

# Healthcare Quarterly

SUPPORTING ENGAGEMENT-  
CAPABLE ENVIRONMENTS

p. 12



**“... the ability to include**  
many voices through different  
engagement methods allows for  
a more robust understanding of  
patients’ experiences to guide  
improvement efforts ...”

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Building Organizational Capacity  
Integrating Research And Evaluation  
Future Outlook



# A Canadian Take on the International Patient Engagement Revolution

Vincent Dumez and Antoine Boivin

Five years ago, in the UK, the *BMJ* argued that a “patient revolution” was afoot in the healthcare system (Richards et al. 2013). The same year, in the US, *Health Affairs* called patient engagement the “blockbuster drug of the century.” Over a 10-year period, the number of international publications on patient engagement tripled (Boote et al. 2012). Canada is no exception to this international trend, and a growing number of health professionals and organizations are engaging patients, families and citizens as partners in the care improvement journey.

This Special Issue of *Healthcare Quarterly* aims to provide an overview of patient and family engagement in healthcare system improvement. It brings together experts (patients, clinicians, researchers, policy makers) from across the country tasked with sharing their experiential learning regarding engagement in the Canadian healthcare system. A team of experts from the Netherlands was added to this group of authors to provide insights into European developments in this area.

The authors who were invited to contribute to this Special Issue are all pioneers and leaders in patient, family and public partnerships. Their contributions to this field as academics and agents of change are made from both the perspective of observers and the standpoint of key influencers in the development of patient, family and public engagement across the country. They are undoubtedly best positioned to provide an assessment of the current situation and to help us better understand the next steps. Most of the articles include patients as co-authors, together with

clinicians, managers and researchers. Similarly, this Special Issue is co-edited by a patient and a clinician-researcher.

## Supporting Engagement-Capable Environments in Canada

The opening article of this issue, “Supporting Patient and Family Engagement for Healthcare Improvement: Reflections on ‘Engagement-Capable Environments’ in Pan-Canadian Learning Collaboratives,” was written by Carol Fancott, G. Ross Baker and Maria Judd, along with patient partners Anya Humphrey and Angela Morin (Fancott et al. 2018). It focuses on the role played by the Canadian Foundation for Healthcare Improvement (CFHI) in recent years to help develop patient engagement capacity in Canadian healthcare organizations. The foundation also made a bold choice in encouraging its teams to embed shared leadership with patients and families in the projects it funds in order to promote a co-design and co-build approach throughout the entire process. Building on the notion of “engagement-capable environments” found throughout this Special Issue, the authors describe how a national organization can foster engagement at the organizational level.

## Building Organizational Capacity for Patient and Family Engagement

The next articles in this Special Issue focus on the three main pillars of engagement-capable environments: leadership, readiness of staff/teams to engage and the role of engaged patients.

“The Leadership and Organizational Context Required to Support Patient Partnerships” focuses on the structures and cultural transformations brought about by leaders of change as champions of patient engagement. It was written by a trio made up of Patricia O’Connor, a former director of nursing, Mario Di Carlo, a patient partner involved in multiple Canadian patient and family engagement initiatives, and Jean-Lucien Rouleau, co-founder of the Patient Partnership Program while he was dean of the Faculty of Medicine at the Université de Montréal (O’Connor et al. 2018).

“Development of Patient-Inclusive Teams: Toward a Structured Methodology” (Pomey et al. 2018) focuses on supportive conditions for the integration of patients and families in professional healthcare teams. It was written by a diverse Quebec-based team made up of researchers, professors and students from the Université de Montréal, as well as experienced decision-makers and patients from the Quebec health and social services system: Drs. Marie-Pascale Pomey, Paule Lebel, Nathalie Clavel, Catherine Neault, Benoît Tétréault and Anna-Paulina Ewalds Mulliez, as well as patients Édith Morin and Mireille Morin.

“Patient Roles in Engagement-Capable Environments: Multiple Perspectives” (Rowland et al. 2018) was written by the trio of Paula Rowland, from the University of Toronto, and the patient-professional dyad currently leading the implementation of Patient Partnerships at Accreditation Canada: Claudia Houle and Mireille Brosseau. Rowland, Houle and Brosseau speak to the complexity of roles played by patients in health organizations, beyond their official “job description.”

Our European collaborators provide an international perspective on engagement practices (Faber et al. 2018) in “Implementation of Patient Engagement in the Netherlands: A Stimulating Environment within a Large Academic Medical Centre.” Marjan Faber and the team of Thomas Vijn, Marja Jillissen, David Grim and Jan Kremer from Radboud university medical center Nijmegen describe the evolution of patient and family engagement activities at a large teaching hospital in the Netherlands, one of the most successful health systems in the OECD. Radboud is part of a core group of teaching hospitals in continental Europe that focus on innovative patient and family engagement strategies. Despite some contextual differences, this European example highlighting organizational dynamics, transformation levers and resistance resonates with several Canadian examples.

## Integrating Research and Evaluation

The last two original contributions of this issue focus on integrating research and evaluation in patient engagement activities with a view to improving care.

“Bringing Together Research and Quality Improvement: The Saskatchewan Approach” (Teare et al. 2018) describes how support structures for patient engagement in research

and quality of care can be integrated at the provincial level. It was written by the duo who took the lead on deploying patient and family engagement in quality improvement across Saskatchewan, Gary Teare, Malori Keller, as well as patient advisor Dale Hall.

Julia Abelson and two postdoctoral fellows, Ania Syrowatka and Julia Bidonde, joined a patient partner with extensive experience in quality improvement projects, Anya Humphrey, and CFHI’s vice-president of programs, Maria Judd, to write “Evaluating Patient, Family and Public Engagement in Health Services Improvement and System Redesign” (Abelson et al. 2018). They offer up ideas on how to integrate evaluation into engagement activities by clarifying its various roles and introducing examples of available assessment tools for practitioners.

## Future Outlook

“The Capacity for Patient Engagement: What Patient Experiences Tell Us About What’s Ahead” (Canfield 2018) was written by Carolyn Canfield, a patient advisor with extensive experience in various Canadian and international patient and family engagement initiatives. She is the co-founder of the budding Patient Advisors Network (PAN), which brings together experienced and engaged patients across Canada. She shares her reflections on barriers to engagement and the self-selection of engaged patients, as well as possible solutions to support the development of a wider and more diversified community of engaged patients.

The editorial team’s summary article (Boivin et al. 2018), “Growing a Healthy Ecosystem for Patient and Citizen Partnerships,” provides an ecosystem perspective on engagement, including key individual, organizational and systemic components that support reciprocal and effective relationships with patients and citizens.

Ultimately, the articles in this Special Issue provide a 360-degree view of our country’s level of maturity with regard to patient and family engagement in healthcare improvement, while describing the challenges that lie ahead for scaling up and sustaining what many call a revolution. **HQ**

## Acknowledgements

The editors would especially like to thank Carol Fancott for the quality of her support throughout all stages of the design and editing process of this Special Issue.

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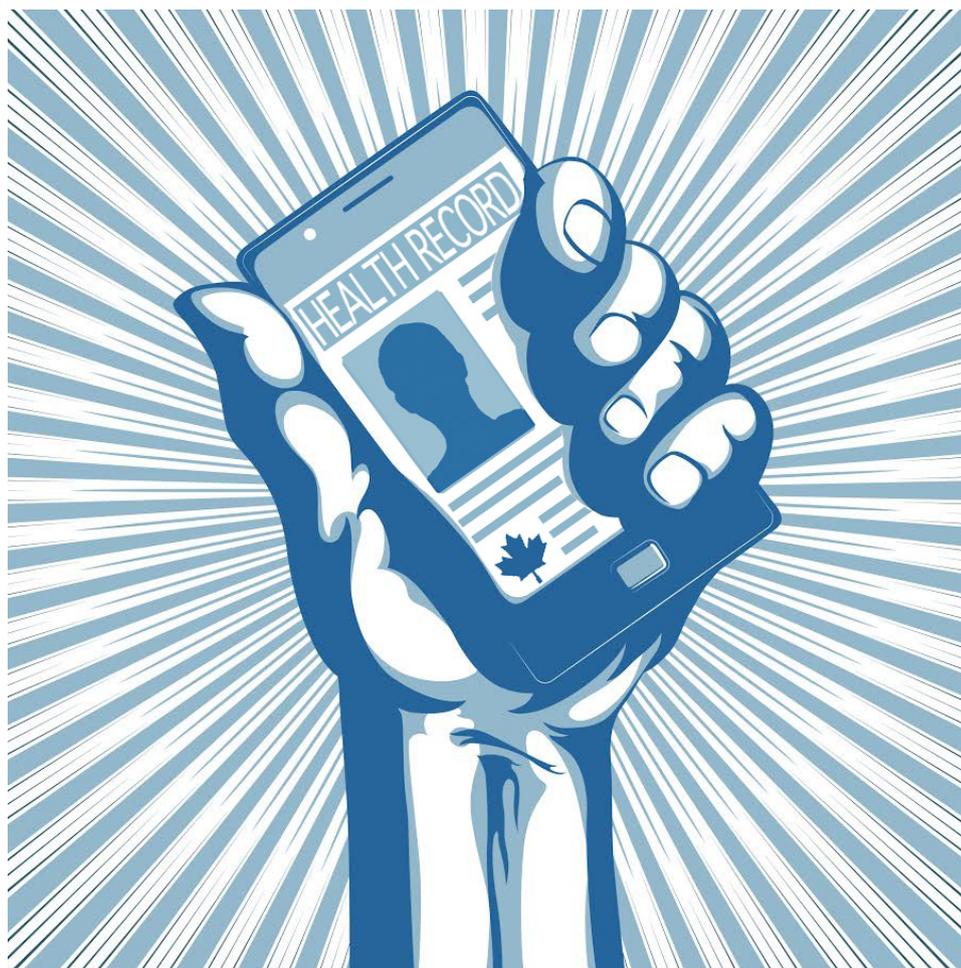
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### About the Authors

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# Un portrait canadien de la révolution internationale sur l'engagement des patients

Vincent Dumez et Antoine Boivin

Il y a 5 ans, le *BMJ* au Royaume-Uni annonçait une « révolution des patients » dans le système de santé (Richards et al. 2013). La même année, le journal *Health Affairs* aux États-Unis présentait l'engagement des patients comme le « traitement du siècle » (*blockbuster drug of the century*). Sur une période de 10 ans, le nombre de publications internationales sur l'engagement des patients a été multiplié par trois (Boote et al. 2012). Le Canada n'échappe pas à cette tendance internationale et un nombre croissant de professionnels et d'organisations de santé s'engagent avec les patients, les familles et les citoyens en tant que partenaires dans l'amélioration des soins.

Ce numéro spécial de *Healthcare Quarterly* vise à dresser un portrait de l'engagement des patients et des familles dans l'amélioration du système de santé au Canada. Il réunit des experts (patients, cliniciens, chercheurs, décideurs) de partout au pays à qui nous avons demandé de partager les apprentissages issus d'expériences pratiques d'engagement dans le système de santé canadien. Une équipe d'experts des Pays-Bas s'ajoute à ces auteurs pour mettre en perspective l'expérience canadienne avec les développements européens dans le domaine.

Les auteurs invités pour écrire dans cette édition spéciale sont tous des pionniers et des leaders du travail en partenariat avec les patients, les familles et le public. Ils ont contribué grandement à ce domaine en tant que concepteurs académiques mais aussi en tant que leaders de changement. Ils sont des observateurs et acteurs clés du développement de l'engagement

des patients, des familles et du public au pays. Ce sont certainement aujourd'hui les personnes les mieux placées pour nous proposer un bilan de la situation mais aussi pour nous aider à mieux comprendre les prochaines étapes de développement. Dans la quasi-totalité des articles, des patients travaillant avec des cliniciens et gestionnaires ont été intégrés comme auteurs. De même, le numéro spécial est co-édité par un patient et un clinicien-chercheur.

## Soutenir les environnements propices à l'engagement au Canada

L'article d'ouverture de ce numéro par Fancott, Baker et Judd, avec les partenaires patients Humphrey et Morin (Fancott et al. 2018), présente le rôle que la Fondation Canadienne sur l'amélioration des services de santé a joué dans les dernières années pour soutenir le développement des capacités d'engagement des patients des établissements de santé au Canada. La Fondation a aussi fait le choix courageux d'inciter les collaborateurs des projets qu'elle finance à intégrer un leadership partagé avec les patients et leur famille afin de promouvoir une approche de co-design et co-construction à travers tout le processus de réalisation. Ancré dans le concept « d'environnement propice à l'engagement » (*engagement-capable environment*) repris à travers ce numéro spécial, les auteurs décrivent comment une organisation nationale peut soutenir les capacités d'engagement d'organisations locales de santé.

### **Construire la capacité organisationnelle pour l'engagement des patients et des familles**

Plusieurs articles de cette édition spéciale se concentrent sur les trois principaux piliers des « environnements propices à l'engagement » : le leadership, la préparation du personnel / des équipes à s'engager et le rôle des patients lorsqu'ils s'engagent.

L'article « Leadership and Organizational Context Required to Support Patient Partnerships » met l'accent sur les structures et les transformations culturelles portées par les leaders de changement agissant comme champions de l'engagement des patients. Il est écrit par un trio constitué tout d'abord par une ancienne Directrice des soins infirmiers, Mme Patricia O'Connor, M. Mario Di Carlo, patient partenaire au sein de multiples initiatives d'engagement des patients et des familles au Canada, et le Dr Jean-Lucien Rouleau, co-fondateur du programme partenariat patient alors qu'il était doyen de la Faculté de médecine de l'Université de Montréal (O'Connor et al. 2018).

L'article « Development of Patient-Inclusive Teams: Towards a Structured Methodology » (Pomey et al. 2018) met l'accent sur les conditions propices à l'intégration de patients et membres de la famille au sein des équipes professionnelles des établissements de santé. Il est écrit par une équipe québécoise diversifiée constituée de chercheurs, d'enseignants et d'étudiants de l'Université de Montréal ainsi que de décideurs et patientes expérimentées du système de santé et des services de santé du Québec : Dres Marie-Pascale Pomey, Paule Lebel, Nathalie Clavel, Catherine Neault, Benoît Tétreault, Anna-Paulina Ewalds Mulliez ainsi que les patientes Édith Morin et Mireille Morin.

L'article « Patient Roles in Engagement-Capable Environments: Multiple Perspectives » (Rowland et al. 2018) est écrit par un trio constitué par Mme Paula Rowland, de l'Université de Toronto, accompagnée par le duo patiente-professionnelle qui assume actuellement le leadership de l'implantation du partenariat patient au sein d'Agrément Canada : Mme Claudia Houle et Mme Mireille Brosseau. Rowland, Houle et Brosseau illustrent la complexité des rôles joués par les patients au sein des organisations de santé, au-delà de leur « description de tâche » officielle.

Nos collaborateurs européens fournissent une perspective internationale des pratiques d'engagement (Faber et al. 2018). Marjan Faber et l'équipe de Vijn, Jillissen, Grim et Kremer de l'hôpital universitaire Radboud Nijmegen décrivent l'évolution des activités d'engagement des patients et des familles au sein d'un centre hospitalier universitaire des Pays-Bas, un des systèmes de santé les plus performants parmi les pays de l'OCDE. Radboud a été parmi les centres hospitaliers en Europe continentale dans le développement d'innovations d'engagement des patients et des familles. Malgré certaines différences contextuelles, cet exemple européen illustre les dynamiques organisationnelles, leviers de transformation et résistances qui résonnent avec plusieurs exemples canadiens.

### **Intégrer la recherche et l'évaluation**

Les deux dernières contributions originales du numéro se penchent sur l'intégration de la recherche et de l'évaluation dans les activités d'engagement des patients en amélioration des soins.

L'article « Bringing Together Research and Quality Improvement: The Saskatchewan Approach » (Teare et al. 2018) décrit l'intégration de structures de soutien à l'engagement des patients en recherche et en qualité des soins au niveau d'une infrastructure provinciale. Il est écrit par le duo qui a assumé le leadership du déploiement de l'engagement des patients et des familles dans l'amélioration de la qualité en Saskatchewan : Dr Gary Teare, Mme Malori Keller et Dale Hall.

Julia Abelson et deux stagiaires postdoctorales, Mme Ania Syrowatka et Mme Julia Bidonde, se sont jointes à une patiente partenaire expérimentée en projets d'amélioration de la qualité, Mme Anya Humphrey, et la vice-présidente des programmes de la Fondation, Mme Maria Judd, pour écrire l'article « Evaluating Patient, Family and Public Engagement in Health Services Improvement and System Redesign » (Abelson et al. 2018). Elles présentent un portrait sur la façon dont l'évaluation peut s'intégrer aux activités d'engagement, en clarifiant ses différents rôles et présentant des exemples d'outils d'évaluation disponibles pour les praticiens.

### **Perspectives futures**

L'article « The Capacity for Patient Engagement: What Patient Experiences Tell Us About What's Ahead » (Canfield 2018) est écrit par Mme Carolyn Canfield, une patiente conseillère (patient advisor) impliquée depuis plusieurs années dans différentes initiatives d'engagement des patients et des familles au Canada. Elle est une des co-fondatrices de l'organisation en émergence Patient Advisors Network (PAN) qui réunit des patients expérimentés et impliqués à l'échelle du Canada. Elle partage ses réflexions sur la problématique des barrières à l'engagement et de l'auto-sélection de patients engagés, de même que des pistes de solution pour soutenir le développement des capacités d'engagement d'une communauté plus large de patients.

L'article synthèse en conclusion de ce numéro spécial, écrit par l'équipe éditoriale (Boivin et al. 2018), « Growing a Healthy Ecosystem for Patient and Citizen Partnership », présente une perspective écosystémique sur l'engagement, présentant les éléments clés à l'échelle individuelle, organisationnelle et systémique soutenant des relations réciproques et efficaces avec les patients et les citoyens.

Au total, la somme des articles rassemblée dans ce numéro spécial donne une vision à 360 degrés du niveau de maturité de ce qui se passe actuellement dans notre pays tout en exposant les défis à relever pour aller plus loin dans la mise à l'échelle et la pérennité de ce que beaucoup appellent une révolution. **HQ**

### Remerciements

Les éditeurs tiennent à remercier tout spécialement Mme Carol Fancott pour la qualité de son soutien à toutes les étapes du processus de conception et d'édition de ce numéro spécial.

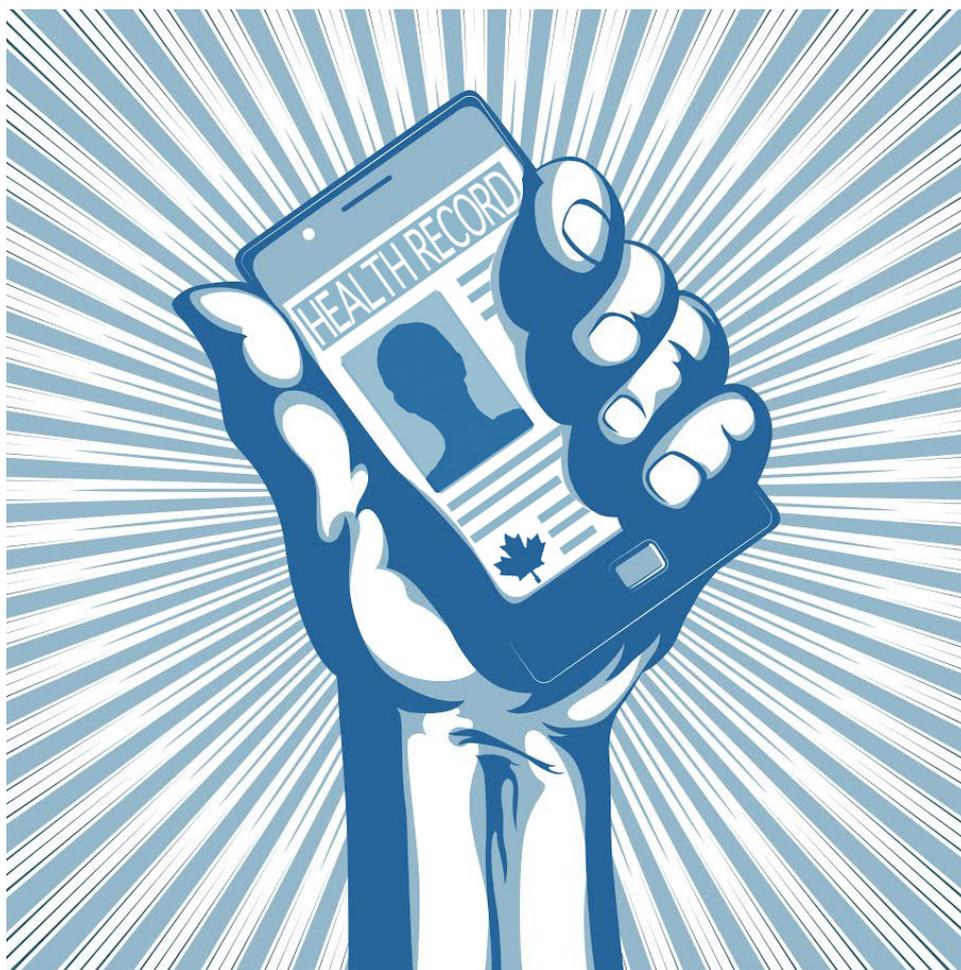
### Références

Veillez vous reporter à la liste dans la version anglaise (pp. 2–3).

### Au sujet des auteurs

**Vincent Dumez** est le patient guest editor de ce numéro spécial et co-directeur, Centre d'excellence sur le partenariat avec les patients et le public, Université de Montréal, Montréal, QC.

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## FROM THE EDITORS

### 1 **A Canadian Take on the International Patient Engagement Revolution**

*Vincent Dumez and Antoine Boivin*

This Special Issue of *Healthcare Quarterly* provides an overview of patient and family engagement in healthcare system improvement. It brings together experts – patients, clinicians, researchers, policy makers – from across the country who were tasked with sharing their experiential learning regarding engagement in the Canadian healthcare system.

## SUPPORTING ENGAGEMENT-CAPABLE ENVIRONMENTS

### 12 **Supporting Patient and Family Engagement for Healthcare Improvement: Reflections on “Engagement-Capable Environments” in Pan-Canadian Learning Collaboratives**

*Carol Fancott, G. Ross Baker, Maria Judd, Anya Humphrey and Angela Morin*

The Canadian Foundation for Healthcare Improvement (CFHI) has supported healthcare organizations across Canada to meaningfully partner with patients in quality improvement and system redesign efforts. The authors discuss CFHI initiatives to enhance patient engagement efforts across Canada and the lessons learned in the context of “engagement-capable environments” and offer reflections for the future of patient engagement in Canada.

## BUILDING ORGANIZATIONAL CAPACITY

### 31 **The Leadership and Organizational Context Required to Support Patient Partnerships**

*Patricia O’Connor, Mario Di Carlo and Jean-Lucien Rouleau*

Patients have knowledge and insight into how the system can be changed to better meet their needs, improve outcomes and reduce costs. This paper describes challenges in creating a culture of patient partnerships and the leadership actions and organizational context required now and in the future to support engagement-capable environments at the organizational and policy levels in Canada.

### 38 **Development of Patient-Inclusive Teams: Toward a Structured Methodology**

*Marie-Pascale Pomey, Paule Lebel, Nathalie Clavel, Édith Morin, Mireille Morin, Catherine Neault, Benoît Tétreault and Anna-Paulina Ewalds Mulliez*

The literature shows that patient engagement is not always ideally applied to improve the quality and safety of care and can be tokenistic. Through experiences conducted in Quebec, it is possible to outline a structured process involving both professional stakeholders and patients that illustrates optimal conditions to be applied for successful teamwork involving patients.

### 45 **Patient Roles in Engagement-Capable Environments: Multiple Perspectives**

*Paula Rowland, Mireille Brosseau and Claudia Houle*

In this commentary, the authors provide a complementary way of thinking about patient roles: an interactionist perspective. For interactionists, roles evolve through social interactions and contextual demands that shape how the work is performed. Drawing from a case example, the authors demonstrate the need for engagement leaders to attend to functional descriptions of patient roles and their interactive possibilities.

### 50 **Implementation of Patient Engagement in the Netherlands: A Stimulating Environment within a Large Academic Medical Centre**

*Marjan J. Faber, Thomas W. Vijn, Marja C.M.C. Jillissen, David Grim and Jan A.M. Kremer*

Radboud university medical center (Radboudumc) is a regional centre for specialized secondary care in the Netherlands where innovation is recognized as a decisive factor in patient engagement. All employees are invited to innovate, experiment, fail and implement promising innovations into practice. The authors demonstrate how this stimulating environment led to a rich collection of patient engagement activities in organizational (re-)design and in educational programs for students and employees.

## INTEGRATING RESEARCH AND EVALUATION

### 56 **Bringing Together Research and Quality Improvement: The Saskatchewan Approach**

*Gary F. Teare, Malori Keller and Dale Hall*

The Saskatchewan Health Quality Council's experience and relationships, from linking research, quality improvement and patient engagement in its leadership of the province's healthcare quality improvement journey, provided core support and leadership in the development of Saskatchewan's Strategy for Patient-Oriented Research SUPPORT Unit. The vision is for the SUPPORT Unit to integrate research and quality improvement into a continuous learning health system.

### 61 **Evaluating Patient, Family and Public Engagement in Health Services Improvement and System Redesign**

*Julia Abelson, Anya Humphrey, Ania Syrowatka, Julia Bidonde and Maria Judd*

As efforts to actively involve patients, family members and the broader public in health service improvement and system redesign have grown, increasing attention has also been paid to evaluation of their engagement in the health system. The authors discuss key concepts and approaches related to evaluation, drawing particular attention to different and potentially competing goals, stakeholders and epistemological entry points.

## FUTURE OUTLOOK

### 68 **The Capacity for Patient Engagement: What Patient Experiences Tell Us About What's Ahead**

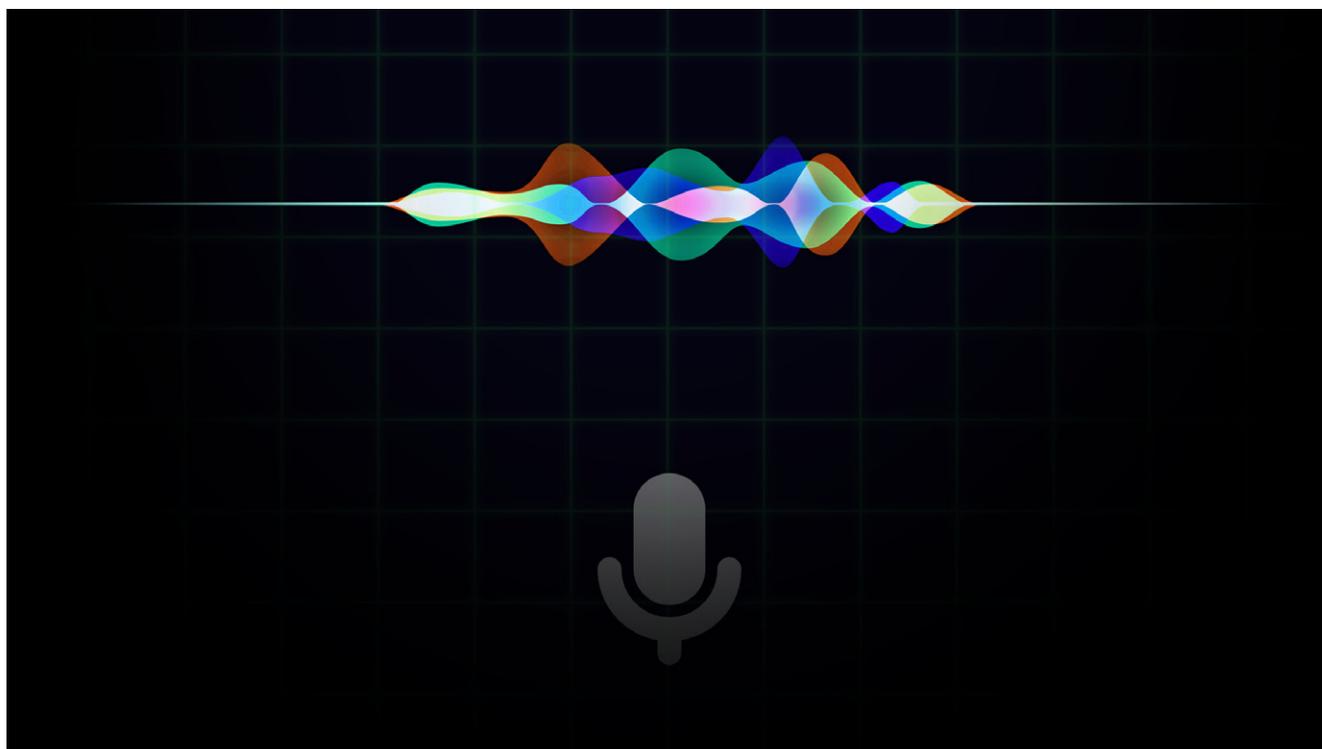
*Carolyn Canfield*

Although great achievements in patient engagement merit celebration, many patient collaborators recognize that growing gaps are straining the promise of seamless partnership. With recruitment failing to keep pace with demand, volunteer burnout increasing, and attempts at diversity failing, more action is needed to support patients to fulfill the potential for fully diverse, competent and fulfilling collaboration across all facets of healthcare.

### 73 **Growing a Healthy Ecosystem for Patient and Citizen Partnerships**

*Antoine Boivin, Vincent Dumez, Carol Fancott and Audrey L'Espérance*

In this synthesis article, the authors propose an ecosystemic perspective on engagement in health. They outline key elements at the individual, organizational and systemic levels that support reciprocal and effective relationships among all partners to provide conditions for the co-production of health and care.



## DES ÉDITEURS

### 4 Un regard canadien sur la révolution internationale de l'engagement du patient

*Vincent Dumez et Antoine Boivin*

Ce numéro spécial de *Healthcare Quarterly* donne un aperçu de l'engagement du patient et de sa famille à l'amélioration des systèmes de santé. Il rassemble des experts (patients, cliniciens, chercheurs, décideurs) de partout au pays qui ont été chargés de partager leur apprentissage expérientiel en matière d'engagement au sein des systèmes de santé canadiens.

## SOUTENIR LES ENVIRONNEMENTS PROPICES À L'ENGAGEMENT

### 21 Soutenir l'engagement du patient et de sa famille à l'amélioration des soins de santé : réflexions sur les « environnements propices à l'engagement » dans le cadre de projets collaboratifs d'apprentissage pancanadiens

*Carol Fancott, G. Ross Baker, Maria Judd, Anya Humphrey et Angela Morin*

La Fondation canadienne pour l'amélioration des services de santé (FCASS) a aidé des organismes de soins de santé du Canada à encourager un engagement véritable du patient aux efforts d'amélioration de la qualité et de refonte des systèmes. Les auteurs décrivent des initiatives de la FCASS visant à renforcer les efforts d'engagement du patient au Canada, ainsi que des enseignements retenus dans le contexte des « environnements propices à l'engagement », et terminent en proposant des réflexions sur l'avenir de l'engagement du patient au Canada.

## RENFORCEMENT DES CAPACITÉS ORGANISATIONNELLES

### 31 Le leadership et le contexte organisationnels nécessaires à l'épanouissement du partenariat avec le patient

*Patricia O'Connor, Mario Di Carlo et Jean-Lucien Rouleau*

Les patients savent comment modifier le système pour mieux répondre à leurs besoins, améliorer leurs résultats et réduire les coûts. Les auteurs décrivent les difficultés auxquelles on est confronté pour créer une culture de partenariat avec le patient, les mesures que doivent prendre les dirigeants et le contexte organisationnel nécessaire, aujourd'hui et à l'avenir, pour instaurer un environnement propice à l'engagement aux niveaux organisationnel et politique au Canada.

### 38 L'accueil du patient dans l'équipe clinique : vers une méthodologie structurée

*Marie-Pascale Pomey, Paule Lebel, Nathalie Clavel, Édith Morin, Mireille Morin, Catherine Neault, Benoît Tétreault et Anna-Paulina Ewalds Mulliez*

La littérature scientifique montre que l'engagement du patient n'est pas toujours appliquée de manière idéale pour améliorer la qualité et la sécurité des soins et qu'elle peut même s'avérer purement symbolique. Grâce à des expériences menées au Québec, il est possible de faire ressortir un processus structuré, portant à la fois sur les intervenants professionnels et les patients, qui illustre les conditions optimales à appliquer pour qu'un travail d'équipe comprenant des patients réussisse.

### 45 Le rôle du patient dans un milieu propice à l'engagement : perspectives multiples

*Paula Rowland, Mireille Brosseau et Claudia Houle*

Dans ce commentaire, les auteurs proposent un mode de pensée complémentaire pour envisager le rôle du patient : une perspective interactionniste. Pour les interactionnistes, les fonctions évoluent au fil des interactions sociales et des exigences contextuelles qui déterminent l'organisation du travail. En se fondant sur un exemple de cas, les auteurs montrent qu'il est nécessaire pour les responsables de l'engagement de se charger des descriptions fonctionnelles du rôle des patients et de leurs possibilités interactives.

### 50 Déploiement de l'engagement du patient aux Pays-Bas : un milieu stimulant au sein d'un grand hôpital universitaire

*Marjan J. Faber, Thomas W. Vijn, Marja C.M.C. Jillissen, David Grim et Jan A.M. Kremer*

L'hôpital universitaire Radboud (Radboudumc) est un centre régional de soins secondaires spécialisés des Pays-Bas. L'innovation y est reconnue comme un facteur probant du déploiement de l'engagement du patient. Tous les employés y sont donc invités à innover, à expérimenter, à échouer et à mettre en pratique des innovations prometteuses. Les auteurs de cet article expliquent comment ce milieu stimulant a conduit à une abondante collection d'activités relatives à l'engagement du patient à la conception et au remaniement organisationnels, ainsi qu'aux programmes de formation des étudiants et des employés.

## INTÉGRATION DE LA RECHERCHE ET DE L'ÉVALUATION

### 56 Conjonction de la recherche et de l'amélioration de la qualité : l'approche de la Saskatchewan

*Gary F. Teare, Malori Keller et Dale Hall*

L'expérience et les relations du Saskatchewan Health Quality Council (pour l'établissement de liens entre la recherche, l'amélioration de la qualité et l'engagement du patient en vue d'orienter le processus d'amélioration de la qualité des soins de santé de la province) ont fourni un soutien et un leadership essentiels au développement de l'unité SOUTIEN de la Stratégie de recherche axée sur le patient de la Saskatchewan. L'objectif que poursuit l'unité SOUTIEN est d'intégrer la recherche et l'amélioration de la qualité à un système de santé apprenant.

### 61 Évaluation de l'engagement du patient, de sa famille et du citoyen à l'amélioration des services de santé et au réaménagement des systèmes

*Julia Abelson, Anya Humphrey, Ania Syrowatka, Julia Bidonde et Maria Judd*

Tandis que les efforts visant à activement faire participer le patient, les membres de sa famille et le grand public à l'amélioration et au réaménagement des systèmes de santé se sont intensifiés, une attention croissante a également été accordée à l'évaluation de leur engagement au système de santé. Les auteurs abordent d'importants concepts et approches liés à l'évaluation, en attirant une attention particulière aux divers objectifs, parties prenantes et points d'entrée épistémologiques éventuellement en concurrence.

## PERSPECTIVES D'AVENIR

### 68 Capacité en matière d'engagement du patient : ce que l'expérience du patient nous laisse entrevoir de l'avenir

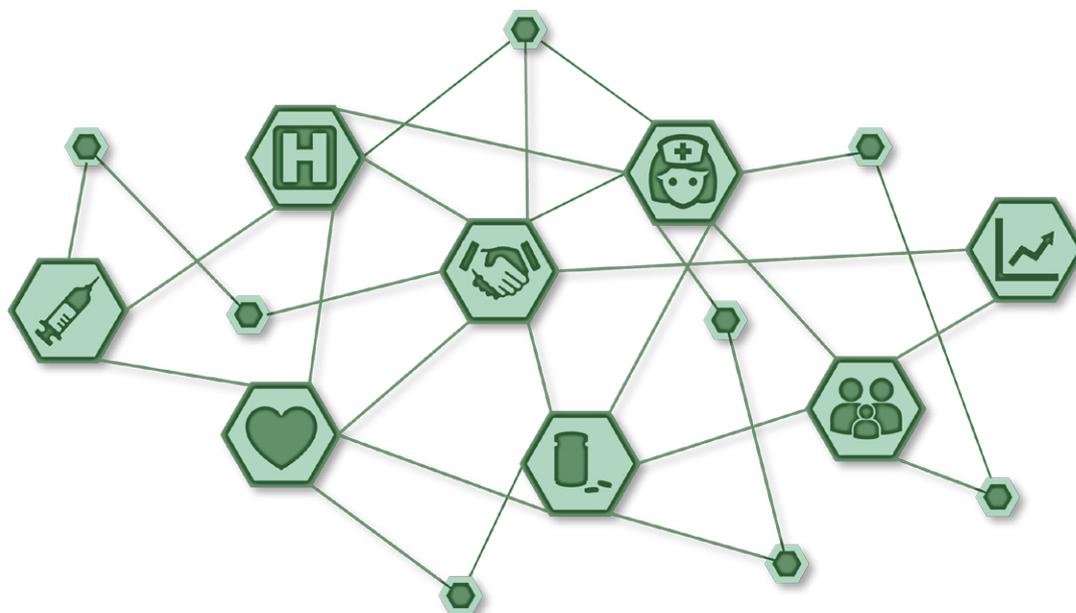
*Carolyn Canfield*

Bien que de grandes réalisations en matière d'engagement du patient méritent d'être soulignées, de nombreux patients collaborateurs reconnaissent que des écarts croissants pèsent sur la promesse d'un partenariat homogène. Le recrutement ne parvenant pas à suivre le rythme de la demande, le bilan de l'épuisement des bénévoles s'alourdissant et les tentatives d'augmentation de la diversité échouant, plus de mesures s'imposent pour aider les patients à réaliser le potentiel d'une pleine collaboration diversifiée, avérée et épanouissante dans tous les aspects des soins de santé.

### 78 Cultiver un écosystème favorable aux partenariats avec le patient et le citoyen

*Antoine Boivin, Vincent Dumez, Carol Fancott et Audrey L'Espérance*

Dans cet article de synthèse, les auteurs proposent une perspective écosystémique de l'engagement en matière de santé, en décrivant les principaux éléments individuels, organisationnels et systémiques qui encouragent des relations réciproques et efficaces entre tous les partenaires afin de réunir les conditions d'une production conjointe de la santé et des soins de santé.



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# Supporting Patient and Family Engagement for Healthcare Improvement: Reflections on “Engagement-Capable Environments” in Pan-Canadian Learning Collaboratives

Carol Fancott, G. Ross Baker, Maria Judd, Anya Humphrey and Angela Morin

## Abstract

Although the involvement of patients in their care has been central to the concept of patient-centred care, patient engagement in the realms of health professional education, policy making, governance, research and healthcare improvement has been rapidly evolving in Canada in the past decade. The Canadian Foundation for Healthcare Improvement (CFHI) has supported healthcare organizations across Canada to meaningfully partner with patients in quality improvement and system redesign efforts. This article describes CFHI initiatives to enhance patient engagement efforts across Canada and the lessons learned in the context of “engagement-capable environments” and offers reflections for the future of patient engagement in Canada.

## Introduction

Healthcare systems around the world are responding to the demand of “nothing about me, without me”<sup>1</sup> as they attempt to operationalize patient- and family-centred care in practice by more actively engaging patients in their care. More broadly, in the realms of education, research, policy making and quality improvement, patient engagement efforts continue to grow. For example, the Canadian Institutes of Health Research-funded Strategy for Patient-Oriented Research (CIHR 2018) has set new expectations for researchers to work together with users of

the health system and to determine priorities for research and for patients<sup>2</sup> and the public to be actively involved throughout the research enterprise, not simply as participants in studies but as partners in the process. In the health professions, education efforts such as those at the Faculty of Medicine at the University of Montreal (Karazivan et al. 2015) have led the way in how patients are embedded as partners in training the next generation of physicians and healthcare professionals to engender collaborative and compassionate care in practice. Healthcare organizations worldwide have endeavoured to tap into the expertise and wisdom of patients and their families to use their experience to drive improvements in the safety and quality of care. Patient-centred care as a domain of quality is incentivized in different systems around the world using a variety of levers (e.g., legislative requirements, accreditation standards), and delivery organizations increasingly recognize that enhancing the patient experience and outcomes of care requires actively involving patients in the design and implementation of these improvements.

In Canada, the Canadian Foundation for Healthcare Improvement (CFHI), a not-for-profit, federally funded organization dedicated to accelerating healthcare improvement and system transformation, has identified the engagement of patients and citizens as one of the key six levers in its improvement framework (Figure 1).

**KEY MESSAGES**

1. Patient and family engagement learning collaboratives have supported healthcare organizations across Canada on their journey to create engagement-capable environments and to meaningfully partner with patients in their improvement efforts.
2. Patient engagement efforts have evolved over the past decade in all realms of healthcare, but further evaluation is needed to better understand the mechanisms of what works and why and with what impact.
3. Human connection and relationships are fundamental to patient engagement efforts.

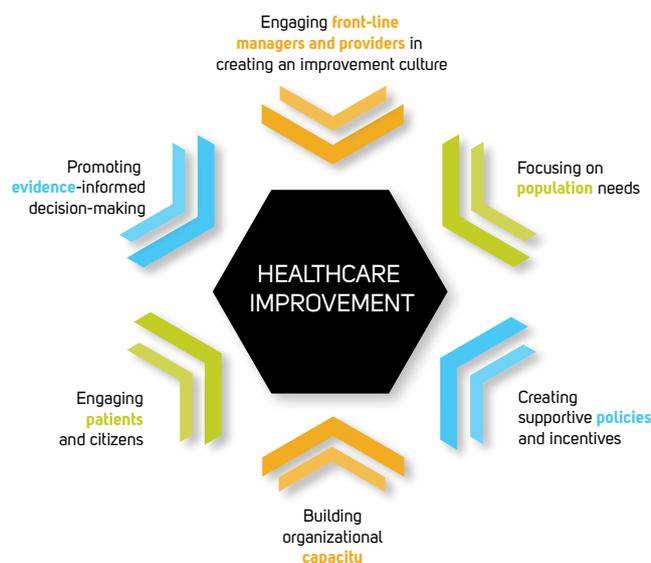
Engaging patients, families and communities to drive health system change and improvement is a strategic focus and is foundational to the activities and programming across the organization. This paper briefly describes the approach CFHI has taken since 2010 to support healthcare organizations across Canada to meaningfully partner with patients and families in quality improvement and system redesign in four pan-Canadian learning initiatives. The concept of “engagement-capable environments” (Baker and Denis 2011; Baker et al. 2016a) has emerged from research conducted in the initial engagement collaboratives and other CFHI-supported work with organizations that have had success in creating positive engagement experiences and outcomes for patients. This paper also considers the evolution of the field of patient engagement and CFHI’s own growth as an organization in its aim to become an engagement-capable environment. We conclude this paper with reflections on the future of patient engagement and what we may offer as a national organization to accelerate healthcare improvements where patients and families are integral to these efforts.

**CFHI’s Approach to Engagement and Programming**

CFHI adapted and adopted a definition by Tambuyzer and colleagues to provide clarity to its engagement work: “Patient engagement is the involvement of patients and/or family members in decision-making and active participation in a range of activities (e.g., planning, evaluation, care, research, training, and recruitment). Starting from the premise of expertise by experience, patient engagement involves collaboration and partnership with professionals” (Tambuyzer et al. 2014). The continuum of public participation noted by the International Association for Public Participation (2015) (e.g., from inform, consult, involve, collaborate and empower) provides clarity as the continuum of participation relates to the public (or patient) influence on decision-making. The engagement framework offered by Carman and colleagues provides further insights by also offering a continuum of engagement (e.g., consult, involve, partner/share leadership) as well as considerations for the level of engagement efforts made at the direct level of care, the program/organizational level and policy making (Carman et al. 2013). CFHI’s efforts have focused primarily on engaging patients at the meso and macro levels – that is, supporting patient engagement at the program/organizational levels for improvement efforts and within policy that supports patient-centred practices, with the ultimate goal of improving patient experiences and outcomes of care.

CFHI’s four learning initiatives and collaboratives have included 51 teams in eight provinces and one territory across Canada, with the overall goal of developing organizational capacity for patient and family engagement (see Table 1 for details of each of the four learning cohorts). When CFHI launched its first initiative of “Patient Engagement Projects” (PEPs) in 2010, the idea of patient-centred care had already been firmly established as one of the key dimensions of quality (Institute of Medicine 2001). Moreover, patient advisory or user councils had been entrenched in some areas of care (e.g., pediatrics) and in some jurisdictions (e.g., Quebec). However, the concept of more active engagement with patients, particularly at organizational levels for improvement, was in its infancy in Canada. As a result, many teams in this first CFHI cohort focused on building the infrastructure required for more intensive engagement efforts. Collectively, together with CFHI, teams learned how to engage with patients in meaningful

**FIGURE 1.**  
**CFHI’s six levers (or enablers) for accelerating healthcare improvement**



CFHI = Canadian Foundation for Healthcare Improvement.

ways, involving patients more intentionally throughout their improvement work. In subsequent collaboratives, CFHI encouraged engagement practices further across the continuum of patient participation, to allow for more collaborative models to develop between patients and providers on improvement teams. Teams within these initial learning initiatives spanned health sectors across the continuum of care (e.g., primary care, home care, acute and subacute care) and populations of interest (e.g., pediatrics, oncology care, orthopedics, chronic disease) and focused on a wide range of improvement initiatives (e.g., transitions in care, admission and discharge processes, development of resources in primary care for patient engagement). In our most recent engagement collaborative, we focused more intentionally on the implementation of a specific policy initiative related to family presence while at the same time embedding patient and family involvement in its development, implementation and evaluation.

The model for these learning collaboratives has evolved over these four cohorts of teams to include regular learning opportunities offered face-to-face and via webinar, peer-to-peer learning, coaching support, networking opportunities and seed funding. In our most recent “Better Together e-collaborative,” we tested a virtual learning model and offered coaching, education and networking opportunities for teams to advance their policy initiatives together with patients and families. The inclusion of patient advisors as coaches and faculty is an advancement made in recent collaboratives to further support teams in their engagement efforts and to help them consider the purpose, roles and expectations for engagement together with patients.

The methods and focus of evaluation of CFHI patient engagement programs have also evolved over time, with increased learning about both the processes and the outcomes of engagement. CFHI has employed and tested numerous approaches to gain insights into what works and why for engagement processes and with what impact. As the field of engagement was emerging at the time of the initial two PEP initiatives, a qualitative approach to evaluation was employed to gain an in-depth understanding of engagement methods employed by teams, the processes used to integrate patients’ voices and how the organizational context enabled or acted as a barrier to engagement efforts. Through this qualitative study, we began to develop a deeper understanding of what it meant for teams to engage with patients. This research also underlined the importance of organizational contexts that enabled teams to engage in meaningful ways. Teams in organizations with strong and visible senior leadership support were able to develop and sustain a patient-centred philosophy of care, creating a more mature context in which they were able to employ more sophisticated engagement strategies, moving along the continuum of involvement toward “co-design” activities (McIntosh-Murray et al. 2013). In these organizations, patients worked in partnership with providers to learn quality improvement methods, assess opportunities for improvement and design solutions together, enhancing both the patient experience of care and the provider’s experience of delivering care, as well as other quality outcomes.

Building on these research findings, the subsequent patient and family engagement collaboratives specifically focused on embedding patient advisors into quality improvement teams to work with providers and leaders in developing and implementing improvement initiatives.

**TABLE 1.**  
Summary of four CFHI learning initiatives/collaboratives in patient and family engagement

Project	Patient Engagement Projects (PEPs) I	Patient Engagement Projects (PEPs) II	Partnering with Patients and Families for QI (PFEC)	Better Together (part of larger campaign)
Aim	Promote and support engagement of patients in the design, delivery and evaluation of health services that lead to high-quality patient-centred care	Promote and support intervention projects that engage patients in the design, delivery and evaluation of health services that lead to high-quality, patient-centred care	Build capacity to enhance organizational culture to partner with patients and families to improve quality across the healthcare continuum	Build organizational capacity to assess, plan, implement, evaluate and sustain family presence and introduce the practices that support patient- and family-centred care in hospitals to improve patient and staff experiences and satisfaction
Duration	24 months	24 months	17 months	11 months
Seed funding	Up to \$100K	Up to \$100K	Up to \$50K	No seed funding
Teams accepted	10 teams (4 provinces)	7 teams (5 provinces)	22 teams (6 provinces, 1 territory)	12 teams (7 provinces)
Evaluation approach	Qualitative research (interviews, document review)	Qualitative research (interviews, document review)	Team surveys, social network analysis, document review, collaborative assessment scale, interviews	Surveys, document review, collaborative assessment scale, interviews

CFHI = Canadian Foundation for Healthcare Improvement; PFEC = Patient and Family Engagement Collaborative; QI = quality improvement.

Evaluation efforts focused on gaining a better understanding of how integrating patient advisors influenced team functioning, using evaluation methods such as social network analysis (Valente 2010) and an assessment of team experience and effectiveness (Orchard et al. 2012; Shortell et al. 2004). These approaches examined the perspectives of all team members, including patient advisors, to build an understanding of how teams functioned with advisors as team members. Edmondson et al. (2001) observed that teams go through a learning process when establishing new routines. Successful teams pay attention to member selection and preparation, create psychological safety for trying new practices, test new routines and reflect on their experiences. Organizational contexts were explored using interviews and focus groups with patients, families and team members to provide a more nuanced understanding of roles and an organizational context for this work. The evaluation also captured team outcomes of the projects, as well as capacity and knowledge gained in areas of quality improvement, change management and engagement practices. This mixed-methods approach to evaluation thus provided the multi-dimensional view of engagement and organizational practices required for teams to partner with patients in meaningful ways. We also gained insights into effective practices for engagement from the perspectives of patients and providers as they worked together to create winning conditions for engagement and improvement. These insights have been summarized into practical engagement tipsheets (refer to Boxes 1 and 2).

### **Conceptualizing “Engagement-Capable Environments”**

Meaningful engagement of patients and families constitutes a culture change in how teams function and how care is organized and delivered within organizations. From research work that explored the initial PEPs, the concept of “engagement-capable environments” (Baker and Denis 2011; Baker et al. 2016a) emerged. The concept was further refined through other CFHI-supported work (Baker et al. 2016b; Judd et al. 2015). The term “engagement-capable environments” refers to those organizations that have enabled meaningful engagement through the enactment of three main pillars: (1) enlisting and preparing patients and families; (2) training and preparing staff for engagement; and (3) ensuring leadership support of engagement activities by providing resources and infrastructure to enable these activities to unfold (Figure 2). Through CFHI collaboratives, we have observed the varying degrees and multiple methods by which teams have enacted these three pillars to create engagement-capable environments, with resulting variation in experiences and outcomes. Although the individual pillars form the foundation to engage, the synergy from the combined impact of these pillars helps bring about the culture change required to support engagement efforts.

The concept of engagement-capable environments taps into the many complex components of organizational readiness for change: leaders who are able to articulate, support and demonstrate the commitment and value of engaging with patients and families and the collective preparation and abilities of providers and patients to work together (Weiner 2009). A recent casebook explores the concept of engagement-capable environments and describes how these pillars have been enacted in different ways by high-performing engagement organizations in North America and the UK (Baker et al. 2016b). Below we offer reflections on the lessons learned through our collaboratives in the context of the evolution of our thinking on engagement-capable environments in Canada and how CFHI has enacted these lessons on our journey to becoming an organization that is engagement capable.

#### **BOX 1. 10 insights from healthcare providers and leaders**

1. Recognize the value of patient engagement.
2. Consider patients as members of the improvement team.
3. Work together to co-design improvements.
4. Engage patients early and involve them throughout the project.
5. Support and role model engagement.
6. Understand the experience of care through the eyes of patients.
7. Provide patients with ongoing support.
8. Provide staff and physicians with ongoing support.
9. Ensure your team has the proper resources to engage patients.
10. Evaluate your engagement efforts.

Source: CFHI 2018a.

#### **BOX 2. 10 lessons learned from patient and family advisors**

1. Clarify my role.
2. Educate others on my role and the value I bring.
3. Equip me with the information I need to be successful.
4. Involve me from the beginning.
5. Including one patient advisor is good; including more is better.
6. Sustain my involvement throughout the process.
7. Make engagement activities accessible and provide options for how I can get involved.
8. Promote networking opportunities.
9. Continue working with us after the project has finished.
10. We can do much more than just tell our stories.

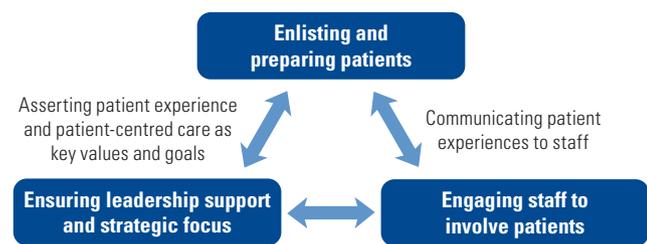
Source: CFHI 2018b.

### **Enlisting and preparing patients and families: from “advisor” to “partner” and beyond**

Over the last eight years, CFHI has supported organizations in the recruitment and development of patients as advisors on organizational priorities and initiatives. As a result, many teams in CFHI collaboratives, particularly in the initial PEP

initiatives, sought to develop infrastructures to support their engagement practices, for example, the development of patient orientation manuals and toolkits, strategies for recruitment and training for patients and families to work as advisors on organizational committees. Increasingly, CFHI has encouraged more collaborative (rather than consultative) models of engagement, to develop the role of patients as partners and to support co-design activities and involvement of patients much earlier in the process to determine organizational priorities based on patients’ needs and experiences.

**FIGURE 2.**  
**Model of engagement-capable environments**



Supporting teams and removing barriers in engaging patients and improving quality

Source: Baker and Denis 2011.

The development of roles of advisors or partners represents an important strategy to support patient engagement initiatives that is both symbolic (i.e., the importance of including the patient voice and their visible presence as a reminder of their centrality in healthcare) and functional (i.e., the ability to co-design initiatives with the inclusion of patients as key actors in the process). However, a real danger exists if the engagement is not authentic and the inclusion of patients as advisors or partners is a token gesture to indicate that they are included but not considered. Legislative or policy requirements to include patients as part of the process may encourage tokenistic efforts if organizations are not fully prepared to engage. Although CFHI has requested the inclusion of advisors and encouraged their involvement more fully as patient partners on quality improvement teams, we have gained a fuller appreciation that there is a “mosaic” of engagement activities (Tritter and McCallum 2006) and sought to augment the role of advisors/partners by encouraging other engagement opportunities that seek out patients’ experiences more broadly across the organization on a wider set of issues and possible solutions. For example, as part of a project with a CFHI collaborative, Bruyère Hospital in Ottawa invited patient and family advisors (PFAs) to work with them to develop a “passport to home” as part of their care transitions improvement initiative (CFHI 2016). The hospital employed multiple methods of engagement beyond the inclusion of PFAs on the improvement team. Bruyère measured and gathered patients’ experiences at different points in the transition and regularly interviewed patients currently receiving care – all

of which broadened the understanding of patients’ experiences of care transitions – while concurrently working together with PFAs to develop new processes and resources to support patients and families in their transition to home. Bruyère’s work with patient advisors as team members led to co-designed solutions; the other strategies for engagement brought more diverse voices into their work. Using a range of methods not only reduces a hierarchy of engagement methods that assumes one is better than others but also recognizes that different engagement methods are required for different purposes (Tritter and McCallum 2006). Clear articulation of the purpose of engagement (i.e., why patients are being engaged) is fundamental to clarifying expectations for engagement and influence on decision-making processes.

Employing numerous engagement methods (from consultative methods, such as focus groups or surveys, to more collaborative methods, such as patient partners on improvement teams) also alleviates the expectation that a few, selected patients can represent the voices of all patients. Greenhalgh and colleagues described these tensions of “representation” versus “representativeness”; the ability to include many voices through different engagement methods allows for a more robust understanding of patients’ experiences to guide improvement efforts (Greenhalgh et al. 2011a). Tensions are also raised regarding “naïve” versus “professionalized” patients who have gained enough knowledge and insight on the inner workings of the healthcare system and thus are considered no longer able to bring a fresh or naïve perspective (Greenhalgh et al. 2011a; Hogg and Williamson 2001; Martin 2008). Paradoxically, it would appear that patients are the one group where limited experience is seen as an asset. However, this represents a conundrum for patients who have equipped themselves by gaining knowledge of the system in their desire to actively contribute to improvements but, by doing so, are seen to have too much “insider” knowledge (Barnes and Cotterell 2012). A spectrum of strategies for engagement helps ensure that a range of patients’ experiences are captured and considered throughout the improvement process, with less reliance on one or a few. Through our collaboratives at CFHI, we have noted that partnering experienced patient advisors with individuals who are new to advising is a powerful combination, to support new advisors in their role and to gain the skills of effective engagement. It often takes time for patients to feel comfortable in sharing their perspective, but their current or recent lived experiences are tremendously valuable, as is having advisors who have experience with advising and know what meaningful engagement looks like. Peer-to-peer support in patient engagement has been cultivated by patients and families through both informal and formal channels.

Growing experiences in the learning collaboratives has also led us to broaden our methods of engagement beyond advisors and partners on our committees. In our most recent programming, we employed a range of engagement methods across the

continuum, from one-on-one interviews to involvement on working groups with CFHI staff, to ensure that we considered a range of patient perspectives. Similarly, when developing policies internally (e.g., for patient scholarships, patient compensation), we have employed methods such as Twitter chats and surveys as forms of consultation to learn more from patients what would work best for them while at the same time engaging with patient partners on working groups to co-design processes and policies.

### **Engaging staff to involve patients: recognizing power and identity**

A key learning from our initial foray into patient engagement was the importance of preparing staff to engage with patients in their improvement efforts and the need for honest self-assessment on the current state of engagement efforts within teams and organizations. Many teams rated themselves higher on their current level of engagement with staff, assuming that they were already “doing it.” However, teams often realized that they had underestimated the need to support staff to learn how to engage and include the perspectives of patients in meaningful ways in their initiatives. Understanding why the involvement of patients is essential for patient-centred practices is foundational for staff in recognizing the value of patients’ perspectives to improve the processes and delivery of care. Organizations that expend the time, resources and energy, learn how to engage in meaningful ways also become more mature in their efforts to engage, deepening relationships with patients and families (McIntosh-Murray et al. 2013). Teams in organizations such as Huron Perth Healthcare Alliance (CFHI 2014) dedicated significant time and effort to support staff members and teams to authentically engage with patients, facilitating efforts to actively include patients’ perspectives in meetings, to develop solutions and to set clear expectations for how teams would work together. Patient advisors also co-developed and co-led education sessions for staff on engagement and on their quality improvement initiatives.

Another team, from McGill University Health Centre (MUHC), supported efforts for patients, providers and leaders to learn together. In their “Transforming Care at the Bedside” initiative (CFHI 2012), teams learned and developed quality improvement skills together during their training. Learning together in this way helped to negate a view of “us versus them” in their improvement efforts. Patients and staff learned new improvement skills together, blurring the boundaries of their defined roles (i.e., that of the health professional and the patient) and reducing the potential to adopt dominant or subordinate roles (Fine 1994). Instead, learning together represented a form of “inclusionary Othering”, by recognizing the unique skills and experiences of each member and developing relationships through learning for coalition building (Canales 2000). As noted by a senior healthcare administrator leading a team within a CFHI collaborative:

It’s hard to talk about, so I kind of understand why the silence is a bit deafening – and it is the whole issue around power and expertise, and what’s taken for granted and who gets to say what when and who gets to decide what matters, what the topics of conversation are. I think all the good intentions around patient engagement, the actual changes to environments, our culture, will not succeed because it doesn’t really address some of these issues related to power, and that is closely tied to identity. You know there is an identity about being a clinician that has to do with expertise and competence and so on and an identity that has to do with being a patient that puts both parties into specific roles and it’s actually really hard to break that and you can never know in advance whether it’s good to break it or not. So I think sometimes there’s an optimism or a belief in emancipation in the patient engagement movement that would say that patient engagement is good and that non-engagement is bad, but I think it’s so much more contextually bound and complex than that and issues around power and identity are really central to teasing all that apart.

Thus, the ability to build relationships and learn together, respecting and valuing the expertise and experience that each brings to the team, begins to break down the current hierarchies that exist locally within teams and more broadly within the system.

As our experience of what is required for meaningful engagement has developed, we have made deliberate efforts at CFHI to ensure that staff have a foundational understanding that recognizes the value that patients and families bring to our improvement efforts and programming. We have hired a patient partner onto our team as a form of inclusionary Othering – in essence, a patient leader who leads capacity-building efforts, coaches staff within the organization and engages with staff to build strong and consistent engagement practices.

### **Ensuring leadership support and strategic focus: Advancing the model of engagement-capable environments**

Teams participating in CFHI collaboratives stressed the importance of leadership support for engagement at multiple levels of the organization, with senior leaders “setting the tone” and providing a strategic focus at an organizational level, but also local leaders in each initiative who supported efforts to involve patients in activities and decisions. This distributive form of leadership for patient engagement ensures that resources, structures and a common commitment were present at all levels of the organization, not simply from the top down. Distributive leadership models have been linked to improvements in services and patient outcomes, with strong relationships among leaders and with their teams as a key factor to enable change (Fitzgerald et al. 2013).

Successful patient engagement is fundamentally a culture change within an organization, incorporating an underlying philosophy of care that values and respects patients' perspectives and needs. Patient engagement is also about relationships – building, maintaining and sustaining relationships and making those human connections, a feature that requires more exploration to be further articulated within the model of engagement-capable environments. The interactions, trust and respect that are developed in these relationships between patients, staff and leaders create the glue for engagement-capable environments. These relationships provide a shared understanding of the purpose, roles, responsibilities and expectations for engagement, helping to shift power relationships and fostering more collaborative and distributive leadership models (Fitzgerald et al. 2013) that will challenge the status quo, remove barriers and create new structures that support teams, including patients, to work in new and different ways. These relationship practices will move us to “relational engagement and relational accountability that can lead to partnered changes and improvements across health care” (Plamondon and Caxaj 2018). The notion of relational engagement and, importantly, human connection is well articulated by Anya Humphrey, a patient advisor who has been involved with the work of CFHI since the first PEP initiative and, subsequently, in the development and evaluation of CFHI programs (Box 3).

### What Next for the Field of Patient Engagement?

The meaningful involvement of patients in improvement and system redesign has been a learning journey for CFHI and for healthcare organizations across Canada – each at different points along the trajectory. As expectations to involve patients – in care, in healthcare improvement and across the health system – continue to grow, CFHI will remain steadfast in its support to propel organizations as they further develop and fine-tune their engagement efforts. Creating, maintaining and sustaining relationships between those who deliver and organize care and those who receive care is a central feature of engagement efforts. These new relationships represent a shift in the power required to authentically partner, which, in turn, will result in the culture change required for meaningful engagement. CFHI has advocated for partnership models of engagement that enable co-design efforts, yet also recognizes that a full mosaic of methods to involve and engage patients is needed. The broader range of methods allows us to be more inclusive of many voices and experiences that will influence our thinking and understanding of patients' experiences and their journey through the healthcare system. As organizations become increasingly savvy in their ability to engage, CFHI will have a role to play in bringing these like-minded organizations together as networks, to exert increasing influence across the entire patient journey and continuum of care. Leading initiatives, such as the Collaborative Chronic Care Network based out of Cincinnati Children's Hospital (Farmanova et al. 2016), demonstrate that

partnerships of organizations, researchers, clinicians and patients nation-wide that are strengthened with technology – the sharing of data, information, priorities and experiences – can result in changes in care practices and models of care that translate into improved patient outcomes.

Patient engagement is a local strategy within organizations but feeds into a larger social movement across the entire system (Bate et al. 2004; Bibby et al. 2009) as patients and families become increasingly vocal regarding their experiences and needs for care. Mobile communications and learning technologies are a key enabler of patients and families taking more control of their care through improved understanding and knowledge, and connections through social media channels will also foster engagement efforts on a broader scale, linking patients across silos and amplifying their voices. CFHI has directed its efforts primarily in the engagement of patients, but public engagement strategies, particularly as they relate to priority setting and policy development, will become more apparent in our work.

There is a need to support more research into the practice of patient engagement, to enhance the evidence base required to demonstrate its value beyond engagement as “the right thing to do.” More work is required to explicate the linkages between engagement processes and structures and the outcomes of engagement activities. We need to understand what works and why and with what impact. Although the field of patient engagement continues to grow at a rapid pace, the work of researchers in the field can shed further light on what makes for meaningful engagement practices and links to improved outcomes and experiences for patients.

At CFHI, we are “learning by doing” and recognize our own journey of walking the talk of engagement and being consistent in our practices as we build an organization that is an engagement-capable environment. Learning from these experiences will enable us to make further changes together with patient partners to enhance patients' experiences and outcomes, transforming the system into one that is truly focused on and responds to the needs and expectations of patients and families. **HQ**

### Notes

1. The saying “nothing about us, without us” has its origins in Central European political traditions (Latin: *Nihil de nobis, sine nobis*). The English form was used by disability activists in the 1990s and is the title of a book on disability rights by James Charlton. The saying has been adopted by many other interest groups and social movements, including, more recently, by patients and users of the health system.
2. Throughout this paper, the authors use the term “patient” as an overarching term inclusive of individuals with lived experience of the healthcare system that also includes the term resident, client, or service user. When referring to patient engagement this may also include patients' families and caregivers.

**BOX 3.****An excerpt from Anya Humphrey, patient advisor with CFHI, from a presentation made at the IPFCC conference in Baltimore, Maryland, June 2018**

I lost both my husband and son to cancer, and although they both received excellent treatment, their deaths did not go well. So I've been a patient/family advisor for over seven years now, because like many – if not all – PFAs, I wanted to prevent others from having the kind of experience my family had.

In every place where I have volunteered, it has been the first time an organization chose to involve someone like me. I have been privileged, but also challenged at times, by the circumstances I have faced when patient and family engagement was a new phenomenon in Canada.

I have worked as a PFA on initiatives with several organizations and in addition to the three pillars of engagement-capable environments that you have heard about – all of which were more or less missing in my less successful opportunities – I would add another crucial ingredient for success: the importance of establishing interpersonal connections. Nothing replaces the feeling of knowing and being known to other people. You might think that this would be impossible when serving on provincial or national committees whose work mostly takes place on the telephone, and when as PFAs we are never in the building with our colleagues so we don't hear about day-to-day matters. But in my experience, the opposite is true. It has become standard practice for such groups to have at least an introductory face-to-face meeting in order for participants to get to know one another a bit. And since we all have to travel long distances for that, we stay in hotels and need to eat at restaurants. So frequently there will be a group dinner as well as lunches and coffee times when we can either talk about the issues at hand in a more informal way, or even avoid them altogether. These opportunities are priceless to me. They make me feel that I am part of a team, that I have a connection with the other people, that I know who they are when I hear their voices on the phone. And since I often tell parts of my story at such big events, there is usually someone there that I know, who might even give me a comforting hug when I break down – something that happened to me not long ago, which makes me cry to remember. I don't think I can express to you how helpful and meaningful it was for me to have someone in healthcare respond to my distress by putting her arms around me. In my opinion the work that comes out of these events goes deeper and is more satisfying than anything that has happened locally. When committee members live and work near to one another, the dinners and coffees just don't happen unless the leadership makes that a priority.

A fellow PFA used a quote at a national meeting that strikes me as nailing this. I was so impressed by it that I looked up its original context. Thomas Merton, the theologian and activist, once received a letter from a young man who was working hard in the world peace movement and had become thoroughly disenchanting. Merton wrote back an encouraging letter in which he said, "In the end, it is the reality of personal relationships that saves everything."

It seems clear then that an organization that is led by someone who deals respectfully and compassionately with their staff is modelling a type of relationship that can spread throughout that institution and beyond that to the people they deal with. When this style is in place, the tone of interactions actually helps inform and guide the direction they take. The roles I have had with such organizations have grown and changed over time as all of us feel our way together about what is possible. The creative potential that exists in the context of relationship fosters interesting conversations, new ideas emerge, and there is a kind of excitement about trying new things. In many ways, none of us really could have any preparation for that, since we are essentially entering new territory, but in an environment where people take precedence over data, this collegial approach filters down through everything they do. And because they model that, it affects all the projects they recruit and support. To my mind, engagement-capable environments are those that have a heart.

CFHI = Canadian Foundation for Healthcare Improvement; IPFCC = Institute for Patient- and Family-Centered Care; PFA = patient and family advisor.

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**Angela Morin**, patient partner at the Canadian Foundation for Healthcare Improvement, has partnered with organizations at every level of healthcare as a patient advisor since 2011, after supporting her friend Bonnie through her cancer experience. She believes we are better together.

# Soutenir l'engagement du patient et de sa famille à l'amélioration des soins de santé : réflexions sur les « environnements propices à l'engagement » dans le cadre de projets collaboratifs d'apprentissage pancanadiens

Carol Fancott, G. Ross Baker, Maria Judd, Anya Humphrey et Angela Morin

## Résumé

**Bien que l'engagement du patient à ses soins personnels joue un rôle essentiel dans la notion des soins centrés sur le patient, au cours des 10 dernières années, son engagement dans les domaines de la formation des professionnels de la santé, de l'élaboration des politiques, de la gouvernance, de la recherche et de l'amélioration des soins de santé a connu une évolution rapide au Canada. La Fondation canadienne pour l'amélioration des services de santé (FCASS) a aidé des organismes de soins de santé du Canada à encourager un engagement véritable du patient aux efforts d'amélioration de la qualité et de refonte du système. Cet article décrit des initiatives de la FCASS visant à renforcer les efforts d'engagement du patient au Canada, ainsi que les enseignements retenus dans le contexte des « environnements propices à l'engagement ». En terminant, il propose des réflexions sur l'avenir de l'engagement du patient au Canada.**

## Introduction

Les systèmes de santé du monde entier réagissent à la revendication « rien sur moi sans moi »<sup>1</sup> tandis qu'ils tentent de mettre en pratique des soins centrés sur le patient et sa famille en encourageant l'engagement plus active du patient à ses soins. Plus généralement, dans les domaines de l'éducation, de la recherche, de l'élaboration des politiques et de l'amélioration de la qualité, les efforts d'engagement du patient continuent de se développer.

Par exemple, la Stratégie de recherche axée sur le patient, financée par les Instituts de recherche en santé du Canada (CIHR 2018), a établi de nouvelles attentes quant à la collaboration des chercheurs avec les usagers du système de santé, entre autres pour définir les priorités en matière de recherche, mais également en vue de solliciter l'engagement active du patient<sup>2</sup> et du public à l'ensemble de l'entreprise de la recherche, en tant que partenaires du processus, plutôt que comme de simples participants aux études. Dans les professions de la santé, les efforts en matière de formation tels que ceux de la Faculté de médecine de l'Université de Montréal (Karazivan et al. 2015) ont ouvert la voie à l'intégration du patient en tant que partenaire dans la formation de la prochaine génération de médecins et de professionnels de la santé. Il s'agit de produire des soins collaboratifs et compatissants dans la pratique professionnelle. Les organismes de soins de santé du monde entier se sont efforcés de tirer parti de l'expertise et de la sagesse des patients et de leurs proches pour exploiter leur expérience afin d'améliorer la sécurité et la qualité des soins. En tant que domaine de qualité, les soins centrés sur le patient sont l'objet de mesures incitatives dans divers systèmes de par le monde et se déclinent en nombreux leviers (p. ex. exigences législatives, normes d'agrément). Les organismes de prestation reconnaissent de plus en plus que l'amélioration de l'expérience et des résultats de soins du patient exige l'engagement active du patient à la conception et à la mise en œuvre de ces améliorations.

**PRINCIPAUX MESSAGES**

1. Les projets collaboratifs d'apprentissage sur l'engagement du patient et de sa famille ont aidé des organismes de soins de santé de partout au Canada dans leurs efforts de création d'environnements propices à l'engagement et de collaboration véritable avec le patient au service de l'amélioration.
2. Les efforts d'engagement du patient ont évolué au cours de la dernière décennie dans tous les domaines de soins de santé, mais une évaluation plus poussée s'impose pour mieux comprendre les mécanismes sur lesquels s'appuient les initiatives réussies, ainsi que les raisons qui expliquent leur succès et leurs effets.
3. Les liens et rapports humains sont indispensables aux efforts d'engagement du patient.

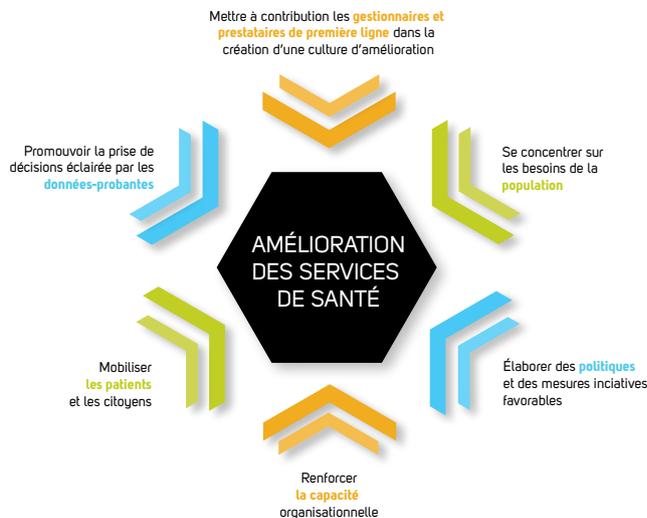
Au Canada, la Fondation canadienne pour l'amélioration des services de santé (FCASS), un organisme sans but lucratif financé par le gouvernement fédéral qui s'attache à l'accélération de l'amélioration des soins de santé et à la transformation des systèmes, estime que l'engagement du patient et du citoyen est l'un des six leviers les plus importants de l'amélioration, comme l'indique son cadre (Figure 1). L'engagement du patient, de ses proches et des collectivités, en tant que moteur de changement et d'amélioration du système de santé, est un objectif stratégique et constitue la charpente des activités et programmes de la Fondation. Cet article décrit brièvement l'approche adoptée par la FCASS depuis 2010 pour aider les organismes de soins de santé du Canada à collaborer de manière authentique avec les patients et leurs proches en vue d'améliorer la qualité des soins et de refondre les systèmes à l'aide de quatre initiatives d'apprentissage pancanadiennes. Le concept « d'environnements propices à l'engagement » (Baker et Denis 2011; Baker et al. 2016a) est issu d'une recherche menée dans le cadre des premiers projets collaboratifs sur l'engagement et d'autres travaux soutenus par la FCASS auprès d'organismes qui ont produit des expériences et des résultats d'engagement tangibles. Cet article examine également l'évolution du domaine de l'engagement du patient et la croissance de la FCASS en tant qu'organisme visant à devenir un environnement propice à l'engagement. Cet article se conclut sur des réflexions par rapport à l'avenir de l'engagement du patient et sur ce que la FCASS peut contribuer en tant qu'entité nationale pour accélérer les améliorations en matière de soins de santé avec l'engagement active du patient et de sa famille.

**Approche de la FCASS en matière d'engagement et de programmes**

La FCASS a adapté et adopté une définition de Tambuyzer et de ses collègues pour apporter plus de clarté à son travail en matière d'engagement : « L'engagement du patient est la contribution du patient ou de ses proches à la prise de décisions et sa contribution active à diverses activités (p.ex. planification, évaluation, soins, recherche, formation et recrutement). Partant du principe que l'on acquiert un savoir au fil de l'expérience, l'engagement du patient signifie une collaboration et un partenariat avec les professionnels » (Tambuyzer et al. 2014). Le continuum d'engagement du public proposé par l'Association internationale pour l'engagement public (2015) (à savoir, informer, consulter,

inclure, collaborer et responsabiliser) précise dans quelle mesure le continuum d'engagement est lié à l'influence du public (ou du patient) sur la prise de décisions. Le cadre d'engagement proposé par Carman et ses collègues fournit des informations supplémentaires en proposant également un continuum d'engagement (consulter, impliquer ou partager le leadership), ainsi que des considérations relatives aux efforts de mobilisation déployés aux niveaux des soins directs, des programmes de l'organisme et de l'élaboration des politiques (Carman et al. 2013). Les efforts de la FCASS sont principalement axés sur l'engagement du patient aux niveaux méso et macro, c'est-à-dire encourager l'engagement du patient aux efforts d'amélioration aux niveaux des programmes ou de l'organisme et dans le cadre de politiques soutenant les pratiques centrées sur le patient. Leur objectif ultime est d'améliorer l'expérience et les résultats du patient en matière de soins.

**FIGURE 1.**  
Les six leviers (ou catalyseurs) de la FCASS pour accélérer l'amélioration des services de santé



FCASS = Fondation canadienne pour l'amélioration des services de santé.

Les quatre initiatives d'apprentissage et projets collaboratifs de la FCASS ont réuni 51 équipes réparties dans huit provinces et un territoire du Canada. L'objectif global de ces travaux était de renforcer la capacité organisationnelle en matière

d'engagement du patient et de sa famille (voir le Tableau 1 pour des détails sur chacun des quatre groupes d'apprentissage). Lorsque la FCASS a lancé sa première initiative de « projets sur l'engagement du patient » (PEP) en 2010, la notion des soins centrés sur le patient était déjà fermement ancrée dans les dimensions essentielles de la qualité (Institute of Medicine 2001). En outre, des conseils ou comités constitués de patients ou d'usagers étaient déjà bien intégrés à certains domaines de soins (en pédiatrie par exemple) et dans certaines instances (au Québec par exemple). Cependant, le concept d'un patient plus engagé et plus intégré, en particulier au niveau organisationnel, n'en était qu'à ses balbutiements au Canada. Conséquemment, bon nombre d'équipes des premiers groupes subventionnés par la FCASS se sont concentrées sur la mise en place de l'infrastructure nécessaire à l'intensification des efforts de mobilisation. Ensemble, de concert avec la FCASS, ces équipes ont appris à agir en véritable partenariat avec leurs patients, en les faisant participer plus délibérément à l'ensemble des efforts d'amélioration. Dans des projets collaboratifs subséquents, la FCASS a encouragé l'intégration de pratiques plus avancées dans le continuum de l'engagement du patient, afin de permettre à davantage de modèles collaboratifs de se développer entre patients et prestataires des équipes d'amélioration. Les équipes de ces initiatives d'apprentissage initiales couvraient tous les secteurs de la santé (soins primaires, soins à domicile,

soins de courte durée et soins de suivi) et les populations d'intérêt (soins pédiatriques, soins oncologiques, orthopédie, maladies chroniques), ainsi qu'un vaste éventail d'initiatives d'amélioration (p. ex. transitions de soins, processus d'admission et de congé, développement de ressources en soins primaires pour l'engagement du patient). Dans notre dernier projet collaboratif sur l'engagement, nous nous sommes concentrés plus délibérément sur la mise en œuvre d'une initiative de politiques précisément liées à la présence des proches dans les milieux de soins, en veillant à intégrer l'engagement du patient et de sa famille à son développement, à sa mise en œuvre et à son évaluation.

Le modèle de ces projets collaboratifs d'apprentissage a évolué au fil de ces quatre groupes d'équipes. Au final, il comprenait des possibilités d'apprentissage régulières en personne et virtuelles, au moyen de webinaires, un apprentissage entre pairs, un accompagnement assuré par des formateurs, des possibilités de réseautage et un financement de démarrage. Dans son tout dernier projet collaboratif virtuel, la cyber-collaboration « Meilleurs ensemble », la FCASS a mis à l'essai un modèle d'apprentissage virtuel et offert des possibilités d'encadrement, d'enseignement et de réseautage aux équipes afin de faire avancer leurs initiatives stratégiques auprès des patients et de leurs proches. D'importants progrès ont été réalisés par des projets collaboratifs récents qui ont fait appel à

**TABLEAU 1.****Résumé de quatre initiatives d'apprentissage / projets collaboratifs de la FCASS en matière d'engagement du patient et de sa famille**

Projet	Projets d'engagement du patient (PEP) I	Projets d'engagement du patient (PEP) II	Agir en partenariat avec les patients et leurs familles au service de l'AQ	Meilleurs ensemble (partie d'une campagne plus vaste)
Objectif	Promouvoir et soutenir l'engagement du patient à la conception, à la prestation et à l'évaluation des services de santé pour aboutir à des soins de grande qualité centrés sur le patient	Promouvoir et soutenir des projets d'intervention qui suscite l'engagement du patient à la conception, à la prestation et à l'évaluation de services de santé pour aboutir à des soins de grande qualité centrés sur le patient	Renforcer la capacité d'améliorer la culture organisationnelle afin de créer des partenariats avec les patients et leurs familles pour améliorer la qualité tout au long du continuum de soins de santé	Développer la capacité organisationnelle en matière d'appréciation, de planification, de mise en œuvre, d'évaluation et de pérennisation de la présence des familles et introduire des pratiques qui soutiennent les soins centrés sur le patient et sa famille dans les hôpitaux afin d'améliorer l'expérience et la satisfaction du patient et du personnel
Durée	24 mois	24 mois	17 mois	11 mois
Fonds de démarrage	Jusqu'à 100 000 \$	Jusqu'à 100 000 \$	Jusqu'à 50 000 \$	Aucun financement de démarrage
Équipes admises	10 équipes (4 provinces)	7 équipes (5 provinces)	22 équipes (6 provinces, 1 territoire)	12 équipes (7 provinces)
Approche d'évaluation	Recherche qualitative (entretiens, révision de document(s))	Recherche qualitative (entretiens, révision de document(s))	Sondages d'équipe, analyse de réseaux sociaux, révision de document(s), échelle d'évaluation collaborative, entretiens	Sondages, révision de document(s), échelle d'évaluation collaborative, entretiens

AQ = amélioration de la qualité; FCASS = Fondation canadienne pour l'amélioration des services de santé.

des patients ressources en tant que formateurs ou enseignants. Ceux-ci avaient pour but de fournir un soutien accru aux équipes dans leurs efforts de mobilisation et de les encourager à réfléchir à l'objectif, au rôle et aux attentes par rapport à leur collaboration avec le patient.

Les méthodes et l'objet de l'évaluation des programmes d'engagement du patient de la FCASS ont également évolué au fil du temps, grâce à une meilleure compréhension des processus et résultats de l'engagement. La FCASS a utilisé et mis à l'essai de nombreuses approches pour mieux comprendre lesquelles sont fructueuses, pour quelles raisons, avec quels processus de mobilisation et avec quels résultats. Tandis que le domaine de l'engagement commençait à s'imposer au moment des deux premières initiatives de PEP, on a choisi une approche qualitative en matière d'évaluation pour approfondir la compréhension des méthodes d'engagement utilisées par les équipes, les processus employés pour intégrer la voix du patient et le contexte organisationnel qui a facilité ou entravé les efforts de mobilisation. Cette étude qualitative a permis de mieux comprendre comment les équipes percevaient l'engagement du patient. Cette recherche a également souligné l'importance d'un contexte organisationnel favorable à l'engagement véritable du patient. Les équipes provenant d'organisations qui profitaient d'un appui solide et visible de la haute direction étaient en mesure d'élaborer et de pérenniser une philosophie de soins centrés sur le patient, établissant par le fait même un contexte plus mûr dans lequel elles étaient capables d'employer des stratégies de mobilisation plus évoluées qui se rapprochaient de la « conception conjointe » dans le continuum de l'engagement (McIntosh-Murray et al. 2013). Dans ces organismes, les patients travaillaient en partenariat avec les prestataires pour apprendre des méthodes d'amélioration de la qualité, évaluer les possibilités d'amélioration et concevoir ensemble des solutions. Ainsi, ils amélioraient à la fois l'expérience du patient en matière de soins et l'expérience du prestataire en matière de prestation de soins, ainsi que d'autres résultats liés à la qualité.

S'appuyant sur les résultats de ces recherches, les projets collaboratifs subséquents en matière d'engagement du patient et de sa famille ont porté plus particulièrement sur l'intégration de patients ressources aux équipes d'amélioration de la qualité afin de travailler avec les prestataires et les dirigeants à l'élaboration et à la mise en œuvre d'initiatives d'amélioration. Les efforts d'évaluation consistaient à mieux comprendre l'influence de l'intégration du patient ressource sur le fonctionnement de l'équipe à l'aide de méthodes telles que l'analyse des réseaux sociaux (Valente 2010) et l'évaluation de l'expérience et de l'efficacité de l'équipe (Orchard et al. 2012; Shortell et al. 2004). Ces approches ont examiné les points de vue de tous les membres de l'équipe, notamment ceux des patients ressources, afin de mieux comprendre le fonctionnement de l'équipe avec des patients ressources en tant que membres de l'équipe.

Edmondson et al. (2001) ont observé que les équipes suivent un processus d'apprentissage lors de l'établissement de nouvelles routines. Les équipes qui réussissent portent une attention particulière à la sélection et à la préparation des membres, créent une sécurité psychologique favorable à l'expérience de nouvelles pratiques, mettent à l'essai de nouvelles routines et réfléchissent à leurs expériences. Le contexte organisationnel était étudié à l'aide d'entrevues et de groupes de discussion composés de patients, de proches et de membres de l'équipe afin de fournir une compréhension plus nuancée des rôles et du contexte organisationnel des travaux. L'évaluation a également pris en compte les résultats de l'équipe de projet, ainsi que la capacité et les connaissances acquises dans les domaines de l'amélioration de la qualité, de la gestion du changement et des pratiques d'engagement. Cette approche d'évaluation à méthodes mixtes a ainsi produit une caractérisation multidimensionnelle des pratiques d'engagement et organisationnelles nécessaires au travail de partenariat véritable entre professionnels et patients. Elle a également permis d'acquérir des connaissances sur les pratiques efficaces en matière d'engagement, tant du point de vue du patient que du prestataire, lorsqu'ils travaillaient ensemble à l'établissement des conditions propices à l'engagement et à l'amélioration. Ces informations ont été résumées dans des fiches de conseils pratiques sur l'engagement (voir les encadrés 1 et 2).

### **Conceptualisation « d'environnements propices à l'engagement »**

L'engagement véritable du patient et de sa famille constitue un changement de culture dans le fonctionnement des équipes et dans l'organisation et la prestation des soins au sein des organismes de santé. Les travaux de recherche qui ont exploré les PEP initiaux ont fait émerger le concept « d'environnements propices à l'engagement » (Baker et Denis 2011; Baker et al. 2016a). Le concept a ensuite été affiné dans le cadre de travaux supplémentaires menés par la FCASS (Baker et al. 2016b; Judd et al. 2015). L'expression « environnements propices à l'engagement » désigne des organismes qui ont encouragé un engagement authentique grâce à la mise en œuvre de trois piliers principaux : (1) la mobilisation et la préparation des patients et de leurs proches; (2) la formation et la préparation du personnel à l'engagement du patient; et (3) le soutien de la Direction aux activités d'engagement traduit en ressources et en une infrastructure permettant le déroulement de ces activités (Figure 2). Au fil des projets collaboratifs de la FCASS, on a observé divers degrés et méthodes de mise en œuvre de ces trois piliers chez les équipes désireuses de créer des environnements propices à l'engagement. Conséquemment, leurs expériences et leurs résultats se sont avérés très variables. Bien que l'ensemble des piliers constitue le fondement de l'engagement, la synergie de l'impact combiné de ces piliers contribue à susciter le changement de

culture nécessaire pour soutenir les efforts de mobilisation. Le concept d'environnements propices à l'engagement s'appuie sur les nombreuses composantes complexes de la préparation au changement organisationnel : des dirigeants capables d'énoncer, de soutenir et de montrer leur engagement en faveur d'une collaboration avec les patients et leurs proches, ainsi que sa valeur, et la préparation et le renforcement de la capacité à travailler entre professionnels et patients (Weiner 2009). Un recueil de cas récent explore le concept d'environnements propices à l'engagement et décrit les divers moyens par lesquels ces piliers ont été mis en œuvre par des organismes très performantes de l'Amérique du Nord et du Royaume-Uni (Baker et al. 2016b). Vous trouverez ci-dessous des réflexions sur les enseignements tirés de nos collaborations dans le contexte de l'évolution de notre réflexion sur les environnements propices à l'engagement au Canada et sur la façon dont la FCASS a mis ces enseignements en pratique pour devenir un organisme propice à l'engagement.

#### ENCADRÉ 1.

##### 10 réflexions provenant de dirigeants et de prestataires de soins de santé

1. Reconnaissez la valeur de l'engagement du patient.
2. Voyez les patients comme des membres de l'équipe d'amélioration.
3. Travaillez ensemble pour concevoir conjointement les améliorations.
4. Faites participer les patients à un stade précoce et veillez à les faire participer tout au long du projet.
5. Soutenez l'engagement et soyez un modèle pour les autres.
6. Envisagez l'expérience de soins au travers des yeux du patient.
7. Accordez un soutien continu aux patients.
8. Accordez un soutien continu au personnel et aux médecins.
9. Veillez à ce que votre équipe dispose de ressources suffisantes pour mobiliser les patients.
10. Évaluez vos efforts de mobilisation.

Source : CFHI 2018a.

#### ENCADRÉ 2.

##### 10 enseignements retenus de patients et de proches ressources

1. Précisez mon rôle.
2. Renseignez les autres au sujet de mon rôle et de la valeur que je contribue.
3. Donnez-moi l'information dont j'ai besoin pour réussir.
4. Faites-moi participer d'entrée de jeu.
5. Un patient ressource, c'est bien; plus d'un, c'est mieux.
6. Maintenez ma participation tout au long du processus.
7. Rendez les activités d'engagement accessibles et proposez-moi des modalités d'engagement.
8. Encouragez les possibilités de réseautage.
9. Continuez de travailler avec moi après la fin du projet.
10. Je peux faire bien plus que raconter mon récit.

Source : CFHI 2018b.

**FIGURE 2.**  
**Modèles d'environnements propices à l'engagement**



Source : Baker et Denis 2011.

#### Recruter et préparer le patient et sa famille : passer de « conseiller » à « partenaire » et bien plus

Au cours des huit dernières années, la FCASS a aidé des organismes à recruter et à former des patients en tant que personnes ressources en matière de priorités et d'initiatives organisationnelles. En conséquence, bien des équipes des projets collaboratifs de la FCASS, en particulier celles des premières initiatives de PEP, ont cherché à développer des infrastructures pour soutenir les pratiques d'engagement; à savoir, l'élaboration de manuels et d'outils d'orientation pour les patients, ainsi que des stratégies de recrutement et de formation pour les patients et leurs proches à titre de conseillers auprès de comités organisationnels. De plus en plus, la FCASS encourage l'instauration de modèles d'engagement plus collaboratifs (plutôt que consultatifs) afin de développer le rôle du patient en tant que partenaire et de soutenir les activités de conception conjointe. Par ailleurs, ces modèles encouragent l'engagement beaucoup plus précoce du patient aux processus afin de déterminer les priorités organisationnelles selon ses besoins, objectifs et expériences.

Le développement des rôles de conseiller ou de partenaire représente une stratégie importante pour soutenir les initiatives d'engagement du patient qui est à la fois symbolique (c.-à-d. l'importance d'inclure la voix du patient et sa présence visible pour rappeler son rôle central dans les soins de santé) et fonctionnelle (c.-à-d. la capacité à concevoir conjointement des initiatives avec l'engagement du patient en tant qu'acteur clé du processus). Cependant, il existe un réel danger si l'engagement n'est pas authentique et que l'inclusion du patient en tant que conseiller ou partenaire n'est qu'un geste purement symbolique voulant qu'il soit inclus, mais que ses opinions ne soient pas prises en compte. Les exigences législatives ou politiques d'inclusion du patient dans le processus peuvent encourager des efforts symboliques si les organismes ne sont pas entièrement préparés à participer. Bien que la FCASS ait demandé l'inclusion de conseillers et encouragé leur participation plus complète aux équipes d'amélioration de la qualité en tant que

patients partenaires, elle a pris plus pleinement conscience qu'il existait une « mosaïque » d'activités de mobilisation (Tritter et McCallum 2006) et a cherché à bonifier le rôle de conseiller / partenaire en favorisant d'autres possibilités d'engagement qui font davantage appel à l'expérience du patient dans l'ensemble de l'organisme pour un ensemble plus vaste de problèmes et d'éventuelles solutions. Par exemple, dans le cadre d'un projet collaboratif de la FCASS, l'Hôpital Bruyère à Ottawa a invité des patients et proches ressources (PPR) à concevoir conjointement un « passeport vers le domicile » dans le cadre de son initiative d'amélioration des transitions de soins (CFHI 2016). L'hôpital a eu recours à plusieurs modalités d'engagement, au-delà de l'inclusion de PPR dans l'équipe d'amélioration. Bruyère a mesuré et rassemblé l'expérience de patients à divers stades de la transition et a régulièrement interrogé des patients qui recevaient actuellement des soins. Cette méthode a permis d'élargir la compréhension de l'expérience du patient en matière de transitions de soins, tout en collaborant avec les PPR pour concevoir de nouveaux processus et ressources en vue de soutenir les patients et leurs proches dans leur transition vers le domicile. Le travail de Bruyère avec des patients ressources en tant que membres de l'équipe a conduit à des solutions conçues conjointement; les autres stratégies d'engagement ont permis de contribuer des voix plus diversifiées aux travaux. L'utilisation d'un éventail de méthodes réduit non seulement la hiérarchie des méthodes d'engagement, qui suppose que l'une est préférable aux autres, mais reconnaît également que diverses méthodes d'engagement sont nécessaires selon l'objectif visé (Tritter et McCallum 2006). Une formulation claire du but de l'engagement (à savoir, pourquoi les patients participent) est essentielle pour préciser les attentes en matière d'engagement et d'influence sur les processus décisionnels.

Le recours à de nombreuses méthodes d'engagement (des méthodes de consultation telles que des groupes de discussion ou des sondages, jusqu'aux méthodes plus collaboratives, telles que des patients partenaires dans l'équipes d'amélioration) atténue également l'espoir que quelques patients retenus pour un projet puissent représenter la voix de tous les patients. Greenhalgh et ses collègues décrivent ces tensions comme la juxtaposition de la « représentation » et « représentativité »; la capacité d'inclure de nombreuses voix au moyen de diverses méthodes d'engagement visant à renforcer la compréhension de l'expérience du patient pour orienter les efforts d'amélioration (Greenhalgh et al. 2011a). Des tensions sont également soulevées concernant les patients « naïfs » par opposition aux patients « professionnalisés » qui ont acquis suffisamment de savoir-faire et de connaissances sur le fonctionnement interne du système de santé et sont donc perçus comme incapables d'apporter une perspective nouvelle ou naïve (Greenhalgh et al. 2011a; Hogg et Williamson 2001; Martin 2008). Paradoxalement, il semble que les patients constituent le

seul groupe pour lequel une expérience limitée est considérée comme un atout. Encore que cela représente un casse-tête pour les patients qui se sont outillés en acquérant une connaissance du système par désir de contribuer activement à des améliorations, mais qui, ce faisant, semblent avoir trop de connaissances « d'initiés » (Barnes et Cotterell 2012). Un éventail de stratégies d'engagement permet de garantir que toute une gamme d'expériences de patients soient prises en compte tout au long du processus d'amélioration, plutôt que se fier à l'expérience d'une seule ou de quelques personnes. Les projets collaboratifs de la FCASS nous ont appris que le jumelage de patients ressources chevronnés avec des patients ressources récemment recrutés crée une alliance puissante qui permet d'aider les nouveaux patients ressources à s'y retrouver dans leurs fonctions et à acquérir les compétences nécessaires pour s'engager efficacement. Il faut souvent du temps avant que les nouveaux patients ressources se sentent à l'aise d'exprimer leur point de vue, mais leurs expériences actuelles ou récentes sont extrêmement précieuses, tout comme celles de patients ressources aguerris qui savent à quoi ressemble le partenariat véritable. Les patients et leurs familles ont encouragé le soutien entre pairs au service de l'engagement par des mécanismes formels et informels.

L'expérience croissante acquise au fil de projets collaboratifs d'apprentissage nous a également amenés à élargir nos méthodes d'engagement au-delà des rôles de conseillers et de partenaires de nos comités. Dans ses programmes les plus récents, pour veiller à tenir compte de la diversité des points de vue des patients, la FCASS a utilisé une gamme de méthodes de mobilisation de l'ensemble du continuum dont : entretiens individuels et participation à des groupes de travail avec le personnel. De même, lors de l'élaboration de politiques internes (par exemple, bourses d'études et indemnisation à l'intention de patients ou de proches), la FCASS a utilisé des méthodes telles que les twitter chats et les sondages à des fins de consultation pour mieux comprendre ce qui conviendrait le mieux aux patients, tout en dialoguant avec des patients partenaires membres de groupes de travail pour concevoir conjointement des processus et politiques.

### **Encourager le personnel à faire participer le patient : apprécier le pouvoir et l'identité**

L'un des principaux enseignements tirés de notre première incursion dans l'engagement du patient est l'importance de préparer le personnel à interagir davantage avec les patients dans leurs efforts d'amélioration et la nécessité de procéder à une auto-évaluation honnête de l'état actuel des efforts d'engagement dans les équipes et organismes. De nombreuses équipes s'évaluaient trop favorablement quant à leur niveau actuel d'engagement et supposaient qu'elles interagissaient déjà beaucoup avec le patient. Cependant, les équipes ont souvent réalisé qu'elles avaient sous-estimé la

nécessité d'aider le personnel à apprendre comment solliciter et inclure les points de vue du patient de manière authentique dans leurs initiatives. Comprendre pourquoi l'engagement du patient est essentielle pour les pratiques centrées sur le patient est indispensable pour que le personnel reconnaisse la valeur des perspectives du patient en vue d'améliorer les processus et la prestation des soins. Les organisations qui consacrent temps, ressources et énergie à apprendre à faire participer le patient de manière authentique deviennent également plus mures dans leurs efforts de mobilisation et d'approfondissement de leurs relations avec le patient et sa famille (McIntosh-Murray et al. 2013). Des équipes provenant d'organismes telles que Huron Perth Healthcare Alliance (CFHI 2014) ont consacré beaucoup de temps et d'efforts au soutien des membres de leur personnel et de leurs équipes en vue de véritablement mobiliser les patients, faciliter les efforts visant à activement intégrer leurs points de vue dans les réunions, élaborer des solutions et définir des attentes claires par rapport au travail d'équipe. Les patients ressources ont également conjointement élaboré et dirigé des séances de formation sur l'engagement du personnel et les initiatives d'amélioration de la qualité.

Une autre équipe, du Centre universitaire de santé McGill (CUSM), a appuyé les efforts déployés par des patients, des prestataires de services et des dirigeants pour apprendre ensemble. Dans le cadre de leur initiative « Transformer les soins au chevet du patient » (CFHI 2012), les équipes cliniques et les patients ont conjointement appris et élaboré des techniques d'amélioration de la qualité au cours de leur formation. Apprendre ensemble de cette manière leur a permis d'éviter le gouffre qui les sépare souvent dans leurs efforts d'amélioration. Les patients et le personnel ont acquis ensemble de nouvelles compétences d'amélioration, brouillant ainsi les limites de leurs rôles (à savoir ceux du professionnel de la santé et ceux du patient) et réduisant la possibilité d'adopter des rôles dominants et subordonnés (Fine 1994). L'apprentissage conjoint représentait plutôt une forme « d'inclusion de l'autre » qui reconnaissait les compétences et expériences uniques de chaque membre et tissait des liens entre eux par le biais de l'apprentissage et de la formation de coalitions (Canales 2000). Comme le signalait un gestionnaire principal des soins de santé qui dirigeait une équipe dans le cadre d'un projet collaboratif de la FCASS :

C'est difficile de prendre la parole, alors je comprends pourquoi le silence peut être assourdissant : c'est toute cette question du pouvoir et de l'expertise, et de ce qui est tenu pour acquis, à savoir qui peut dire quoi, quand et qui décide de ce qui compte, quels sont les sujets de conversation. Je pense que toutes les bonnes intentions concernant l'engagement du patient, le changement réel dans les milieux de travail et notre culture échoueront,

car ils ne traitent pas vraiment de certaines questions concernant le pouvoir qui sont étroitement liées à l'identité professionnelle. On sait que le travail de clinicien confère une identité fondée sur l'expertise et la compétence et que l'identité propre au patient lui attribue d'autres fonctions. Il s'avère très difficile de rompre ces a priori et, d'ailleurs, on ne sait jamais à l'avance s'il est bon de les rompre ou non. Donc, je pense que parfois, dans le mouvement d'engagement du patient, il existe un optimisme ou une conviction par rapport à l'émancipation qui veut que l'engagement du patient soit bénéfique et que l'absence de son engagement soit délétère. Or, je crois que la réalité est beaucoup plus nuancée et dépendante du contexte; qu'il est important de mieux saisir les particularités de l'identité pour dissiper les a priori.

Ainsi, la capacité d'établir des rapports et d'apprendre ensemble, en respectant et en valorisant l'expertise et l'expérience de chacun, amorce le démantèlement des hiérarchies actuelles des équipes, voire du système.

Au fur et à mesure que son expérience des éléments nécessaires à un engagement véritable s'est développée, la FCASS a déployé des efforts délibérés pour veiller à ce que le personnel ait une compréhension élémentaire qui reconnaisse au moins la valeur que les patients et leurs proches apportent à ses efforts d'amélioration et à ses programmes. Elle a recruté un patient partenaire au sein de son équipe pour faire preuve « d'inclusion de l'autre ». Essentiellement, il s'agit d'un chef de file qui dirige les efforts de renforcement des capacités, accompagne le personnel de la FCASS et engage le personnel dans l'instauration de pratiques d'engagement solides et cohérentes.

### **Garantir le soutien de la Direction et une orientation stratégique : faire progresser le modèle d'environnements propices à l'engagement**

Les équipes qui participent aux projets collaboratifs de la FCASS ont souligné l'importance de l'appui des dirigeants pour mousser l'engagement à plusieurs niveaux de l'organisme. Les cadres supérieurs doivent « donner le ton » et proposer une orientation stratégique organisationnelle, or les dirigeants de toute initiative locale doivent encourager l'engagement du patient aux activités et aux décisions. Cette forme de leadership partagé en matière d'engagement du patient garantit la présence de ressources, de structures et d'un engagement commun à tous les niveaux de l'organisme, non pas simplement de haut en bas. Les modèles de leadership partagé sont associés à des améliorations de services et de résultats pour le patient, car les relations solides entre les dirigeants et leurs équipes constituent un facteur clé du changement (Fitzgerald et al. 2013). Le succès de l'engagement du patient est, au final, un changement de culture au sein d'un organisme qui intègre une philosophie de soins visant à

valoriser et respecter les points de vue et les besoins du patient. L'engagement du patient concerne également les relations : établir, entretenir et pérenniser des relations (établir des rapports humains), une caractéristique qui exige une étude plus poussée pour qu'on puisse l'expliquer davantage au moyen du modèle d'environnements propices à l'engagement. Les interactions, la confiance et le respect qui se développent dans ces relations entre patients, personnel et dirigeants deviennent la cheville ouvrière des environnements propices à l'engagement. Ces relations fournissent une compréhension commune de l'objet, des rôles, des responsabilités et des attentes en matière d'engagement, contribuant ainsi à modifier les relations de pouvoir et à favoriser des modèles de leadership plus collaboratifs et partagés (Fitzgerald et al. 2013) qui remettent en question le statu quo, éliminent les entraves et créent de nouvelles structures qui aident les équipes, notamment les patients, à travailler de manière nouvelle et différente. Ces pratiques relationnelles nous conduiront à « un engagement et à une responsabilité relationnels pouvant déboucher sur des changements collectifs et des améliorations pour l'ensemble des soins de santé » (Plamondon et Caxaj 2018). Anya Humphrey, patiente ressource pour les travaux de la FCASS depuis la première initiative de PEP et, depuis, pour l'élaboration et l'évaluation des programmes de la FCASS, a bien présenté la notion d'engagement relationnel et, de manière plus significative, les rapports humains (encadré 3).

### Que réserve l'avenir au domaine de l'engagement du patient ?

L'engagement authentique du patient à l'amélioration et à la refonte du système a été un véritable apprentissage pour la FCASS et les organismes de soins de santé du Canada; chacun étant à un stade donné du parcours. Tandis que les attentes par rapport à l'engagement du patient (aux soins, à l'amélioration des soins de santé et à l'ensemble du système de santé) continuent de s'accroître, la FCASS maintient son soutien inébranlable à la faveur d'organismes qui s'intéressent à l'engagement du patient et redoublent d'efforts pour concrétiser ce grand projet. La création, le maintien et la pérennisation de relations entre ceux qui prodiguent et organisent les soins et ceux qui les reçoivent constituent un élément central des efforts de cette mobilisation. Ces nouvelles relations représentent un changement dans le pouvoir nécessaire à l'établissement de partenariats authentiques, ce qui entraîne inévitablement le changement de culture indispensable à l'engagement véritable. La FCASS préconise des modèles de partenariat axés sur l'engagement qui encouragent la conception conjointe tout en reconnaissant qu'une mosaïque complète de méthodes d'engagement s'impose pour efficacement mobiliser les patients. Un large éventail de méthodes permet d'inclure un grand nombre de voix et d'expériences qui, partant, influencent notre façon de penser et de comprendre l'expérience et le parcours du patient dans le système de soins de santé. À mesure que les

organismes prendront de l'aisance avec l'engagement, la FCASS jouera un rôle dans le regroupement d'organismes aux vues similaires en réseaux afin d'exercer une influence croissante tout au long du parcours du patient et du continuum de soins. Des initiatives d'envergure, telles que le Collaborative Chronic Care Network de l'hôpital pour enfants de Cincinnati (Farmanova et al. 2016) montrent que des partenariats entre organismes, chercheurs, cliniciens et patients, renforcés par la technologie (pour le partage de données, d'informations, de priorités et d'expériences), peuvent entraîner des changements dans les pratiques et modèles de soins qui se traduisent par de meilleurs résultats pour le patient.

L'engagement du patient est une stratégie locale au sein des organismes, mais elle s'intègre à un mouvement social plus vaste à l'échelle du système (Bate et al. 2004; Bibby et al. 2009) au fur et à mesure que les patients et leurs familles font entendre leur expérience et leurs besoins en matière de soins. Les communications mobiles et les technologies d'apprentissage sont un facteur clé qui permet aux patients et à leurs proches de mieux contrôler leurs soins grâce au renforcement de leur compréhension et de leurs connaissances. Les liens établis au moyen des médias sociaux encouragent également les efforts de mobilisation à plus grande échelle en reliant les patients et en décloisonnant leurs activités pour affermir leur voix. La FCASS a principalement axé ses efforts sur l'engagement du patient, mais les stratégies d'engagement du public, en particulier en ce qui concerne l'établissement de priorités et l'élaboration de politiques, deviendront plus évidentes dans son travail à l'avenir.

Un soutien accru pour la recherche sur les pratiques d'engagement du patient s'impose afin d'améliorer la base de données probantes nécessaire à la démonstration de sa valeur au-delà de l'engagement en tant que « bonne ligne de conduite à suivre ». Des efforts supplémentaires sont nécessaires pour expliquer les liens entre les processus et structures d'engagement et les résultats des activités d'engagement. Il faut parvenir à comprendre ce qui fonctionne, pourquoi et avec quel effet. Bien que le domaine de l'engagement du patient s'accroisse à une cadence soutenue, le travail des chercheurs sur le terrain peut contribuer à jeter un nouvel éclairage sur ce que sont les pratiques d'engagement véritable et les liens qui permettent d'améliorer les résultats et les expériences du patient.

À la FCASS, on « apprend par la pratique »; on est conscient du cheminement nécessaire à la mobilisation et à la cohérence des pratiques tandis qu'on tâche de créer un organisme propice à l'engagement. Les enseignements tirés de ces expériences apportent de nouveaux changements, déployés avec le concours de patients partenaires, dans le but d'améliorer les expériences et les résultats du patient, de transformer le système pour qu'il soit véritablement centré sur les besoins et attentes du patient et de sa famille. **HQ**

**ENCADRÉ 3.****Extrait d'un discours prononcé par Anya Humphrey, patiente ressource à la FCASS, lors d'une conférence de l'IPFCC à Baltimore, au Maryland, en juin 2018**

Mon mari et mon fils sont tous les deux morts d'un cancer et, bien qu'ils aient tous deux reçu d'excellents soins, leur décès ne s'est pas bien passé. Je suis donc patiente-proche ressource depuis plus de sept ans, parce que, comme beaucoup de patients ressources, sinon tous, je veux éviter aux autres de vivre une expérience similaire à celle de ma famille.

Aucun des organismes où j'ai été bénévole ne m'avait jamais proposé de jouer un rôle actif dans ses activités. Je suis privilégiée, mais je suis parfois confrontée à des circonstances difficiles, car l'engagement du patient et de sa famille est un nouveau phénomène au Canada.

J'ai travaillé en tant que patiente-proche ressource à des initiatives auprès de plusieurs organismes et, en plus des trois piliers des environnements propices à l'engagement que vous connaissez (qui étaient tous plus ou moins absents dans les projets auxquels j'ai participé qui ont échoués), j'ajouterais un autre ingrédient indispensable à la réussite; l'importance d'établir des relations interpersonnelles. Rien ne remplace le sentiment de connaître et de se savoir connu des autres. On peut s'imaginer que c'est impossible lorsqu'on siège à des comités provinciaux ou nationaux dont le travail se déroule principalement au téléphone, et que, comme patient ressource, on n'est jamais dans le même immeuble que les autres et qu'on ne fait pas partie du train-train quotidien. Or, selon mon expérience, c'est plutôt le contraire. La pratique d'organiser au moins une réunion initiale en personne pour permettre aux participants d'apprendre à se connaître est désormais courante. En pareilles circonstances, comme les participants doivent tous parcourir de longues distances, loger à l'hôtel et manger au restaurant, les occasions de réseautage ne manquent pas. Souvent, un dîner de groupe, des déjeuners et pauses-café permettent aux participants d'évoquer des enjeux de manière informelle, voire de les éviter collectivement ! Ces occasions sont inestimables pour moi. Elles me donnent l'impression de faire partie de l'équipe, d'avoir un lien direct avec les autres membres, et de savoir qui intervient lorsque j'entends une voix désincarnée au téléphone. Par ailleurs, comme je suis souvent invitée à raconter une partie de mon récit personnel lors de grands événements, j'y retrouve souvent quelqu'un que je connais, qui peut venir à mon secours avec un câlin réconfortant lorsque j'en ai besoin. Ce cas de figure c'est d'ailleurs produit il y a peu de temps et me fait toujours monter les larmes aux yeux lorsque j'y pense. Je ne saurais exprimer l'importance du réconfort que j'ai ressenti lorsque cette professionnelle de la santé a spontanément réagi à ma détresse en m'embrassant. À mon avis, le travail qui découle de ces événements est plus profond et satisfaisant que tout ce qui se passe localement. Lorsque les membres d'un comité vivent et travaillent côte à côte, les dîners et les cafés ne sont pas partagés à moins que la Direction n'en fasse une priorité.

Un collègue patiente ressource a utilisé une citation lors d'une réunion nationale qui tape dans le mille. Elle m'a tellement impressionnée que j'ai cherché son contexte d'origine. Thomas Merton, théologien et militant, a un jour reçu une lettre d'un jeune homme qui travaillait dur pour le mouvement de la paix dans le monde et qui était devenu complètement désabusé. Merton a écrit une lettre encourageante dans laquelle il disait : « au final, c'est la réalité des relations interpersonnelles qui sauve tout. »

Il semble donc évident qu'un organisme dirigé par une personne qui traite son personnel avec respect et compassion incarne un modèle qui peut se diffuser à l'ensemble de l'établissement et au-delà des personnes qui œuvrent dans son giron immédiat. Lorsque ce style de leadership s'installe, le ton des interactions contribue à éclairer et à orienter les activités. Les rôles que j'ai occupés au sein d'organismes de ce genre ont évolué et pris de l'ampleur au fil du temps, à mesure que nous déterminions, ensemble, quel était notre plein potentiel. Le potentiel créatif présent dans ce genre de contexte relationnel favorise des conversations intéressantes, l'émergence de nouvelles idées et même une forme d'enthousiasme à l'idée d'essayer de nouvelles choses. À bien des égards, aucun d'entre nous n'a vraiment pu se préparer à cette réalité, car nous nous aventurons essentiellement sur un terrain encore inconnu, mais dans un environnement où l'humain l'emporte sur les données et l'approche collégiale ruisselle dans tout ce que l'on fait. Et comme tout le monde incarne ces valeurs, tous les projets choisis et soutenus vont dans le même sens. À mon avis, les environnements propices à l'engagement sont ceux qui ont un cœur.

FCASS = Fondation canadienne pour l'amélioration des services de santé; IPFCC = Institute for Patient- and Family-Centered Care.

**Notes**

1. Le dicton « rien sur nous sans nous » trouve ses origines dans les traditions politiques de l'Europe centrale (latin : *Nihil de nobis, sine nobis*). Sa formulation en anglais a été invoquée par des militants handicapés dans les années 1990. Il est aussi le titre d'un ouvrage de James Charlton sur les droits des personnes handicapées. Ce dicton a été adopté par de nombreux autres groupes d'intérêts et mouvements sociaux, notamment, dernièrement, par des patients et usagers du système de santé.
2. Tout au long de cet article, les auteurs emploient l'expression « patient », un terme général visant à désigner toute personne ayant une expérience vécue du système de santé.

Elle englobe également les termes résident, client ou usager du service. S'agissant de l'engagement du patient, celle-ci peut également inclure les proches et aidants naturels du patient.

**Remerciements**

Les auteurs souhaitent remercier les nombreux dirigeants, membres du personnel, formateurs, enseignants et patients ressources de la FCASS qui ont contribué à la conception, à l'élaboration, à la mise en œuvre et à l'évaluation des initiatives de projets collaboratifs en matière d'engagement du patient et de sa famille évoquée dans cet article.

## Références

Veillez vous reporter à la liste dans la version anglaise (pp. 19–20).

### Au sujet des auteurs

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patient et du citoyen à la FCASS. Sa conception de la centralité du patient a évolué au fil des diverses fonctions et expériences qui ont marqué sa carrière au sein du système de santé et oriente à présent son travail.

**Anya Humphrey** est psychothérapeute à la retraite. Motivée par le décès de son mari et de son fils, elle est patiente-proche ressource pour le système de santé dans le but d'améliorer les soins prodigués aux patients gravement malades et mourants et à leurs proches.

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The graphic features a dark background with a large, stylized green arrow pointing right on the left side. The text 'Patient Engagement Resource Hub' is written in a bold, light green font. Below this, the text 'Find tools to engage patients and families in improving health and healthcare' is written in a white font. On the right side, there is a network diagram consisting of a central green circle connected to several smaller circles (some green, some blue) by lines of varying lengths. At the bottom, a URL is provided in a light green font.

**Patient  
Engagement  
Resource Hub**

Find tools to engage patients  
and families in improving  
health and healthcare

<https://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx>

# The Leadership and Organizational Context Required to Support Patient Partnerships

## Le leadership et le contexte organisationnels nécessaires à l'épanouissement du partenariat avec le patient

Patricia O'Connor, Mario Di Carlo and Jean-Lucien Rouleau

### Abstract

Healthcare providers and managers typically design programs based on what they believe patients need and want. Yet patients have knowledge and insight into how the system can be changed to better meet their needs, improve outcomes and reduce costs. We describe challenges in creating a culture of patient partnerships and the leadership actions and organizational context required now and in the future to support engagement-capable environments at the organizational and policy levels in Canada. Case examples illustrate the need for leaders to set clear expectations, develop the infrastructure to support patient partnerships and provide education to staff, physicians and patient partners.

### Résumé

Les prestataires et gestionnaires de soins de santé conçoivent généralement des programmes selon une conception théorique des besoins et des volontés du patient. Pourtant, le patient a des idées et des connaissances par rapport aux éléments du système qui gagneraient à être changés pour mieux répondre à ses besoins, améliorer ses résultats et réduire le coût des soins. Cet article décrit les défis liés à la création d'une culture de partenariat avec le patient pour aujourd'hui et demain, les actions que doivent prendre les dirigeants et le contexte organisationnel nécessaire pour instaurer des milieux propices à l'engagement aux niveaux organisationnel et politique au Canada. Les exemples de cas illustrent la nécessité pour les dirigeants d'établir des attentes claires, d'aménager l'infrastructure nécessaire pour soutenir le partenariat avec le patient et de former le personnel, les médecins et les patients partenaires.

## KEY MESSAGES

1. Leaders at all levels need to walk the talk by setting clear expectations, developing infrastructure and committing resources to support patient partnerships and person- and family-centred care.
2. Patients, families and caregivers need to be partners in the co-design of health system improvements as they have experiential knowledge and insight into how the system can be changed to better meet needs, improve outcomes and reduce costs.
3. Training and education of staff, physicians and patient partners in quality improvement and co-production creates a common language and a foundation for innovation.

## Background

Leading successful change in healthcare and sustaining the gains are challenging work. This work is influenced by many factors and involves recognizing the need for change and being able to mobilize the time, effort and expertise of others. Contextual factors known to be important to quality improvement (QI) success include leadership from top management, organizational culture, improvement initiatives that engage staff, resource allocation, data infrastructure and information systems and years involved in QI (Kaplan et al. 2010; VanDeusen Lukas et al. 2007). There is growing recognition that for true health system transformation to occur, those receiving care must be included in co-designing the needed improvements in care, service delivery and policy. This involves mobilizing the time, effort and expertise of patients, families and caregivers as partners working side by side with providers and managers. There is now substantial evidence that strategies to strengthen patient and public engagement are effective (Batalden et al. 2015; Bate et al. 2008; Boivin et al. 2014; Holmes et al. 2018; O'Connor et al. 2016; Verma et al. 2017) and lead to better health outcomes and lower costs (Anhang Price et al. 2014; Doyle et al. 2013; Manary et al. 2013).

Meaningful and effective partnership occurs when the trilogy of leadership support for person- and family-centred care is matched with staff skilled in delivering person-centred care and when patients and families are treated as necessary partners in care and QI (Baker and Denis 2011). Meaningful partnership involves a complex culture change in values and organizational transformation rooted in a long-term commitment and vision of what can be achieved through effective partnerships with patients, families and communities (Baker 2014; Baker et al. 2016). The Carman framework (Carman et al. 2013) serves as a useful guide in understanding the many ways in which patients and families can be meaningfully engaged at the direct care level, as well as in organizational design and governance and in policy making.

This article describes challenges in creating a culture of patient partnerships and the leadership actions and organizational context required now and in the future to support engagement-capable environments at the organizational and governance levels and at the policy level. This article reflects the authors' collective experiences and common vision in

leading patient partnership initiatives within Canada. Di Carlo is a patient partner with extensive experience in leading improvements at the local, provincial and national levels (a patient surveyor with Accreditation Canada) and a master trainer in chronic illness self-care management; O'Connor is a nurse leader who has led co-design transformations at the organizational level and supported over 100 pan-Canadian teams in co-leading QI initiatives with patient partners; and Rouleau, a physician and former dean of medicine, was the key leader in supporting the creation of a new centre at the University of Montreal for patient partnerships in the undergraduate education of all healthcare disciplines and in identifying the advancement of patient partnership research as one of the five core objectives of the Strategy for Patient-Oriented Research (SPOR) of the Canadian Institutes of Health Research (CIHR). We hope to provide actionable guidance on a set of leadership actions that people working on health system improvements, including patients, families and caregivers, can use.

## Challenges in Creating a Culture of Patient Partnerships

Many of the barriers to effective partnerships at the organizational level are cultural in nature. Although patient involvement is advocated, healthcare providers and managers typically design programs based on what they believe patients need and want. Unlike other industries that have a long history of tapping into their customers' experiences and objectives to create value for services, healthcare has largely remained focused on the experiences and objectives of providers. With true patient engagement, solutions are designed and delivered with patients rather than to or for them. Theories on shared or distributed leadership propose that a multi-level, dispersed but integrated system of leadership holds many of the keys to a whole systems approach to quality (Bate et al. 2008; Denis et al. 2001; Nelson et al. 2002). Deliberation theory further suggests that patient involvement can foster mutual influence and increased agreement between patients and professionals, resulting in collective decisions about healthcare services and policies that are more acceptable by those affected (Abelson et al. 2003). Patient involvement on healthcare boards of directors is still a relatively new phenomenon in many Canadian

provinces, with the exception of Quebec, which mandated this in 1991 with the *Act Respecting Health Services and Social Services* (Province of Quebec 1991). Evidence of multi-level involvement of patient partners in QI initiatives, although growing rapidly, is recent, and the degree to which this is consistently in place throughout all levels of a service delivery organization is still highly variable.

Reflecting broader changes in society, patients and caregivers are increasingly more vocal about their challenges with the care delivery system. Finding ways in which they can address these concerns in meaningful and constructive ways to help co-design improvements with those running the health-care system is a new developmental course for most persons. Feedback from many patient partners underscores their perception of how long it takes for decisions to be made and change to occur.

### **Leadership Actions to Support Partnerships and Co-Design**

The ultimate aim of successful patient engagement is accelerating healthcare improvement and better health outcomes, with patients and staff having collective ownership of efforts to improve their shared healthcare service. Power resides not within any one stakeholder group but within the process of co-production or co-design (Robert 2016). Borrowing from design thinking, we identified two core design elements underlying effective partnerships and co-design to guide leaders in their work. The first element is to understand the experiences, needs and expertise of patients and families (care as seen through their eyes) before moving to solutions. There are many ways of capturing the voice of patients (Alberta Health Services 2014), and their stories can serve to motivate and inspire providers to consider how experiences shared by patients may be improved. The second core element is the premise “nothing about me, without me.” In this instance, patients, families and caregivers are part of the co-design team in generating a range of ideas to solve problems in service or care delivery that matter to them and then testing and evaluating the solutions. Described below are leadership actions and case examples of how Canadian and other organizations are embedding these design principles into the building of engagement-capable environments. This list is far from exhaustive.

#### **Set clear expectations, develop infrastructure and commit resources to support patient partnerships and person- and family-centred care**

As a starting point, executive leaders enable the transformation of an organization’s culture by building a common vision, articulating the expectations and helping embed person-centred values as a strategic focus. It is their job to communicate to staff and physicians the need for change and explain

how they will benefit from having patients as partners, for example, answering the “what’s in it for me” to various stakeholder groups, showing the link between their own priorities and those of patient partners. Engagement of a wide range of stakeholders is important, and leaders at all levels play an important role in identifying champions to move priorities forward. Although co-design methods provide ideal opportunities for addressing complex change, organizations should be using a wide range of partnership activities.

At Kingston General Hospital in Ontario, strong and courageous leadership from the executive team over several years led to the deliberate integration of patients into every layer of the organizational structure, including in the hiring of all clinical staff, sending a clear message about accountability and “a new way of doing business” within the organization. A bundle of practice changes specifically aimed at improving communication with patients and families were also implemented with all staff. Similarly, at McGill University Health Centre in Quebec (MUHC), the “Transforming Care at the Bedside” initiative, with initial funding from the Canadian Foundation for Healthcare Improvement (CFHI), rolled out over five years extensive practice changes across six acute care hospitals. Building on a strong foundation of person- and family-centred care at MUHC, patients and caregivers were partnered with front-line clinical teams to identify the problems in care delivery, generate and test new ideas and then evaluate the outcomes. Grants totalling \$1M and \$1.6M of in-kind resources were critical in enabling both significant innovations in care and staff capacity to co-lead QI with patients. Ultimately, infrastructure and resources were created at the corporate level to support patient partnership opportunities in a more systematic way across all clinical programs. Co-leadership of quality committees became the new expectation, along with patient membership at many decision-making tables. Accreditation Canada acknowledged this work with two leading practice awards. Commitments to building the capacity of patients to self-manage their health conditions was supported over many years through funding the My Toolbox program, based on Stanford University’s Chronic Disease Self-Management Program. MUHC’s multi-year journey reflects the relationship between the maturation of context and the sophistication of engagement methods used.

Since 2010, CFHI has provided funding and support to hundreds of teams through its learning collaboratives, with an explicit focus on building capacity to partner with patients in QI. One organization, Huron Perth Healthcare Alliance in Ontario, was supported in its multi-year journey in person-centred care and patient partnerships, providing an excellent example of how leadership with a clear vision and strategic

focus has transformed its organization. Unit action councils were created in 2011 with patient partners as members, followed in 2012 by the change to open visitation across all their sites and the use of bedside whiteboards to improve communication with families. In 2013, the alliance created a patient experience committee, followed in 2015 by the introduction of standardized uniforms when patients indicated that they could not tell who was who among the staff; and in 2016, they implemented bedside change-of-shift reporting including families, again in response to families' requests for better information about what was happening with their loved ones. Improvements in the patient and family experience of care were matched by better efficiencies and greater staff satisfaction.

Creating the infrastructure support includes recruitment of patient partners who reflect diversity, as well as the proper match of patients and projects. Recruitment tailored to the specific illness-related quality teams allows professionals to draw upon the lived expertise of patients. Many organizations have struggled with overuse of specific patient partners, contributing to burnout. Online resources regarding recruitment and training of patient partners are available from many provinces and jurisdictions, such as British Columbia, where they recruit and train a large pool of patients and caregivers from which organizations can draw. In a Quebec study, Boivin and colleagues conducted the first cluster randomized controlled trial of public involvement in collective healthcare decisions at the population level, comparing priority setting in two different regions, one with and one without public (patient) involvement (Boivin et al. 2014). In addition to their findings of the positive influence of patient involvement in shifting priorities at the regional level, their study was notable for recruitment methods of a diversified pool of patients, which ensures a balanced representation of age, gender, socio-economic condition and health status.

Compensation of patient partners is an important issue that needs to be addressed by organizations. There is considerable variation in practices, with some organizations not even compensating patients, families or caregivers for basic out-of-pocket expenses. In Saskatchewan, policy guidelines exist where patient and family advisors are eligible to receive an honorarium, in recognition of their contributions. The Change Foundation (2017), Ontario's independent health policy think tank, has provided a decision tool developed and used internally by the organization to determine the conditions under which patient engagement participants should be paid.

**Patient partners have a wealth of experience beyond their lived experiences in the healthcare system.**

### **Provide training/education to staff, physicians and patient partners in QI and co-production**

Engagement-capable environments not only value partnerships with patients; they also focus equally on staff engagement, encouraging local innovation. They realize that a top-down and a bottom-up approach are required for real transformation. Staff satisfaction (or lack thereof) is a key driver of patient experience. Mandating that clinical QI teams must include patient partners does not guarantee that real partnerships will be developed. Clear role descriptions for all team members and patient advisors must be provided, as well as guiding principles for partnerships and the evidence that supports person- and family-centred care practices. Also, someone should be designated to facilitate active listening, shared decision-making and collaboration to gradually build trust. Fundamentally, this process involves professionals learning to share control of the decision-making processes.

Co-education of patient partners, staff and physicians on QI and change management creates a common language. Most organizations now systematically survey patients on their experience of care. But if front-line care teams have not been provided with the time and support to learn QI methods, little change will occur (Coulter et al. 2014; Robert and Cornwall 2013; Sheard et al. 2017). Feedback from patients who have been invited to work as co-design partners on QI initiatives (versus a single consultation process) is unequivocal that their involvement needs to be from the very beginning of the initiative. Tip sheets on how to successfully engage patient partners in QI initiatives, designed by patient partners, have been developed by CFHI (2018a, 2018b, 2018c). Mentoring of patient partners, preferably from experienced partners, provides them with an important peer support network.

Patient partners have a wealth of experience beyond their lived experiences in the healthcare system. In the case of Huron Perth, patient partner Cathy Bachner directed her vast skills and creativity as an elementary schoolteacher into designing and providing the training for nurses on how to conduct meaningful and effective bedside shift reports. Her multiple hospitalizations gave her invaluable insights into how care and communication "could be better if ...". A further example of patient partners lending their expertise was evident in a recent CFHI collaborative focused on improving access to specialist consultations for persons living in rural and remote areas (the Connected Medicine program). During a workshop, a group of patient partners from different teams jointly developed a survey tool to measure the effectiveness of the new consultation process based on what mattered most to them. As a global pioneer in the science of patient partnership, the Centre of Excellence on Partnership with Patients and the Public (CEPPP) at the University of Montreal prepares healthcare students from all disciplines to understand patients as partners in care (CEPPP

2018). Built on a laboratory, a school and a network of partnership experts, the centre is developing new practices that focus on dialogue and sharing knowledge to improve the patient experience and the effectiveness of healthcare.

At a more macro-system and policy level, programs aimed at strengthening chronic illness self-management skills are a strategic decision and investment with far-reaching positive impacts and return on investments. The Stanford model and the Centre ÉPIC at the Montreal Cardiology Institute are just two examples. As well, a vast amount of information is now available, from diagnostic tools to side effect profiles, which people are acting on. There is an urgent need in Canada to harness the power of “big data” through practical information-sharing electronic platforms and to optimize its use by patients and their families in self-managing their health. The CIHR Strategy for Patient-Oriented Research (SPOR) is another example of strategic leadership leveraging its resources to ensure better alignment with what matters most to patients and communities.

### **Walk the talk**

Strong, inspired and highly persistent leadership is necessary to overcome barriers to engagement and to demonstrate what it looks like in practice. This needs to come from organizational leaders, clinicians and patient partner leaders. It involves clearly articulating the organization’s goals related to partnerships, being visible as a leader, asking how the partnerships are going, ensuring that patients or caregivers are present at all levels of decision-making, conducting regular rounds to support teams, ensuring robust measurement and evaluation, celebrating progress and communicating the results extensively within and outside the organization or network. Organizations recognized for having achieved significant culture change have been highly focused, directing resources to ongoing learning of all staff and physicians and toward the development of real-time data platforms that provide continuous feedback on patient experience of care and clinical outcomes. They then hold their staff accountable for using that data to drive the next stages of improvement, in partnership with patients, families and caregivers.

Southcentral Foundation (SCF), an Alaska Native-owned non-profit healthcare organization serving Alaska Natives and Native Americans, is a prime example of leadership “walking the talk.” A winner of the 2011 and 2017 Malcolm Baldrige National Quality Award, SCF is recognized as one of the world’s leading models of healthcare redesign, built upon the simple yet revolutionary belief that the relationship between the primary care team and the patient (known as the customer-owner) is the single most important tool in managing chronic disease, controlling healthcare costs and improving the overall wellness of a population. The focus on relationships extends beyond healthcare delivery. To ensure whole-system transformation, each key work system was redesigned – including workforce

development, compliance, human resources and finance – to ingrain an organization-wide focus on relationship building and shared decision-making. Patient satisfaction/experience ratings are 95%, whereas employee satisfaction is 95%, and SCF has been pursuing these improvements since 1998. SCF serves as an outstanding example of the relationship between maturation of context and use of sophisticated, multi-level engagement behaviours over time.

On a smaller scale, Bruyère Continuing Care in Ontario serves as a case example of how organizational commitment to improving transitions in care by better understanding care through the eyes of patients can lead to multi-level practice changes. A CFHI-funded team between 2014 and 2015, Bruyère implemented Always Practices – aspects of the patient experience that are so important to patients and families that healthcare providers must perform them consistently for every patient, every time. Bruyère heard from its advisory committee that patients and families wanted to be more included in their plan of care, so staff began conducting bedside handovers using patient-co-designed care boards. Patients indicated that they wanted to see their nurses more, so Bruyère instituted hourly rounding. Clinical teams told leaders they wanted better communication, so priority huddles and lists became part of the intervention bundle. In addition, Bruyère developed a volunteer ambassador program, established a patient and family advisory committee and partnered with CCAC and the Champlain LHIN to open its Path to Home Resource Lounge. In 2016, these changes were recognized as Leading Practices by Accreditation Canada.

At the macro-system level, several examples are noteworthy. Patients, families and caregivers are mobilizing to accelerate change through the creation of forums such as Patients Canada, the Patient Advisory Network, the Patients Critical Co-op and a plethora of illness-specific associations, all aimed at advocating for a stronger role in shaping health policy, service delivery, research or education in Canada. In both Saskatchewan and Prince Edward Island, leaders walked the talk by implementing policy changes to support open visitation by families and loved ones across the province, recognizing their role as partners in care, not just visitors. CFHI has been a powerful leader in stimulating transformative change within organizations through its funding priorities, its learning collaboratives with skilled coaching to interprofessional teams and patient partners and the hiring of a patient partner in 2017. The Canadian Patient Safety Institute (2016) also strongly promotes patients as partners in all of their work promoting safer healthcare environments. Accreditation Canada and Health Standards Organization have leveraged their influence by setting new standards related to person- and family-centred care and by including patient surveyors as part of the accreditation review team.

## Reflections on the Future

There has been considerable progress in Canada in developing knowledge and leading practices related to partnering with patients, families and caregivers. Although there are encouraging signs that the culture is starting to shift, we are still a way off from being able to demonstrate that patient partnerships have become culturally embedded in the norms and values in “the way we do business” – where patients and staff have collective ownership to improve their shared healthcare service. Increased awareness of the value of partnering with patients to improve care, service delivery and health outcomes needs to be matched with long-term strategy from leaders in developing more comprehensive and systematic approaches to engaging patients, families and caregivers as true partners in transforming our healthcare system. Ministries of health could leverage their influence by prioritizing measurement of patient experience as a key performance indicator across sectors and by mandating patient-partnership involvement (e.g., patient membership on boards, quality committees and other decision-making fora). Upstream interventions include changing university curricula for healthcare disciplines and, at a policy level, investing to increase patient capacity for self-management as this improves patient activation and lowers healthcare expenditures. One thing is clear: patients and their loved ones want to be co-leading this change. It is time for leaders at all levels of care and service delivery to recognize the potential and expertise of patients in co-leading system improvements to better respond to what matters most. **HQ**

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# Development of Patient-Inclusive Teams: Toward a Structured Methodology

## L'accueil du patient dans l'équipe clinique : vers une méthodologie structurée

Marie-Pascale Pomey, Paule Lebel, Nathalie Clavel, Édith Morin, Mireille Morin, Catherine Neault, Benoît Tétreault and Anna-Paulina Ewalds Mulliez

### **Abstract**

Over the last few years, the role of patients in the health system has become essential to improving the quality of care and services. However, the literature shows that patient engagement is not always ideally applied to improve the quality and safety of care and that patient engagement can be tokenistic. Through experiences conducted in Quebec, it is possible to outline a structured process involving both professional stakeholders and patients that illustrates optimal conditions to be applied for successful teamwork involving patients.

### **Résumé**

Au cours des dernières années, le rôle des patients dans le système de santé est devenu essentiel pour améliorer la qualité des soins et des services. Cependant, la littérature montre que l'engagement des patients n'est pas toujours réalisé idéalement pour améliorer la qualité et la sécurité des soins et que l'engagement des patients peut être symbolique. Au travers de l'expérience menée au Québec, il est possible de faire ressortir un processus structuré portant à la fois sur les intervenants et les patients, qui permet de mettre en œuvre les conditions optimales à une réussite du travail d'équipe incluant des patients.

**KEY MESSAGES**

1. The success of teams that include patients rests upon a structured process applied not only to patients but also to professionals, to identify patient partners who wish to get involved and stakeholders motivated to transform their practices.
2. This structured process involves raising awareness at all levels of a health institution, selection and training of all team members, co-leader facilitation by a patient-professional duo, stakeholder coaching and mentoring and, finally, recognition of the work achieved by the team.
3. An evaluation of the contribution of the professionals and the patients must be systematically carried out to continuously improve the different approaches throughout the process, allowing teams to work in a harmonious way.

**Introduction**

Over the last few years, the role of patients in the healthcare system has become essential to improving the quality of care and services (Armstrong et al. 2013; Baker et al. 2016; Coulter 2012; Coulter and Ellins 2007; Grande et al. 2014; Groene et al. 2014; IHI 2014; Pomey and Lebel 2016; Richards et al. 2013). Indeed, only patients and their families know what it means to live with illness on a daily basis (Jouet et al. 2012; Pomey et al. 2015b), and they possess an integrated view of the organization of care and services within any care setting (Batalden et al. 2016; Cunningham and Walton 2016). In fact, Accreditation Canada revised all of its accreditation standards in 2016 to introduce, on the one hand, the need for care and services to be delivered in partnership with patients and their families and, on the other hand, the need for standards to be evaluated not only by health professionals and managers but also by patients and their families (Accreditation Canada 2015). However, the literature shows that patient engagement is not always ideally applied to improve the quality and safety of care. A recent literature review found that methods to engage patients at the clinical, organizational or political level of the healthcare system are not always optimal (Bombard et al. 2018) and that the patient's engagement can be tokenistic (Tritter and McCallum 2006). Indeed, patients sometimes report not making real contributions to decision-making because their input is not taken into account or because decisions are made before their participation (Todd et al. 2000). Also, beyond evaluating the openness of care teams and managers to work with patients, how can organizations ensure that these teams and individuals are well prepared to engage with them? This additional step of preparing teams for engagement is needed to affirm the pertinence of patients' and families' added value to care teams in different healthcare settings and at different levels of governance (AHRQ 2013).

In this article, using examples from the patient partnership movement emerging in Quebec, we present best practices to prepare teams to better engage with patient partners and families and show how teams appreciate patients' and families' engagement. In Quebec, the Ministry of Health and Social Services (MSSS) has incorporated patient partnership into its strategic orientations (MSSS 2015) and developed a framework for this approach (MSSS 2018), and the development of the Centre of Excellence on Partnership with Patients and the

Public (CEPPP) at the University of Montreal is helping to bolster the science of partnership and facilitate the integration of patient partnership into training, research and the healthcare system (CEPPP 2018). Different modalities and levels of patient engagement show how teams can be active in different settings (e.g., institutions of healthcare, primary care) and at different healthcare system levels (political, organizational and clinical).

In Quebec, the Montreal model (Pomey et al. 2015a) is one of patient partnership in healthcare and social services that is based on three main principles: (1) the recognition that patients and their families have experiential knowledge of a health situation and the use of services; (2) the acknowledgement of the status of patients/family members as full members of the (care) team; and (3) the recognition of their ability to make free and clear decisions based on their life goals.

**The Approaches and Levels of Engagement of Patients in Teams**

From the work of Carman et al. (2013) and Pomey et al. (2015a), it is possible to identify different contexts and situations that can lead teams to work with patients either at the clinical, organizational or political level.

**Approaches of engagement**

Knowing that patient engagement can take place on a continuum from information to co-construction (Carman et al. 2013; Pomey et al. 2015a), we focus here on how to prepare teams for collaboration and co-construction in partnership. By collaboration, we mean that patients are present to share their needs so that their perspective is taken into consideration. At the partnership level, engagement goes one step further to where involvement of patients leads to the co-construction of interventions or solutions.

**Levels of engagement**

At the clinical level, coherent with the principles of the Montreal model of partnership in care mentioned above (Pomey et al. 2015a), it is desirable to integrate patients and their families when developing their own interdisciplinary intervention plans. When patients require the coordination of several professionals for their health problems, it is important to create a specific moment(s) during which they can discuss

with their care team members their priority needs, life goals and previous experiences with the disease and its treatments. Through these exchanges, patients, helped by health professionals, can make the best decisions to meet their own health expectations, and, concurrently, their healthcare professionals will understand why their patients prefer certain aspects of treatment when compared to others.

Another example of the integration of patients at the clinical level is the integration of peer patients into the care team as a service offered complementary to that of other health professionals. Accompanying (peer) patients are individuals who have had significant experience with a health condition and are willing to use this experience to help other patients facing similar situations (Vigneault et al. 2015). This model, which was notably developed in the area of mental health in the context of peer helpers (Repper and Carter 2011), can also be applied in other areas of medicine where patients have episodes of care that can have a significant impact on their everyday lives. Working in conjunction with other healthcare professionals, these accompanying patients provide both emotional and informational support related to the lived experience of the health condition encountered.

Engagement of patients and families at the organizational level can encompass all situations related to the organization of the delivery of services. This engagement can be at the strategic level, for example, in a managerial committee (Ewalds Mulliez et al. 2018), or at an operational level, such as in a continuous quality improvement team preparing for the accreditation of a health institution (CPSI 2017). In this context, patients are using their lived experience to guide and co-construct solutions to the benefit of all patients who may use these services that require development or improvement.

At a political level, we find patients and families engaged with policy makers and other experts, finding solutions for communities, helping to define public policies and establishing health priorities and resource allocation (Pomey et al. 2015a).

In Quebec, during the development of the reference framework of the partnership approach between patients, their relatives and health and social services professionals, patient partners were also integrated into work teams with the MSSS (MSSS 2018).

### **Best Practices for Preparing Teams for Engagement and Partnership with Patients and Families**

One of the reasons that can be invoked to explain the mixed results of patient engagement in the literature (Bombard et al. 2018; Todd et al. 2000; Tritter and McCallum 2006) is the lack of rigorous preparation, on the one hand, of teams to work with patients and families and, on the other hand, of patients and families to be ready to engage. A methodology for structuring

team preparation to work with patients has been set in place to optimize engagement that leads toward collaboration and co-construction. To describe this method, we take the example of Quebec's Partnership in Care Program (PCP) (Pomey et al. 2015c). This program launched in 2011 and enabled 26 teams from different institutions or organizations (hospitals, family medicine groups and long-term care residences) to set up continuous quality improvement committees (CICs) including patient and family partners. These CICs had wide-ranging mandates and reached areas as diverse as logistics, space planning, administrative decision-making, including clinical organization, and the relational and educational aspects of care.

### **Raising awareness among directors and managers is essential for the smooth implementation of teamwork with patients ...**

#### **Awareness**

When teams are mandated to work with patients, it is essential that at the level of governance, where the commitment to engage patients has been made, there is an adherence to the partnership approach and to the structured methods to be implemented. During implementation of the PCP, the program was presented to the executive directors of the health and social services institutions involved to ensure that they understood and adhered to an overall philosophy of partnership in care and services as well as to the importance of teamwork, including clinical managers, professionals and patient partners. Raising awareness among directors and managers is essential for the smooth implementation of teamwork with patients because when these individuals adhere to this philosophy, they are thus more inclined to allocate the necessary resources to fulfill this commitment. The PCP allowed time for the participation of professionals/personnel in the conduct of the program. Also, leaders in departments for which CICs were set up were also interviewed to ensure that they understood the partnership program and thereby allocated the resources necessary for the realization of these committees.

A communications plan should be considered from the beginning to ensure that each stage of the team's work will capture relevant information to be publicized at the right time and to the right stakeholders, including an emphasis on the positive impact of the engagement of patients. In the PCP, presentations to the entire team were made so that all team members were aware of the current process of patient engagement. Stakeholders were also made aware via communications on the organizations' websites or in local newspapers.

#### **Selection and preparation of team members**

When a team is interested in or has been chosen to work with patient partners and families, special attention must be paid to

the team's mandate. The nature of the mandate will help determine the constitution of the team to ensure that the people chosen are the best to respond to the mandate's objectives and to determine the profile of patients who will have the necessary significant experience of care and services.

In many institutions in Quebec, personnel of quality improvement departments are identified to support the development of patient partnership. These individuals can help with the selection and preparation of patient partners. For example, recruitment begins with the identification of potential patient partners via clinicians, patient associations or calls via social media. The patients are then selected, if possible, by a duo made up of a patient recruiter and a qualified manager or staff person in charge of partnership. The patient recruiter is often a patient who has had previous experience working in partnership with professionals, managers or healthcare leaders. The recruitment of the patient partner is made by this duo through a telephone or face-to-face (in-person) interview based on predetermined criteria (see the example in Box 1). In all cases, it is important to recruit patient partners who want to get involved as well as teams of professionals motivated to transform their practices.

#### **BOX 1.**

##### **Patient selection criteria**

- Expresses him/herself clearly and simply
- Expresses general health network concerns through a constructive attitude in his/her interventions
- Has significant life experience with the disease
- Has significant experience in healthcare and services targeted by the project
- Is in a steady state of health at the time of recruitment (not in an acute or crisis situation)
- Has the ability to share his/her own experience with the disease and has learned to live with it
- Can generalize his/her own experience to other contexts of care
- Demonstrates a desire to help people and contribute to an objective that goes beyond his/her individual experience
- Has interpersonal skills to facilitate collaboration (listening, empathy, etc.)
- Has a critical mind, even within teams in which he/she has already been a patient
- Understands the vision and implications of the partnership in health(care) model
- Is available and motivated to commit during the duration of the project

Source: Direction collaboration et partenariat patient 2015.

Once selected, patients and family members are given training on patient partnership in care and services and on co-construction. This training can be given either by the individual(s) in charge of patient partnership in the quality improvement departments, ideally with patient partners as co-trainers, or by CEPPP, which offers training both online

and in person. Training can be done for patients and for professionals independently or simultaneously; however, training of the whole team together is preferable to begin team building and cohesion. In some circumstances, the number of patient partners recruited can be equal to the number of professional stakeholders as this can help promote co-construction.

In the PCP, the creation of the CIC made it possible to establish the number of people, between six and eight, necessary to constitute these teams. The composition of the team took into consideration representation of the different professionals of each program. These professionals were motivated to participate, were recognized as leaders by their peers and had sufficient time to attend meetings and complete work between these meetings. Patients were recruited in sets of two for each committee so that they would not feel isolated and to ensure the presence of at least one patient partner in case the other was not able to participate. Recruitment and training were done at the same time for all CIC members, supported by external expert patient recruiters.

#### **Realization of the mandate**

One of the optimal factors for teams to achieve a mandate that meets SMART (Specific, Measurable, Attainable, Relevant and Timely) objectives is the presence of two key players. The first is an individual who coaches professionals and managers, and the other is an individual who coaches patients and families. The person who coaches patients and family members is a patient coach who has experience working in partnership with professionals and managers. These coaches help ensure that all team members understand what is expected of them; they are also responsible for the smooth running of work sessions (Baker et al. 2016; CPSI 2017; CPASS 2014; Pomey et al. 2015c), including ensuring that the teams have structured agendas, along with accessible documents with adequate levels of literacy (CPASS 2014; Pomey et al. 2015c). This support helps prevent patients from being used in a tokenistic way. Another important element in achieving the mandate is to favour shared leadership between a patient and a healthcare professional. Indeed, the facilitation of a working group by a patient-professional duo makes it possible to balance powers and to ensure that the point of view of patients is taken into consideration at the same level of importance as that of the care provider. During the mandate, testimonials from patient partners at different levels of the organization can also help support the implementation of the patient partnership model with other internal stakeholders.

In the case of the PCP, health organizations identified individuals, called institutional collaborative leaders (ICLs), to stimulate and support collaboration among patients, managers and clinicians. In complement, patient coaches supported and accompanied other patient partners to ensure that these

patients could express themselves freely and respectfully. In case of problems, patient coaches also played the role of mediator with other members of the team in collaboration with the ICL to find solutions. The CIC teams were facilitated by a team manager; however, it would have been interesting to go as far as to co-animate with one of the two patient partners. Patient partners who participated in the CIC were not paid but were able to receive compensation for costs incurred to participate in these activities. Information on the status of the CIC's progress was regularly presented to upper management committee(s) of the institutions.

The presence of patients in committees also raises the question of remuneration or compensation. Current MSSS regulations prohibit remuneration of patients by public healthcare institutions (MSSS 2018). However, it is possible to consider these patients as volunteers and, as such, to compensate them for the costs incurred by their engagement (e.g., transportation, parking, meals).

**The selection of managers to carry out the approach within the organization is crucial and must be strategic ...**

### Assessing patient engagement

One point that is too often neglected is the importance of assessing the contribution of patient partners and professionals as well as their experience of the work conducted together (Pomey et al. 2017). Indeed, throughout the life cycle of a mandate for teams including patient partners, it is important to evaluate (i.e., via questionnaires or interviews) not only the progress of the work but also the perception of team members. These assessments, whatever the form, should allow stakeholders to reflect on what they did or did not like and to suggest ways to improve. Increasingly, new questionnaires are being developed to make this type of assessment possible (Phillips et al. 2015). Another important activity is to ensure that all members of the team are recognized for their commitment and are made aware of the impact they have had on the future and continuation of each mandate. This can be done through written acknowledgements (i.e., letters, e-mails, recognition on reports, etc.), oral communications (telephone calls) and acknowledgement at the organizational level (e.g., internal and external publications).

Halfway through the mandate of the CIC, an autoreflexive exercise within the teams helped adjust the mechanisms of co-construction and optimize the partnership between care providers, managers and patient partners. At the end of the CIC, both patient partners and the professionals completed a questionnaire on their experience that revealed great satisfaction from both groups on the process of co-construction and of the achievement of the objectives pursued. Interviews with

managers at various levels of governance of the institution(s) and members of the CIC highlighted the factors that facilitated the implementation of patient partnership within each institution. CIC products (e.g., clinical pathway algorithms, educational tools, websites, questionnaire results and surveys) were disseminated within and across institutions. The contribution of all members was systematically recognized by certificates or recognition events, supported by the communications plans implemented by each institution.

### Conclusion

The engagement of patient partners in teams needs to be structured not only for the patients involved but also for all stakeholders in these teams. A formal methodology to prepare and structure teamwork with patients has been implemented in Quebec to optimize engagement that leads toward collaboration and co-construction in partnership. This methodology is composed of four steps: (1) awareness, (2) selection and preparation of team members, (3) realization of the mandate and (4) assessment of patient engagement. Raising awareness requires a strong management team with the courage and audacity to transform an institution by embracing the patient partnership model. Partnership should be seen as everyone's business, from the CEO to orderlies. The selection of managers to carry out the approach within the organization is crucial and must be strategic as these individuals will champion and embody this partnership model. The second step requires the establishment of a structure allowing for the identification, recruitment, training and coaching of patient partners and their professional counterparts either at a central function or at the level of each program. It can be helpful to ask for support from external expert organizations to enhance this process. Moreover, a communications plan must be in place to mobilize regular patient testimonials at key moments during implementation of the patient partnership model. As the mandate progresses, patients, families and caregivers must be supported throughout the engagement process to help free them from concerns in what can sometimes be uncharted territory for all stakeholders. Team members will learn in action through a reflexive approach led by an experienced professional or a professional/patient partner tandem. To optimize engagement, it is important to evaluate the teamwork throughout to ensure that patients are never used as tokens and that their participation is well recognized through an assessment of their contribution. Finally, the will and perseverance of committed leaders; appropriate preparation of management, teams, patients and families; support for sustained engagement; and stimulating and charismatic efforts from both patient and professional champions will eventually pave the way toward a more humanized healthcare system. **HQ**

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# Patient Roles in Engagement-Capable Environments: Multiple Perspectives

## Le rôle du patient dans un milieu propice à l'engagement : perspectives multiples

Paula Rowland, Mireille Brosseau and Claudia Houle

### **Abstract**

Engagement-capable environments have well-defined roles for patients. These roles are often described in terms of their functional aspects. In this paper, we provide a complementary way of thinking about patient roles: an interactionist perspective. For interactionists, roles evolve through social interactions and contextual demands that shape how the work is performed. Drawing from a case example at Health Standards Organization (HSO), we demonstrate the need for engagement leaders to attend to functional descriptions of patient roles and their interactive possibilities. Finally, we argue for the connection between multiple patient roles and engagement-capable environments.

### **Résumé**

Le milieu propice à l'engagement du patient lui propose des fonctions bien définies. Ces fonctions sont souvent décrites en termes d'aspects fonctionnels. Dans cet article, nous proposons une manière complémentaire d'envisager le rôle du patient : une perspective interactionniste. Pour les interactionnistes, les fonctions évoluent au fil des interactions sociales et des exigences contextuelles derrière l'organisation du travail. En se fondant sur un exemple de cas de l'organisation de normes en santé (HSO), nous démontrons la nécessité pour les responsables de l'engagement du patient de s'attacher aux descriptions fonctionnelles de son rôle et à ses possibilités interactives. Enfin, nous plaidons en faveur de liens entre les diverses fonctions occupées par le patient et les milieux propices à l'engagement.

**KEY MESSAGES**

1. Engagement-capable environments embed meaningful engagement throughout the core work of the organization, providing support to patient roles and ensuring their success.
2. Patient roles are a result of both functional descriptions and emergent interactions. The success of patient roles relies on both functional and interactional aspects, combined with clarity about the purpose of the role.
3. Engagement-capable environments have a range of well-defined patient roles and multiple strategies to ensure access to a variety of voices of patients who might not otherwise participate in engagement activities.

**Introduction**

Patient engagement is viewed as an important quality improvement lever with the potential to transform health-care organizations. This emphasis certainly refers to patients engaged in their own care but also includes patients participating in a range of organizational decision-making that will influence the care and work of others. This may mean patients becoming involved in a range of organizational activities, including program planning, evaluation, research, training and recruitment. Organizations that have been recognized as leaders in these kinds of patient engagement practices have been labelled as “engagement-capable environments” (Baker et al. 2016a). Although many organizations may engage patients in various activities, clearly defined and specified roles for patients are a distinguishing feature of engagement-capable environments.

With this increased clarity and specificity on patient roles as part of patient engagement efforts there is an opportunity to meaningfully reflect on these roles. The purpose of this reflection is to take stock of what is being learned about these activities in practice while also benefiting from existing research that could inform ongoing and pressing questions about patient engagement. To this latter point, there is a rich tradition of research on roles in the social sciences. In this tradition, there are two main conceptual camps: (1) those that consider roles as particular kinds of *functions* and (2) those that consider roles in terms of their *interactions* with others. Although these camps are not mutually exclusive, they tend to draw different conclusions about how various roles could be best supported and how their impacts should be evaluated.

In this brief essay, we offer examples of patient roles in terms of their functional features. These examples are drawn from Baker and colleagues’ (2016b) casebook on patient engagement as well as lived examples of patient engagement work at Health Standards Organization (HSO) and its affiliate, Accreditation Canada. To complement this functional perspective, we also draw attention to various reflections on the interactive nature of these roles. These interactive roles are alluded to within the aforementioned casebook, are reflected upon at HSO and are actively explored in the social sciences. Throughout this essay, we are not attempting to create a dichotomy between functional roles and interactive roles. No such dichotomy exists in practice as patients fulfill

both functional and interactive roles in patient engagement initiatives. Instead, we are simply offering additional conceptual tools by which to understand patient roles as part of patient engagement practices. In doing so, we hope to inspire insightful questions about important concepts in patient engagement: how do we define and support purposeful roles for patients and others involved in engagement processes?

**Theory Burst: A Brief Introduction to Social Science Perspectives on Roles**

Role theory presents an interesting and long-standing dilemma in the social sciences (Biddle 1986). Although the concept of role features prominently in the study of society, organizations and groups, there tends to be little agreement on the definition of “role.” For the purposes of this essay, we simplify this debate to two perspectives: functional and interactive. Those that take a functional perspective on roles tend to focus on the various norms and expectations that shape the behaviours of individuals in those roles. The emphasis is put on technical role expectations and how these expectations will be governed in an organization. Thus, roles are considered in terms of how people will be recruited, what knowledge and skills they are expected to have and how performance will be managed. In contrast to this functional perspective, those that take an interactionist perspective argue that roles are not entirely described according to their assigned tasks but evolve through social interaction, contextual demands, various negotiations and evolving understandings of the present situation (Goffman 1959). For interactionists, job descriptions and performance management systems are just one resource among many that shape how the role is performed. Taking these ideas to the study of patient engagement practices, we can see much attention to the functional aspects of patient roles. Less discussed are the interactionist perspectives on patient roles. This is far more contested territory and requires some additional consideration.

**Descriptions of Patient Roles: Functional Aspects**

Over time, the roles of patients as participants in patient engagement activities have become more clearly defined. In Baker and colleagues’ casebook (2016b), these roles are primarily described functionally. Such roles include: serving as members of various committees, acting as patient and family

advisors, providing direct service as patient and family support coordinators and providing peer support and/or education for other patient and family advisors. In the casebook, these roles are described in terms of the kinds of patient knowledge that the individual brings to the activity at hand. Sometimes this knowledge is described almost entirely in terms of someone's knowledge of his or her illness and associated experiences in healthcare organizations. At other times, patient knowledge also includes insights developed through training and experience as a patient advisor. For example, acting as a peer support for other patient advisors requires not just knowledge of one's illness but also the ability to impart knowledge about the practice of being a patient advisor.

Along with functional roles come clearly defined documents and policies. Thus, some organizations have explicit application processes – including the requirement for a resumé and an interview process – prior to a patient being enrolled into a particular activity. Job descriptions and terms of reference also serve to increase the formality of these roles, providing explicit expectations about how these roles will be enacted with the organization. In one sense, this level of formality signals the organizational importance being placed on these roles. As a necessary corollary, this explicitness also provides an avenue for organizations to potentially exclude patients who cannot (or will not) meet these expectations. Therefore, the emphasis on functional roles may have some unintended consequences, potentially creating a dynamic where patient roles become exclusive, reserved only for those who can demonstrate the required competencies. This is why the focus on engagement-capable environments is so vital. To be a truly engagement-capable environment, an organization must support a full range of engagement, including a myriad of functional roles and a range of ways to access the voices of patients who do not participate in formal or functional roles.

### **Interactionist Perspectives on Patient Roles: Social Science Contributions**

In healthcare, we tend to talk about roles in the functional sense. For example, we talk about teams that involve patients, physicians, nurses, health professionals from other disciplines, quality improvement leaders and administrators. However, each of those role descriptions relies primarily on assumptions about the knowledge base of each person. Patients know about their illness experience, physicians know about medicine and so on. Yet none of those knowledge-based descriptions are explicit about the interactive roles fulfilled by each individual. Such descriptions are usually beyond the scope of how we talk about roles in our organizations. To get a sense of how people interact with one another in these roles, we need to go to the social sciences.

In social science studies of patient engagement, we develop a complex picture of how patient roles play out in organizational contexts. Social scientists have described patients acting as knowledge brokers, connecting and translating knowledge across communities of clinicians and communities of patients (Martin 2008), as symbolic representations of ideals (Rowland et al. 2016), as sources of persuasion for clinicians who require convincing about the need for a change (Armstrong et al. 2013), as informed observers of organizational practices (Rowland et al. 2018) and as mechanisms for challenging dominant perspectives in healthcare (Ocloo 2010). Of course, a discussion of the interactive roles fulfilled by patients would not be complete without acknowledging the critical social sciences. Critical social scientists worry that patients' roles are being used to support managerial intentions, primarily to provide patient endorsement to otherwise unpopular decisions (Carter and Martin 2017; Madden and Speed 2017). In this case, the interactionist role being served is related to managerial interests, where patients bolster the power and credibility of managers through their involvement. Therefore, to take into account the interactionist perspective means to constantly pay attention to how the role is emerging and to anticipate that not all impacts can be predicted.

**... an organization must support a full range of engagement, including a myriad of functional roles and a range of ways to access the voices of patients who do not participate in formal or functional roles.**

### **Case Example: Health Standards Organization**

The previous sections offered two perspectives on patient roles: a functionalist perspective and an interactionist one. However, this is a conceptual divide. In practice, the functional and interactional aspects interact within a single individual. The ways in which they interact are important to consider. To illustrate this point, we draw from an example of a patient role at HSO, highlighting lessons that have been learned over time. HSO is a non-profit organization dedicated to developing standards, assessment programs and other methodologies to enable health and social service providers to advance on their quality journey. Accreditation Canada provides accreditation and assessment programs in Canada and around the world. In our example, we explore the development of a specific functional role: patients as members of an accreditation survey team.

For many years, the on-site portion of the four- to five-year accreditation cycle has been an essential element of Accreditation Canada's assessment process. Traditionally, this on-site assessment has been conducted by "peer surveyors," individuals who are healthcare leaders in organizations other than the organization being assessed. In 2017, Accreditation

Canada started to introduce patients<sup>1</sup> as part of this on-site assessment process. The functional definition of this role meant that patients would be working alongside peer surveyors as part of the on-site assessment. However, much needed to be discovered about how this role would interact with peer surveyors, as well as with the patients, staff and leaders of the healthcare organizations undergoing assessment.

Over a period of 10 months, a group of staff, peer surveyors and patients worked together to define the role of patient surveyors, how these roles were both distinct and complementary to the peer surveyors and what processes needed to be in place to support their unique contribution to the survey team. Collaboratively, the group determined that patient surveyors would have a lead role in assessing criteria related to people-centred care (PCC) processes and structures – specifically, the ways in which organizations espouse “an approach to care that consciously adopts individuals’, carers’, families’ and communities’ perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people” (World Health Organization 2016). This interactive element eventually became solidified into a functional description, made more visible through the scripting of a PCC “priority process.”<sup>2</sup> This process was developed to ensure that surveyors were at the right place and time to hear from the staff, patients and leaders of organizations being assessed about how they implement PCC in governance, leadership and service excellence. What started as reflective and collaborative observations on interactive processes became organized into functional descriptions of the role. Evaluation of this process of role creation has been an important part of the overall learning.

Although the patient surveyor focuses on PCC priority processes, the assessment tasks of the patient surveyor are not substantively different from those of any other peer surveyor. However, the working assumption is that including a patient in the assessment process will broaden the range of interactive possibilities. Specifically, there is reason to think that patients within the organization under assessment may provide different insights to someone identified as a “patient surveyor.” Thus, the theory of change animating this particular strategy is strongly interactional, based on the proposition that patients will interact differently with patient surveyors than they might with a peer surveyor. It is expected that pairing the patient’s unique lived experience with the expertise of peer surveyors will lead to a deeper and more comprehensive assessment of organizational performance, ensuring a robust and inclusive process.

**The opportunity is to create mechanisms for more robust conversations that take in the range of human experiences, helping us to ... make better decisions about healthcare.**

We have highlighted the patient surveyor role as an example. However, it is important to note that this role does not exist in isolation at HSO. The work of patient surveyors – indeed, the work of all surveyors – is inherently dependent on the quality of the standards developed, which then serve as the foundation of the assessment process. Without appropriate, meaningful and robust standards, the assessment process would fall short of its desired aims. At HSO, patients are deeply involved in helping to shape these standards. This again points to the importance of an engagement-capable environment that embraces meaningful engagement as embedded throughout the core work of the organization. Individual patient roles – no matter how well planned, supported or implemented – cannot reach their full potential in isolation.

### Implications for the Future of Patient Engagement

With the increasing emphasis on patient engagement and various functional roles available to patients within organizations there is both opportunity and risk. The opportunity is to create mechanisms for more robust conversations that take in the range of human experiences, helping us to collaboratively and collectively make better decisions about healthcare. The risk is that these patient roles may unintentionally become relatively elite, potentially excluding the voices of those who cannot (or will not) participate in such formal ways. To foster the opportunity while remaining sensitive to the risk will require ongoing learning and reflection. Engagement-capable environments of the future may be best described as having multiple patient roles, acting within multiple processes throughout the organization and accompanied by robust strategies for accessing the range of voices not otherwise represented. Furthermore, these roles need to be intentionally shaped – not just by their functional descriptions but also by the interactional possibilities – with great shared clarity as to the purpose of the role.

### Concluding Thoughts

In this paper, we have argued that the functional descriptions of patient roles only tell part of the story of the success of engagement-capable environments. Through these past years of working toward engagement-capable environments, we have learned that the commitment to the work is expansive. As a result, we often find that recruitment is not the most difficult aspect of engagement. The hard part is designing and implementing engagement activities so that they make a meaningful difference to the work at hand. Given the complexities of organizational change, these difficulties are expected. That this is difficult work does not diminish its importance. Instead, it reflects the social complexity of creating new roles within existing organizations, anticipating how these roles will interact with existing structures and where the opportunities

for transformative change will lie. Considering both the functional and interactional aspects of these roles is foundational to their success and the success of engagement-capable environments. **HQ**

## Notes

1. Depending on the health setting or context, patients may be referred to as clients, residents or community members and individuals could include carers and families.
2. HSO defines priority processes as critical areas and systems within an organization that have a significant impact on the quality and safety of the services provided. A priority process is made up of a group of criteria taken from one or more sets of standards and is an efficient way for surveyors to assess compliance with the standards.

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# Implementation of Patient Engagement in the Netherlands: A Stimulating Environment within a Large Academic Medical Centre

## Déploiement de l'engagement du patient aux Pays-Bas : un milieu stimulant au sein d'un grand hôpital universitaire

Marjan J. Faber, Thomas W. Vijn, Marja C.M.C. Jillissen, David Grim and Jan A.M. Kremer

### **Abstract**

Patients are the official third party of the Dutch healthcare system, apart from healthcare providers and insurers. Radboud university medical center (Radboudumc) is a regional centre for specialized secondary care in the Netherlands. Here innovation is recognized as a decisive factor when it comes to the implementation of patient engagement. Therefore, all employees are invited to innovate, experiment, fail and implement promising innovations into practice. In this paper, we demonstrate how this stimulating environment led to a rich collection of patient engagement activities in organizational (re-)design and in educational programs for students and employees.

### **Résumé**

Les patients sont une tierce partie officielle du système de santé néerlandais, en plus des prestataires de soins de santé et des assureurs. L'hôpital universitaire Radboud (Radboudumc) est un centre régional de soins secondaires spécialisés des Pays-Bas. L'innovation y est reconnue comme un facteur probant du déploiement de l'engagement du patient. Tous les employés sont donc invités à innover, à expérimenter, à échouer et à mettre en pratique des innovations prometteuses. Dans cet article, nous montrons comment ce milieu stimulant a conduit à une abondante collection d'activités relatives à l'engagement du patient dans la conception ou la refonte organisationnelle, ainsi que dans des programmes de formation destinés aux étudiants et aux employés.

**KEY MESSAGES**

1. Support the non-homogeneous evolution of engagement in which employees are free and motivated to experiment. Allow initiatives to fail.
2. Build long-term relationships with patients by involving them from the beginning until the end.
3. Create an environment that is comfortable and makes involvement meaningful:
  - For patient engagement at the organizational design and governance levels, ensure that patients stay in their role of patient, guaranteeing that they make a unique and complementary contribution.
  - For patient engagement at the level of direct care, ensure that each patient is seen as a person, with a unique and complementary perspective on healthcare.
4. Prepare patients for their efforts in patient engagement and organize patient engagement in a professional manner to ensure that it is valuable to the organization.

**Background**

The Netherlands, with 17 million citizens, is internationally known for its affordable and accessible healthcare system (Osborn et al. 2016). Primary care is the cornerstone of this success; that is, the primary care physician is the first point of contact. Consequently, people have a close and long-standing relationship with their primary care physician. In addition to primary care, secondary care is offered in 89 general hospitals, including eight university hospitals, and 231 (small-scale) private and non-profit treatment centres whose services are limited to same-day admissions for non-acute, elective care (Wammes et al. 2018).

Patients are the official third party of the Dutch healthcare system, apart from healthcare providers and insurers (Helderman et al. 2005). National legislation is designed to support patients in executing this role, both as individuals and as a group. For example, the *Medical Treatment Contracts Act* (WBG0, since 1995) governs the relationship between the individual patient and the healthcare provider. Important aspects of this legislation are the right to receive comprehensible information and the right to give consent to or refuse treatment. The right to view and amend your own medical file is also defined in the WBG0. The legislation “Elektronische gegevensuitwisseling in de zorg (*Clients’ Rights in Electronic Information Processing*)” (since July 2017) was introduced in anticipation of the digitalization of healthcare (including electronic patient records) and the European Union’s General Data Protection Regulation. The collective rights of patients are defined in the *Clients’ Representation Act* (WMCZ, since 2010); by law, hospital boards are obliged to consult a client council for advice about each policy decision.

**Radboudumc: A hospital where patients are included**

Radboud university medical center (Radboudumc) is a regional centre for specialized secondary care. With 600 beds, 50 departments, nearly 11,000 employees and 3,300 students, it serves a population of 2 million people. In 2006, an investigation found that death rates after cardiac surgery were close to three times the national average at Radboudumc. This wake-up call pointed out the importance of monitoring the

quality of patient care. Dr. Melvin Samson, who became the chief medical officer of the hospital in 2007 and chairman of the executive board in 2011, used his influence to increase the quality and safety of patient care. He also created opportunities for active partnering with patients (Richards 2014). This decision to involve patients as partners in their healthcare was not driven by any legislation. Instead, intrinsic motivation was the driving force behind these efforts, in line with deontological ethical theories positing that patient engagement is good in and of itself (Duggan et al. 2006).

Currently, the hospital’s mission is to have a significant impact on healthcare, with two cornerstones: person-centredness and innovation. The patient is seen, listened to and respected as an equal stakeholder. The story of the person behind the patient and his or her life is the beginning and end point of care, and thereby respecting differences between people. Innovation is recognized as a decisive factor when it comes to the implementation of patient engagement at Radboudumc; all employees are invited and enabled to innovate, experiment, fail and implement promising innovations in patient engagement in medical research, education and practice. Every department defines patient engagement strategies in its annual plans, and all participate in the collection of standardized patient experience surveys. The REshape Center (<http://radboudreshapecenter.com>) is available to support the design and testing of e-health and m-health solutions. Finally, dedicated implementation experts are available for departments that need support to bring patient engagement into practice. As a university medical centre, the hospital’s mission and focus areas not only apply to patient care but are also reflected in the training of medical and nursing students. Consequently, after revision of the Medicine and Biomedical Sciences curricula in 2014, patient engagement became a fundamental part of the educational program.

In this paper, we demonstrate how this stimulating environment led to a rich collection of patient engagement activities in organizational (re-)design and educational programs for students and employees. Table 1 provides insight into a broader selection of initiatives.

**TABLE 1.**  
**The multi-dimensional continuum of patient and family engagement at Radboudumc (Carman et al. 2013)**

Level of engagement	Consultation	Involvement	Partnership and shared leadership
Direct care	<ul style="list-style-type: none"> <li>• CMylife: Online information tailored to the individual patient's circumstance (www.cmylife.nl)</li> <li>• MediMapp: Digital travel guide for patients treated at Radboudumc (www.medimapp.nl)</li> </ul>	<ul style="list-style-type: none"> <li>• Direct access to electronic medical records is available for all patients since 2012; it started on a small scale, for patients treated for an infertility-related problem in 2003 (Tuil et al. 2007)</li> <li>• Patients who have experienced a complication during hospitalization participate in the meeting with the involved professionals to evaluate the complication and identify the lessons learned</li> </ul>	<ul style="list-style-type: none"> <li>• Welearn: An interprofessional and person-centred educational program wherein patients, medical and nursing students and different professionals learn together (Vijn et al. 2018)</li> <li>• "Ask 3 Questions" campaign: Every patient visiting Radboudumc is invited to ask questions and become actively involved in decision-making</li> <li>• First decision aids are integrated into the electronic medical record system</li> </ul>
Organizational design and governance	<ul style="list-style-type: none"> <li>• Annual patient experience surveys: Results are fed back to departments and are used during internal audit visits to identify areas for improvement</li> <li>• Mirror meetings: Open discussion between patients about their care experiences, led by a professional mediator; involved healthcare professionals sit in the back of the room, listening to patients' stories; they are not allowed to interfere</li> </ul>	<ul style="list-style-type: none"> <li>• FoodforCare: Redesign of the meal service for hospitalized patients (van den Berg 2017)</li> <li>• Patient advisory board: Provides solicited and unsolicited advice to the hospital board</li> <li>• Educational patient advisory board: Patients are consulted for advice on educational policies</li> </ul>	<ul style="list-style-type: none"> <li>• Co-redesign of care tailored to the needs of young people diagnosed with Parkinson's disease</li> <li>• Patients participate in management teams about educational design and governance</li> </ul>

**Examples of Radboudumc's Patient Engagement Practices**

**Patient Advisory Board**

Established on January 1, 2013, as one of the first initiatives, the Patient Advisory Board (PAR) emerged as the embodiment of patient engagement at Radboudumc. All PAR members, eight in total plus a chair, are either patients or the parents or caregivers of patients treated at Radboudumc. The rights and tasks of the PAR are defined in a formal arrangement between the PAR and the hospital board and include providing solicited and unsolicited advice about hospital policy and safeguarding the position of patients in care, education and research. This advice is not without consequences: when the hospital board does not commit to acting on the advice, a formal reply with arguments supporting this decision is required. Now, five years after the PAR was established, there is awareness throughout the organization that patients should be included in every decision being made. Fourteen clinical departments established a local PAR for better representation of patients' perspectives in their departmental policies. The central PAR collaborates with the department-oriented PARs to support patient engagement but lets the local PARs determine their own structure and practice. The success of the PAR is driven by an open dialogue between PAR members and the hospital board, with formal and, most of all, informal contact. Although PAR members have a mandate to advise the board, the PAR chair emphasized

that PAR-members should understand the politics involved and be able to deal with them in order to be effective. This requires certain competencies and skills.

A separate education PAR was established for the Radboudumc Health Academy. The education PAR is responsible for representing the patient's voice in various educational curricula: Medicine, Biomedical Science, Dentistry, Master in Molecular Diseases, Master in Quality & Safety and postgraduate education for medicine and nursing professionals. For example, the education PAR advised on the definition and practical shaping of person-centred care in different programs. Moreover, members of the education PAR actively contribute to the education of medical students by giving lectures and leading working groups for students. Education PAR members have various backgrounds, but all have completed higher education and have an affinity for education and healthcare.

**Patient participation in internal audits**

The installation of a hospital-wide system of internal auditing was one of the measures taken after the 2006 discovery of the high death rates after cardiac surgery. The auditing model consists of independent, objective assurance and consulting visits to all hospital departments. To guarantee the patient's perspective, a small group of patients who showed interest in representing this perspective were trained to become members of the audit team. Training focused on interview techniques

and they were taught how to represent diverse patient perspectives. After a few years, the sobering conclusion was reached that patient-members found their task to be very difficult. They did not succeed in representing the entire patient population. Therefore, an alternative level of patient engagement for internal auditing was selected. Currently, annual patient experience surveys, completed by patients from both in-patient and out-patient clinics, provide input for the audit visit. Also, observations of the patient's journey, combined with interviews with professionals and patients, are part of the auditing model. As a third pillar, checklists based on the patient-centred Joint Commission International (JCI) accreditation standards are used to assess the patient's perspective.

### **Redesign of meal services for hospitalized patients**

Food is vital for recovery from illness. Nevertheless, too often hospital food is unappetizing, and patients are unable to choose what and when to eat during hospitalization. As part of the redesign of care for young oncology patients (in 2012), a so-called "food dream team" was created, including patients, dietitians, facility management and one of the leading catering firms in the Netherlands. Their task was to determine what hospital food should look like and how to organize food delivery when you can start from scratch. The team designed an innovative concept, named FoodforCare: nutrition assistants serve freshly made, appetizing meals at the bedside. Although the servings are small, they are served up to seven times during the day. During each serving, a patient can choose from at least two different meals. Nutrition assistants not only serve the meals: a new and major task for them is to provide proactive advice, taking the risk of malnutrition into account and nudging the patient toward his or her individual nutritional needs. The impact of the concept is impressive: compared to the traditional three-meals-a-day service, the intake of proteins and energy increased significantly (Dijxhoorn et al. 2017). In particular, patients appreciated the appearance and smell of the meals. Also, from a management perspective, FoodforCare was positively evaluated as food waste dropped from 37% to 11%, which counterbalanced the increased costs (van den Berg 2017). The concept is currently implemented throughout the entire hospital. Patients are still involved; for example, patient satisfaction is being collected continuously and used to optimize the selection of meals so that they can be personalized to the needs and preferences of the individual patient.

**Within this team, all members had equal rights: information flows were bidirectional, and decision-making responsibility was shared.**

### **Principal clinicians: Supporting doctors with ideas**

In 2014, the concept of a principal clinician was introduced by the hospital board, honouring doctors who have a strong vision and innovative ideas on how to accelerate the implementation of person-centred care with an investigator award. One of those principal clinicians, Bart Post, MD, PhD, is a young neurologist who treats many young people diagnosed with Parkinson's disease. His training and the organization of patient care were based on the notion that Parkinson's disease mainly affects the elderly and so did not meet the needs of his younger patients, who work and have families with children living at home. To change the approach to their care, Dr. Post first installed a project team with two people living with Parkinson's disease and two healthcare professionals. Within this team, all members had equal rights: information flows were bidirectional, and decision-making responsibility was shared. In all meetings with patients and professionals, the 50:50 representation of patients and professionals was safeguarded. These meetings resulted in priorities for change in clinical practice, with patients electing the four topics to start with. For each topic, separate groups were initiated, again with patients in the lead and clinicians following. One group focused on case management, where the case manager becomes a personal "coach" who, for example, can answer simple questions, offer triage, support self management, organize dedicated referrals, and coordinate care. Another group focused on the relationship between work and Parkinson's disease, for example, by listing the legal rights of patients and identifying knowledge gaps in employers. Group meetings were used to share the results of the project, raise new questions and discuss the road ahead. The impact of the methodology was founded on the principles of partnership and shared leadership, supporting the power of individual people with Parkinson's disease to change clinical care into an environment that is driven by the needs of patients.

### **Welearn: Patient and family engagement in medical education**

From the notion that training healthcare professionals and patients separately significantly improves patient-centredness of care came the idea for a co-learning model, called Welearn. Welearn is an interprofessional and person-centred educational program wherein patients, medical and nursing students and different professionals learn together. The educational program, consisting of five educational sessions and meetings in the care practice or at home, provides patients, students and professionals with the opportunity to meet each other, exchange knowledge and experiences and practice care situations, such as consultations, in a safe environment. In Welearn, patients, as well as students and professionals, co-design, co-produce and co-evaluate educational activities

(Vijn et al. 2018). Several pilot studies were executed with Welearn wherein medicine and nursing students jointly learned, together with patients and/or family members and professionals in the field, about rheumatoid arthritis, low health literacy and congenital anomalies. Evaluation showed that through Welearn, patients acquired disease and treatment knowledge and developed a responsible attitude toward their disease and treatment. Students learned about the patients' perspective, which further enhanced their communication and shared decision-making skills. After the positive evaluation and high recommendation from participants, Welearn was implemented in a Bachelor research minor course on vulnerable groups and diversity in healthcare and a minor on human embryology at the medical school.

## Discussion

### Lessons learned

Over 10 years of leadership within the Radboudumc, supporting an engagement environment for patients, has provided lessons for implementation. Consistent leadership on the importance of patient engagement at the board and middle-management levels, innovators who dare to fail and financial support for those with innovative ideas contributed to an environment that currently fosters patient engagement. The most important lessons learned are:

- The essential culture change should be advocated by the hospital board, whereas bottom-up initiatives give meaning to the patient engagement policy.
- A non-homogeneous evolution of engagement in which employees are free and motivated to design engagement activities that reflect their own drives and ideas and set up experiments that are allowed to fail should be supported.
- With new initiatives, patients should be involved from the beginning to prevent decisions being made that do not align with patients' preferences.
- It takes years to implement a new stakeholder, that is, the patient, in an existing governance model.
- For both professionals and patients, role models, who inspire and motivate their peers, should be used.
- Patient engagement may lead to resistance, for example, in areas of management where patients engage closely with professionals.
- Patient engagement should be organized and facilitated to ensure its quality.

### Next Steps for the Future of Engagement

The examples presented here show that a small critical mass of innovators is enough to bring change to an entire organization. Numerous innovations with impact typically started small, and some of those will result in hospital-wide implementation. To further strengthen engagement, successful initiatives should be identified and spread throughout the organization. To achieve this, the hospital board organized speaker corner sessions with every department. Departments shared their achievements with, concerns for and wishes about the implementation of person-centred care. From these sessions, best practice teams will now further support the implementation of patient engagement and create hospital-wide learning communities. Education for patients is imperative to address the tension between the patients' professional deformation (i.e., the tendency to look at things based on previous professional roles instead of the patient perspective). Education can ensure that patients know how they can maintain their perspective and reduce (1) the anxiety they feel given their position, which is partly due to (implicit) power differences, (2) professional deformation, and (3) copying behaviour due to patients' lack of skills, knowledge and experience in the healthcare setting.

To conclude, patient engagement is no longer tokenism. It has become part of Radboudumc's identity, and practice will gradually mature toward partnership and shared leadership as the preferred engagement model. **HQ**

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# Bringing Together Research and Quality Improvement: The Saskatchewan Approach

## Conjonction de la recherche et de l'amélioration de la qualité : l'approche de la Saskatchewan

Gary F. Teare, Malori Keller and Dale Hall

### **Abstract**

Improving health and health services requires both better knowledge (a key function of research) and better action to adapt and use what is already known (quality improvement). However, organizational and cultural divides between academic research institutions and health system organizations too often result in missed opportunities to integrate research and improvement. The Saskatchewan Health Quality Council's experience and relationships, from linking research, quality improvement and patient engagement in its leadership of the province's healthcare quality improvement journey, provided core support and leadership in the development of Saskatchewan's Strategy for Patient-Oriented Research SUPPORT Unit. The vision is for the SUPPORT Unit to integrate research and quality improvement into a continuous learning health system.

### **Résumé**

L'amélioration de la santé et des services de santé exige à la fois une meilleure connaissance (la fonction primaire de la recherche) et une meilleure action pour adapter et utiliser ce que l'on sait déjà (amélioration de la qualité). Cependant, les clivages organisationnels et culturels entre les instituts de recherche universitaires et les organismes du système de santé sont trop souvent responsables de rendez-vous manqués entre la recherche et l'amélioration. L'expérience et les relations du Saskatchewan Health Quality Council (pour l'établissement de liens entre la recherche, l'amélioration de la qualité et l'engagement du patient en vue d'orienter le processus d'amélioration de la qualité des soins de santé de la province) ont fourni un soutien et un leadership essentiels au développement de l'unité SOUTIEN de la Stratégie de recherche axée sur le patient de la Saskatchewan. L'objectif que poursuit l'unité SOUTIEN est d'intégrer la recherche et l'amélioration de la qualité à un système de santé apprenant.

**KEY MESSAGES**

1. Linking research and improvement science is foundational to establishing a learning health system; one that learns from its own experience and from research in order to continually improve the value it provides.
2. Health services and academic research each have their own purposes and cultures that can be difficult to bridge. The CIHR Strategy for Patient-Oriented Research provided an opportunity for Saskatchewan's universities and health system to find a common focus on advancing patient and family participation and leadership in research and health services quality improvement.
3. There is diversity in skills and mindsets needed for patients' engagement in research or quality improvement teams. Rather than perpetuate a divide between research and quality improvement in its work to promote patient participation, Saskatchewan's SPOR SUPPORT Unit promotes alignment in patient engagement processes to make the patient/family experience of participation in improvement or research as easy and satisfying as possible.

**R**esearch and quality improvement science both have their own purposes, traditions, methodologies and institutional support structures, and there is considerable variety within these elements of research and quality improvement. However, both health research and quality improvement have a common fundamental aim to contribute to optimizing people's health and well-being and improving the quality of services in support of that aim. Broadly speaking, improving health and services requires both better knowledge (*research*) and better action to adapt and use what is known (*quality improvement*). Bringing these functions together to create active, mutual learning cycles, which tap the experience and expertise of health service users, service providers, researchers and people skilled in facilitating quality improvement, has been labelled a "learning health system" (Greene et al. 2012; IOM 2007). Creating the conditions for a learning health system in Saskatchewan was the motivation for the approach taken in establishing Saskatchewan's patient-oriented research SUPPORT Unit, with co-funding from the Canadian Institutes of Health Research's (CIHR) Strategy for Patient-Oriented Research (SPOR).<sup>1</sup>

As a key element of SPOR, CIHR partnered with provinces and territories across the country to establish SUPPORT Units to provide infrastructure, expertise and support for patient- and community-engaged research to help improve people's health and health services. A unique feature of Saskatchewan's SPOR SUPPORT Unit is the active partnership of the provincial Health Quality Council (HQC), with academic and health system organizations and the provincial government, to provide funding, space and personnel to the operations of the unit (SCPOR 2016). This was a strategic investment of both resources and expertise by HQC – drawing on its mandate and history of research, training and facilitation of health-care quality improvement – to foster the multi-stakeholder partnership needed to develop a learning health system.

### **Context for the Saskatchewan Approach: A Provincial, Patient-Centred Quality Improvement Journey**

Over nearly two decades, the Province of Saskatchewan has been on a journey to establish a quality-focused culture within

its health system. A key recommendation of the 2001 provincial Fyke Commission on the sustainability of publicly funded healthcare was that a quality council be established to provide focus and leadership in this quest (Fyke 2001). In late 2002, the HQC was launched in Saskatchewan, with a mandate including research and education, to promote the improvement of quality in healthcare (Government of Saskatchewan 2002).

Over the last 15 years, HQC has led collaborative efforts with health system organizations to build quality improvement capacity and capability among administrators, leaders, clinicians and quality improvement support staff (HQC 2018). Over that period, nearly 5% of the 40,000-strong health system workforce has had significant practice-based education in the theory and application of quality improvement methods. Additionally, at least half of the workforce has been exposed to quality improvement concepts through brief awareness and orientation courses. These investments in capacity and capability have provided the impetus for thousands of local improvement projects and several province-wide improvement initiatives.

Research has also been a key element of the Saskatchewan quality improvement journey. From very early on, HQC was provided with ongoing, privileged access to a wide range of privacy-protected health system data. These data were used in the measurement and analysis of healthcare quality. HQC also led collaborations with healthcare providers and organizations in Saskatchewan to conduct surveys of patient experience in multiple healthcare sectors. HQC conducted research to identify and describe quality gaps ("opportunities for improvement"), develop quality measurement, synthesize global evidence on effective interventions and evaluate improvement interventions in the Saskatchewan context. HQC has also collaborated with a variety of researchers, provincially, nationally and internationally, on dozens of projects linked to quality improvement initiatives in areas such as hospital ward nursing care, chronic disease management, medication safety, stroke care, cancer care, patient flow, long-term care and primary care.

Early in its quality improvement journey, Saskatchewan began to adopt and implement patient- and family-centred care (PFCC) principles and approaches as core to its improvement efforts. This patient orientation was spurred by what

we learned from high-performing health systems – notably the Southcentral Foundation in Alaska, where the concept of patients and communities as health system “customers/owners” is central to their Alaska Native-owned health system (Southcentral Foundation 2018). The Patient First Review, conducted by the Saskatchewan provincial government in 2009, formally set the entire health system on a course of patient- and family-centred improvement (Dagnone 2009). To further advance patient-centred improvement efforts in Saskatchewan, the province focused on learning and applying Lean management and improvement methodology across the health system, starting in 2012. Lean emphasizes a strong focus on increasing value from the perspective of the customer, that is, the health service users in the case of the health/healthcare system. HQC provided central support to this provincial health system initiative.

A provincial patient- and family-centred care forum was created as a partnership between health system organizations and patient and family advisors (PFAs) to exchange innovative ideas, knowledge and experiences in adopting PFCC. This included establishing processes and policies that supported the involvement of PFAs in quality improvement events. In 2014, HQC began to provide leadership and administrative support to advancing PFCC in the province, and the forum was reorganized and formalized as the Patient- and Family-Centred Care Guiding Coalition (Fancott et al. 2016). The membership then included PFAs from regional health authorities and one executive sponsor and one staff lead from each of the 18 health system partner organizations. From 2015 through 2017, there were over 2,500 opportunities for PFAs to participate in quality improvement events, advisory committees and other engagements with Saskatchewan’s health organizations.

The coalition developed numerous resources and PFCC strategies and policies, which were shared across the health system organizations in the province. These include:

- Recruitment materials to support the engagement of patients and families across the province
- Orientation and training to support the learning needs of PFAs
- Education for staff on PFCC and effective patient engagement
- Policies and processes to enable meaningful participation (i.e., honoraria and expense reimbursement policy and processes)
- Reporting templates, which enabled monitoring of basic metrics around the number of patient families engaged in each organization and associated costs

This collaborative work by health system organizations, facilitated and coordinated by HQC, helped to create an

“engagement-capable environment” in the health sector across Saskatchewan.

The confluence of the ongoing, provincial health system improvement journey, the CIHR strategy to promote patient-oriented research and an initiative to renew the College of Medicine at the University of Saskatchewan set the context for linking patient-engaged improvement to patient-engaged research in Saskatchewan. HQC, with relationships and expertise developed through its training/education, coordination, research and patient engagement in the health system quality journey, was able to provide leadership in the partnering of universities, healthcare organizations and patients in research that can inform and be informed by the quality improvement efforts in the province. This linkage of research and improvement science is foundational to the establishment of a learning health system, where the development of new knowledge is integrally connected to the people and mechanisms by which that knowledge will be used to achieve better results in health and healthcare.

### **Operationalizing the SPOR SUPPORT Unit in Saskatchewan**

SPOR SUPPORT Units are required to provide a set of core supportive functions, including data and data services, patient engagement, knowledge translation, research methodology, training and capacity building and consultation services. In Saskatchewan, our SUPPORT Unit, the Saskatchewan Centre for Patient-Oriented Research (SCPOR), also added a dedicated function to support the engagement of Indigenous communities and to provide expertise in research methodology that is respectful of Indigenous culture. The services for these various functions are provided by SCPOR platforms hosted by some of our academic and health system organizations: the University of Saskatchewan hosts the Knowledge Translation, Methodology and Training Platforms, and each of the Saskatchewan universities provides traineeships and has methodologists to contribute to these functions; the Indigenous Engagement and Expertise Platform is hosted by a research unit affiliated with the University of Regina; the Data and Data Services Platform is led and resourced by HQC and eHealth Saskatchewan, with contributions from the province’s Ministry of Health and the participation of the Saskatchewan Health Authority; and the Patient Engagement and Empowerment Platform is hosted by HQC.

The SCPOR Patient Engagement and Empowerment Platform seeks to identify roles for patients to engage in health research. In alignment with the SPOR Patient Engagement Framework, patients are actively recruited to engage in SCPOR governance, priority setting, research and knowledge translation (CIHR 2014). The platform is hosted by HQC to build upon the structures and processes for patient partnership in healthcare improvement that were developed by health system organizations

and PFAs through the PFCC Guiding Coalition and provincial quality improvement initiatives. We developed a continuum of engagement opportunities for PFAs, as outlined in the SPOR Patient Engagement Framework (CIHR 2014) and built complementary mechanisms to support engagement in patient-oriented research and for other opportunities to improve healthcare.

**There was wide** variation among researchers of understanding of patient-oriented/patient-engaged research.

### **Coordinating Patient Engagement for Research and Quality Improvement: Benefits and Opportunities for Shared Learning**

Leveraging the existing PFCC infrastructure has been beneficial as it has increased the speed at which we are able to recruit and onboard patients and families to participate in the governance and priority-setting committees of SCPOR. We were able to recruit PFAs for research teams via HQC's membership in the Saskatchewan Patient & Family Advisor Network Facebook group and through our established relationships with partner organizations in the health system. These networks enabled access to a large number of PFAs from across the province to support the research teams' needs. Tapping the existing health system PFA network was especially helpful in recruiting experienced PFAs to join the SCPOR Patient and Family Advisory Council. For example, Dale Hall was a patient advisor for several years with the Five Hills Health Region in southern Saskatchewan. He collaborated with staff on quality improvement and facility design events. In 2016, he became a member of the SCPOR Patient and Family Advisory Council. His previous experience as a PFA in the health system proved helpful in his contributions to the co-design of content for patients and families on the SCPOR website and in evaluating the patient advisor experience. He also drew on his advisor experiences to help develop PFA role descriptions to support patient advisor recruitment.

Operationally, there have been many benefits and efficiencies gained from having the Patient Engagement and Empowerment Platform housed at HQC; however, there have also been some learning opportunities in our early work in patient engagement in research. Most importantly, platform staff needed to build relationships with staff and researchers from academic institutions. There was wide variation among researchers of understanding of patient-oriented/patient-engaged research. Some researchers had extensive experience with engaging patients or communities as partners in their research teams, whereas others had never engaged patients or families. It was vital for SCPOR Patient Engagement and Empowerment staff to first learn and understand the experience and norms researchers had with respect to patient engagement, after which the staff offered

training on the best practices in patient engagement promoted nationally through SPOR patient-oriented research training curricula for PFAs and research teams. The training provides an opportunity to develop common understanding and shared meaning of patient engagement and patient-oriented research. A positive impact has been demonstrated in the ongoing evaluation feedback received concerning the training session. For example:

The training provided by the Patient Engagement Platform helped us to recognize that we were engaging patients at a consultative level. Going forward, we have amended our plans to be more collaborative and empowering in our patient engagement approach.  
(Researcher, University of Regina)

We also learned that researchers who have been engaging patients for many years had developed processes to support PFA engagement, such as orientation, honoraria and expense reimbursement. This led to variation in practice, which meant that patients working on more than one team would be asked to follow different processes. This was confusing for PFAs. Therefore, SCPOR platform staff provided information and support to orient researchers from the academic organizations to the practices and processes used to support PFA engagement in health system improvement teams and committees. Researchers then had the choice to continue to work with the processes they had developed or have the Patient Engagement and Empowerment Platform provide these services for them in the context of projects supported by SCPOR. This flexible approach was necessary to avoid unnecessary burden for patients and researchers.

Going forward, SCPOR's goal is to continue to promote alignment in patient engagement processes across the health system and academic organizations to make the patient/family experience of participation in improvement or research as easy and satisfying as possible. Patients and families have clearly told us that it is burdensome to register with multiple organizations to signal their interest in contributing their expertise, to attend multiple different orientations with overlapping content and to have to learn varied administrative processes to process expense and honoraria claims. They have also expressed an interest in the development of a PFA peer support community that enables them to share experience with each other and encourage each other in their engagements with health system improvement and research.

Although the efficiencies and benefits for PFAs of coordinating patient engagement processes for research and quality improvement have been evident, there are challenges concerning differences in the roles that PFAs play in research contexts compared to quality improvement contexts. Anecdotal evidence indicates that some academic researchers may be

concerned that PFAs, whose advisory experience has been in quality improvement, may have become overly embedded in the assumptions and mindsets of the health system. Similarly, some healthcare providers or administrators have expressed concern that PFAs who have only had experience as advisors to research teams may not understand the constraints and complexities involved in making changes in healthcare. This helps us recognize that the roles and expectations of PFAs in research and quality improvement are not always identical, so it is important that they are well oriented to and supported in making their best contribution in those different contexts. The training and orientation for PFAs – as well as the researchers and health system personnel they will work with – must help bridge these two worlds. In Saskatchewan, we have purposefully brought support for these different kinds of patient engagement together in the design of our SCPOR Patient Engagement and Empowerment Platform.

## A Vision for the Future

Improving services that help people get better and stay well is the reason we have invested in connecting the capabilities of research and quality improvement in Saskatchewan. Improvement requires both new thinking and knowledge as well as the ability to change structures and behaviours in ways that use better knowledge. The expertise and experience of patients, researchers, service providers and administrators are all needed, yet too often these groups are divided by professional, organizational or power barriers and are unable to effectively contribute their various capabilities toward shared learning and the common good. We envision a future where universities, health services organizations and providers, government, patients and other people work together in an ecosystem that supports innovation, learning and improvement. Within such an ecosystem, all the stakeholders would work together on issues where improvement would make meaningful differences to the lives of patients and people, changes would be planned and integrated with the realities of budgets and human resources and solutions would be developed and evaluated based on good science. Given the organizational and other divides that need to be overcome, organizations such as HQC in Saskatchewan, with expertise and relationships across those divides, can be helpful in establishing such an ecosystem. **HQ**

## Note

1. Support for People and Patient-Oriented Research and Trials (SUPPORT) Units are a key element in the CIHR Strategy for Patient-Oriented Research (SPOR). They provide specialized research resources, policy knowledge and patient perspectives to pursue patient-oriented research and help lead reforms in response to locally driven healthcare needs. More information on SPOR and SUPPORT Units is available at <http://www.cihr-irsc.gc.ca/e/41204.html>.

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# Evaluating Patient, Family and Public Engagement in Health Services Improvement and System Redesign

## Évaluation de l'engagement du patient, de sa famille et du citoyen à l'amélioration des services de santé et au réaménagement des systèmes

Julia Abelson, Anya Humphrey, Ania Syrowatka, Julia Bidonde and Maria Judd

### Abstract

As efforts to actively involve patients, family members and the broader public in health service improvement and system redesign have grown, increasing attention has also been paid to evaluation of their engagement in the health system. We discuss key concepts and approaches related to evaluation, drawing particular attention to different and potentially competing goals, stakeholders and epistemological entry points. Evaluation itself can be supported by an increasing number of frameworks and tools, matched to the relevant purpose and approach. The patient engagement evaluation field faces several challenges, including the need for greater specification of both the form and the context of engagement, the need to balance the measurement imperative with the relational aspects of care and the need for supportive organizations with the capacity and commitment to undertake high-quality engagement and its evaluation.

### Résumé

Tandis que les efforts visant à activement faire participer le patient, les membres de sa famille et le grand public à l'amélioration et au réaménagement des systèmes de santé se sont intensifiés, une attention croissante a également été accordée à l'évaluation de leur engagement au système de santé. Nous abordons d'importants concepts et approches liés à l'évaluation, en attirant une attention particulière aux divers objectifs, parties prenantes et points d'entrée épistémologiques éventuellement en concurrence. L'évaluation elle-même peut s'appuyer sur un nombre croissant de cadres et d'outils adaptés à l'objectif et à l'approche en question. Le domaine de l'évaluation de l'engagement du patient doit relever de nombreux défis, à savoir le besoin de préciser les modalités et le contexte de l'engagement, le besoin d'équilibrer l'impératif de la mesure avec les aspects relationnels des soins et l'aspiration des organismes disposant de la capacité et de la volonté nécessaires à concrétiser et à évaluer ce projet en engagement de grande qualité.

**KEY MESSAGES**

1. An increasing focus on evaluation of patient engagement activities advances the science of the field.
2. Robust frameworks for evaluation should guide organizations to precisely specify the purpose, form and context of their engagement activities so they can understand what is working and what is not.
3. High-quality engagement and its evaluation aligns with the core features of rapid learning health systems which emphasize improving care experiences, timely data and evidence, enabled by organizations that support learning and improvement.

**Introduction**

Many – perhaps most – of us who choose to volunteer to improve healthcare have had a bad experience. I am referring to something that has made a person feel dismissed, or ignored, or invisible, or mistreated, or otherwise hurt in a way that could have been avoided. We all expect and deserve to be treated considerately when we or our family members are ill. Because that is largely what does happen, when it doesn't happen that takes us by surprise, when we are at our most vulnerable, and exacerbates an already traumatic situation. So that kind of wound is often the back story to a Patient and Family Advisor's interest in getting involved. That means that not only do we have a powerful motivation to make things better for the next person, we also need to repair our own relationship with the medical world. And the only way to do that is to restore a respectful, kindly, mutually trusting connection with other people. When that is established, not only do all the participants benefit personally, but that tone radiates out from their committee or project like a fractal. So that's what I really want to see measured because I think it is vitally important.

– Anya Humphrey, patient and family advisor

Health system organizations in Canada and around the world continue to expand their efforts to actively involve patients, family members and the broader public in health service improvement and system redesign initiatives (Barello et al. 2012; Carman et al. 2013; Richards et al. 2013). Evidence suggests that these efforts have the potential to translate into organizational and system improvements in quality, safety and patient experience, but the mechanisms through which these occur are not well understood (Bombard et al. 2018). This is due, in part, to the many and varied approaches used to engage patients, family members and the public in health services improvement and system redesign initiatives – approaches that typically range from more traditional *consultation* methods to more inclusive *partnership*, *shared leadership* and *co-design* models (Health Canada 2000). In the young field of patient and family engagement, the task of evaluation and to moving beyond a focus on *practice* (i.e., the everyday work of engagement) to what some refer to as

the *science* of engagement (Anderson and McCleary 2016) has only recently begun. Questions such as how current approaches are working, which methods are most effective for which types of problems and whether any of this is making a difference have become more commonplace as governments, organizations, researchers and patient organizations seek to demonstrate the benefits, value or return on investment of patient and family engagement.

As both the practice and the science of engagement grow and mature, we offer guidance to health system leaders that will support their patient, family and public engagement efforts. Our specific aims in this paper are threefold: (1) to seek clarity about the different goals and meanings attached to evaluation in relation to patient, family and public engagement; (2) to review current frameworks, tools and approaches for supporting evaluation in this area; and (3) to highlight key challenges faced with suggested strategies for addressing these. Throughout the article, we primarily use the term *patient and family engagement*, defined as the “involvement of patients and/or family members in decision-making and active participation in a range of activities (e.g., planning, evaluation, care, research, training, and recruitment) ... which involves collaboration and partnership with professionals” (Baker et al. 2016). We also use the terms *public*, *citizens* and *service users* in some places to reflect the broader construct of “the public” that may be relevant to health service improvement initiatives and decision-making at the system and policy levels.

**An Evaluation Primer for the Engagement Field Meanings, motivations and measures**

Approaching the task of evaluation in the context of patient, family and public engagement requires awareness and receptivity to the different epistemologies of evaluation that are situated in contributing disciplines. Familiar labels such as *program*, *realist* and *impact evaluation* have different underlying theories. Equally, terms such as *effectiveness* and *impact* convey different meanings to engagement professionals, scientists and funders. As evaluation efforts expand and proliferate, sensitivity to these different entry points to the field will be needed, as well as toward those who may challenge the evaluation effort altogether given its intrinsic value.

Seeking clarity and agreement about the purpose for evaluation can be a helpful way forward. Just as engagement

requires clarity about *why* (we are engaging), with *whom* and *how* (we will do this), the same principles apply to its evaluation. In Table 1, we identify four overarching goals for public and patient engagement evaluation. The research community tends to be preoccupied with *summative* evaluation and the goal of contributing to the evidence base about what works and under what conditions for the purposes of refining engagement methods. In contrast, organizational staff and patient partners may be more focused on *formative* evaluation and the goal of improving the quality of their engagement practices. Funders and health system leaders, in turn, may be interested in evaluation from an accountability and value-for-money perspective. Within organizations, this can often take the form of assessing whether organizational requirements (or expectations) for engagement have been met. They and other key stakeholders will be interested in these questions as well as the evaluation of longer-term outcomes, such as what and how the engagement activity, process or strategy contributes to health system planning, system redesign and quality of care.

The engagement literature is often criticized for offering little in the way of tangible evidence about what works or what added value engagement provides (Conklin et al. 2015; Mockford et al. 2012). This is due in part to the emphasis typically given to evaluating the procedural aspects of engagement rather than its outcomes (Abelson and Gauvin 2006; Rowe and Frewer 2005). Process measures typically focus on the execution or implementation of the engagement activity (e.g., whether participants were supported adequately to participate, whether they felt that they were able to contribute meaningfully or whether the objectives of the activity were clearly communicated). In contrast, outcome measures focus on changes that have taken place as a result of the engagement activity or process. These may include increased knowledge and capacity of patient and family members or a more comprehensive and accountable approach to service planning.

In the longer term, they may include services that are more responsive to patients' and family members' needs and priorities or an improved patient experience resulting from patients being directly involved in the redesign of a service. An example of an outcomes-oriented approach to patient engagement is a study comparing patients' and providers' priorities for healthcare improvement for chronic care in Quebec (Boivin et al. 2014). Using a patient engagement intervention involving interaction between patients and providers (compared to a control that had no patient involvement), the healthcare priorities of patients and providers (the outcome being measured) were found to converge with each other over the course of the engagement and to differ significantly from those of professionals alone (in the control group).

### **Supporting the Evaluation of Patient, Family and Public Engagement** **Current frameworks and tools**

Health system organizations are increasingly supported by a broad array of engagement frameworks and tools that have been developed by researchers, engagement practitioners and patient partners (Abelson et al. 2016; Carman et al. 2013; Frampton et al. 2017; Hamilton et al. 2018; Health Quality Ontario 2017). These resources provide the foundation for rigorous evaluation in their specification of the key dimensions of engagement: (1) the principles that should guide these efforts (e.g., partnership, learning, responsiveness, respect); (2) the levels and domains at which engagement is embedded (e.g., governance, program and service design and policy); and (3) the range of approaches or methods used (e.g., consultation, deliberation or full collaboration).

Despite a rich array of frameworks, the development of structured evaluation tools has progressed more slowly, mostly through unpublished, project-specific instruments, limiting opportunities for comparison and mutual learning across engagement initiatives (Boivin et al. 2018).

**TABLE 1.**  
**Overarching goals for patient, family and public engagement evaluation (linked to relevant stakeholders and examples)**

<b>Evaluation goal</b>	<b>Key stakeholders</b>	<b>Evaluation example</b>
Contribution to engagement science	Researchers Patient partners Health system organizations	Summative evaluations to improve the evidence base around engagement methods
Improvement of engagement practices	Health system organizations Patient partners	Formative evaluations to track and refine organizational approaches to engagement
Accountability	Funders Health system leadership	Formative and summative evaluations demonstrating that organizational requirements for engagement have been met
Linking level and quality of engagement to outcomes	All of the above	Formative and summative evaluations linking meaningful engagement to changes in delivery of healthcare or health outcomes

Recently, more concentrated efforts have been made to synthesize the evaluation literature, map the dimensions of high-quality engagement on to measurable outcomes and develop generic evaluation tools and instruments (Dudley et al. 2015; Esmail et al. 2015; Forsythe et al. 2018; Gibson et al. 2017). Much of this work has focused on the evaluation of patient engagement in the health research arena, but there are several promising developments in the health services improvement and health system decision-making field, which are discussed in the following sections.

### Selected examples

As the number of evaluation frameworks and tools expands, those seeking to evaluate their engagement efforts will need to choose carefully among these resources. These decisions should be guided by clarity about evaluation goals, methods and perspectives. In the sections that follow, we provide examples from our own evaluation work in this area, highlighting the different goals, methods and perspectives featured.

In 2014, the Canadian Foundation for Healthcare Improvement (CFHI) approached the evaluation of patient and family engagement in quality improvement (QI) with the goal of understanding how well patient and family advisors integrated into QI teams as part of a Partnering with Patients and Families Collaborative (CFHI 2016). They aimed to build capacity and enhance organizational culture for partnering with patients and families to improve quality across the healthcare continuum. A mixed-methods approach was used to evaluate the social dynamics, experience and effectiveness of QI teams. Social dynamics were evaluated using the International Association for Public Participation (IAP2) Spectrum and Social Network Analysis (SNA) (IAP2 2015; Valente 2010). Team members provided self-reported assessments of the levels of engagement from the IAP2 Spectrum that best described their interactions with key people involved in the QI project (e.g., inform, consult, involve, collaborate or empower). This information was also used to build a network map showing the positions of the patient and family advisors within the teams – in particular, the number of connections with other team members. Team experience and effectiveness were measured using questions adapted from existing survey instruments: the Team Effectiveness Instrument, the Primary Health Care Team Climate Survey and the Assessment of Interprofessional Team Collaboration Scale (Orchard et al. 2012; Poulton and West 1999; Shortell et al. 2004). The responses provided insight into how well teams were integrating and working together. Focus group interviews and online surveys using open-ended questions with patient and family advisors and other team members were used to better understand the experience of partnering as a part of a QI project.

The overarching goals of this evaluation were: (1) to contribute to engagement science with the specific aim of improving future patient and family engagement practices within CFHI collaboratives and programs and (2) to link the level and quality of patient and family engagement with outcomes – in particular, to understand the impact of high-quality patient and family engagement on the teams' progress through their QI project. Twenty-two teams were supported to engage patients and family members in the design, implementation and evaluation of a QI project. Based on this work, CFHI has developed tip sheets on how to engage patients and families in building high-quality improvement initiatives from both the healthcare provider and patient perspectives (CFHI 2018a; CFHI 2018b).

### Supporting Patient and Family Engagement Using the Public and Patient Engagement Evaluation Tool

In 2015, the Public and Patient Engagement Evaluation Tool (PPEET) (McMaster University 2018) was launched as a simple-to-administer tool intended for use by a wide range of health system organizations to assess the quality and impacts of engagement, with the goal of contributing to both the practice and the science of public and patient engagement. Developed through an iterative, collaborative process involving researchers and practitioners across the country, the tool is structured around core principles of quality engagement informed by a synthesis of published and grey literature (Abelson et al. 2016). The tool consists of three questionnaires aimed at evaluation from the following perspectives: (1) those participating or partnering in engagement activities and processes (patient contributors and partners); (2) those responsible for the planning, execution or sponsoring of engagement activities within organizations (engagement practitioners and users); and (3) those providing the leadership and capacity for public and patient engagement within their organizations (organizational leadership). The tool was recently subjected to additional feasibility testing in seven health system organizations in Ontario in collaboration with staff and patient partner representatives from each organization. The results of this feasibility testing have informed tool modifications through a revised PPEET (launched in August 2018) that focus on increased tailoring for different respondent groups, the creation of separate evaluation modules for different types and stages of engagement (e.g., one time versus ongoing and planning versus implementation) and achieving greater balance between open-ended and scaled questions with opportunities for more in-depth follow-up.

### A searchable online resource of engagement evaluation tools

Another recent contribution to the evaluation field is an open-access online evaluation toolkit resource (CEPPP 2018) that

features 27 evaluation tools and instruments searchable by user type (whether you are a researcher, a patient partner or a health-care organization). Each has been assessed for scientific rigour, comprehensibility, usability and the involvement of patients in its development. The toolkit itself was developed through a Canadian collaboration of evaluation tool users from across the country, including patient partners, engagement practitioners and researchers.

A systematic review carried out in conjunction with the development of the toolkit yielded two key areas for improvement: (1) the scientific rigour with which these evaluation tools were developed and (2) the level of patient and/or public engagement in their design and reporting (Boivin et al. 2018). These findings signal some important challenges that lie ahead as the science and practice of patient engagement continue to evolve.

### **Evaluation Challenges and Strategies for Addressing Them**

#### **Specifying the purpose, dimensions and context of engagement**

A core principle of evaluation is the need to be clear about the dimensions or attributes of the concept, phenomenon or activity being evaluated. The evaluation of patient, family and public engagement faces considerable challenges on this front. The engagement often takes many forms (different types of contributions on an *ad hoc* or ongoing basis); it involves different people in different roles (advisors, partners, committee members) and occurs at different levels (e.g., governance, project based) and over different time periods (e.g., weeks, months or years). As a result, patient, family and public engagement needs to be understood as a complex and dynamic set of context- and process-dependent activities that require unpacking. As Staley (2015) pointed out:

... we need to precisely define the form it takes, paying close attention to the context and the detailed mechanism, rather than using a loose definition of “public involvement” that in fact describes many different types of activity.

Through more precise specification of the purpose, form and context of engagement, organizations will be in a stronger position to know what is working, what is not working and what contributed to things going well or not.

#### **Balancing the measurement imperative with the relational aspects of care**

Engagement professionals and evaluation researchers often prefer questionnaires and survey instruments to collect information about engagement activities. Although these tools

allow for the efficient collection of data, they can be limited in what they are able to capture about what really matters to people and may be viewed negatively when used on their own, without opportunities for personal interactions (Abelson et al. 2018). A complementary approach to collecting both quantitative and qualitative evaluation data provides a richer portrait of the public and patient engagement experience and mirrors the relational aspects of care that are so central to patient- and family-centred health systems.

There are some situations that cannot be addressed by any survey, no matter how carefully designed it is. So in order to hear about them, we have to talk to people.  
– Anya Humphrey, patient and family advisor

#### **Evaluation requires organizational readiness, capacity and commitment**

Just as high-quality engagement requires a major commitment from organizations, its evaluation requires the same level of commitment. Organizations that have not articulated clear goals for their engagement efforts or a coherent engagement program or strategy will struggle to meaningfully evaluate their efforts. In fact, the lack of a coherent engagement program and supporting organizational capacity is often revealed in the early stages of evaluation. Commitment to engagement and its evaluation is more than simply putting a patient and family advisory council or a patient advisors program in place and administering the occasional questionnaire or set of interviews to see how things are going. Organizations need to go beyond this “virtue signalling (Johannesen 2017) to carefully attend to the tasks of what is being sought through the evaluation, what are the most appropriate methods for carrying it out, and with whom and how they will share the results – all key considerations, just as they are for any engagement process or activity. This requires considerable organizational readiness and capacity. As more and more organizations are mandated to engage with patients, family members and the public, the degree to which this capacity currently exists and can be sustained over time will need to be addressed. Creative and meaningful collaboration with university-based researchers and knowledge organizations may provide fruitful avenues for addressing these capacity gaps.

The concept of engagement-capable environments (addressed in another paper in this issue) should consider the inclusion of evaluation as one of its core attributes (Baker and Denis 2011; Baker et al. 2016). Receptivity to the involvement of relevant stakeholders in the evaluation process is another important consideration for organizational readiness. Recent advances in the evaluation field support collaborative efforts that emphasize partnerships between evaluation experts and key stakeholders such as patients, family members, health

professionals and decision-makers (Gilbert and Cousins 2017). These principles also align with the core features of rapid-learning health systems and their emphasis on patient needs, perspectives and aspirations (focused on improving care experiences); timely data and evidence, enabled through a culture of, and competencies for, learning and improvement (Lavis et al. 2018).

Even in the absence of the more systematic approaches to conducting and supporting evaluation described above, health system leaders should also recognize the intangibles associated with evaluation. The introduction of an evaluation tool within an organization can play an influential, consciousness-raising role even without collecting any data and take some steps toward modelling a caring approach within organizations.

### Remember why we are doing this

Patient- and family-centred care is about putting human needs ahead of those of the system; it is about taking care of people. This relational piece can be the most difficult to evaluate but in many ways is the most important. If the quality of the engagement in health service improvement and system redesign initiatives is a good indicator of how patients and families are treated across an organization, then evaluating this experience is a great opportunity to gain insights into what is going on across the larger organization. The problems that patients and families encounter are less about the people and more about the fact that the health system does not ask how things are going or does not ask this in appropriate ways. Attending to this is the heart of patient and family engagement. If we want to know how well it is working, we have to ask.

### Conclusion

We have articulated key concepts and summarized the current state of evaluation in the context of patient, family and public engagement in health services improvement and system redesign. The focus to date in this nascent field has primarily been on understanding how to engage each of these perspectives in various roles and levels within organizations and health systems and how to determine which approaches work best in different contexts. This is a necessary first step to evaluating the links between quality engagement and care delivery and health outcomes. As the engagement landscape shifts, future efforts will also need to consider the interactions *between* these different perspectives (e.g., patient/user and the broader public). If the recent growth in this area is any indication, we expect considerable progress to be made in addressing these important evaluation questions over the coming years. Careful attention will be needed to ensure that *all* interested parties are meaningfully involved in this work and that high-quality engagement *and* evaluation efforts are adequately supported at the organization, system and policy levels. **HQ**

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# The Capacity for Patient Engagement: What Patient Experiences Tell Us About What's Ahead

## Capacité en matière d'engagement du patient : ce que l'expérience du patient nous laisse entrevoir de l'avenir

Carolyn Canfield

### **Abstract**

Although great achievements in patient engagement merit celebration, many patient collaborators recognize growing gaps are straining the promise of seamless partnership. Recruitment is failing to keep pace with demands for diversity and expertise. Attempts to sustain enthusiasm face volunteer burnout and dropout. The investment in professional capacity to partner with patients contrasts sharply with the missing equivalent for patients asked to meet ever more demanding roles. While peer-led initiatives attempt self-help, more is needed to support patients to fulfill the potential for fully diverse, competent and fulfilling collaboration across all facets of healthcare.

### **Résumé**

Bien que de grandes réalisations en matière d'engagement du patient méritent d'être soulignées, de nombreux patients collaborateurs reconnaissent que des écarts croissants pèsent sur la promesse d'un partenariat homogène. Le recrutement n'arrive pas à suivre le rythme des revendications en matière de diversité et d'expertise. Toute tentative de préserver l'enthousiasme est confrontée à l'épuisement et au décrochage des bénévoles. L'investissement dans la capacité professionnelle de partenariat avec les patients contraste vivement avec l'équivalent absent pour le patient appelé à remplir ce rôle de plus en plus exigeant. Tandis que les initiatives dirigées par des pairs misent sur l'entraide, il faut faire davantage pour aider les patients à réaliser le potentiel d'une pleine collaboration diversifiée, avérée et épanouissante dans tous les aspects des soins de santé.

**KEY MESSAGES**

1. Canada has a wealth of motivated and seasoned patient and family partners drawn largely from a limited fraction of the Canadian population because recruitment filters and engagement requirements have been constructed so narrowly.
2. The expanding appetite of healthcare for greater breadth and depth of lived experience and partnership skills already exceeds current recruitment, which is not surprising given the lack of structural support for capacity development on the patient side of collaboration.
3. The Patient Advisors Network is a national peer community of practice that responds to this capacity gap by addressing two urgent needs: (1) a personal supportive introduction to collaboration for individuals and communities through trust-based peer relationships and (2) experienced assistance with needed skills, information exchange and continual support for the increasingly specialized partnerships expected by healthcare partners.

Over the past decade, I've been privileged to join a revolution in patient participation in multiple facets of healthcare. Following my husband's 2008 avoidable death just days after successful surgery, I sought answers for common-sense questions and was dumbfounded by inadequate answers. Soon I observed patients constructively seeking sensible improvement. While following their lead, I probed for opportunities to influence thinking about patient harm, practitioner safety, systems resilience, research priorities and distributive leadership. As an independent "citizen-patient," I've now contributed across Canada and five continents without formal training, prior knowledge or ongoing sponsorship.

This Special Issue's inspiring account of rapid achievement in patient engagement also exposes critical gaps in attempting to truly "democratize healthcare" (Coney and New Zealand Guidelines Group 2004; Staniszewska et al. 2008). How does self-selection bias the patient voice? What hidden barriers block participation? What do patients need to sustain their development as partners? Could investing in patient capacity reap rewards as effectively as with healthcare providers? Confronting difficult issues, as in this commentary, will help realize the shared ambitions of patient partners and healthcare providers for system transformation.

**The Lay of the Land**

Generations of community volunteers have contributed endless hours to "engage" with sick and recovering people for individual support. Clinicians ask their patients to "engage" in their own care to manage conditions for better quality of life. By contrast, the present patient-engagement movement sees recruits as agents for change in system-level improvement.

Patients are invited into professional settings to destabilize the status quo, introduce fresh perspectives and catalyze innovation. They address not only the safety and quality of care but also improved professional training, research, governance, policy, regulation and integrated social services for individual and community well-being.

In Canada, leaders such as Kingston General Hospital (n.d.), the Canadian Foundation for Healthcare Improvement (CFHI n.d.) and BC's Patient Voices Network (n.d.) created partnership roles far beyond the familiar patient and family advisory bodies. Citizen-patients are panelists hiring staff,

improvement coaches, policy advisors, funding adjudicators, peer mentors, research co-investigators, patient safety instructors, accreditation surveyors, inspirational speakers, workshop facilitators, manuscript reviewers, awards judges, advisors on endless committees and more. We touch every healthcare sector. For the most part, these volunteer skills garner no compensation or support beyond expenses for an individual assignment.

One asset carried by all patient collaborators is how to define "care" as spanning the silos of specialties and jurisdictions. Patient perspectives transcend scopes of practice, job descriptions, terms of reference, career stages, funding envelopes and hierarchies. Patients readily distinguish "work as imagined" from "work as done" (Hollnagel 2014). Healthcare is not what planners, managers, clinicians and regulators *believe* happens or what *should* happen. In patients' eyes, healthcare is what *actually* happens, for better or worse.

**Not all Canadians feel the force of civic empowerment nor access to mechanisms for change.**

**Self-Selection: Altruism Is the First Screen**

Those of us who step forward as engagement partners do so after encountering care just like every other patient. Some of us wish to ensure that a particular care failure never happens to another person. Others want to encourage others to know just how good care can be. What distinguishes us is our confidence in taking action.

In this altruistic act, stepping forward deliberately asserts the right to co-create the society in which we wish to live. Not all Canadians feel the force of civic empowerment nor access to mechanisms for change. So altruism may seem to be unevenly distributed.

Self-selected volunteers are clearly not "patient representatives." Health experiences are specific and unique. UK patient leader David Gilbert suggests that our best contributions may be in posing the right questions, not in making definitive statements (Gilbert 2015). Humility, generosity, trust, vulnerability, curiosity, commitment and kindness characterize those who step forward for change. Spite and militancy are rare.

### Getting Through the Door: Who's Left Out?

Nearly 50 years ago, Julian Tudor Hart proposed his Inverse Care Law, observing that better delivery of medical advances offers the most to those who least need care (Hart 1971). As a corollary for patient engagement, those who most need their voices heard within the system seem least likely to gain entry. Conversely, those with no immediate need for care, like me, tend to have the greatest access and capacity to pursue engagement opportunities. In other words, the privileged become even more privileged.

Let's examine a few dimensions of this passive but brutally effective recruitment screen to see how it plays out from a patient perspective. Here is who's let in, but consider who's left out:

#### Self-selection

We believe we can act, that people will notice us and listen and that we can affect the status quo. We are confident in new challenges and environments where we know no one. As change agents, we can dispassionately outwait institutional inertia before expecting an impact.

#### Power

We confront social norms of medical authority without fear of rejection as troublemakers. Elites, education, wealth and life-and-death control do not intimidate us. We tolerate disrespect as unintended, not allowing past harm to impose mistrust of the powerful.

#### Availability

We can predict scheduled availability in advance, free of constraints of health, household, schooling, work and exhaustion. Others will cover for us during what's nearly always office hours during the workweek. If we need assistance, our attendant's schedule is available too. Instant contact is guaranteed by cell and e-mail connectivity wherever we are.

#### Stamina

Our spare energy for altruism exceeds demands for ourselves and those for whom we are responsible. We will prevail over obstacles of travel, mobility, vision, hearing, mental focus, medications, hydration, pain, fatigue, diet, toileting and treatment.

#### Voice

We can explain our ideas vividly and forcefully, confident of those absent persons for whom we also can speak. Recalling our own experiences does not mean reliving them. When confronted by unfamiliar people, information and settings, we fluently adopt the jargon, at ease with speaking and listening in groups, write expressively and clearly and address large and small audiences comfortably, if not at the podium then from the floor.

#### Setting

We find it easy to ask our way through the labyrinth of offices and boardrooms. We are familiar with agendas, facilitators, project teams, minutes, focus groups, PowerPoint presentations, meeting rules, budgets, strategic plans, confidentiality, webinars and survey questionnaires. Entering medical facilities does not trigger debilitating post-traumatic stress and anxiety. We wade effortlessly into large crowds of unfamiliar people, rest comfortably in hotels when away from home and thrive in noisy conferences with no quiet refuge. We are confident always, even when entirely on our own.

#### Appearance

We know how to dress "for business," with more than one costume and seasonal adaptability. Our style sense will not betray our outsider status and missing wardrobe budget.

#### Finances

Our excess savings can cover the costs of engagement, the unaddressed overhead for transportation, computers, software, Internet bandwidth, cell service, missed meals and incidental expenses. We can also bridge any promised expense reimbursement for many months or indefinitely when Accounting can't process a non-employee non-contractor. We accept that we will almost never be paid for our time but gratefully hear we are greatly valued (Twitter n.d.).

Not only do these filters discriminate harshly, but the learning curve once "inside" can be far steeper than even the most adept can sustain. The recruiting criteria predetermine a preponderance of people like me: white, retired with an income, adept with technology and office skills, with their own transportation and comfortable as the "dominant culture." When professionals identify me as one of "the usual suspects" or "already loud voices," such disrespect cuts deeply.

### Filling the Capacity Gap

To many of us, the rising frenzy for patient partners seems to be outstripping supply. We are overwhelmed by quick response invitations to cryptic solo assignments. Are expectations so intimidating that they discourage new recruits? Are requirements presuming too much prior knowledge, skills or commitment? Or is it that experienced patient partners are dropping out, feeling disappointed, isolated, ineffective or unsupported? Perhaps a bit of each.

Ten years ago when I began my questioning, almost all learning was accessible only to medical professionals. With a neighbour's loaned professorial identity, I tapped a university's vast treasury of online health journals. My bedtime reading of choice became *BMJ Quality and Safety*. Soon, I talked the Institute for Healthcare Improvement into free access to its

online Open School, completing the full curriculum in only a few days. While I didn't expect to plot a PDSA run chart, I wanted to know what it meant. Citizen volunteers should not have to work so hard to become informed. I imagined a citizens' Virtual Institute for Patient Leadership and Capacity Development, free to all, independent and funded by enough sources to withstand electoral swings.

That dream is emerging now through the Patient Advisors Network (PAN), a unique peer-founded and -led bilingual community of practice across Canada with the proud tagline "Independent, Informed, Connected" (PAN 2016). As our membership grows, it is becoming clearer that peer-to-peer, cross-cultural connections to support this social movement will enable us to mature and flourish together. Our ambition is to lower barriers to involvement through accessible knowledge and friendly, human connections with those sharing their patient volunteer experience. This national "network of networks" reaches deeply through our personal connections to more diverse patient populations, demographic sectors and communities. Who better to identify recruiting, access, support and capacity needs than those who are scrambling to fill gaps in the field? As always, "strength in diversity" and collective creativity will enable healthcare to connect patients, families and communities without limit.

**There should be no debate that such workers deserve financial recognition for sophisticated and essential labour ...**

### Emerging Frameworks

Three paradigm-shifting ideas to advance a future of "patient-driven" healthcare systems have attracted much interest for their staying power and integrative thinking. First, the "Value Equation" places accountability firmly within the patient perspective: value is defined as the outcomes of care that are meaningful to patients, relative to the full costs of an episode of care, again defined by patients (Porter and Lee 2013). Secondly, "Learning Health Systems" propose high-level innovation with disciplines beyond healthcare fuelling a practice of continuous learning (Friedman et al. 2017). And thirdly, a community-anchored approach to recasting healthcare is the Indigenous ways of knowing with respect to health and well-being (First Nations Health Authority 2012). All three frameworks for transformation draw upon robust and inclusive citizen-patient involvement to gain legitimacy.

In Canada, urgency is returning to our perennial national challenge to engage the public in reform of the *Canada Health Act*. Perhaps we will finally update the scope, size and interoperability of our 13 insured and 6 direct healthcare systems, to clarify coverage for pharmacare, home care, residential care,

dental health and mental health. The movement for patient, public and community engagement in health systems is equipping an unprecedented number of citizens as adept healthcare "knowledge translators." What could more effectively mobilize public dialogue than collaborations already under way?

As a natural evolution, some experienced citizen-patients are taking up the challenge to acquire greater knowledge for specialized contribution. No longer casual volunteers, these skilled-up and motivated colleagues to professionals must have their efforts compensated as a matter of ethics and equity. To respect personal circumstance and wishes, volunteers could donate or divert their earnings to underwrite a fund for capacity development, such as conference attendance. There should be no debate that such workers deserve financial recognition for sophisticated and essential labour in Canada's health infrastructure (Richards et al. 2018).

Where today we have a national Strategy for Patient-Oriented Research (CIHR 2011), tomorrow innovative patient-led models, such as the Patient and Community Engagement Research (PaCER, n.d.), will train legions of patient investigators. Where today's Health Mentors offer students at the University of British Columbia (n.d.) experience with living with chronic conditions, new pedagogic innovation will enable more communities to lead learning throughout healthcare careers. Where today professional bodies have patient advisors, soon patient directors will invigorate governance and accountability. Where today patients join improvement teams, tomorrow teams of people and communities will track their own cycles of improvement for transformation. Where today expert patients inform health redesign, tomorrow system users will co-create revolutionary models of care.

Actually, tomorrow has arrived. Let's open the door to let it in. **HQ**

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## About the Author

**Carolyn Canfield** is a citizen-patient who volunteers across Canada and internationally to expand system partnerships with patients, carers and communities. Her work since 2008 earned her recognition as Canada's first Patient Safety Champion and faculty appointment at the University of British Columbia.

# Growing a Healthy Ecosystem for Patient and Citizen Partnerships

Antoine Boivin, Vincent Dumez, Carol Fancott and Audrey L'Espérance

## Abstract

Patient and citizen engagement is taking root in a number of healthcare organizations. These initiatives show promising results but require a supportive environment to bring systemic and sustainable impacts. In this synthesis article, we propose an ecosystemic perspective on engagement in health, outlining key elements at the individual, organizational and systemic levels supporting reciprocal and effective relationships among all partners to provide conditions for the co-production of health and care. We argue that growing a healthy engagement ecosystem requires: (1) building local and national “hubs” to facilitate learning and capacity building across engagement domains, populations and contexts; (2) supporting reciprocal partnerships based on co-leadership; and (3) strengthening capacities for research, evaluation and co-training of all partners to support reflective engagement practices that bring about effective change.

## Introduction

Patient engagement is taking root in a number of healthcare organizations across Canada and internationally. Local expertise is growing, as well as understanding of key elements facilitating the creation of engagement-capable organizations at the local level. These pilot engagement projects and organizations show promising results but will require a supportive environment to bring systemic and sustainable impacts on healthcare.

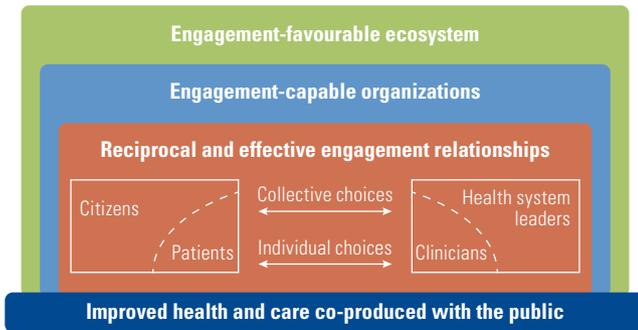
As a synthesis article for this Special Issue of *Healthcare Quarterly*, we propose an ecosystemic perspective on patient and citizen engagement in health, outlining key elements at the individual, organizational and systemic levels supporting reciprocal engagement relationships between patients, clinicians, citizens and health system leaders. Rooted in the idea that healthcare is a human, relationship-based activity, partnership is a condition for the co-production of health and care. Using examples from articles included in this Special Issue, we illustrate support elements at all levels of the healthcare ecosystem for building effective partnerships in healthcare improvement.

## An Ecosystemic, Reciprocal Perspective on Patient and Citizen Engagement Relationships

Ecosystems are communities of individuals interacting with their environment (Gurevitch et al. 2002: 522). Ecosystems are “holonic structures”: they are made of entities that are a whole and a part of a larger system at the same time (e.g., atoms, cells, organisms, planet), with the levels dynamically interacting with one another (Koestler 1967: 48). In healthcare, individuals are embedded within the healthcare organizations and systems they interact with (Mella and Gazzola 2017). An ecosystemic perspective on patient and citizen engagement reminds us that healthcare, in its essence, is about relationships between people. This perspective also highlights the idea that these relationships

interact with and are influenced by their environment (e.g., communities, economic and political environments, healthcare organizations and systems) (Figure 1).

**FIGURE 1.**  
**An ecosystemic, reciprocal perspective on patient and citizen engagement relationships**



A reciprocal perspective on engagement highlights the idea that patients and citizens are not only engaged by health professionals (who set the goals and decide who is going to be engaged or not). This perspective suggests that patients and citizens can also take the leadership of engaging as full partners with clinicians, researchers and decision-makers, sharing with them the responsibility of individual and collective health choices (Boivin et al. 2018). This reciprocal approach to engagement is foundational to the idea that health is co-produced by patients and citizens (being recognized as caregivers for themselves and others) (Barr et al. 2003).

**Engagement Support Elements at the Individual, Organizational and Systemic Levels**

The articles included in this Special Issue illustrate a number of key elements at the individual, organizational and systemic levels that support (or hinder) effective and reciprocal engagement between patients, clinicians, citizens and health system leaders (Table 1).

At the individual level, all partners need to uncover and develop their competencies, skills and resources, allowing them to engage in productive relationships with individuals who have different interests, knowledge and perspectives. This includes understanding that each individual brings valuable and complementary expertise (e.g., experience-based knowledge of living with an illness as a patient, the diagnostic skills and clinical experience of health professionals, the research methods of a scientist, the management experience of a system leader) (Flora 2013). Working in partnership also requires cross-cultural skills, including the ability to see problems from multiple perspectives, to deal with uncertainty and to share leadership and power (Kahane 2017). Connection to relevant peers (e.g., connecting patient partners to a broader community of peers) as well as mentorship with engagement experience (e.g., experienced

patients, clinicians and managers with partnership experience) can also help build individual capacity to engage more effectively (Boivin et al. 2014). In this issue, articles by Rowland and colleagues and Canfield underline the broad varieties of roles that patients can play in the healthcare system: for example, planning, designing, advising, surveying, evaluating, recruiting and training. Increasingly, organizations ask patients and family members not only to be a “voice around the table” but to take on leadership roles (Canfield 2018; Rowland et al. 2018). In this context, enlisting and preparing patients and families are paramount. Recruitment starts with a defined mandate and modes of engagement, as well as rigorously clear roles and responsibilities for patients and the professionals with whom they will be partnering. The capacity and space to better define these roles and responsibilities are increasing, with the realization that forms of knowledge can be complementary and expertise is not strictly reserved to professionals. Patients and family members can act as knowledge brokers, connecting and translating knowledge across communities in the healthcare ecosystem, but can also redefine priorities by bringing pragmatic solutions to healthcare system challenges (Pomey et al. 2018).

As highlighted in a number of articles in this Special Issue, organizations can create conditions that facilitate (or hinder) effective engagement relationships between patients, clinicians and health system leaders. Drawing on the concept of “engagement-capable environments,” a number of authors outline institutional structures that can support effective engagement practices, including recruitment capacities (e.g., patient and clinician partners’ competency frameworks, local experts in partners’ recruitment and matching, development of patient partners’ databases) and the ability to co-train patients and their partners to work effectively together. Productive conflict is a normal aspect of partnership building (Jagosh et al. 2015); local conflict resolution and mediation capacities are also important organizational structures. O’Connor and colleagues highlight the importance of leaders and “champions” at different levels of an organization to establish the relevant infrastructure and promote a shift in attitudes and culture favourable for engagement. (O’Connor et al. 2018). Strategic positioning and good communication go hand in hand with methodological support structures. Local leaders are also important for promoting adaptation of the work environment to reduce barriers to engagement of vulnerable groups. Recognition of partners also goes further than mere acknowledgement but can be entrenched in recognized institutional status and fair and equitable compensation (Canfield 2018). The development of a shared infrastructure for recruitment, training and mentoring throughout the engagement cycle is also important. The experience of Quebec’s local and regional healthcare organizations demonstrates that healthcare organizations need to be agile and responsive to building these engagement infrastructures in a way that is adaptable to local contexts (Pomey et al. 2018).

**TABLE 1.**  
**Examples of engagement support elements at the individual, organizational and systemic levels**

Engagement support levels	Engagement support elements
Individual level	<ul style="list-style-type: none"> <li>• Recognition of complementary expertise and experience-based knowledge</li> <li>• Cross-cultural and cross-perspective communication and collaboration skills</li> <li>• Shared leadership capabilities</li> <li>• Connections with relevant peers, leaders, engagement mentors and collaborators</li> <li>• Clarification and complementary alignment of individual roles and responsibilities</li> <li>• Uncovering and development of existing and new competencies</li> </ul>
Organizational level	<ul style="list-style-type: none"> <li>• Recognized local engagement leaders</li> <li>• Partner recruitment and matching capacity</li> <li>• Shared engagement infrastructure (e.g., recruitment partners' database, methodological guides)</li> <li>• Engagement process experts</li> <li>• Co-training and mentorship capacity</li> <li>• Conflict resolution and mediation expertise</li> <li>• Engagement evaluation and feedback capacity</li> <li>• Equitable compensation, adaptation and support to reduce barriers for engagement of all partners</li> </ul>
Systemic level	<ul style="list-style-type: none"> <li>• National, provincial and local hubs to facilitate learning across engagement organizations, leaders, contexts, methods and populations</li> <li>• Engagement communities of practice</li> <li>• Shared provincial and national engagement infrastructure (e.g., engagement guidelines, common indicators, evaluation tools and research methods)</li> <li>• Support for pilot and scaling up of engagement innovations at the systemic level</li> <li>• Common training content development and platforms</li> <li>• Engagement research funding and support</li> </ul>

Evaluation is another vital mechanism for organizations to stay agile and build learning environments for engagement. Abelson et al. (2018) show that evaluation is not a separate activity and can help individuals, teams and organizations to reflect on their relationship and learn how to better engage with one another, using a growing set of evaluation tools and methods. Evaluation not only helps organizations better communicate the relevance and effectiveness of patient and public engagement but also strengthens the working relationship of patients and health professionals and enhances their ability to initiate significant and productive projects. Building and promoting an applicable evaluation program assist engagement planning and monitoring as well as support ethical and equitable engagement practices.

These organizational infrastructures are not static and separate from one another. Faber et al. (2018) provide an illustration of healthcare organizations as “living organisms” when it comes to the adoption, implementation and transformation of engagement practices. Their article suggests that champions and early adopters, both at the “top” and “bottom” of the organization, can support engagement initiatives that will influence the culture, engagement, infrastructure development and identity of an organization (even becoming a “marketing trademark” for the institution). Faber et al. also show that the movement toward engagement is not irreversible and can be challenged and pushed back, especially when it touches “core” or sensitive activities such as the audit and feedback of professional practice.

Finally, systemic factors can influence (and be influenced by) engagement practices at the organizational and individual levels. A core systemic-level element of an engagement support ecosystem is the notion of “engagement hubs,” which are dedicated institutions, spaces and activities facilitating cross-learning across engagement organizations, leaders, methods and populations. Hubs are important because engagement practices occur in a variety of contexts that do not naturally interact with one another (e.g., engagement in individual care, research, education, policy and priority setting) but face common methodological questions and challenges (e.g., recruitment strategy, defining and measuring success, dealing with power imbalance) that benefit from the sharing of experiences and expertise.

Fancott's (2018) article describes how the Canadian Foundation for Healthcare Improvement (CFHI) acted in recent years as a national hub for patient engagement in quality improvement across different healthcare organizations in Canada. By supporting engagement collaboratives, pilot projects and communities of practices across healthcare organizations and engagement leaders, CFHI acted as a catalyst for capacity development at the individual, organizational and systemic levels. The CFHI example also illustrates two-way interactions between the systemic, organizational and individual levels: whereas national organizations such as CFHI can support local healthcare institutions and teams with common resources and networking opportunities, local

leaders can shape national dialogues with concrete case studies, examples, tools and lessons learned. This shows that engagement communities are not functioning as hierarchical systems (e.g., with the national level driving local initiatives) but as holarchical systems (with two-way interactions between local initiatives and systemic support structures). This has important policy implications for the future of patient and citizen engagement in Canada, which will require continued leadership at all healthcare system levels, including national and provincial governments working collaboratively with local healthcare institutions and leaders.

Teare and Keller's (2018) example from Saskatchewan illustrates a different kind of engagement hub (at the provincial level), building a common infrastructure across two engagement domains (research and quality improvement) to facilitate cross-learning and resource sharing. By embedding its SUPPORT Unit for patient-oriented research (with a dedicated mandate for patient engagement in research) inside the Saskatchewan Health Quality Council (with existing expertise on patient engagement in quality improvement), Saskatchewan capitalized on existing engagement resources (e.g., recruitment material and training) to strengthen the transformational potential of engagement practices. The Centre of Excellence on Partnership with Patients and the Public (ceppp.ca) provides another example of engagement hub organization, bridging engagement science and practice across multiple domains (research, care, education and community) working at different levels of the healthcare system (local, provincial, national and international).

All of these examples show the complexities of the emerging engagement ecosystem in Canada, with "root" organizations building engagement expertise within a specific context and population (e.g., local healthcare organizations or research institutions embedding engagement practices in their own programs and population) and "bridge" organizations acting as hubs to facilitate cross-learning across engagement methods, populations and contexts.

As shown in a number of articles in this issue, the Canadian patient and citizen engagement community faces a number of common challenges that can be addressed through international and national collaborative approaches. For example, many healthcare organizations are now equipped with dedicated staff to help recruit patient partners in quality improvement activities, as well as basic indicators to track activities and short-term outcomes. However, many are still struggling with common fundamental questions that can only be partially answered locally (e.g., long-term impacts, comparative effectiveness of different engagement methods, validated monitoring tools to avoid tokenistic engagement). Policy makers need to recognize the need for dedicated engagement science funding, support and infrastructure to further advance methods and practice. In a sense, the challenge in balancing support for engagement

practice implementation and support for engagement science is similar to that faced by other "horizontal" activities in healthcare (e.g., quality improvement, implementation science, knowledge translation science) and finds an echo in the international literature on patient and public engagement (Carman et al. 2013; Frank et al. 2015; Tritter and McCallum 2006).

**... the Canadian patient and citizen engagement community faces a number of common challenges that can be addressed through ... collaborative approaches.**

## Conclusion

Although patient engagement is taking root in a number of healthcare organizations across Canada, teams get to understand not only how their environments are conducive to engaging patients and family members but also how they can constrain their ability to fully engage with them. A healthy ecosystem is needed to sustain effective relationships between patients, clinicians, citizens, and health system leaders. A growing body of evidence points toward key engagement support elements at the individual, organizational and systemic levels. Within the Canadian context, critical elements to strengthen this ecosystem include: (1) building local, provincial and national "hubs" to facilitate cross-learning and capacity building across engagement domains, populations and contexts; (2) supporting reciprocal partnerships based on co-leadership (balancing "inside" engagement of patients by professionals with "outside" engagement of professionals by patients and citizens); and (3) strengthening capacities for research, evaluation and co-training of all partners to support reflective engagement practices that bring about effective change. Rooted in the idea that healthcare is, at its core, a human activity based on relationships, creating a supportive ecosystem for patient and citizen partnerships is a precondition for the co-production of health and care. **HQ**

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# Cultiver un écosystème favorable aux partenariats avec le patient et le citoyen

Antoine Boivin, Vincent Dumez, Carol Fancott et Audrey L'Espérance

## Résumé

L'engagement des patients et des citoyens s'implante dans de nombreux organismes de soins de santé. Ces initiatives donnent des résultats prometteurs, mais exigent un environnement favorable pour que leur impact soit systémique et pérenne. Dans cet article, nous proposons une perspective écosystémique de l'engagement en matière de santé, en décrivant les principaux éléments individuels, organisationnels et systémiques qui encouragent des relations réciproques et efficaces entre tous les partenaires, afin de réunir les conditions d'une co-production de la santé et des soins de santé. Nous soutenons que la création d'un écosystème favorable au partenariat exige : (1) la création de « carrefours » locaux et nationaux pour faciliter l'apprentissage et le renforcement des capacités dans un ensemble de domaines, de populations et de contextes d'engagement; (2) le soutien de partenariats réciproques fondés sur un leadership partagé et (3) le renforcement des capacités de recherche, d'évaluation et de formation conjointe de tous les partenaires afin de soutenir les pratiques réflexives favorables à l'engagement dans le but d'entraîner un changement effectif.

## Introduction

L'engagement des patients et des citoyens s'implante dans de nombreux organismes de soins de santé au Canada et à l'étranger. Il existe un savoir-faire local grandissant, de même

qu'une compréhension croissante des éléments qui facilitent la création de milieux propices à l'engagement au niveau local. Ces projets pilotes et leurs organismes d'attache donnent des résultats prometteurs, mais exigent un environnement favorable pour avoir un impact systémique et pérenne sur les soins de santé.

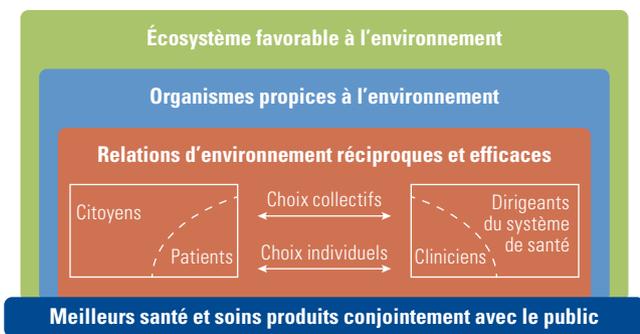
En guise d'article de synthèse pour ce numéro spécial de *Healthcare Quarterly*, nous proposons une perspective écosystémique de l'engagement des patients et des citoyens en matière de santé, en soulignant les éléments importants aux niveaux individuel, organisationnel et systémique qui favorisent des relations d'engagement réciproques entre patients, cliniciens, citoyens et dirigeants du système de santé. Si l'on admet que les soins de santé sont une activité humaine, fondée sur des relations, le partenariat est une condition essentielle à la production conjointe de la santé et des soins de santé. À l'aide d'exemples tirés d'articles de ce numéro spécial, nous illustrons des éléments favorables à tous les niveaux de l'écosystème de santé en vue de tisser des partenariats efficaces au service de l'amélioration des soins de santé.

## Une perspective écosystémique et réciproque des relations de l'engagement du patient et du citoyen

Les écosystèmes sont des collectifs d'individus qui interagissent avec leur environnement (Gurevitch et al. 2002 : 522). Les écosystèmes ont la nature d'un « holon » : ils sont constitués

d'entités constituant un ensemble, faisant eux-mêmes partie d'un système plus vaste (atomes, cellules, organismes, planète, etc.) dont les niveaux interagissant de manière dynamique les uns avec les autres (Koestler 1967 : 48). Dans le secteur de la santé, les personnes sont intégrées aux organisations et aux systèmes de santé avec lesquels elles interagissent (Mella et Gazzola 2017). La perspective écosystémique de l'engagement du patient et du citoyen nous rappelle que les soins de santé, par leur essence, concernent les relations entre les personnes. Cette perspective souligne en outre l'idée selon laquelle ces relations interagissent avec l'environnement et sont influencées par celui-ci (p. ex. les communautés, les contextes économique et politique, les organisations et systèmes de soins de santé) (Figure 1).

**FIGURE 1.**  
**Une perspective écosystémique et réciproque des relations d'environnement du patient et du citoyen**



Une perspective réciproque de l'engagement met en lumière l'idée que le patient et le citoyen ne sont pas seulement mobilisés par les professionnels de la santé (qui fixent les objectifs et décident de qui participera ou non). En effet, cette perspective préconise la mobilisation du patient et du citoyen en tant que partenaires à part entière d'une équipe constituée de cliniciens, de chercheurs et de décideurs, afin de partager la responsabilité des choix de santé individuels et collectifs (Boivin et al. 2018). Cette approche d'engagement réciproque s'appuie sur le postulat selon lequel la santé est coproduite par le patient et le citoyen (reconnus en tant que soignants pour eux-mêmes et pour autrui) (Barr et al. 2003).

### **Éléments de soutien à l'engagement aux niveaux individuel, organisationnel et systémique**

Les articles de ce numéro spécial illustrent un certain nombre d'éléments importants aux niveaux individuel, organisationnel et systémique qui soutiennent (ou entravent) un engagement efficace et réciproque entre patients, cliniciens, citoyens et dirigeants du système de santé (Tableau 1).

Au niveau individuel, tous les partenaires doivent découvrir et développer leurs compétences et leurs ressources personnelles en vue de nouer des relations productives avec des personnes qui ont des intérêts, des connaissances et des perspectives distincts. Cela signifie comprendre que chaque personne apporte une expertise distincte et complémentaire (p. ex. connaissances du patient issues de l'expérience vécue d'une maladie, capacités de diagnostic et expérience clinique du professionnel de la santé, méthodes de recherche d'un scientifique, expérience de gestion d'un dirigeant) (Flora 2013). Le travail en partenariat exige également des compétences interculturelles, notamment la capacité d'appréhender les problèmes à partir de plusieurs points de vue, de faire face aux incertitudes et de partager le leadership et le pouvoir (Kahane 2017). L'établissement de liens avec des pairs (p. ex. la mise en relation de patients partenaires avec une communauté élargie de pairs) ainsi qu'un mentorat axé sur l'expérience d'engagement (p. ex. des patients, cliniciens et gestionnaires disposant d'une expérience approfondie de partenariats) peuvent également contribuer à renforcer la capacité individuelle à participer plus efficacement (Boivin et al. 2014). Dans ce numéro, des articles de Rowland et de ses collègues, ainsi que celui de Canfield, soulignent les nombreux rôles que peuvent occuper les patients partenaires dans le système de santé : par exemple, planifier, concevoir, conseiller, interroger, évaluer, recruter et former. De plus en plus, les organismes demandent aux patients et à leurs proches non seulement d'être « une voix de plus », mais également d'assumer des fonctions de leadership (Canfield 2018; Rowland et al. 2018). Dans ce contexte, il est primordial de recruter et de préparer les patients et leurs proches. Le recrutement commence par des attributions et des rôles bien définis, ainsi que par une définition rigoureuse des fonctions et des responsabilités des patients et des professionnels avec lesquels ils travailleront en partenariat. La capacité et la volonté de mieux définir ces rôles et responsabilités s'accroissent tandis qu'on réalise que les formes de savoir peuvent être complémentaires et que l'expertise n'est pas strictement l'apanage des professionnels. Les patients et leurs proches peuvent occuper le rôle de courtiers de connaissances pour conjuguer et appliquer les connaissances de l'écosystème de la santé dans l'ensemble des communautés, mais ils peuvent également redéfinir les priorités en apportant des solutions pragmatiques aux défis du système de santé (Pomey et al. 2018).

Comme le révèlent plusieurs articles de ce numéro spécial, les organismes peuvent créer des conditions qui facilitent (ou entravent) les relations d'engagement efficaces entre patients, cliniciens et dirigeants du système de santé. S'appuyant sur le concept de « milieux propices à l'engagement », certains auteurs décrivent des structures institutionnelles salutaires pour les pratiques d'engagement efficaces, notamment la capacité de recruter (p. ex. cadre de compétences pour les patients et cliniciens partenaires, experts locaux en recrutement et en

appariement de partenaires, développement de répertoires de patients partenaires) et la possibilité de former les patients et leurs partenaires conjointement afin qu'ils travaillent efficacement ensemble. Le conflit productif est un aspect normal de la création de partenariats (Jagosh et al. 2015); la résolution locale des conflits et les capacités de médiation sont également des structures organisationnelles importantes. O'Connor et ses collègues soulignent l'importance des leaders et des « champions » aux divers niveaux d'un organisme pour établir l'infrastructure nécessaire et promouvoir un changement d'attitudes et de culture propice à l'engagement (O'Connor et al. 2018). Le positionnement stratégique et une bonne communication vont de pair avec les structures de soutien méthodologiques. Les dirigeants locaux jouent également un rôle important dans la promotion de l'adaptation du milieu de travail afin de réduire les obstacles à l'engagement des groupes vulnérables. La reconnaissance des partenaires va également au-delà de la simple reconnaissance : elle doit être ancrée dans un statut institutionnel reconnu et une rémunération juste et équitable (Canfield 2018). Le développement d'une infrastructure partagée pour le recrutement, la formation et le mentorat tout au long du cycle de l'engagement est également important. L'expérience des organismes de santé locaux et régionaux du Québec montre que les organismes de santé doivent être agiles et réactifs pour que la construction de ces infrastructures d'engagement s'adapte au contexte local (Pomey et al. 2018).

L'évaluation est un autre mécanisme essentiel qui permet de créer des environnements d'apprentissage propices à l'engagement. Abelson et ses collègues (2018) montrent que l'évaluation ne constitue pas une activité isolée et qu'elle peut aider les personnes, équipes et organismes à réfléchir à leur relation et à apprendre à mieux dialoguer en utilisant un ensemble grandissant d'outils et de méthodes d'évaluation. L'évaluation aide non seulement les organismes à mieux communiquer la pertinence et l'efficacité de l'engagement du patient et du public, elle renforce également les relations de travail des patients et des professionnels de la santé, ainsi que leur capacité à mener à bien des projets d'envergure. La conception et la promotion d'un programme d'évaluation raisonné contribue à la planification et au suivi de l'engagement, ainsi qu'au soutien de pratiques de participation éthiques et équitables.

Ces infrastructures organisationnelles ne sont pas statiques et séparées les unes des autres. Faber et al. (2018) présentent les organismes de soins de santé sous la forme « d'organismes vivants » pour ce qui regarde l'adoption, la mise en œuvre et la transformation de pratiques d'engagement. Leur article laisse entendre que les champions et utilisateurs précoces, à la fois du « haut » et du « bas » de l'organisme, peuvent soutenir des initiatives d'engagement qui influenceront la culture, le degré d'engagement, le développement de l'infrastructure et l'identité de l'organisme (allant même jusqu'à devenir une « marque de commerce » pour l'établissement). Faber et al. montrent également que le mouvement en faveur de l'engagement n'est

**TABLEAU 1.**  
**Exemples d'éléments de soutien à l'engagement aux niveaux individuel, organisationnel et systémique**

Niveaux de soutien à l'engagement	Éléments de soutien à l'engagement
Niveau individuel	<ul style="list-style-type: none"> <li>Reconnaissance du savoir-faire complémentaire et des connaissances fondées sur l'expérience</li> <li>Compétences en matière de communication et de collaboration interculturelles et transversales</li> <li>Capacités de leadership partagées</li> <li>Liens avec des pairs, des dirigeants, des mentors et des collaborateurs sur l'engagement</li> <li>Éclaircissement et alignement complémentaire des rôles et responsabilités individuels</li> <li>Découverte et développement de compétences nouvelles et existantes</li> </ul>
Niveau organisationnel	<ul style="list-style-type: none"> <li>Chefs de file locaux reconnus en matière d'engagement</li> <li>Capacités de recrutement et jumelage des partenaires</li> <li>Infrastructure d'engagement partagée (p. ex. base de données de recrutement, guides méthodologiques)</li> <li>Experts en processus d'engagement</li> <li>Capacité de formation conjointe et de mentorat</li> <li>Expertise en résolution de conflits et en médiation</li> <li>Capacité d'évaluation et de rétroaction sur l'engagement</li> <li>Rémunération équitable, adaptation et soutien pour réduire les entraves à l'engagement de tous les partenaires</li> </ul>
Niveau systémique	<ul style="list-style-type: none"> <li>Carrefours nationaux, provinciaux et locaux pour faciliter l'apprentissage sur l'engagement entre organismes, dirigeants, milieux, méthodes et populations</li> <li>Communautés de pratique</li> <li>Infrastructure de collaboration provinciale et nationale commune (p. ex. lignes directrices sur l'engagement, indicateurs communs, outils d'évaluation et méthodes de recherche)</li> <li>Soutien à l'expérimentation et à la mise à l'échelle d'innovations en matière d'engagement au niveau systémique</li> <li>Élaboration d'un contenu et de plateformes de formation communs</li> <li>Financement et soutien pour la recherche sur l'engagement</li> </ul>

pas irréversible et peut être remis en cause ou repoussé, en particulier s'il touche à des activités sensibles telles que l'évaluation des pratiques professionnelles.

Enfin, les facteurs systémiques peuvent influencer (et être influencés par) les pratiques d'engagement aux niveaux organisationnel et individuel. La création de « carrefours » constitue un élément systémique central de l'écosystème de soutien à l'engagement. Ces carrefours prennent la forme d'établissements, d'espaces et d'activités consacrés à l'apprentissage mutuel entre organismes, dirigeants, méthodes et populations. Ces carrefours sont importants, car les pratiques d'engagement se produisent dans des contextes qui n'interagissent pas naturellement les uns avec les autres (p. ex. participation aux soins individuels, à la recherche, à la formation, aux politiques et à l'établissement de priorités), mais qui se heurtent à des questions méthodologiques et à des défis communs (stratégie de recrutement, définition et mesure de la réussite, gestion des déséquilibres de pouvoir). Ainsi, ces pratiques profitent du partage des expériences et des compétences.

L'article de Fancott (2018) décrit comment, depuis quelques années, la Fondation canadienne pour l'amélioration des services de santé (FCASS) occupe la place de carrefour national de l'engagement des patients à l'amélioration de la qualité dans divers établissements de soins de santé du Canada. En soutenant des projets collaboratifs, projets pilotes et communautés de pratiques proposés par des organismes et dirigeants de la santé, la FCASS sert de catalyseur au renforcement de la capacité individuelle, organisationnelle et systémique. L'exemple de la FCASS illustre également les interactions bilatérales entre les niveaux systémique, organisationnel et individuel : tandis que des entités nationales comme la FCASS peuvent soutenir des équipes et établissements de santé locaux au moyen de ressources communes et de possibilités de réseautage, les dirigeants locaux peuvent orienter le dialogue national au moyen d'études de cas, de ressources et d'apprentissages concrets. En effet, les communautés actives dans le domaine de l'engagement ne sont pas organisées de façon hiérarchiques (le niveau national ne dirige pas les initiatives locales), mais plutôt en holarchies (il se produit des interactions bidirectionnelles entre les initiatives locales et les structures de soutien systémiques). Cette réalité a d'importantes répercussions politiques sur l'avenir de l'engagement des patients et des citoyens au Canada, car elle exige un leadership à tous les niveaux du système de santé, dont une collaboration des gouvernements national et provinciaux avec les établissements et responsables locaux des soins de santé.

L'exemple de Teare et Keller (2018), en Saskatchewan, illustre un autre type de carrefour d'engagement (au niveau provincial), qui crée une infrastructure commune entre deux domaines d'engagement (la recherche et l'amélioration de la qualité) afin de faciliter l'apprentissage mutuel et le partage de ressources. En intégrant son unité de soutien à la recherche axée sur le patient

(dotée d'un mandat consacré à la recherche sur l'engagement des patients) au sein du Saskatchewan Health Quality Council (qui possède déjà une expertise en matière d'engagement des patients à l'amélioration de la qualité), la Saskatchewan a exploité des ressources existantes (p. ex. matériel de recrutement et formation) pour renforcer le potentiel de transformation des pratiques d'engagement. Le Centre d'excellence sur le partenariat avec les patients et le public (ceppp.ca) constitue un autre exemple de pôle d'engagement qui soutient la science et les pratiques d'engagement dans plusieurs domaines (recherche, soins, éducation et communauté) à divers niveaux du système de santé (local, provincial, national et international).

Tous ces exemples illustrent la complexité de l'écosystème embryonnaire sur l'engagement des patients et des citoyens au Canada : des organismes « souches » développent une expertise d'engagement pour un contexte et une population précis (p. ex. organismes de santé locaux ou instituts de recherche qui intègrent des pratiques d'engagement à leurs programmes et populations) tandis que des organismes « pivots » font office de relais transversaux pour encourager l'apprentissage mutuel entre méthodes, populations et contextes d'engagement.

Comme l'illustrent plusieurs articles de ce numéro, la communauté canadienne sur l'engagement des patients et des citoyens est confrontée à des défis communs qui peuvent être résolus à l'aide de collaboration internationales et nationales. Par exemple, de nombreux organismes de soins de santé sont maintenant dotés d'un personnel spécialisé dans le recrutement de patients partenaires pour les activités d'amélioration de la qualité, ainsi que d'indicateurs élémentaires pour suivre les activités et résultats à court terme. Cependant, beaucoup se heurtent toujours à des questions fondamentales communes auxquelles une réponse locale n'est que partiellement possible (p. ex. effet à long terme, efficacité comparative de diverses méthodes d'engagement, outils de suivi validés pour éviter un engagement purement symbolique). Les responsables des politiques doivent reconnaître la nécessité d'un financement, d'un soutien et d'une infrastructure consacrés à la science de l'engagement afin de faire progresser les méthodes et les pratiques. En un sens, le défi qui consiste à équilibrer le soutien pour la mise en œuvre des pratiques et pour la science de l'engagement est similaire à celui que doivent relever d'autres activités dites « horizontales » dans le secteur de la santé (amélioration de la qualité, science de la mise en œuvre, science de l'application des connaissances) et trouve un écho dans la littérature internationale sur l'engagement du patient et du public (Carman et al. 2013; Frank et al. 2015; Tritter et McCallum 2006).

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## Conclusion

Bien que l'engagement des patients et des citoyens s'implante dans de nombreux organismes de soins de santé canadiens, les équipes de professionnels doivent non seulement comprendre comment leur milieu favorise l'engagement du patient et de ses proches, mais également comment il limite leur capacité à y contribuer véritablement. Un écosystème sain s'impose pour maintenir des relations efficaces entre patients, cliniciens, citoyens et dirigeants du système de santé. Un corpus croissant de données probantes décrit les principales mesures de soutien favorables à l'engagement aux niveaux individuel, organisationnel et systémique. Dans le contexte canadien, les éléments essentiels pour renforcer cet écosystème comprennent : (1) la création de « carrefours » locaux, provinciaux et nationaux qui faciliteront l'apprentissage mutuel et le renforcement des capacités dans tous les domaines, populations et contextes d'engagement; (2) le renforcement de partenariats réciproques fondés sur un leadership partagé (équilibre entre l'engagement « interne » du patient établi par le professionnel et l'engagement « externe » du professionnel établi par le patient et le citoyen); et (3) le renforcement des capacités de recherche, d'évaluation et de formation conjointe chez tous les partenaires afin de soutenir les pratiques d'engagement réflexives en vue d'entraîner un changement véritable. Fondée sur l'idée que les soins de santé sont, à la base, une activité humaine relationnelle, la création d'un écosystème favorable aux partenariats avec le patient et le citoyen est une condition préalable à la coproduction de la santé et des soins de santé. **HQ**

## Références

Veillez vous reporter à la liste dans la version anglaise (pp. 76–77).

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