Patient council member]*

“I thought I was as well-informed as I could be, but I can see that it will take me three or four meetings to really sort of find my place within the board as well. I felt curiosity within the room about who I am and what impact I would have on the board...I need some time to know who the players are and what their personal mandates are as well as the mandate from the board itself. Everyone has issues that drive them in any board.”

Barriers on the road to patient and family engagement

Without a clear road map for what a primary care patient and family advisory council should do, there is a lurking concern that Peterborough’s council might prove a token gesture, and its members find opportunities to make useful contributions limited. “I struggle to find meaningful tasks for them,” a staff member said. “This is new and there are not a lot of examples in primary care, we’re trailblazing, finding out what works and what doesn’t work.”

In their first year, council members reviewed all the Family Health Team’s publications and the web site, looking to make them as patient and family-friendly as possible. Some members help staff with booths around town in Peterborough to raise awareness of the services the health team offers. Now they are test driving an app called Co-Health, which is being tailored for the Peterborough FHT by its developers in Toronto. It’s a one-stop shop to help patients with everything from managing medication and appointments to finding information on health and health care.

The board member, however, didn’t think tokenism would be a problem. “Is there a danger of being ignored? Yeah, I suppose there is, but I don’t think, in a community like Peterborough, where everyone kind of knows everyone that that would be a popular position for long.”

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“If it was a case of them saying, ‘thank you for your opinion, have a good day, we’ll see you in three months,’ that’s tokenism. If it’s a case of ‘this is what we’re doing, we’d like you to take part in it,’ that’s a whole different thing.” *[Patient council member]*

The lack of models to follow and colleagues to consult is a constant problem. In patient and family engagement, as in all aspects of care, family practice is the poor cousin, one staff member said. There is no support. “Any change I want to do, I have to figure out on my own. I know all these things can happen — like the council being just tokenism — that I don’t want to happen, but there is no guidance.”

In 2017 and 2018, the Peterborough Family Health Team has sent staff and patients to the Patient Experience Forum, an annual national conference held in Toronto. “We’re talking about all these wonderful things at Sunnybrook and [University Health Network] and all of that, but they don’t interact with primary care at all...It’s frustrating as all get out, but it’s the only place I can network and interact with people and learn and get ideas.”

Although Peterborough physicians have mostly been open to the idea of patient engagement, there is some reluctance, according to one staff member. “There’s a fear that these people who don’t have the education are going to start telling us what to do. Well, guess what, what you’re doing is for them and it’s about that saying ‘nothing about me without me,’” she said.

I was lucky enough to serve on the board when a couple of the new members of the public were there, and they would ask good questions. They would challenge us about points of view, and what we should maybe be looking at and what was important. Bringing challenges to the board that as physicians we hadn’t thought about — and I think the organization was better for it.

[Board member]

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Is the treatment working?

With the Patient and Family Advisory Council just one year old as these interviews were done, people interviewed said it was too soon to assess its success, but most had ideas about what has made it work so far. One thing is the nature of the healthcare community in Peterborough, where every family physician except for one is a part of the Family Health Team, sharing in the benefits it offers their patients. The FHT's board, before and after restructuring, strongly supported what they thought was best for the patients of the community.

"There are no fiefdoms here," the board member said. "Everyone accepted that the finances coming through our organization belong to the patients and they deserve to know where the money is going and why it's going and have an influence on where it goes and what's important to them. I think the board itself was a big factor."

Supportive leadership is essential for innovations to succeed in health care and the commitment of the Family Health Team's staff to patient engagement was cited by all the council members interviewed as a crucial factor in getting the advisory council up and running.

The executive director, one said, has been "a really great advocate for patients' voices being heard. I know she's got a team around her, but I think she seems to be the one who has really advocated for this being developed. I think her sense of leadership and wanting to break the mold and be ahead of things has helped," said one council member.

Another said that commitment runs throughout the organization. "The passion from the whole organization, about well-being in the community, that's really predominant in every interaction I have with anybody on staff or faculty or whatever you want to call them," the patient said. "They're really focused on reaching everyone in the community with good care."

One staff member with previous experience with a province-wide patient and family advisory council said she believes the concept will work better at the local level.

"At this level you really do see how much the clinicians care about their patients and they really do put their patients first. So when the patients' voice is brought to the table through this group, I feel that change will happen." In contrast, on the provincial council she worked with, patients dealt with bureaucrats, and were there mainly to vet ideas they had little to do with developing.

Having a group of patients and family members available to speak about the team's services — whether in a meeting with politicians or at the weekly farmers market — puts a great face

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on the Peterborough Family Health Team, the staff member added. “The words that come out of their mouths are better than any advertisement we could put out there. It’s the words of patients, talking about how our programs and services have changed their life...those anecdotes are like gold.”

What comes next?

Peterborough’s Patient and Family Advisory Council meets quarterly, so at the time of writing had met less than half a dozen times. The plan was to do some self-reflection before its second anniversary — how the committee’s doing, what it’s doing, are there gaps in things it should be doing, what seems to be working well. “From that I hope we’ll determine some concrete steps and some actionable items we can take to make changes, to get where we want to go,” a staff member said.

Where it should go as far as she’s concerned is to a place where “every time we talk about something it becomes automatic to say ‘what is the patient perspective on this?’ To me that’s when we’ll be successful, when it becomes routine to ask that question, just like we ask all the other questions we’ve been asking for the past hundred years.”

The staff member is looking forward to getting patients involved in program design, helping create services that make sense from a patient and family point of view; it just happens Peterborough has not created a new program since the council was established.

Several people interviewed want to see patient and family influence expanded. One staff member is looking forward to the day the supply of physicians exceeds demand, so doctors have to become customer-focused and “actually have patients saying, ‘Meh, this isn’t working for me.’ We do that with everything else in our life, but we can’t do it with health. This [patient and family engagement] is the way to allow that switch to start happening, that patients can stand up and say ‘no, this isn’t working, you’re not hearing us.’”

One of the patient advisors said the council’s strength lies in its ability to bring more balance to the relationship between patients and their healthcare providers, “hopefully taking some of the onus of pressure off providers to be the ones with all of the information and all of the knowledge and all of the expertise, because patients will be seen as coming in with knowledge and expertise.”

Another wants to see another patient on the health team’s board. “In order to have equal impact on the community at the board level, I think you have to even the playing field even more, eventually.”

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The board member interviewed thinks primary-care patient engagement should expand, but upwards toward the provincial level. Part of a large practice group that regularly gathers and reviews patient input, he can't see a place for a more formal role for patients in operating practices which are, in fact, independent small businesses. "We're kind of confined to a system that doesn't welcome new processes and new ways of looking at things. Our engagement with family is usually in the exam room and the consultation room."

He can, however, see an important role for patients in policy and program discussions — with the Peterborough Ontario Health Team⁴, with provincial organizations, with the province itself. "I think [working with individual physicians] would probably be more token and less effective in changing the system, whereas if we involve patients up the ladder, I think we'll get a more useful healthcare system."

The hope for the Peterborough Patient and Family Advisory Council is that it grows with time, finding effective ways and places to shape health care by bringing the perspective of the people it affects most. Peterborough was one of the first Ontario Health Teams (OHTs) approved; the Peterborough FHT aims to have representatives of its PFAC on the Peterborough OHT patient and family advisory council. In addition, one of their advisory council members is on the Peterborough Regional Health Centre's Mental Health Council with an aim of easing transitions between primary and acute care and addressing the stigma associated with mental health care.

"I want to continually try and be on the cutting edge," one staff member said, "moving forward in a progression and fashion that's not too fast, because the change we do has to be integrated down to the practice level, and that kind of change takes time. I think it's going to take 10 years, to get it to a maturity level where it is just a part of doing business."

"My motto is, everything's always in draft."

Key Messages

1. A good advisory council offers a range of voices, representing the diversity of your organization's patients. Seek a representative range of ages, cultures and neighbourhoods (or communities, in rural areas). Try for balance in gender, economic and health status.
2. It can be difficult to recruit people for advisory councils — use multiple channels, including brochures, posters, announcements or stories in the media, and ask all your providers and staff to approach people they think would be good candidates directly.

4. In 2019, Ontario Health Teams were introduced as a new approach to "organizing and delivering care that is more connected to patients in their local communities....healthcare providers, including hospitals, primary care providers and home and community care providers work as one coordinated team"; See: <http://health.gov.on.ca/en/pro/programs/connectedcare/oht/>

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3. Have volunteers fill out application forms asking why they're interested in being a patient advisor and what they have to offer, then interview them to get to know them better. Keep a file of people not selected you can draw on for projects in the future.
4. Successful patient advisory councils are strongly supported by organization management.
5. If you're looking for patient representatives for your board or committees, choose people who won't get intimidated and have the confidence to speak openly and honestly.
6. Make sure your advisors have interesting, meaningful work to pursue; don't let your council slide into tokenism.
7. Invite advisors to act as ambassadors for the health team: they can be great at informing the public about your services.

**there had never
been any patient
involvement in
anything we had
done. Once you see
that and you pay
attention, you
begin to recognize
how much
you're missing**



PATIENT AND FAMILY ENGAGEMENT AT THE ST. MICHAEL'S ACADEMIC FAMILY HEALTH TEAM

The St. Michael's Academic Family Health Team operates at five sites around the downtown Toronto hospital of which it is a part. The area encompasses some of Toronto's poorest neighbourhoods — and some of its wealthiest. To the west, the city's commercial towers soar; to the east the towers are residential. In and around them live the Family Health Team's 46,000 patients.



Geography: **Toronto**

patients rostered or served within the community: **46,350**

of affiliated physicians: **75**

of IHPs: **28**

of sites: **5**

<https://www.stmichaelshospital.com/programs/familypractice/index.php>

Even by the standards of one of the most diverse cities in the world, the FHT's patients represent a remarkable range of humanity: 40% of patients were born outside of Canada and 8% have immigrated in the past 10 years. Just over a third of patients own their homes, 5% are “marginally housed” and 30% live below the low-income cut off. There is homelessness in the area and at the same time, a residential mix that ranges from subsidized housing, market rent apartments and high-end condos to million-dollar townhouses, all built on what was Regent Park, Toronto's first public-housing project.

Out of this mix of lives, cultures and needs, the St. Michael's Academic Family Health Team (SMAFHT) has been working for several years to bring the voices of patients to the forefront, to reflect the mounting trend for patients and their families to be more involved in health-care planning, policy and operating decisions. In this case study we look at two of the team's initial efforts to engage patients, and how the lessons from those shaped the creation of its patient and family advisory council.

To preserve the anonymity of people interviewed, we are identifying speakers only as team members or patients — all the members of the public interviewed for this were patients, rather than family members; the “team” means the Academic Family Health Team.

Motivation

The move toward involving primary care patients more began slowly, after family doctors who worked for St. Michael's joined together to form a Family Health Team in 2010. Partly, the shift was a natural extension of family practice principles: as one team member said, “All family physicians are trained in patient-centred care, and we're also trained to consider the community our patients live in; that to me includes family and it could include other things as well.” Another noted that more and more patients are stepping forward to say “science hasn't captured my experience.”

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Interest in formally collaborating with patients to shape healthcare services and even policy had been getting increased attention across Canada and beyond. Setting up ways to draw on patients' knowledge, insights and experience was becoming an expectation. In 2011, after the FHT decided to increase work on quality improvement, the reasons for that expectation became clear. As a team member observed, "There's only so far you can go before you realize, 'No wonder we're not realizing the change we want, we didn't involve the people.' It's just a fact."

The St. Michael's Academic Family Health Team is fully affiliated with the University of Toronto, Department of Family and Community Medicine and in 2014, several members of the team attended a workshop given by the university's Department of Family and Community Medicine on *Experience Based Co-Design*, where patients and team members work together on a structured approach to redesigning and improving health care.⁵ It went a long way, one of the participants said, both to show the value of partnering with patients and to make the whole idea of patient engagement seem less intimidating. That same year, the team was ready to try a patient engagement exercise of its own, led by a quality improvement consultant. The team used co-design methods to tackle an ongoing problem with after-hours care. A patient survey in 2014 had shown only 56% of patients felt it was easy to get care on evenings, weekends and holidays, although in fact after-hours care was available most weeknights and Saturdays (Sunday hours have been added since then).

One member of the team said they went into the workshop assuming the problem was that after-hours care rotated among the team's six clinics and people did not want to travel further, to clinics they weren't used to. "Turns out, that wasn't the problem, it was just that the posters were just really confusing...we thought the suggestions might be change the structure, add more clinics, things that are not easy to do, but instead they said, 'Make the poster better and send us an email blast telling us about it.' An email blast costs nothing and redesigning the poster was a nominal cost. The proportion of people [surveyed] who say they could easily access after-hours care went up and it's been sustained for years now." (Follow up data from 2017 shows the percentage of patients who said after hours care was easy or very easy to get had risen from 56% to 79%.)

5. Developed in the UK, the methodology empowers teams and patients to make the changes necessary for safe and effective care that is patient-centred. See: <https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/step-by-step-guide/1-experience-based-co-design>.

An early success: Patient Engagement Day

While interest in partnering with patients to deliver better care was growing across the team, several people interviewed for this case study described one day as the transformative event in the journey toward patient engagement: a workshop held on a cold February Saturday in 2016. Called simply the Patient Engagement Day, it inspired and excited patients and team members alike, and shaped the team's approach to patient engagement from then on.⁶

Working with MASS LBP was sparked by one Family Health Team physician who went to hear a talk by Peter MacLeod, the company's co-founder (its name links the idea of the mass of knowledge in the community with the initials for "led by people"). Inspired and excited by the work he described, the team physician arranged a meeting with him. "It really rang true for me that this is the right way to go and I started thinking, how can we do this?" the physician said. Although the scope and budget of the Family Health Team's work was much smaller than MASS LBP normally deals with, MacLeod agreed to help.

Under MacLeod's guidance, the small group working to organize the day did a modified version of a civic lottery, using the Family Health Team's patient email list, as well as putting up posters in clinics. Almost 350 people offered to participate, answering questions about age, gender identity, housing, and self-reported health. Again, using MASS LBP methods, the organizers randomly selected a diverse group of patients based on the reported characteristics.

On MacLeod's advice that the issue tackled should be something tangible where people can make a difference, the group scrapped their original plan to ask participants for help in setting priorities for improvement projects. MacLeod warned it was unfair to ask members of the public to choose one disease over another to select a topic for a quality improvement project. Instead, the 36 participants chosen (to make up six groups of six, the optimum number for small-group work) were asked to discuss a typical medical appointment, from start to finish, to determine what didn't work well and how to improve it.

Importantly, the 300 or so people not chosen for the day were asked if they would be part of a pool the team could draw on for future patient engagement work; most agreed and have been an invaluable resource since then for other projects.

The day began, as citizen panels do, with education on what a Family Health Team is, where it fits in the healthcare system and what its accountabilities are — background that

6. An article about the Patient Engagement Day, "Citizen Engagement in Primary Care," appeared in *The Annals of Family Medicine*: <http://www.annfammed.org/content/16/2/175.full.pdf+html>

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is essential for effective public participation, the team member who had connected with MacLeod said.

“One of the things that resonated with me when I heard him speak was the thoughtfulness of their approach, that they are educating people, ordinary citizens about these complex areas, and they take the time to do that so that people feel they have the information in order to be able to address this complex question.”

MASS LBP and the vision behind the patient engagement day

To understand the success of the St. Michael's Academic Family Health Team's first big effort in patient engagement, it's necessary to learn a bit about MASS LBP, a Toronto-based consulting firm, which calls itself “Canada's home for democratic innovation and public strategy.” Founded in 2007, the company was described by the *Globe and Mail* as “part of a new wave of consultants trying to reinvigorate Western democracies with greater public engagement.”⁷

MASS LBP's approach goes deeper than the public opinion gathering we're used to, according to the *Globe* article. “[P]olls tend to measure single moments in time. Focus groups and online dialogues rarely seek or establish consensus. And town halls often become venting platforms, filled with more heat than light. Certainly, none gives to — or asks of — citizens as much as the in-depth process these groups are adopting.”⁸

MASS LBP works with governments and organizations looking to develop new policies or make difficult decisions by using a careful process of random selection they call a “civic lottery” to identify a representative cross-section of people from the community, who are then invited to serve on a “citizen's reference panel.”

Typically, members of the panel are asked to give up several Saturdays in a facilitated process that brings them together with representatives of the organization seeking their input. The process always begins with education, to ensure participants have a reasonable understanding of the situation they are being asked to discuss and make recommendations on. They work in groups through various types of exercise until they reach consensus on recommendations for action. To honour their commitment of time and effort, the organization seeking their advice reports back to them on the outcomes of those recommendations — whether they were acted on, and how, or rejected, and why.

7. Posner, M. The new citizens' panels: a powerful antidote to cynicism. *The Globe and Mail*, April 29, 2011. Downloaded from <https://www.theglobeandmail.com/news/politics/the-new-citizens-panels-a-powerful-antidote-to-cynicism/article578195/> January 16, 2019

8. Ibid

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Some of the issues raised by participants during the Patient Engagement Day were not a surprise. They complained of long waits on the phone (15 minutes on hold during peak times was not uncommon), of long waits after arriving for appointments and of waits for referrals to specialists. But others were unexpected — they didn't like the plexiglass that separated them from receptionists when they arrived and they didn't understand the role of residents, and how their qualifications were different than other doctors.

In the four years since that day, almost all the issues raised have been discussed and where possible, acted on. The team has adopted email appointment booking, patients facing long waits to see the doctor are now told how many other people are before them, work is being done on streamlining referrals, and the role of residents is explained. The complaints about the plexiglass shields were more difficult to resolve, because some staff were worried about potentially aggressive patients and felt unsafe without a barrier. In the end, it was removed from some reception desks, but not all.

Most important of all, however, is that the 36 participants have been regularly updated on changes: one of MASS LBP's principles is that completing the feedback loop is essential.

“I feel like closing the loop is a good way to respect the time and effort that patients put in...it seems pretty disingenuous to ask for your input and then never tell you what happened with it.”

[Team member]

Patients and team members who attended the engagement day still sound excited as they describe the feeling in the room. One patient who had volunteered in hopes of learning more about the healthcare system hadn't expected anyone would care what she thought: “They were asking my point of view and what I could say that would make it better. I was actually looking forward to learn more but not to advise somebody or give my opinion. That to me was a shocker, in a good way.” A roomful of strangers, she added, became a community in just a few short hours.

“It felt like we all had the same issues, it felt like we were all trying to help, not just each other, but by raising our voices, giving advice and our point of view, we might be able to have a hand in improvement, in betterment, for everybody.”

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Four years later, one long-time team member still sounded dazzled: “I was blown away by that day. It was a transformative day for me because I was just amazed at the amount of value the patients were offering to things that we took for granted — you know, things we did the same way over and over again for years, and suddenly hearing their perspective, it was like all ‘Aha!’ moments all day.”

The challenge for the handful of team members present was to convey the power of the day to colleagues who had not been present. Two frequent concerns about partnering with patients — that people without expertise will be making decisions about how professionals work, or that patients’ recommendations will be impractical — are both best overcome by exposure to the reality, people who participated said.

“We don’t have to be afraid that we’re going to get these crazy ideas that are just not things we can do. Occasionally yes, but most of the time you’re going to get very reasonable suggestions of things that need to be improved upon.” *[Team member]*

To start that process, two patients from the patient engagement day were invited to speak at a general team meeting for the whole Family Health Team. One of the organizers of the engagement day said it was a turning point that “touched people with a different energy... there were 100-plus people all in a room listening to these two patients give us a very compelling description of how important engagement was. I know that after that day, many people were excited to try and do more engagement.”

Learning about engaging patients: Social Determinants of Health Committee

It’s important to note here that the 2014 workshop on experience based co-design and the 2016 Patient Engagement Day were not the only efforts to engage patients. As we’ve said, the St. Michael’s Academic Family Health Team’s downtown catchment area is home to many marginalized residents, people whose health is likely to be undermined by what are called the “social determinants of health,” factors such as poverty, insecure housing or work, a lack of education and social support, racism and homophobia. As a result, members of the SMAFHT formed a [Social Determinants of Health Committee](#) in 2013 to focus on those issues, starting by supporting development of programs on income security, literacy, access to decent work, medical-legal partnership and community engagement. It also created a pilot program for collecting socio-demographic data.

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“The goal of that was to focus on equity, on preferentially improving health for the groups that are the most marginalized, to put the most vulnerable at the forefront of everyone’s minds in terms of what we do as a health team,” one team member said. There was something missing, however: everyone on the committee was a healthcare provider — there were no patients included to discuss issues that affected them deeply. When they recognized that gap, the committee’s leadership made a decision to move quickly to fill it — but that brought its own challenges.

“It can be hard when engaging with patients is necessary to do the work you’re trying to do, but you don’t really have the skill set for it. It’s not something you learn in a crash course.” *[Team member]*

In its eagerness to include patients, the committee did not put much thought into recruitment. “We didn’t really have a process for sorting through what we wanted, other than someone who was interested. That was a mistake,” one team member said.

Another said they had not defined the role the patients were to fill, which should be understood by both sides. It was also hard for the new members to mesh with a committee of

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health professionals who had been meeting for almost two years, even though they were given background information and offered training about how to work effectively as patient advisors to a health team.

At the same time, the clinicians needed training to be effective partners with patients. They had to be reminded not to use professional jargon and learn to interact with non-experts by slowing down, giving context and explaining issues. It took some time, and repeated reminders, to get committee members to remember. Simple changes, like being sure to make introductions and reminders that patient advisors were present at every meeting, helped.

“Bringing patients into a group that is not absolutely secure in what it’s doing is also challenging,” one team member said. “Having a Social Determinants of Health Committee was incredibly novel...there was a sense we had to keep proving we needed to be there, that we deserved to take up space within the department, which left us less space for thinking about restructuring to properly hear the lived experience voice.”

Four patient advisors were recruited, mostly from among patients who used programs the committee helped establish. Within six months, three had left — one for full-time work, the others telling a team member it didn’t seem to make sense for them to be there and they felt they had no opportunity to really engage.

“It wasn’t the right time. We didn’t have the right structure and capacity built in,” that team member says now. “It was a good lesson learned, because sometimes you have to make mistakes in order to figure out what to do better. Maybe we weren’t specific enough on who we should have been thinking about to be on the committee and how we would work with them.” A committee structure doesn’t work for everyone, that team member added. Even if they don’t feel intimidated or overwhelmed, sitting and talking can be frustrating for volunteers looking to make a contribution. “For some, the areas where they wanted to bring their voice, it just felt like it would take too long to get to that point and they weren’t willing to wait and just hope that it gets better,” the team member said. Another team member said it was a lesson that had to be learned: “Not every patient can just walk into a room of providers and feel like they are being utilized well or serving a purpose...we’ve gotten better at making sure people actually have the information they need and the structure is set up so the patient voice is truly heard and appreciated.”

In retrospect, team members believe that early experience with patient advisors was a “wonderful learning experience” for the committee and the Family Health Team. Lessons from it were essential in the creation of the Patient and Family Advisory Council and other engagement efforts.

Launching the Patient and Family Advisory Council

One of the breakthrough messages from the Patient Engagement Day was that “when patients and providers get together in the same room they realize their agendas are very similar,” according to a team member who has worked on patient engagement in other settings as well. Several other patients and team members interviewed said the same thing. As word of the day’s success spread, people began to draw on the pool created from engagement day volunteers for a variety of projects. Because patients were being engaged in so many ways, there was debate over whether a formal advisory council was necessary or advisable. A committee was formed to look at the matter — made up entirely of team members. (“In hindsight, it would have been beneficial if we actually had a patient,” one organizer said. “That was definitely a miss”).

However, patient and family advisory councils had become a requirement for accreditation and across the hospital, departments were launching them. As well, other Family Health Teams were starting advisory councils and one team member said, “of course we wanted to get competitive and be part of the conversation.” In the fall of 2017, St. Michael’s Academic Family Health Team decided to proceed.

Recruiting patient and family advisors

The team applied lessons from the work with MASS LBP to recruit volunteers. They sent out emails, put up posters in all the waiting rooms and asked people working with patients to identify anyone who might be a good council member. The result was a list of about 30 potential council members to interview. Two team members each took half the candidates, asking questions about demographics, including gender identity, housing situation and postal code and the state of their health as well as why they were interested in being part of a patient and family advisory council. Candidates were also asked about any assistance they might need to participate — such as childcare or transit fare — so barriers would not get in the way of attending meetings. The two team members then shared summaries of the interviews, listing their nominees, and discussed each before settling on a core group of 14 advisors.

“Don’t be afraid to do something you don’t feel you have expertise in, to embrace the uncertainty, to be humble and learn from all the great things that people around you are doing.” *[Team member]*

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The process was not perfect — the council is not as diverse as organizers hoped and it lacks representation from some corners of the catchment area. “The patients themselves have identified the gaps, and the patients themselves have said you know we’re sitting here and we’re trying to speak for the patient population when we’re not entirely representative of the whole patient population,” one team member said. Still, the council represents a broader range of society than might appear at first glance, because of the “lived experience” of its members, including a formerly homeless person and members of the LGBTQ+ community.

Prepping the ground

Protecting members of the advisory council from the kinds of problems that led two of the four patient members of the Social Determinants of Health Committee to leave was a top priority for the team members organizing the advisory council. A big part of that, they realized, was careful groundwork. “What I have recognized now, after doing more work with patients as advisors and learning from others, particularly listening to patients, is that when roles and expectations are not defined and clear, it does not make for a great experience for patients,” one team member said.

The team knew that some advisors come on board hugely ambitious to make changes, some of which are far beyond the scope of what a Family Health Team has the power to do, another team member explained. “I think that’s going to be the challenge, that mix of managing expectations and people really feeling like they are adding value in a concrete way.”

That was certainly the experience of one team member who worked closely with the council from its first meeting in March of 2018 and found a group who were not happy with what they were being told about what the FHT could do and what it couldn’t. “These are very, very eager folks, and there were things they wanted to move forward with right away and when we couldn’t, it was a bit frustrating for them, so we spent some time in the early meetings around managing expectations, a little bit of learning around our organizational structure and what our roles are,” the team member said.

Despite the careful approach, the group got off to a rocky start. Just a couple of members dominated meetings, which one patient advisor described as noisy “free-for-all” — so bad, she said, that one advisor quit because of it. “If another group were wanting to start this, they should come in with rules of engagement right off the top. It’s not enough to say respect your fellow.”

One team member said the challenges of group dynamics and achieving cohesion are often understated when people talk about creating patient advisories. Some members of the

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council have lived difficult lives, some come from considerable privilege, some have formal experience on boards and for some this is their first role on an advisory body. “As you would expect, certain voices are stronger than others, so part of ensuring everyone feels valued and everyone feels like they have a voice is to create a safe space where everyone feels like they can say something,” the team member said.

Things improved when the group elected a member to be co-chair – a patient member sharing chairing duties with a team member. Speakers must now raise their hands and wait to be called on before they speak, while the co-chairs try to ensure everyone is heard from. Another member said she got through the chaotic early meetings by reminding herself that even in families not everyone thinks the same “but the more we meet, the more the relationship’s building...What I like most is that by the end of two hours, there’s a lot of opinions and talks and discussions done.”

Cautious first steps

One team member who spent time observing some of the other St. Michael’s Hospital patient and family advisory committees said improving the quality of care and patient and family experience in primary care is quite different from hospitals. The topics in hospitals are mostly concrete problems – where can patients’ belongings be stored, how many visitors can a patient have at one time, can visiting hours be eliminated. “With our patient advisory council, right from the start, there were questions around inclusivity and equity and how can I build a better relationship with my provider, how do I know my provider is valuing my input. These are not easy fixes that we could address immediately.”

Even with tensions at the table and uncertainty around roles, council members were united in commitment. When it was originally proposed by the team that the council meet every other month for an hour, the advisors’ reaction, one of them said, was essentially “What are we here for?” before they changed the plan to meeting monthly for two hours.

The advisory council made it clear from the beginning they didn’t want to be just a consultative body, where people bring ideas, looking for input. One team member warns against letting the advisory council become a dumping ground for presentations by people who want quick access to a group of patients, or even for a short cut to being able to say they engaged patients. In fact, so many groups are trying to get access to the patient and family advisory council, the team finds it has to protect the advisors from people who want to “tick the patient engagement box.”

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What the advisory council members did want to do was to lead initiatives “by patients, for patients,” not just comment on them. That’s manifested itself in different ways. The advisors launched a newsletter in April 2019. At a meeting, one member brought up a decision by the hospital to restrict access to its labs for Family Health Team patients: “That kind of bureaucratic red tape impacts patients and those are the sorts of situations I’d like to be a change agent for,” the member said.

One member interviewed would like the council to hear patient complaints directly and try to help. Another, who suggested an alert system to let the team know when a patient with special needs requiring accommodation is coming in, was delighted when it was put in place. Two other members said in addition to patients, they see themselves as advocates for the physicians and nurses who care for them, who they think are overworked and stressed out. Both had been told by their healthcare providers the Family Health Team’s managers are more inclined to act on patients’ complaints than what team members say. Meanwhile, like the patient and family advisory council of the Peterborough Family Health Team, the advisory council at St. Michael’s Academic Family Health Team started by reviewing the team’s communications.

Bumps in the road

Healthcare providers can be concerned at the prospect of patients and families advising on how to run an organization. “I think in health care we’ll all say that’s where we have to go and that’s where we want to go, but people are still not comfortable with that, because that means they have to step back and let their power decrease,” a team member said.

However, resistance to the idea at the St. Michael’s Academic Family Health Team was not too bad, other people interviewed said (while acknowledging their own enthusiasm might have masked it). “I think the difference is, no one told us we had to do this. We started where there was the greatest amount of interest in and value for the patient voice, and it kind of spread, with more and more people wanting access...once you do it, you realize how valuable it is,” a team member said.

Keeping patients engaged can be tricky. As one team member observed, some volunteer because they have had a good experience of health care and want to give back, and some do it because they have had a bad experience and want to prevent it from happening to anyone else. Both groups, however, want to see action. Feedback, as the people at MASS LBP teach, is essential to keeping patient advisors engaged and feeling useful — but in a large, complex organization, change may be slow and feedback on success can take a while to arrive. Some items recommended at the Patient Engagement Day took more than two

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years to deliver on. “To be honest, operational follow through is always a problem” one team member said. People are already busy and approvals and (especially) funding can be slow.

The logistics of partnering with patients are also difficult. “It does take longer because you have to plan appropriately to have a range of people represented at a table. It just means there’s an extra layer of work involved,” one team member said. Finding that extra time can be a problem among the conflicting priorities and timelines of a big organization. In many cases, patient volunteers have health problems — or their family members do — which may give them precisely the kind of knowledge and experience that makes them good advisors, but can make regular meetings a challenge. As well, true partnership with patients may mean your plans don’t get support. “How intentional are you through the whole process? Even if it means incorporating more time, even if it means you need to be more flexible with your deadline and your outcome?” one team member asked.

However busy people are, and however slow things may be to change, failing to keep patient advisors informed on what’s happening on their issues cannot be permitted, one team member said. “I tell this to people often, if you don’t have time to do that, then actually don’t do engagement, because you’re not really doing it anyway,” the team member said. “If you’re going into this knowing you don’t have the time to do what needs to be done, particularly with vulnerable patients and populations who are over-researched and over-asked, you have no right to disempower them again in a different way.”

One idea that’s been suggested to keep the patient and family advisory council engaged is to start every meeting with a report of a successful initiative they’ve contributed to.

Tokenism

Team members interviewed for this study all said there is a risk of tokenism in patient and family advisory councils — one went so far as to say the design of patient and family advisory councils is inherently tokenistic. Essentially, the line between partner and token comes down to decision-making power — is there any real role for a patient or family advisor?

In an interview, one member of the advisory council admitted to wondering “are we here for looks or are we here for actual advising? I do question constantly — are we being sloughed off?” So far, however, that member says “I feel sincerity in it...I feel very comfortable with the leadership of the group and that’s important, to be comfortable in that regard.”

Another patient advisor said she didn’t think anyone on the advisory council saw their role as token. “They’re trying, we’re trying, it’s a very new process. We’re trying to learn, they’re trying

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to learn...the fact that they take the initiative to listen, and every meeting they're there to listen to us — I see that as the start of a movement that would be for good and for a longer term.”

One team member said that fear of tokenism has actually limited efforts at patient partnership. “I think tokenism happens when you don't have a space for someone to truly participate and truly be an expert in a space. I mean, we're all tokens of something, right? We have to empower advisors, make them part of the group, part of the conversation and hopefully we'll move beyond that.”

Where success comes from

Although relatively new to patient engagement, members of the St. Michael's Academic Family Health Team could point to some factors they felt had contributed to its success so far. One said they started from a good place: “I just think it was the culture of our site and the openness of our team and the openness and enthusiasm of our leadership. Also, we did have some people and resources we were able to devote to this. We had a decision-support specialist and that person is half funded by our physician group, so that tells you our physician group is really supportive of improving the quality of care, and that resource was instrumental in being able to do quality improvement work including engaging patients.”

The fact that patients and the team so often find themselves agreeing on what's important also helps, another team member said. “There was always this fear that if you ask patients or families, they're going to ask for things that are not realistic. But that wasn't the case. It was like this Aha! moment where we were able to share and learn about each other's reality and come up with solutions that we could implement.”

More than one person commented that the gradual approach and spread of patient and family engagement has likely increased acceptance of it. “I think it has also made a difference in terms of openness to new ideas and new perspectives on our thoughts. That's obviously a little harder to measure, because I think it has been a shift in perspective,” one team member said, describing how teams discussing change proposals now tend to suggest a patient be on a committee, or that a waiting-room survey be done.

Another team member said the team is learning to question whether an idea for change is driven by what the team would like or what patients need, so they ask themselves — Why did I choose this time [to offer a program]? Why am I marketing this way? Am I reaching the individuals who would most benefit from this service? “Those kinds of questions make people realize we are quite dictative,” the team member said. “Like, ‘I don't want to work evenings, so I'm not going to hold my group in the evenings.’ That's serving our interests, not patients'.”

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Leadership —from the broader health community, from hospital management and from individuals in the FHT who pressed ahead with patient engagement events — was essential for success, most team members said. “We weren’t actually moving the dial on patient engagement. We’d been talking about it, but it hadn’t been happening. I think taking advantage of a window of opportunity with [MASS LBP] ...really helped to change things,” said one.

That same team member said the Family Health Team’s place as part of an academic health sciences centre, with the networks and connections that offers was in many ways — but not all — an advantage. “There are some very big advantages to being a big team like ours, well-resourced, it also works to make some things more complex...in a smaller office with fewer people you can imagine that some aspects might be more challenging but others like operational follow through might be a lot more straightforward.”

“When you’re working in a complex environment it’s hard for people to know how to take the next step or move forward even if they want to. Sometimes you kind of almost have to embrace action and just say you’re going to do it, it might not be perfect but I’m going to. And I think that’s a little bit kind of what happened. We did this kind of bold move and it helped people to see the potential, but then I think it also gave people the confidence to just move forward and keep doing it.” *[Team Member]*

Patients deserve a great deal of credit for the engagement success the team has achieved so far, team members said. From the members of the patient and family advisory committee to those who fill out the online patient experience surveys that are sent on their birthdays, they are eager to help. “Generally, I think patients in Family Health Teams are pretty grateful. That’s a little bit easier than some other councils where you have a patient group that might not be so grateful or where they’re just more on guard — I think it’s because the primary care relationship tends to be a closer relationship...all that being said, there’s still members who give us strong suggestions on things, but they’re not coming with an axe to grind.”

That closeness between patients and providers also shows itself in all the ways the St. Michael’s Academic Family Health Team reaches beyond the advisory council to engage patients. There are those birthday surveys, of course, but it’s also not uncommon for patients

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in waiting rooms to be consulted in a quick survey on an initiative, while others sign up for a short-term committee to advise on a project.

Perhaps though, as one team member said, the biggest factor in success is being willing to take a risk and just get going: “Experience. Failing. Failing and all that contributes, no question.”

Key Lessons

1. Invest the resources and take the time to recruit a diverse group of patient and family advisors — seek expert help on engagement strategies, if possible.
2. Be clear on the goal of your engagement project and on the roles and expectations for everyone involved.
3. Start all meetings with education and explanations that will give community participants the information they need to make meaningful contributions to the discussion (including details on what Family Health Teams can and cannot do).
4. Prepare team members and physicians to be open — to listening, to accepting that patients are experts in their own lives, and especially to the idea engagement requires ceding some of their power. Remind them not to lapse into jargon or other intimidating behaviour.
5. Don't start engagement projects if you don't have the resources or the intention of following through.
6. Keep in touch, and report promptly on what recommendations are being acted on, or to explain why they can't be done.
7. Recognize and accommodate the special needs your patient advisors may have — from childcare to transit fare, to support to speak out.
8. Understand that engaging with patients may take more time and could well lead to different outcomes than you anticipate.
9. Never bring a group together just so you can say there was patient engagement on a project. Patient knowledge is a valuable resource: don't waste it.
10. Share your successes — with team members who may be having doubts about partnering with patients, and with patient advisors, who need to know their work is having an impact.

**all family physicians
are trained in
patient-centred
care, and we're also
trained to consider
the community our
patients live in;
that to me includes
family and it
could include other
things as well**

the purpose of the council is to advise primary care providers on how best to meet the needs of patients from patients' points of view



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When Ontario's provincial government included new requirements for patient engagement in the co-design of programs and services in contract agreements with Family Health Teams, the Dufferin Area Family Health Team was keen to set up a patient advisory council.⁹ The purpose of the councils is to advise primary care providers on how best to meet the needs of patients from patients' points of view. Family Health Teams started introducing patient advisors in 2017, following the lead of hospitals, where they have existed in one form or another for many years.¹⁰



Geography: **Orangeville-Dufferin-Caledon**

patients rostered or served within the community: **48,000**

of affiliated physicians: **35**

of IHPs: **56**

of sites: **9**

<https://dafht.ca>

Plans were made, posters put up and notices went out on TV screens in doctors' offices, inviting people to sign up. This was the chance for patients to bring their insight, experience and perspective to planning and delivering the Family Health Team's care.

Nobody applied.

Too passive, is the thought now. "I think because we were advertising that way, there was no conversation," one staff member¹¹ said in an interview.

Time for Plan B: ask the team's interprofessional healthcare providers to look out for potential patient advisors. And to make sure that worked, throw in an incentive: the person who persuaded the most patients to apply would win an extra day of vacation. "It was something that didn't cost the organization a lot of money, but it drove a healthy competition," the staff member said, adding "Sometimes — OK, a lot of times — you need the carrot. You need a little motivator. Same thing when we do our annual quality improvement surveys. We give a pizza party to the clinic that gets the most completed surveys."

The Dufferin Area Family Health Team (DAFHT) serves people who live just northwest of the Greater Toronto Area, on the edge of farmland that leads north to Georgian Bay. What were once small towns serving the surrounding rural areas are swelling with subdivisions and edged with commercial development; residents range from well-off retirees and

9. The Dufferin Area Family Health Team calls its group a "patient advisory council."

10. See: <https://www.changefoundation.ca/patient-family-advisory-council/> — a three-part report on the evolving function and best practices of Ontario's hospital-based patient and family advisory councils.

11. As in all these case studies, we are not naming the people we interviewed, to ensure they felt comfortable opening up to us.

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professionals to people struggling to get by. The DAFHT was formed in 2006 and has 35 physicians working in offices in Orangeville and the surrounding towns of Shelburne and Grand Valley to serve more than 48,000 patients.

In addition to primary care from physicians, the Dufferin team comprises dietitians, nurses, social workers, mental health therapists, respiratory therapists, occupational therapists, chiropractors, nurse practitioners, physician assistants, a wound care specialist, and a pharmacist. It offers a range of programs to help patients live healthier lives, including diabetes care, exercise groups and mental health counselling. There are also sessions on quitting smoking, managing pain, preventing falls and dealing with memory loss, and help for patients who need advocates or help navigating government systems. DAFHT is a close-knit group, where many staff have worked more than 10 years (there's less than 1 per cent turnover per year), which may have contributed to a general receptiveness to the idea of a patient advisory council.

First steps to a patient advisory council

When Dufferin staff started working to create a patient advisory council, they turned for help to the Peterborough Family Health Team, where a patient and family council was already up and running (described in the first case study in this series). Peterborough's executive director sent along its recruitment tools, including newspaper ads and the interview guide for potential advisors, which (with permission) Dufferin put its own logo on and used.

Once the extra day off was in play, staff at Dufferin went to work to find potential advisors, sounding out patients who they thought would do well on the council; one of the original members was recruited by a chiropractor, another by a smoking-cessation counsellor. Not all who filled out applications were chosen: there were interviews (using Peterborough's questions), and in the end, 12 people joined for a two-year term.

The council's first meeting (they are held quarterly) was in May 2018 and from the start, the Dufferin team worked hard to create the advisory council its members wanted, not a corporate vision of a council. "We leave it up to the [advisory council] to decide which issues or actions they want to focus on...we want it patient driven," a staff member said.

Early on, the group agreed it probably couldn't tackle more than one issue at a time, so members discussed what each thought mattered most, and in the end voted to focus on increasing patients' awareness of the programs and services the Family Health Team offers, because they all felt not enough people knew about them. Other issues were noted for future work.

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The best way to do the project, the group decided, was to form working groups that would let council members work on the things that interested them most. One group redesigned the newsletter, one updated the brochure given to new patients and one set out to revamp the website. Almost two years later, those tasks are complete, and the Family Health Team's social media presence has been improved. Work on the website, a bigger project, was still underway at the time this case study was done.

The patient advisors have also provided feedback on ideas and projects, such as when the FHT wanted to improve how it screens patients for poverty (which health providers need to know about because living on a low income can have profound effects on health). Staff felt the questionnaire most people consider the gold-standard for assessing poverty was cumbersome and they worried that people need access to a computer to fill it in. With the help of patient advisors, the long questionnaire was narrowed down to three questions: Have you filed your most recent tax return, do you have drug benefits and do you find it difficult to make ends meet at the end of the month? (The answers may influence what drugs a physician prescribes, or lead to a referral to a social worker, who can help with tax issues or access to food).

One team, two perspectives

Around the same time as work began on a patient advisory council, the Ministry of Health encouraged Family Health Teams to move to a skills-based board with the associated encouragement of involving members of the community on the board. That started a search for a patient to join the board and the decision was to ask one of the new patient advisors to serve on the Family Health Team board as well so he could act as a direct link between the two bodies.

Making room for real change

Tokenism can be a problem for patient advisors: some are little more than window dressing, appointed but then essentially asked to rubber stamp what's already been decided. One interviewee with experience of a couple of advisory councils was told "You know what? We're just not ready for you. It's really messy. We're trying to sort this out and, you know, we're just not ready to have patients at the table." "I think my response was, well, maybe it's so messy and difficult because you don't have all the people at your table that you need," that advisor said.

An outside voice brings insight

The patient advisor cross-appointed to the board was a retired professional who had just finished off a term running another non-profit board and says he was “looking for things to stick my nose in” when he was recruited to the patient advisory council and then the board. “I was told to make sure I was voicing, sharing the perspective of the patient. Nothing more dramatic than that,” he said in an interview.

The physicians welcomed him and are very accepting, he said (so much so, they have since made him the board’s president). And yet, he’s conscious of how far apart their perspectives can be: there have been times when they have not grasped the patient point of view he presented them with. Sometimes issues have been returned to several times. But they work them out in the end, the advisor says. “I love these people. They’re bright, they’re articulate, they’re caring, and they work well in our community...we may disagree around the table, but we are making and doing things to make sure our Family Health Team is functional.”

One physician on the board said that while there was some trepidation whether they could be open with a patient in the room, it hasn’t been a problem. “I think it’s much better to actually hear a patient than just go ‘I think this is what a patient would say.’”

The patient advisor does take issue with the acronym-riddled obscurity of the doctors’ conversations. “A lot of providers will require a change in how they perceive and conduct business,” he said. “The doctors need to understand how patients feel, the fear they’re having, the lack of knowledge of terms, of procedures...they have to be more open for their patients.”

One staff member said the patient advisor/board president is tireless in reminding physicians to focus on patients. “He is always the one speaking up saying ‘from a patient perspective’ or ‘I don’t understand this, it’s above and beyond what a patient knows or should know.’ It always keeps it top of mind that we are here for the patient, we exist for the patient.”

The multi-tasking advisor reports to the board of directors on what the advisory council is working on and tells the other patient advisors what he has shared with the board.

We have to make sure we understand we are accountable to this group. These are our patients and if we want to keep them coming back and giving to us, we have to give them something. And that something is a response. *[Staff member]*

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Organizational culture has a lot to do with acceptance of patient advisors. A Dufferin staff member said, “I think our allied [interprofessional] healthcare providers are very responsive just because that’s the group of people they are.” She added the fact the physicians were so comfortable with the community member on their board they made him its president indicates they’re welcoming the change too. “I’m sure with the physicians there might be a handful that maybe don’t want to really hear what the patient has to say, because I think you’d get that anywhere...but the board, they’re always very respectful and mindful of his opinion.”

One patient said acceptance of patient advisors is coloured by the traditional medical hierarchy which has taught physicians and other healthcare workers that they hold the knowledge, and learning goes one way only. That advisor thought group sessions to help healthcare professionals, administrators and decision makers reflect on their implicit biases toward patients might help get advisory councils more respect. “The hierarchy in health care is alive and well and everybody sitting around that table knows exactly where they are in the hierarchy,” the advisor said. “Either the patients go at the bottom or we say patients are at the top, but really they’re not. We don’t manage the money, we don’t manage the resources. We don’t have power within the hierarchy.”

One staff member is more optimistic: “Historically, because we are physician led, provider led, decisions in the early days around programming were physicians saying ‘I think, I feel, my patients need this,’ and it was always very much what the physicians needed. Now there’s been a shift and now obviously, we’re more driven by data and outcomes and looking at statistics, not ‘I think, I feel,’ but we’re also driven by what we actually hear from patients.”

Another staff member agreed, saying “I think without the patient voice being there, I think the reasons why we do things and decisions are made can sometimes move further away from the patient, not with ill intent in mind. I think it can sort of happen because they’re all physicians sitting at the table...I think they try to always have the patient front and centre, but that’s difficult sometimes for them, just based on how they operate.”

Bumps along the road

Staff and members of the patient advisory council are concerned by its lack of diversity. “If I look around the table, they all look a lot like me, other than there’s an equal split of women and men — actually more women,” one advisor said, noting that many, like him, were seniors. “We’re all white, Anglo-Saxon. We need people of colour. We need younger people...young moms.”

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Orangeville is the largest centre in the Dufferin Area Family Health Team's catchment area, with a population of 28,900 in the 2016 census, 91% of whom are white. In nearby Shelburne, however, which had 8,126 residents in 2016, the population is almost 18% made up of visible minorities. There are no rural residents, visible minorities, low-income residents or Indigenous people on the council. With the original two-year terms ending in 2020, the team was working to recruit members who would bring greater diversity to the group.

Another bump in the road was more of a detour: in early 2019, just over a year after the Dufferin Area FHT's patient advisory council was formed, Ontario's Ministry of Health announced the creation of Ontario Health Teams¹² which were to be "groups of providers and organizations ... delivering a full and coordinated continuum of care to a defined geographic population."

The government set goals for what teams were to deliver, but largely left how to achieve them to be "self-organized." Health providers in and around the general area covered by the Dufferin Area Family Health Team already had good working relationships and got together to work on an application to create the "Hills of Headwaters Ontario Health Team." One rule the government did set was that groups preparing applications must engage the community in their work. Faced with tight deadlines and much to do, the Headwaters group brought in two patient advisors, one from the Family Health Team and one from the hospital, to provide the voice of patients during the process.

Later, when the Headwaters group was among the first two dozen Ontario Health Teams approved, work began on a community wellness council, which they envision being made up of patient and family members representing the Family Health Team, the hospital, health advocacy groups, community service organizations and the community at large. There had been two well-attended introductory meetings at the time of writing this case study, and future meetings of this group are expected to consider the potential purpose, roles and responsibilities for a regional patient and family advisory council.

Ingredients for a successful patient advisory council

People interviewed for this case study offered a variety of reasons they thought the Dufferin Area Family Health Team patient advisory council was working. One staff member said the most important thing is to show action on council recommendations — "We have had to make sure we understand we are accountable to this group."

12. Ontario Health Teams were introduced as a new approach to "organizing and delivering care that is more connected to patients in their local communities....healthcare providers, including hospitals, primary care providers and home and community care providers work as one coordinated team"; See: <http://health.gov.on.ca/en/pro/programs/connected-care/ohr/>

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My advice would be to listen to all the voices and to gather as many voices as you can. *[Patient advisor]*

That credibility is important, another staff member agreed. “I think it’s been a success because we have followed through on the actions that we have all agreed on. I think if things got left by the wayside, I think they [the advisors] would lose faith that we as a Family Health Team want to support this patient advisory council, that we want to hear their voice, want to follow through on all of their actions.”

A skilled staff facilitator is also essential, one staff member said, whether to explain where actions may be limited by ministry regulations, or to manage disagreements or members who, perhaps, are too dominant or focused on a single issue.

The council has a fairly casual, laid-back vibe, which I think makes them feel more comfortable. I don’t want it to feel like an administrative thing, suits in a room talking, and it certainly isn’t that. I think that contributes to its success. *[Staff member]*

Just as the Peterborough Family Health Team does, the Dufferin Area Family Health Team offers a light dinner at patient advisory council meetings. The atmosphere is generally casual rather than corporate and the different personalities work well together.

One of Dufferin’s goals is to have patient representatives on each program committee — so, for example, changes to the foot-care program would be discussed with a patient who uses it. The challenge, of course, is time — how much of it are people willing to give to a Family Health Team? Program meetings are held in the day, unlike council meetings, and take more hours. “I’m hoping to get the interest,” one staff member said, “but you can’t force that.”

The journey continues

At its two-year anniversary, the Dufferin Area Family Health Team’s patient advisory council felt well established. Its members were comfortable with the route they had taken and with their progress toward their first destination — improving communication. One staff member said the council has gotten to where the team needed it to be: “The most important thing is, they are ensuring that our programs and services are delivered for patients, with patients. That they’re created with patients.”

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Key Lessons

1. Recruiting is not easy — don't wait for people to come to you, and work hard to find members from underrepresented groups.
2. Let the patient advisory council set the agenda — they're the experts on what matters to your patients.
3. Having a skilled staff facilitator is essential.
4. Let individual advisors "land where they're comfy" — they'll be most engaged when they care deeply about a project they're working on.
5. Remember not everyone wants to sit around a board table. Look for a variety of ways to involve patients in shaping your organization.
6. Give your advisors the information they need to tackle the issues and help them overcome any lingering fear of speaking up to doctors.
7. Encourage (and teach) your physicians to communicate more clearly by using language patients understand.
8. It takes time to build trust with patient advisors and resources (including staff support) to ensure they can work effectively to improve care for patients.
9. If you're asked to be a patient advisor, Dufferin's advisors say: "Jump in!" "Say yes!" "Take a leap of faith!"

**I think it's
been a success
because we have
followed through
on the actions
that we have all
agreed on**



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