



## Patient and Family Engagement in the DFCM: Current State and Future Directions

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## INTRODUCTION

In February 2021, the University of Toronto Department of Family and Community Medicine (DFCM) hired a Patient and Family Engagement Specialist—a unique position in the department and the Temerty Faculty of Medicine. The full-time position is shared 50:50 with the Joanna and Brian Lawson Centre for Child Nutrition; the DFCM portion is supported through the Fidani Chair funds from the Quality and Innovation (Q&I) program.

The hiring of a DFCM Patient and Family Engagement Specialist signifies a paradigm shift that has occurred in healthcare. It is clear that patients need to be partners in clinical care — but also in designing services, influencing health policy, and educating healthcare professionals of the future.

Many DFCM sites and programs have been involved in patient engagement activities, but anecdotally the scope and breadth of activities varied and there was a desire to do more. It was unclear how the Patient and Family Engagement Specialist position could most effectively advance patient and family engagement within the DFCM.

We undertook a consultation to understand the current state of patient and family engagement within the DFCM programs and sites and the supports that faculty, staff, learners, and clinicians would like to enable further work in this area. Based on the results of the consultation, we propose a set of activities that the Patient and Family Engagement Specialist can lead over the next 2-3 years to advance patient and family engagement in the DFCM.

Note that the focus of the report is on engaging patients who receive care at a DFCM practice or whose care is influenced by a DFCM program. We often use the term “patients” but intend for the term to also describes families, their representatives, and health professionals working in active partnership with patients.

## METHODS

Between March and October 2021, the DFCM Patient and Family Engagement Specialist, Dana Arafah, conducted 27 meetings—one-on-one meetings and focus groups, each lasting 30-60 minutes—with the DFCM’s Quality Improvement (QI) Program Directors (Exhibit 1) as well as faculty and staff members from DFCM programs (Research, Global Health & Social Accountability, Education, Leadership). QI program directors and DFCM faculty invited other stakeholders to these interviews including patient partners, executive directors, family physicians, medical students, residents, nurses as well as other care team members with experience and interest in patient engagement. Two sets of questions were developed: one for QI Directors and their teams and one for other DFCM program leaders (Exhibit 2). Themes from the interviews and potential next steps were discussed with Ms. Trish O’Brien, Q&I Program Manager, and Dr. Tara Kiran, Vice Chair of Q&I and presented here in this report.

## CURRENT STATE

### A. DFCM interest in patient engagement and current activities

It was clear from the interviews that **there is a lot of interest and enthusiasm for engaging patients**. Interviewees all felt it was important and beneficial to engage patients and expressed an interest in learning more. At the same time, **there is variation in the patient and family engagement work undertaken at each** of the DFCM sites and programs. Primary care practitioners, faculty and learners have different levels of experience in their engagement work and have generally chosen to focus on specific efforts or approaches that match their resources and needs. In addition to resources and experience, site culture and hospital affiliation also influence the degree of engagement with patients.

All sites **share** easy-to-understand information with patients in a variety of ways and **consult** patients, getting feedback on their care experience, for example, through the common DFCM patient experience survey (a cross-site initiative) or focus groups. Some have begun to **involve** patients in improvement initiatives, for example, through a project advisory group, patient safety reviews, oversight committee, or teaching. A few have moved to **partner** with patients, having them lead specific improvement initiatives or teaching sessions.

5 sites have a Patient and Family Advisory Committee (PFAC) and 6 have a staff member that supports patient engagement and experience work (Exhibit 3). The way sites work with PFACs vary as does the perceived impact. Some of the PFACs are led by patient co-chairs. Some meet virtually while others meet in person. One of the PFACs has made such a huge impact that it was called on for several hospital initiatives. Other sites have found having a PFAC did not meet their needs and instead have gathered a list of patient names they call on a project-by-project basis. Other sites have shared that they identified patient partners through clinical interactions and have asked for their input during follow up visits and other clinic visits. Box 1 provides a glimpse of some of the ways DFCM sites are currently engaging patients.

## Box 1. Sample patient engagement activities occurring at DFCM sites, organized using Health Quality Ontario's [Patient Partnering Framework](#)

Note: Many examples span the categories presented

### Share - Provide easy to understand health information

- Social media was used to send COVID-19 updates to youth to keep them informed on the number of ways they can receive care during the pandemic (*The Southeast Toronto Family Health Team*)
- Pamphlets provide patients with up-to-date information around childhood immunization schedules (*Barrie Family Health Team*)
- Posters in examination rooms that stress the importance of post-discharge follow up care (*Scarborough Health Network*)
- Website is updated regularly to notify patients about initiatives in the unit ensuring the language is simple for patients to understand (*Multiple sites*)

### Consult - Get feedback from patients about care experiences

- Patient in the waiting room give feedback through a survey, on how to improve the waiting room experience and what better experience look likes for patients (*The Joseph's Urban Academic Family Health Team*)
- Resident physicians contacted women who were discharged and have not had a pap test in 4 or 5 years, to explore reasons behind this (*Women College Hospital Family Health Team*)
- Patients in a focus group helped resident physicians understand how they want their family doctor to approach the topic of obesity informing a multidisciplinary approach to obesity management (*Southlake FMTU*)

### Involve – Discuss an issue with patients and explore solutions

- Patient family advisory committee members gave feedback on the new online booking system suggesting areas that can improve the patient user experience (*2 sites*)
- Patient advisors join “Doing It Better” rounds to discuss where things went wrong, share the patient experience, and propose solutions (*Multiple sites*)
- Family Health teams share the results of the patient experience survey with their patient family advisory committee members who give feedback to help the team interpret the results and provide improvement ideas (*Multiple sites*)
- Patients join a resident teaching session to convey the value of patient feedback and importance of access (*e.g., St. Michael's Hospital Family Health Team*)
- Patients work with residents to identify health care gaps and relevant issues that the residents can focus on for their Quality improvement projects (*Multiple sites*)

### Partner – partner with patients to address an issue and apply solutions

- Patients led the Family Health Team waiting room initiative whereby patients guided the re-design of the space and provided a mock-up of the waiting room (*Mount Sinai Hospital Family Health Team*)
- Patients are involved in creating patient-related communications, inform website content and develop narrative for social media posting (*Multiple sites*)
- Patients offer support to resident physicians around communication skills providing examples of lay language, simple terms, and communication tools to use with patients (*Toronto Western Family Health Team*)
- A patient and family engagement strategy committee was formed to outline a plan on engaging with patients at the clinic to make sure relevant tools are created catered to patients at the clinic (*Markham Family Medicine Teaching Unit*)
- Parents in clinic improve support and education around immunization hesitancy, by educating other parents about vaccine schedules (*Barrie Family Health Team*)
- Patients with lived experience provide counselling and peer support to parents diagnosed with cancer (*Women College Hospital Family Health Team*)
- Patient advocates partner with family physicians on a health equity certificate program, aiming to address the fundamentals of equity and advocacy on how to advocate for patients (*Scarborough Health Network*)

It was nice to see that **the COVID- 19 pandemic did not stop engagement efforts**. Many sites are drawing on patient-reported data through the COVID-19 patient experience survey to deliver better care during the pandemic. Many have also been intentional in sharing easy-to-understand information about the COVID-19 vaccine through emails, websites, newsletters, townhalls, and other mediums. Teams have adeptly switched to using virtual focus groups and meeting virtually with their patient and family advisory committees.

Despite the enthusiasm and breadth of work, many DFCM faculty and staff interviewed expressed a **fear of “getting it wrong”**. DFCM site leaders and staff shared hesitations in getting started, worried that they will not ‘meaningfully’ engage with patients. Although many were aware of existing frameworks, they lacked knowledge and confidence in moving forward with different approaches.

There is a breadth of activities at the central DFCM, resulting in a variety of opportunities for patient partnership. To date, patients have not been involved in the department’s strategic planning or institutional decision making, however, patients have been involved in different ways across DFCM programs. At the undergraduate level, patients have been invited to speak to students about experiences and a patient panel answers student questions. Students also complete an advocacy project whereby they meet with patients to understand their needs and priorities. The Postgraduate Education program is conducting a literature review to understand how to incorporate patient feedback in resident evaluation. The Office of Education Scholarship (OES) engages patient partners in research and has developed strong connections with local

experts in patient engagement at collaborating institutions. Recently, the OES consulted patients in the development of the Virtual Care Competency Training Roadmap Modules (VicCTR). The Research program is working with patient partners and have published a paper with families with lived experiences. The Global health and Social Accountability Program has invited patient partners to conferences and strategic planning sessions to share the patient perspective with attendees. The faculty development program has engaged patients in the Basics program whereby patients sit on a panel sharing the impact of their physician.

Overall, DFCM faculty and program leaders expressed **enthusiasm for having a DFCM PFAC**. There was interest in having a pool of patients to call on that are supported by someone with expertise to identify patients with the right profile for their needs. DFCM leaders asked for guidance on how to partner with patients in education, for example, requesting case examples demonstrating when and how patients can add value to DFCM programs and operations. Leaders recommended starting with a few initiatives and strategic priorities prior to expanding the scope of patient partnership to all aspects of DFCM work.

## **B. Common needs related to patient engagement**

### **Knowledge and practical tips**

Faculty and staff expressed concern that their efforts to engage patients were inadequate and are curious about how they are doing with respect to other sites, programs, and medical institutions. Many expressed interests in learning about applications of theoretical models of engagement, resources, guidance documents and practical tips. Some also want to learn more about best practices from local and international experts. During the first few months of their position, the Patient and Family Engagement specialist was approached by many different faculties to consult on specific projects and initiatives.

### **Program and site leads are struggling to engage underrepresented groups**

Engaging with patients that represent the patients that are seen at primary care clinics is a common struggle and concern. Many of the family health teams spoke about the need to better explore methods to engage with a diverse range of patients.

### **Best practices to engage with a pool of patient advisors meaningfully**

DFCM faculty expressed a need to have case studies and best practices on how a PFAC has been used in the past to support a program centrally and in informing institutional decision making. Some sites described instances of patient engagement at the site level that felt tokenistic perhaps because patient partners did not have a clear role.

### **QI leaders' joint interest in taking the patient experience survey from 'consult' to 'involve'**

Many sites are drawing on patient-reported data through the patient experience survey in hopes of using this data to generate change ideas. Some sites have involved patient partners in discussion or initiated the co-design of solutions. Despite sites having varying levels of

experiences in their engagement work on the patient experience survey; all sites share a common interest and desire to go further than their existing level of engagement (i.e., consult to involve or involve to partner).

### **Guidance on how to engage with patients in postgraduate family medicine education and institutional decision making**

Partnering with patients in postgraduate education is a relatively new area and the postgraduate team felt there were many opportunities to explore including how to partner effectively with patients in co-teaching and resident evaluation. There was an expressed need to understand how other institutions have partnered with patients and where in the postgraduate education journey patients added value to student learning. There also seemed to be an opportunity to better share with patients how family physicians are educated, trained, and evaluated so they can more easily partner with us in education.

### **NEXT STEPS**

Figure 1 summarizes the goal that will underpin the work of the DFCM Patient and Family Engagement Specialist as well as the proposed activities that the role will support over the next 1 to 2 years. Advancing in all areas will require collaboration with other DFCM staff and faculty and in some cases, may require additional resourcing. The following is a summary of the proposed activities.



**Figure 1.** Proposed goal and activities for the DFCM Patient and Family Engagement Specialist over the next 1-3 years

**Goal: Build a culture of patient engagement within the DFCM and increase the capability of DFCM faculty, staff, learners, and clinical teams to effectively engage patients that are representative of the communities we serve**



## PROPOSED ACTIVITIES

### **A. Develop, collate, and share new and existing resources to support engagement**

#### **Collate a toolbox of resources**

A selection of practical tips and resources can be shared with sites, faculty, and staff through the DFCM to fill the knowledge gaps and answer questions DFCM staff and faculty often ask about (for example, onboarding packages, templates, experience capture tools, compensation guidelines etc.). The toolbox will collate resources from other organizations; we will also create our own resources where the need exists.

#### **Develop patient facing communications to explain the DFCM sites and programs and prepare them as advisors**

As the DFCM embarks on further patient engagement activities, patients would benefit from knowing more about the DFCM, for example, what we do, how we work together, and how family physicians are trained and evaluated.

#### **Design and deliver educational sessions to DFCM faculty, staff, learners, and clinical teams on patient engagement**

There is a benefit to having structured educational opportunities to build DFCM faculty, learners, and teams' confidence in engaging patients at clinical sites, in postgraduate education work, and in other aspects of the DFCM's work.

### **B. Provide support to sites and programs to learn from best practices and each other**

#### **Provide ongoing consultations to sites and DFCM faculty, staff, and learners**

Given the diversity of work at each site and between programs, their varying resources as well as different challenges and needs, we anticipate an ongoing need for one-on-one consultations with the DFCM Patient and Family Engagement specialist. The Patient Engagement specialist can provide guidance on what patient engagement approaches to use and when to engage with patients.

#### **Share patient engagement stories and tips through a regular column in the DFCM newsletter**

A regular column in the DFCM newsletter can share local stories and tips about patient engagement. These stories and tips can be informative and inspiring for DFCM faculty and staff but can also inform members of the public about our work.

#### **Build connections between dedicated patient engagement staff and patient partners**

A community of practice for patient engagement designated staff and patient partners connected with Family Health Teams and our affiliated sites can facilitate sharing of knowledge and lessons learned.

### **C. Work with the post-graduate program to advance patient partnership in the DFCM residency training program**

#### **Environmental scan**

There is an opportunity to learn from other institutions who have gone further in partnering with patients in education (e.g., Montreal<sup>1</sup> and the University of British Columbia<sup>2</sup>) to inform DFCM future efforts.

#### **Develop patient-facing materials that describe the role of the resident in clinical care**

For patients to be effective partners in education, they could benefit from understanding the role of the resident physician in the clinical setting where they receive care. We aim to develop clear patient-facing materials describing the role and activities of a resident physician promoting access and continuity to resident physicians across sites.

#### **Propose potential paths forward to engage patients in curriculum design & delivery, resident evaluation, and optimizing care delivered by residents at DFCM sites**

Based on the environmental scan and further consultations, we can propose different paths forward to optimize patient engagement in the Postgraduate education program.

### **D. Develop and support a DFCM patient pool and advisory committee**

#### **A DFCM Patient and Family Advisory Committee and patient pool of advisors will support central and cross-site DFCM activities.**

Developing and supporting these advisors will be a large focus for the DFCM Patient and Family Engagement specialist and involve recruitment of active DFCM patients from across DFCM sites with diverse backgrounds and experience; ongoing orientation and practical support for patient advisors; and collaboration with DFCM faculty, staff, and learners to identify opportunities for patient partnership. The committee will initially be set-up for a three-year trial period at which point its contribution will be reassessed.

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<sup>1</sup> Pomey, M. P., Flora, L., Karazivan, P., Dumez, V., Lebel, P., Vanier, M. C., Débarges, B., Clavel, N., & Jouet, É. (2015). Le <> : enjeux du partenariat relationnel entre patients et professionnels de la santé [The Montreal model: the challenges of a partnership relationship between patients and healthcare professionals]. *Sante publique (Vandoeuvre-les-Nancy, France)*, 27(1 Suppl), S41–S50.

<sup>2</sup> Towle, A., Bainbridge, L., Godolphin, W., Katz, A., Kline, C., Lown, B., Madularu, I., Solomon, P., & Thistlethwaite, J. (2010). Active patient involvement in the education of health professionals. *Medical education*, 44(1), 64–74. <https://doi.org/10.1111/j.1365-2923.2009.03530.x>

## **CONCLUSION**

DFCM sites and programs are already involved in engaging patients and families in the work they do. There is enthusiasm to take things to the next level, building on current success to engage more deeply, with a more representative group of patients, in a variety of initiatives. There are several practical ways that the DFCM Patient and Family Engagement specialist can support sites and programs—from one-to-one consultation to collation of resources. There is a great opportunity to enhance patient partnership in post-graduate education and to develop and support a group of DFCM patient advisors who can partner on central and cross-site DFCM initiatives.

## APPENDIX

### EXHIBIT 1: STAKEHOLDERS INTERVIEWED

A. Interviews conducted by the DFCM Patient and Family Engagement specialist with QI Program Directors and their teams

Site Name	Stakeholder(s)
Markham Stouffville Hospital Health For All Family Health Team	Dr. Karuna Gupta Dr. Kelly Forse Ms. Andrea Groff- Executive Director Ms. Denver Hilland- Health Promotor
Michael Garron Health Centre The South East Toronto Family Health Team	Mr. Stephen Beckwith- Executive Director
Mount Sinai Hospital Family Health Team	Dr. Sakina Walji Ms. Clarys Tirel
North York General Hospital Family Medicine Teaching Unit	Dr. Joanne Laine- Gossin Dr. Tiffany Florindo Dr. Jennifer Stulberg Mr. Briar DeFinney- Quality Improvement Decision Support Specialist
Royal Victoria Regional Health Centre Barrie Family Medicine Teaching Unit	Dr. Melissa Witty Ms. Hannah Silk- Co-chair of the Patient Safety committee Dr. Kishor Johnson- First Year Resident Dr. Lynda Ekeh- Second Year Resident Ms. Brigitte Abernot- Administrator Ms. Lori Alexander- Administrator
Southlake Regional Health Centre Family Health Team	Dr. Navsheer Gill Ms. Mary Nguyen
St. Joseph's Health Centre Urban Family Health Team	Dr. Linda Weber Ms. Alejandra Priego- Patient Care Manager
St. Michael's Hospital Family Health Team	Dr. Noor Ramji Ms. Nassim Vahidi-Williams- Patient and Community Engagement Specialist
Sunnybrook Health Centre Academic Family Health Team	Dr. Debbie Elman Mr. Walter Leahy- Executive Director Ms. Jean Sugarboard- Vice Chair of the PFAC Ms. Ingrid Wirsig- Program Coordinator
The Scarborough Hospital <b>Scarborough Health Network</b>	Dr. Susanna Fung Dr. Mruna Shah

Toronto Western Hospital Family Health Team	Dr. Rory O'Sullivan Dr. Carly Schenker Ms. Rita Kang- Patient Experience Manager
Summerville Family Health Team	Dr. Frances Cousins
Credit Valley Family Health Team	Dr. Ali Damji Dr. Rakib Mohammed Dr. James Pencharz Ms. Angel Ali- Decision Support
Women's College Hospital Family Practice Health Centre	Dr. Susie Kim Dr. Ruth Heisey Dr. Dara Maker Dr. Payal Agarwal Mr. Andre Bowen- Executive Director

B. Interviews conducted with faculty and staff leading central DFCM programs

Department	Role	Stakeholder
<b>DFCM</b>	Interim chair	Dr. David Tannenbaum
	Business & Administration Director	Ms. Caroline Turenko
	Communications Strategist	Ms. Amy Noise
<b>Education</b>	Vice Chair	Dr. Risa Freeman
	Director, Education Scholarship Education Scholarship Team	Mahan Kulasegaram (PhD) Dr. Risa Bordman Dr. Lindsay Herzog Dr. Joyce Nyhof-Young Dr. Cynthia Whitehead
	Director, Postgraduate Program Postgraduate Program Team	Dr. Stuart Murdoch Dr. Fok- Han Leung Dr. Giovanna Sirianni Dr. Batya Grundland
	Director, Undergraduate Program	Dr. Azadeh Moaveni
<b>Global Health and Social Accountability</b>	Vice Chair Social Accountability Faculty Lead Program Coordinator	Dr. Katherine Rouleau Dr. Danyaal Raza Ms. Jamie Rodas
	<b>Research</b>	Vice Chair
	Director, UTOPIAN	Dr. Michelle Greiver
<b>Family Doctor Leadership</b>	Vice Chair	Dr. David White

	Director	Dr. Viola Antao
Care of the Elderly	Division Head	Dr. Sid Feldman

## EXHIBIT 2: NEED ASSESSMENT SAMPLE INTERVIEW QUESTIONS

### *Site Based QI Interview Questions*

#### Current Work

Can you tell me about patient and family involvement at your site?

#### Current Supports/infrastructure

Is there a patient and family advisory group at your site?

What supports are available to you to help engage patients and families in your work?

#### Identifying Opportunities and Barriers

What are some of the reflections you have based on the work you have done? What is currently working well?

What have some of the barriers been to engage with patients?

#### Recommendations and perspective on desired DFCM support

What supports could the central DFCM offer to support site-based patient engagement efforts?

Are their areas you wish to know more about or build skills in?

### *Central DFCM Interview Questions*

#### Current Work

Can you tell me about patient and family involvement within your program? Any recent experiences working with or desire to work with patients and families?

Do you see any opportunities to work more closely with patients and families in your current or future work?

#### Identifying Opportunities and Barriers

How do you envision working with patients and families

What areas of your work would you like patients and families to be engaged in?

#### Recommendations and perspective on desired DFCM support

What supports could be the Patient and Family engagement Specialist offer to support DFCM programs to partner more with patients and families

**EXHIBIT 3: QI SITES WITH RESOURCES TO SUPPORT PATIENT AND FAMILY ENGAGEMENT**

Site	Responsible staff or Patient Engagement specialist leading PE work?	PFAC?	Other Supports?
Markham Stouffville Hospital Health For All Family Health Team	Yes	No	None
Michael Garron Health Centre The Southeast Toronto Family Health Team	No	Yes	None
Mount Sinai Hospital Family Health Team	Yes	Yes	None
Southlake Regional Health Centre Family Health Team	No	No, some patient advisors who sit on the FHT board	None
St. Joseph's Health Centre Urban Family Health Team	Yes	No, patient advisors that get called on for a specific activity or project	None
St. Michael's Hospital Family Health Team	Yes	Yes	Hospital Supports
Sunnybrook Health Centre Academic Family Health Team	Yes	Yes	Hospital Supports
Women's College Hospital Family Practice Health Centre	Yes	Yes	Hospital Supports