Université de Montréal

Building safer health systems: strategies used in the institutionalization of patient engagement for patient safety

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Cette thèse est intitulée:

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ABSTRACT

Background: Worldwide, four out of 10 patients are harmed while receiving health care in a hospital setting, of which 80 % could have been prevented (WHO, 2009; WHO, 2002; Slawomirski, 2017; WHO, 2019). Recent evidence demonstrates that 15 % of total hospital expenditure and activities in OECD countries is a direct result of adverse events, amounting to trillions of US dollars every year (Slawomirski, 2017). According to a Canadian Patient Safety Institute report in 2016, incidents in both the acute and home care settings resulted in additional costs of $2.75 billion each year. Therefore, it is no surprise that investing in the cost of prevention is much lower than the cost of care due to harm. Today, research suggests that patient engagement (PE) can help improve outcomes and reduce the burden on health institutions. However, the use of PE in various strategies to promote PS has yet to be fully integrated across healthcare organizations and systems in Canada, the USA and many OECD countries.

Objectives: The aim of this research study is to identify emerging and innovative PE mechanisms and strategies put in place by organizational leaders in leading healthcare institutions after implementation of Bill 10 in 2015, that would allow the institutionalization of PE in the health care system for patient safety (PS). Two specific questions were asked.

Research question 1: What are the different PE strategies/mechanisms put in place by leaders in health institutions (CISSS and CIUSSS) to institutionalize PE for PS?

Research question 2: What are the innovative practices (strategies, mechanisms) as well as the limiting and enabling factors put in place by institutional leaders in one of the integrated healthcare centers in Quebec (case study) that would allow PE to be fully institutionalized[1] in risk management for the enhancement of patient safety?

Methods: The project is a longitudinal descriptive research project by design with interwoven levels of analysis (strategic, organization and clinical) separated into **two phases**. **Phase 1: 1)** development of a tool for leaders to assess emerging PE integration strategies implemented in healthcare institutions to enhance PS (Article 1 of the thesis results); **2)** collect ongoing emerging and innovative strategies of PE for PS in health institutions (N= 24: 9 CIUSSS, 11 CISSS, 2 non-integrated universities health institutions) across Quebec (Canada) by using the tool created in phase 1, and collect qualitative data through semi-structured interviews with leaders of these health institutions. **Phase 2: 3)** Analysis of a case study, which started implementing strategies to engage patients for PS (analysis of fall prevention and reduction pilot project by a clinical team integrating a PP) in their health institution was conducted in a long-term care facility. A qualitative data collection approach was used to conduct semi-structured interviews of strategic, organizational and clinical leaders (N = 7) of 40 min to 2 h 30 min each. Observation, as well as internal and external documents analysis was also conducted (Article 3 of the thesis results).

Findings: In phase 1: **1) (Article 1 of the thesis results)** a tool assessing emerging PE integration strategies implemented in healthcare institutions to enhance PS was created consisting of 82 questions. **2) (Article 2 of the thesis results),** seven main emerging/innovative sub strategies of PE for PS were identified and discussed through the process of knowledge acquisition, knowledge sharing, and knowledge preservation at the three levels of governance: clinical, organizational and strategic. **In phase 2: (Article 3 of the thesis results),** one case study implementing a strategy of fall analysis process by the clinical team integrating a PP for prevention and reductions of falls,

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[1] Intitutionalization: a process through which something (a change, such as a concept, a behavior, a common value, etc.) anchors itself within an organization, a social system or society (DiMaggio & Walter, 1983; Scott, Michael & Smith, 2004).

was selected to participate (CISSS Montérégie-Est). Three main sub-strategies were revealed in this article.

Conclusion: The research study is the first of its kind at a provincial level. Future work should focus on (1) comparative studies between provinces, nations, and their evolution. There is currently an ongoing Pan-Canadian and a Brazilian research project based on the original research project from Quebec's. In addition, France, have also conducted this study to describe their PE for PS strategies using the tool created in this thesis. Moreover, additional research should focus on (2) collaboration mechanisms and strategies used in the institutionalization of concrete initiatives / innovative practices (case studies) of PE for PS, the role of patient groups, volunteers, as well as compensation models for PE for PS in these collaboration mechanisms and strategies. In addition, more research on (3) best leadership practices to instill a no-blame culture by way of concrete examples (case studies) will be required to implement a safe culture based on practical leadership experiences. Furthermore, moving from a hospital setting, future research should evolve into (4) Citizen's engagement for safety, especially during these pandemic periods (e.g. Covid-19).

Keywords: Health organizations/institutions; institutionalization, risk management/patient safety; fall prevention/reduction; patient engagement; strategies/mechanisms/innovative /emerging

RÉSUMÉ

Contexte : Quatre patients sur dix qui reçoivent des soins de santé en milieu hospitalier sont victimes d’évènements indésirables et 80 % de ces évènements auraient pu être évités (OMS, 2019). Des données récentes montrent que 15 % des dépenses et activités hospitalières totales dans les pays de l'OCDE sont le résultat direct d'événements indésirables, ce qui représente des milliards de dollars US chaque année (Slawomirski, 2017). Selon un rapport de l'Institut canadien pour la sécurité des patients publié en 2016, les incidents survenus dans les établissements de soins de courte durée et à domicile ont entraîné des coûts supplémentaires de 2,75 milliards de dollars chaque année. Il n'est donc pas surprenant que l'investissement dans le coût de la prévention soit bien inférieur au coût des soins dus aux préjudices. Aujourd'hui, la recherche suggère que l'engagement des patients (EP) peut contribuer à améliorer les résultats et à réduire la charge des établissements de santé. Cependant, l'utilisation de l'EP dans diverses stratégies de gestion des risques et de promotion de la sécurité des patients n'est pas encore totalement intégrée dans les organisations et systèmes de soins de santé au Canada, aux États-Unis et dans de nombreux pays de l'OCDE.

Objectifs : L'objectif de cette étude de recherche est d'identifier les mécanismes et stratégies d'EP émergents et innovants mis en place par les dirigeants des principaux établissements de santé dans la province du Québec (Canada) après la mise en œuvre de la loi 10 en 2015, qui permettraient l'institutionnalisation de l'EP dans le système de santé pour la sécurité des patients (SP). Deux questions spécifiques ont été posées.

Question de recherche 1 : Quels sont les différents mécanismes/stratégies d'EP mis en place par les dirigeants des établissements de santé (CISSS et CIUSSS) pour institutionnaliser l'EP pour la SP?

Question de recherche 2 : Quelles sont les pratiques émergeantes et innovatrices (stratégies, mécanismes) ainsi que les facteurs limitatifs et habilitants mis en place par les leaders institutionnels dans un des centres de santé intégrés du Québec (étude de cas) qui permettraient d'institutionnaliser complètement l'EP dans la gestion des risques pour l'amélioration de la SP?

Méthodes : Le projet d’étude est une recherche descriptive longitudinale avec des niveaux d'analyse imbriqués (stratégique, organisationnel et clinique) séparés en deux phases.

Phase 1 : La phase 1 se divise en deux sous-étapes. La première sous-étape est le développement d'un outil pour les dirigeants afin d'identifier et d’évaluer les stratégies émergentes d'intégration de l'EP et leurs mises en œuvre dans les établissements de santé pour améliorer la SP (article 1 des résultats de la thèse). Suite à ce développement d’outil, la deuxième sous-étape est une collecte de données sur les stratégies émergentes et innovantes d'EP pour la SP dans les établissements de santé (N= 24 : 9 CIUSSS, 11 CISSS, 2 établissements de santé universitaires non intégrés) à travers le Québec (Canada) qui a été complétée en envoyant le questionnaire aux différents établissements participants. De plus, pour approfondir les réponses apportées par les participants, une collecte de données qualitative a été complétée en appui par le biais d'entretiens semi-structurés de 1 heure avec les dirigeants de ces établissements de santé (responsables de la qualité et de la gestion des risques, dirigeants ou équipes en charge de l'EP dans leur établissement (intégrant un patient partenaire (PP)) (article 2 des résultats de la thèse).

Phase 2 : La phase 2 est une analyse d'une étude de cas, qui a commencé à mettre en œuvre des stratégies visant à faire participer un PP à la SP (analyse d'un projet pilote de prévention et de réduction des chutes par une équipe clinique intégrant un PP) dans leur établissement de santé, a été menée dans un établissement de soins de longue durée. Une approche de collecte de données qualitatives a été utilisée pour mener des entretiens semi-structurés de 40 min à 2 h 30 min chacun avec des responsables stratégiques, organisationnels et cliniques (N = 7) (article 3 des résultats de la thèse). Pour ces deux phases, l'observation, ainsi que l'analyse de documents internes et externes ont également été menées.

Résultats: En phase 1 : 1) (Article 1 des résultats de la thèse), un outil d'évaluation des stratégies d'intégration de l'EP et leurs mises en œuvre dans les établissements de santé pour améliorer la SP a été créé, composé de 82 questions. 2) (Article 2 des résultats de la thèse), sept sous-stratégies émergentes/innovantes de l'EP pour la SP ont été identifiées et discutées à travers le processus d'acquisition, de partage et de préservation des connaissances aux trois niveaux de gouvernance : clinique, organisationnel et stratégique. Sept sous-stratégies principales ont été identifiées.

Dans la phase 2 : (Article 3 des résultats de la thèse), une étude de cas mettant en œuvre une stratégie de processus d'analyse des chutes par l'équipe clinique intégrant un PP pour la prévention et la réduction des chutes, a été sélectionnée pour participer. Trois sous-stratégies principales ont été révélées ici.

Conclusion : Cette étude est la première du genre au niveau provincial. Les travaux futurs devraient se concentrer sur (1) des études comparatives entre les provinces, les nations et leur évolution. Il existe actuellement deux projets de recherches en cours : un au niveau pancanadien et un autre au niveau brésilien, basés sur l'étude originale du Québec. En outre, la France a également mené cette étude pour décrire ses stratégies d'EP pour la SP en utilisant l'outil créé dans cette thèse. Des recherches supplémentaires devraient se concentrer sur (2) les mécanismes et stratégies de collaboration utilisés dans l'institutionnalisation d'initiatives concrètes / meilleures pratiques ou pratiques innovantes (études de cas) de l'EP pour la SP, le rôle des groupes de patients, des bénévoles, ainsi que les modèles de compensation de l'EP pour la SP dans ces mécanismes et stratégies de collaboration. Il faudra aussi mener davantage de recherches sur (3) les meilleures pratiques de leadership afin d'inculquer une culture de non-blâme au moyen d'exemples concrets (études de cas) pour mettre en œuvre une culture de sécurité fondée sur des expériences pratiques de leadership. De plus, les recherches futures devraient évoluer vers (4) l'engagement des citoyens pour la sécurité, en particulier pendant ces périodes de pandémie (ex. Covid-19).

Mots clés : Organisations/institutions de santé ; institutionnalisation, gestion des risques/sécurité des patients ; prévention/réduction des chutes ; engagement des patients ; stratégies/mécanismes/bonnes pratiques/pratiques émergentes

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

AH-223 : Formulaire de déclaration des incidents et accidents

AE: Adverse Events

CA: Conseil d' Administration

CFHSI: Canadian Foundation for Health Services Improvement

CHUM: Health Centre of the University of Montreal

CHSLD: Hospital centers, long-term care centers

CLSC: Local community health centers

CISSS: integrated health and social service centres (free translation of *Centre intégré de santé et services sociaux*)

CIUSSS: integrated university health and social service centres (free translation of *Centre intégré universitaire de santé et services sociaux)*

CPSI: Canadian Patient Safety Institute

CRCHUM*:* Research Centre of the *Université de Montréal* Hospital Centre

DQEPE: Directorate of Quality, Evaluation, Performance and Ethics

EI: Évènements indésirables

ESSS : Établissements de santé et services sociaux

FMG : Family Medicine Group

HCP: Healthcare professional

HOSPES: Health Organization Strategies in Patient Engagement for Safety

IA: Incidents et accidents

IOM: Institute of Medicine

LSSSS: Loi sur les services de santé et les services sociaux

MeSH: National Library of Medicine’s controlled vocabulary thesaurus

MUHC: McGill University Health Centre

MSSS: Quebec’s health and social health ministry

OECD: Organization for Economic Co-operation and Development

PE: Patient engagement

PExp: Patient Experience

POR: Required Organizational practices

PS: Patient Safety

PP: Patient partner

PPEET: Public and Patient Engagement Evaluation Tool

QuIC: Coordination inter-institutions en matière de qualité des États-Unis

RM: Risk Management

ROP: Required Organizational Practices

SISSS : Système d’information sur la sécurité des soins et des services

SP: Sécurité des Patients

UHC: University Healthcare Centre

USA: United States of America

WHO: World Health Organization

GLOSSARY

Comité des usagers

Le comité des usagers représente les usagers de l'établissement. Il renseigne les usagers sur leurs droits et responsabilités, ainsi que promeut l'amélioration de la qualité et des conditions de vie des usagers. Le comité des usagers est composé de membres bénévoles ne travaillant pas pour l'établissement. Ces membres sont élus par tous les usagers. Un représentant par et parmi les membres du comité des usagers est désigné pour siéger au CA de l'établissement.

Évènements indésirables (EI)

Dans leur étude, Leape et al. considèrent les EI comme des évènements non seulement indésirables pour le patient, mais également pour le personnel. Ces évènements surviennent pendant la prestation des soins, dans le cadre de la prévention, du diagnostic, du traitement ou de la réadaptation, que l'évènement soit relié ou non à une exposition à un produit de santé ou à tout autre dysfonctionnement. Il existe deux types d'EI : évitables et graves. Les évènements évitables peuvent être décrits comme ceux qui ne se seraient pas produits si les soins – ou l'environnement dans lequel les soins sont dispensés – étaient conformes aux règlements en vigueur ; alors que les évènements indésirables graves sont ceux qui sont responsables du décès, d'une menace immédiate pour la vie, de la prolongation d'une hospitalisation, d'une incapacité ou d'un handicap. Les EI sont utilisés pour catégoriser les incidents au cours desquels un tort a été commis auprès de la personne recevant des soins de santé (Leape L, *Institute – National Patient Safety Foundation*, 2014).

Déclaration

Action de porter à la connaissance de l'organisation au moyen du formulaire AH-223, et selon la procédure établie par l'établissement, tout incident ou accident constaté par un employé, un professionnel qui exerce sa profession dans le centre, un stagiaire ou toute personne qui, en vertu d'un contrat, dispense des services aux usagers de cet établissement.

Divulgation

Action de porter à la connaissance de l'usager ou de ses proches ou de ses représentants légaux, toute l'information nécessaire relative à un accident avec conséquences, dont l'usager a été victime. (Selon le Règlement portant sur la divulgation de l'information nécessaire à un usager à la suite d'un accident et mesure de soutien, à partir de la gravité E1, il est obligatoire de divulguer l'information relative à l'évènement et de la noter au dossier de l'usager).

Échelle de gravité

Outil de mesure de la gravité des incidents et accidents selon une échelle graduée des lettres « A I », utilisé dans tous les établissements du réseau de la santé et permettant de catégoriser les évènements selon la gravité des conséquences pour l'usager**.**

Fall

Is defined as an event which results in a person coming to rest inadvertently on the ground or floor or other lower level. Fall-related injuries may be fatal or non-fatal *(1)* though most are non-fatal. For example, of children in the People's Republic of China, for every death due to a fall, there are 4 cases of permanent disability, 13 cases requiring hospitalization for more than 10 days, 24 cases requiring hospitalization for 1–9 days and 690 cases seeking medical care or missing work/school [1].

FORCES project

Project focusing on the strengths of the institutions in order to implement initiatives

Gestion des risques

Il existe plusieurs définitions de la gestion des risques dans la littérature. Par exemple, une revue systématique de Duckers et al. mentionne l'une proposée par le thésaurus de vocabulaire contrôlé (MeSH) de la *National Library of Medicine*, à savoir : « *le processus qui consiste à réduire au minimum les risques pour une organisation en élaborant des systèmes pour cerner et analyser les dangers potentiels afin de prévenir les accidents, les blessures et les autres évènements indésirables, et en tentant de gérer les évènements et les incidents qui surviennent de manière à en minimiser les effets et les coûts* » [2].

Intentional tours

Before entering the room of a Patient, any person should ask four questions. (see Appendix K – Intentional tours for more information's on the type of questions that are asked)

Institutionalization

A process through which something (a change, such as a concept, a behavior, a common value, etc.) anchors itself within an organization, a social system or society [3, 4].

Les incidents

Situations dans lesquelles un mal a été causé mais sans conséquences [5].

Les accidents

Situations dans lesquelles un mal a été causé et des conséquences constatées ; et finalement, les « Erreurs médicales » – un défaut d'exécution d'une action prévue ou application incorrecte d'un plan. Les erreurs peuvent se manifester en faisant la mauvaise chose (commission) ou en omettant de faire la bonne chose (omission), soit à la phase de planification ou d'exécution [5]. Lors de l'analyse sommaire, un accident correspond aux niveaux C, D, E1, E2, F, G, H, ou I sur l'échelle de gravité.

"Patient- and family partnership"

Is a broader term that conveys a vision for what health care should be: "a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care"

Safety cross

Part of the visual board in which safety indicators are integrate

ACKNOWLEDGEMENT

This section is certainly the most pleasant part of this thesis, because, in addition to having the opportunity to recognize all the people who have contributed significantly to this project, it is also a unique moment to revisit the many stages of this journey, and each of them reminds me of some good moments. This beautiful story lasted from the year 2014 until 2019, or should I say 2020 (year of my future graduation date). Thus, lasting for 6 years and counting.

I firstly would like to thank Dr. Marie-Pascale Pomey, my thesis director. I still remember the first time I entered her office (I was still naïve and lacking life experience and stillness), asking to become her Ph.D. student. She took a moment asking me my motivations and from there, we started our journey together. We have learnt to work well together and more than ever; I can recognize her strength and rigour in making sure this project sees the end of day. You have inspired me, and I am very grateful to you for that. I couldn't have chosen a better teacher.

Second, I would like to thank my accomplice, and friend Yannick Gayama with whom I have exchanged many ideas within this project. He had made raining times more enjoyable. Thank you for always supporting me, no matter how of a pain I could be sometime.

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PREAMBLE

At age 5 and half, after I see my mother pass in ashes in front of me (our house was gone into the flames from an awful accident and inattention of dangerous chemical), it was now engrained with the passion of not letting anything happen to my father. My mother did not pass right away, it was a battle of not having the right care in Benin (my birth country), a battle to obtain an ok from the minister of health to send her to countries like France to get the proper care. All that came too late and she passed in the middle of all this strenuous process. From then on, it became an obsession of mine, I was supposed to be a hospital administrator and or come up with better policies for healthcare, for systems where the care is not available but better policy could make a whole difference when partnering with neighbouring countries and or healthcare centers with the mean to do so.

Even though I haven't yet reached that goal, I have to tell you I can feel, smell, hear and see it from where I am now. I am closer than ever before.

The journey has been long, sometimes questionable, but overall, I can say, I know better now, and I am enjoying the process of becoming Canada Health minister, a noble price winner and great influencer for high quality and Eco responsible healthcare systems around the world.

What motivated me to complete a doctorate in public health was the fact that I needed to continue doing something, since I haven't reached my goal yet. I had no clue when starting the PhD, It would make so much sense. First, I have to mention that I stumbled into public health by chance. After my bachelor's degree in microbiology in 2009, I was volunteering at AIDS organization when one of the microbiologists told me she was finalizing a master's in public health at the University of Montreal. I asked her more information about it, and that was the beginning of me completing a master's in public health and then deciding to continue into the PhD, for more challenge for a lack of not being satisfied with my current situation.

What will be my next stage? A post Ph.D. I would like to continue into understanding how Citizens engage in their own health and how governments and communities can support these engagements through an alternative healthcare currency (stay put for the findings to come out). Yes, my short-term goals are to open my own chair of an alternative currency in healthcare systems.

As I finished writing my thesis, the thought that kept coming in my mind is one of interdisciplinary collaboration for PE for PS. A famous quote that I like to refer to is:

"*We are interdependent, and it is impossible to succeed without others… It is our attitude towards others which will determine their attitudes towards us*".

Earl Nightingale "*The strangest secret in the world*".

1. CHAPTER 1: INTRODUCTION & RESEARCH PROBLEM

1.1. Context

1.1.1. Patient Engagement, a solution for patient safety and risk management

Over the past 20 years, paternalistic approaches to patient care have been losing ground. With the growth of chronic diseases incidence [6, 7, 8], the increased prevalence of complex diseases (creating more disciplinary silos) [6], decreasing levels of compliance with treatment [9]; major transformations in health systems [6, 9] the role of health care professionals is no longer strictly one of healing. Nowadays, it also includes accompaniment, solicitude, and guidance as patients and caregivers undertake selfcare.

This phenomenon occurred when security logic was challenged through a continuous crisis of confidence with regards to security (e.g., contaminated blood; nosocomial infections and other sanitary crises [10, 11].

Innovative and new ways of working in health institutions are in order [11, 12, 13]. Scientific literature suggests that the concept of Patient engagement and their family (PE) has become a cornerstone for improving quality of care, so much so that healthcare organizations wanting to build safer systems and control costs are increasingly setting PE goals [6, 8, 9, 14, 15, 16]. PE in health care and social services are part of a new collaborative strategy, whose aim is to ensure higher levels of engagement from patients with regards to managing their own care and overall risk management in health care services and social services [7].

Among the patient engagement strategies, the engagement with patients is meant to limit risks, also known as near miss, incidents and accidents. An article published in the Journal of the American Medical Association states that healthcare patients are part of highly functional healthcare teams, as opposed to patients being solely the object of the team's attention [17]. In fact, according to “Safety is Personal” report, presented by the Lucian Leape Institute of the National Patient Safety Foundation, patients and families can play a primary role in the prevention of medical errors and harm reduction [18]. Several circumstances encourage a growing emphasis on PE. First, work related to both patient engagement and shared decision making reflects and accelerates the shifting roles of patients and families in health care as they become more active, informed, and influential [14]. Second, a growing body of evidence suggests that PE can lead to better health outcomes [9, 14, 19, 20, 21, 22], contribute to improvements in quality and patient safety [23, 24, 6, 25, 26, 27], and help control health care costs [16, 28]. While procedures exist and have been implemented over the years in various healthcare institutions, most of them remain local and limited to clinical levels. Rarely are they found at organisational or policy levels. Moreover, it is also rare to find health systems that have actually institutionalized or integrated mechanisms and strategies to embody and enhance PE practices (where risk is measured as a whole and not as parts). Patients will be encouraged to engage in the process of risk management for patient safety due to their unique experience with the disease and health care institutions in collaboration with other health care professionals. Health care professionals value the patient output and a relation of trust is built in order to develop better processes / programs / in risk management for patient safety.

Far from being a one-dimensional issue, patient safety is an institutional problem that affects healthcare as a whole, requiring collective and coordinated action between micro (clinical), meso (organizational) and macro (strategic) levels [9, 14, 6, 29, 30, 31]. Treating patient safety as a system could help address the persistent challenge of implementing safety solutions, which are either poorly grounded in available evidence, inadequately tested in local contexts, and / or add to stresses and strains experienced by members of staff [30]. That being said, if trends remain ongoing, there will be structures and models that can institutionalize PE in risk management and patient safety in the near future.

In the search for solutions, gaining ground is the belief that patients are at the core of our system and, as such, are part of the solution [28]. Over the last decade a great deal of research has been conducted to assess the prevalence, severity and causes of many different types of adverse events, as well as the effectiveness of efforts and approaches to enhance safety, reduce risks and adverse events. Knowledge about implemented strategies / mechanisms / best ways (based on actual case studies) to build a safer health care system (which envision all its parts and not just silos) grounded on the collaboration between patients and healthcare institutions in risk management has not yet been properly synthesized [9, 14, 30].

1.2. Problem

1.2.1. Patient safety: still a concern for generations to come

In December 1999, the Institute of Medicine (IOM) released a report entitled "*To Err is Human: Building a Safer Health System*", the response from the health community was immediate and far-reaching [11]. The IOM report revealed that medical errors caused between 44,000 and 98,000 avoidable deaths per year in the US [11]. Within two weeks of the report's release, congressional hearings on the issue began and the President directed the Quality Interagency Coordination Task Force (QuIC) to evaluate the IOM's recommendations and respond with a strategy for reducing medical errors. The IOM report carried four core messages: first, the magnitude of harm that results from medical errors is great; second, errors result largely from systems failures, not human failures; third, voluntary and mandatory reporting programs are needed; and fourth, a concerted national effort is needed urgently to improve patient safety [11].

The Institute of Medicine started flagging frequent adverse events in healthcare institutions and their consequences on patients. After that report, in Canada and in the US, health care institutions where required, by law, to declare and inform all patients about adverse event which occurs during the delivery of care [9]. Furthermore, board of directors were required to get involved, given their responsibility in figuring out rules and support measures relative to disclosing incidents/accidents to patients, as well as taking care of them [9]. Additionally, boards oversee preventive measures meant to curb the recurrence of potential incidents and accidents.

Despite great strides and intentions, patient safety is still a concern and a challenge worldwide [32], mostly due to the lack of a general portrait of risk management within health institutions. In fact, risk management is still dealt with in silos, while ignoring connections and interdependencies [30, 33].

1.2.2. Some facts about patient safety

Delivery of safe care and services is extremely important across all levels of health systems. One in 10 patients is harmed while receiving hospital care in OECD countries [34, 35, 36, 37]. Nearly 50% of these harms are considered preventable [38]. Worldwide, four out of 10 patients are harmed while receiving health care in these settings, with up to 80% of the harm considered to have been preventable [38].

According to a WHO report, some of the most detrimental patient safety situations causing concerns are [32]:

- **Medication errors:** The cost associated with medication errors has been estimated at US$ 42 billion annually [39].
- **Health care-associated infections (HAIs):** Occur in 7 and 10 out of every 100 hospitalized patients in high-income countries and low-and middle-income countries respectively (HAIs) [32, 40, 41]. Appropriate hand hygiene interventions can reduce HAI rates by up to 55% [42].
- **Unsafe surgical care procedures:** Unsafe surgical care procedures cause complications in up to 25% of patients. Almost 7 million surgical patients suffer significant complications annually, 1 million of whom die during or immediately following surgery [43, 34, 44].
- **Unsafe injections practices**: in health care settings can transmit infections, including HIV and hepatitis B and C, and pose direct danger to patients and health care workers; they account for a burden of harm estimated at 9.2 million years of life lost to disability and death worldwide (known as Disability Adjusted Life Years (DALYs) [45].
- **Diagnostic errors**: Diagnostic error, that is the failure to identify the nature of an illness in an accurate and timely manner, occurs in about 5% of adults in the United States outpatient care settings. About half of these errors have the potential to cause severe harm [32, 46].
- **Unsafe transfusion practices:** from a group of 21 countries "*data on adverse transfusion reactions show an average incidence of 8.7 serious reactions per 100 000 distributed blood components*" [47].
- **Radiation errors:** Radiation errors involve over exposure to radiation and cases of wrong-patient or wrong-site identification [48]. A review of 30 years of published data on safety

in radiotherapy estimates that the overall incidence of errors is around 15 per 10 000 treatment courses [49]. In the United States, diagnostic errors contribute to approximately 10% of patient deaths according to autopsy research performed in the past decades. Moreover, medical record reviews demonstrate that diagnostic errors account for 6–17% of all harmful events in hospitals [50].

- **Sepsis: causing more than** 5 million deaths per year, sepsis is often antibiotic-resistant and affect an estimated 31 million people worldwide [51].
- **Venous thromboembolism (blood clots): contributes to** one third of the complications attributed to hospitalization. Which amounts to, annually, an estimated 3.9 million cases in high-income countries and 6 million cases in low-and middle-income countries [52].

In Canada, deaths related to incidents occur every 13 minutes [53]. A new report called "Measuring Patient Harm in Canadian Hospitals" reveals that in 2014–2015, harm was experienced by patients in 1 of every 18 hospital stays, or 138,000 hospitalizations. Of those, 30,000 (or 1 in 5) involved more than 1 form of harm [54]. Moreover, incidents in both acute and home care settings can cost $6,800 per patient, resulting in additional costs of $2.75 Billion each year [53].

Estimated costs related to incidents and accidents in Canada nearly equal to the combined costs of both drugs and physicians. This is particularly true for hospitals, which represent the costliest form of care, accounting for over $58 billion per year across Canada [55].

Recent evidence shows that 15% of total hospital expenditure and activities in Organisation of Economic Co-operation and Development (OECD) countries is a direct result of adverse events.

Estimates show that the total cost of harm in these countries' alone amounts to trillions of US dollars every year [36]. 1 out of every 7 Canadian dollars is spent treating the effects of patient harm in hospital care [56].

It is no surprise that investing in the cost of prevention is much lower than the cost of care due to harm [36]. As an example, in the United States, safety improvements led to an estimated US$ 28 billion in savings in Medicare hospitals between 2010 and 2015 [57].

1.2.3. Greater patient involvement is the key to safer care

Implementing patient engagement strategies is a good value for health care systems to have. It is a great return on investment, if successful. Patient engagement can reduce the burden of harm by up to 15%, saving billions of dollars each year [36].

Today, it is recognized that PE can help improve outcomes and reduce the burden on health services [9, 58, 2, 59, 16, 60, 22, 21, 20], thus, moving away from a paternalistic model - where clinicians act down on people - towards a model favouring greater interaction [28]. Nowadays, partnering with patients for their health and care is recognised as a key component for developing the highest quality of healthcare [6, 14, 20, 21, 22, 61].

In a mixed method study of Taber et al., a multidisciplinary quality improvement initiative including patient engagement can improve medication safety in kidney transplant patients, which can lead to improved clinical outcomes [62]. In fact, follow-up analysis demonstrated reduced medication discrepancies by >2 per patient and obtaining 100% adherence with reconciliation [62]. Pharmacists reviewed discharge medications, reaching 100% by study end, leading to a 40%

reduction in medication safety issues. LOS remained short, and delayed discharges were reduced by 14%; 7-day readmission rates decreased by 50% [62].

In another study of six months randomized control trial, the evidence suggests that a Chronic Disease Self-Management Program Can improve health status while reducing hospitalization [63]. The study included 952 patients 40 years of age or older with a physician-confirmed diagnosis of heart disease, lung disease, stroke, or arthritis; health behaviors, and health status [63].

A systematic review summarizing evidence of 55 studies [58], indicates that it was more common to find positive associations between patient experience (which includes Involvement of, and support for family and carers in decisions in its variables) and patient safety and clinical effectiveness than no associations. Experience is consistently positively associated with patient safety and clinical effectiveness across a wide range of disease areas, study designs, settings, population groups and outcome measures. "Patient experience is positively associated with self-rated and objectively measured health outcomes; adherence to recommended medication and treatments; preventative care such as use of screening services and immunisations; healthcare resource use such as hospitalisation and primary-care visits; technical quality-of-care delivery and adverse events." [58]. Another systematic review (included qualitative and quantitative studies from 1997 to 2009) on the impact of patient and public involvement on UK health care; shows a positive impact of patient engagement on health services, implementation, organization, etc. However, better evidence in study design and evaluation is needed in PE measurement and in cost reduction's evaluation [64]. More so, more longitudinal studies are needed [64].

Despite keen interest, PE approaches to care are not particularly novel. Such concepts have been discussed for about a quarter of a century in fields like social care, mental health services, learning disabilities and services for people with dementia [65]. However, novelty can be found in how central PE philosophy has become for matters regarding health policy in many countries, such as the UK and Canada [65].

1.3. Objective of the thesis

The aim of this research study is to identify essential patient engagement (PE) mechanisms and strategies put in place by organizational leaders in leading healthcare institutions located in the province of Québec (Canada) that would allow this engagement to be fully institutionalized[2] in the health care system for the enhancement of patient safety (PS).

1.4. Research questions

To answer the general objective of the research project, two specific questions were brought forward:

1. **What are the different PE strategies/mechanisms put in place by leaders in the Integrated Health and Social Service Centers (free translation of *Centre intégré de santé et services sociaux* or CISSS) or in the Integrated University Health and Social Service Centers (free translation of *Centre intégré universitaire de santé et services sociaux* or CIUSSS) to institutionalize PE for PS?**

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[2] Intitutionalization: a process through which something (a change, such as a concept, a behavior, a common value, etc.) anchors itself within an organization, a social system or society (DiMaggio & Walter, 1983; Scott, Michael & Smith, 2004).

   a. How did those PE strategies/mechanisms change overtime?
   b. What are the factors that enhance or inhibit the institutionalization of PE strategies/mechanisms for patient safety in the Integrated Health and Social Service Centers and the Integrated University Health and Social Service Centers (free translation of *Centre intégré universitaire de santé et services sociaux* or CIUSSS)?

2. **What are the innovative practices (strategies, mechanisms) as well as the** limiting and enabling factors **put in place by institutional leaders in one of the integrated healthcare centers in Quebec (case study)** that would allow PE to be fully institutionalized for the enhancement of patient safety**?**

1.5. Presentation of the three articles of the thesis

The three articles in Chapter 5, which present the results articles of the thesis, will help answer the two specific research questions of the thesis in the following order:

- **Article 1, “An Evidence-Based Tool (PE for PS) for Healthcare Managers to Assess Patient Engagement in patient Safety in Healthcare Organizations”,** presents how the questionnaire (tool) used in the research study to describe the merging strategies and mechanisms of patient engagement in safety and risk management in health institutions in Quebec was build.
- **Article 2, “Health institutions Strategies in Patient Engagement for Safety (HOSPES): Research Results from a Longitudinal Case Studies in Quebec”**, presents a longitudinal study done in all CISSS and CIUSSS in Québec from the data collected at two different times.

Article 1 and 2 both answer the question of the specific research question 1,

- **Article 3, “Innovative practices used in the institutionalization of Patient Engagement in risks analysis process: A Qualitative Longitudinal Case Study of a fall reduction and prevention strategy from an Integrated Healthcare Centers in Quebec**”

Article 3 answers the specific question 2 of the thesis.

1.6. A ripe Opportunity reflected by the readiness of many governments

This research project finds its relevance not only because of the lack of a synthesized overview of risk management in patient safety [30], but also because of a ripe opportunity reflected by the readiness of many governments. In fact, in collaboration with the Canadian Patient Safety Institute, Accreditation Canada has stated in their 2013-2018 strategic plan that their main goal in patient safety is to encourage PE in order to "*provide leadership on the establishment of a National Integrated Patient Safety Strategy in order to sustain health care policy transformational change, to build and influence patient safety capability (knowledge and skills) at organizational and system levels, to engage all audiences across the health system in the national patient safety agenda*" [66]. Thereafter, on January 1st, 2016, Accreditation Canada standards - updated and clearly focused on the patient- and family-partnership. Under these revised standards, more emphasis is put on partnership and collaboration: quality improvement teams and safety in care are incomplete without patients and their families. Thus, Accreditation Canada will support organizations and health systems to enhance PE and is committed to playing an important role in improving patient safety [66].

Even Quebec has seen major reforms come about, with a publicly expressed stronger focus on quality, performance and patient safety. In 2015, the Quebec national plan in public health and the national strategic plan for 2015-2020 mentions PE as one of its core principles for health outcomes, patient safety and quality improvement [67, 68].

Despite great strides and intentions, initiatives of PE related to PS are still dealt with in silo and not as a global vision of the institution, or as a collaborative way between directorates to better institutionalize, therefore, better sustain implementation initiatives in PE for PS. The Canadian

Patient Safety Institute (CPSI) in their request for proposal on the 18th of April 2016, stipulated the importance of a guide to help both patients/families and providers/organizations effectively partner to accelerate patient safety and quality efforts (accreditation, legislatives, etc.). The idea was to develop a Guide based on evidence and best practices at every level of the healthcare system [54]. Many variations exist in how PE is provided, but very few include a system-wide institutionalisation approach. More recently, however, evidence has been emerging on how to implement PE by involving patients in their own care, and in health service design, evaluation or research [7, 14]. Indeed, patients can be involved at patient-level (micro), organization-level (meso), and at system-level (macro) through policies, accreditation standards and on board of Directors, etc. Currently, there is a lack of knowledge around PE implementation mechanisms and strategies involving all levels of the health care systems in patient safety and risk management; hence it is important to complete more research on factors, mechanisms and strategies on how to engage with patients and their families in order to enhance patient safety in risk management throughout the entire healthcare institution.

The results of this thesis will contribute to the knowledge transfer in understanding the emerging strategies, mechanisms, and factors, healthcare institutions as well as leaders' structure in order to engage patients in safety and risk management. The thesis will thus guide practices and policies in healthcare on enabling structures of patient engagement in risk management for better patient safety.

In the following pages, **Chapter 2** will be dedicated to the literature review of the thesis. The literature review will focus on describing the context of risk management and patient safety in Quebec in which the research has taken place and describing patient engagement initiatives in safety and risk management to give an overview of the advancement in that field.

In **Chapter 3,** the theoretical framework around the institutional theory of change is explained and a conceptual framework is adopted and adapted around the research study.

In **Chapter 4,** we will present the methodology used to answer 2 research questions.

In **Chapter 5,** we present the three results articles of the thesis.

Article 1: presents the questionnaire (tool) used in the research study to describe the merging strategies and mechanisms of patient engagement in safety and risk management in health organizations in Quebec.

Article 2: presents the longitudinal results from the data collected from the questionnaire in article 1.

Article 1 and 2 both answer the question of the specific research question 1.

Article 3: presents, the results from the case study. The article will present strategies of patient engagement for patient safety used in a long-term care. Article 3 answers the specific question of the thesis objective 2.

After presenting the results, **Chapter 6,** will be discussing the connections between the findings in those three articles (presented previously) and their links to the literature review.

Finally, in **Chapter 7**, we will be concluding with a global discussion around PE for PS and its implications in future researches.

2. CHAPTER 2 : LITTERATURE REVIEW

This chapter will focus on describing the context of risk management and patient safety in Quebec (in section 2.1) in which the research has taken place and (in section 2.2) describing patient engagement in safety and risk management to give an overview of the advancement in that field.

2.1. Context of risk management and patient safety in Quebec (Canada)

An article [69] written (in French) by the author and published in the "Risques et Qualité" journal will describe the context of risk management and patient safety in Quebec (Canada).

Titre – État des lieux sur la gestion des risques et la sécurité des soins et des services au Québec : évolution, exemples et recommandations

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Résumé

Dans les années 2000, la gestion des risques est devenue une priorité majeure en Amérique du nord à la suite du rapport *To err is human: building a safer health system* de l'*Institute of Medicine*. D'après ce rapport, les erreurs médicales constituaient la troisième cause de décès aux États-Unis. Au Québec, le *Rapport Francœur* publié en 2001 a eu le même effet, ce qui incita le gouvernement du Québec à mettre en place la loi 113 imposant la création de comités de gestion des risques au sein des établissements de soins et services et la déclaration obligatoire des évènements indésirables. En 2014, le projet de loi 83 a permis la création de postes de commissaire aux plaintes et de comités de vigilance et de la qualité dans tous les établissements afin de renforcer l'imputabilité en gestion des risques. En outre, la réforme de 2015 qui a amené à la création des Centres intégrés universitaires ou pas de santé et de services sociaux (CIUSSS) et (CISSS) a créé les directions de la qualité, de l'évaluation, de la performance et de l'éthique (DQEPE) afin de permettre une meilleure coordination de la qualité et de la sécurité des soins et services et de faciliter l'engagement des patients. De plus, l'engagement des patients en gestion des risques a pris son envol grâce aussi au Plan stratégique national 2015-2020 et au Cadre de référence de l'approche de partenariat entre les usagers, leurs proches et les acteurs en santé et en services sociaux qui ont été publiés dans la foulée. Une première étude longitudinale débutée en 2015 offre un survol de l'évolution des stratégies d'engagement des patients en gestion des risques mises en place dans les établissements de santé et services sociaux au Québec, en plus de proposer certaines recommandations.

Keywords : Accident, Évènement indésirable, Gestion du risque, Incident, Sécurité du patient

Abstract

In the 2000s, risk management became a top priority in North America following the Institute of Medicine's *To Err is Human: Building a Safer Health System* report. According to this report, medical errors were the third leading cause of death in the United States. In Quebec, the *Francœur Report* published in 2001 had the same effect, which prompted the Quebec government to put in place the 113-law requiring the creation of risk management committees within health care and services establishments and mandatory reporting adverse events. In 2014, Bill 83 resulted in the establishment of Complaints Commissioner and Vigilance and Quality Committees in all institutions to strengthen accountability in risk management. In addition, the 2015 reform that led to the creation of the Integrated University or No Health and Social Services Centers (CIUSSS) and (CISSS) created the Directorate of Quality, Evaluation, Performance and Ethics (DQEPE) in order to better coordinate the quality and safety of care and services and to facilitate patient engagement. Thus, patient engagement in risk management has taken off thanks also to the *2015-2020* National Strategic Plan and the Framework of reference for the partnership approach between patients, their families and health actors and social services that were published in the midst. Hence, a first longitudinal study started in 2015 provides an overview of the evolution of patient engagement strategies in risk management implemented in health and social services institutions in Quebec aiming in addition to proposing certain recommendations.

***Keywords**: Adverse event; Patient safety, Risk management*

2.1.1. Introduction

Dernièrement, au Canada, l'Institut canadien d'information en santé a publié un rapport soulignant le retard cumulé en ce qui a trait à la sécurité des patients par rapport aux autres pays de l'OCDE « *Un total de 553 objets tels que des instruments chirurgicaux ont été oubliés dans le corps de patients au Canada lors des deux dernières années* » [70]. Malgré les efforts émis pour améliorer la sécurité des soins et des services de santé à travers le monde, les erreurs médicales restent toujours, aux États-Unis comme au Canada, la troisième cause de décès après les maladies cardiovasculaires et le cancer, avec environ 250 000 morts par an aux États-Unis [71] et 24 000 au Canada avec 37% de ces erreurs qui auraient pu être évitées [72].

Au cours de la dernière décennie, les préoccupations relatives à la sécurité des patients n'ont cessé de croître. Afin de limiter les situations à risque dans les établissements de soins, un certain nombre de démarches ont été mises en place comme la création de système de collecte de données, la déclaration obligatoire des évènements indésirables (EI), la divulgation des incidents et accidents, des mesures de soutien pour les personnes touchées par des EI, la mise en place de mesures préventives, etc. Toutefois, ces démarches n'ont pas toujours donné les résultats escomptés. Une des raisons invoquées est l'absence de participation des patients et des proches dans l'ensemble des mesures adoptées. Aussi dans ce contexte, les gouvernements, les organismes nationaux et provinciaux, les régions sanitaires et les établissements de santé et services sociaux (ESSS) travaillent de plus en plus en partenariat avec les usagers pour améliorer la sécurité dans les ESSS.

C'est ainsi que cet article se donne comme objectif de présenter les origines et l'évolution de la gestion des risques en Amérique du Nord et plus particulièrement au Québec et comment progressivement les patients ont été engagés dans un certain nombre de dispositifs.

2.1.1.1. Vers une prise de conscience en Amérique du nord

Tout a débuté avec la publication par l'*Institute of Medicine* (IOM) en décembre 1999 de *To err is human : building a safer health system* qui a mis en évidence que les erreurs médicales causaient entre 44 000 et 98 000 décès évitables par an aux États-Unis [11]. Cette étude a débouché sur la réalisation d'une étude semblable dans les hôpitaux canadiens, qui démontra qu'un patient hospitalisé sur quatorze avait souffert d'un EI, dont le tiers était évitable [72]. Au Québec, cette étude a montré que parmi les 431 908 hospitalisations annuelles, environ 24 187 étaient associées à des EI et 6 479 d'entre elles auraient pu être évitées (1,5% des hospitalisations), dont 670 avaient amené à des décès évitables [73]. À la suite de ces études, le ministère de la Santé et des Services sociaux du Québec (MSSS) publia le *Rapport sur les incidents et accidents survenus lors de la prestation des soins et services de santé au Québec* [74], relevant un total de 484 021 EI déclarés entre le 1er avril 2015 et le 31 mars 2016 au Québec.

Dans les deux semaines qui ont suivi la publication du rapport, l'IOM créait un groupe de travail pour la coordination inter-institutions en matière de qualité des États-Unis (QuIC) chargé de proposer des recommandations et d'adopter une stratégie pour réduire les erreurs médicales. Le rapport publié par l'IOM à la suite comportait quatre messages fondamentaux : 1) les résultats de l'état des lieux des dommages causés par les erreurs médicales sont significatifs ; 2) les erreurs sont en grande partie dues à des défaillances systémiques et non des défaillances humaines ; 3) des programmes de déclaration volontaire et obligatoire sont à mettre en place ; et 4) la prise de conscience d'une urgence nationale de mettre en place de manière concertée des activités favorisant l'amélioration de la sécurité des patients [11].

À la suite de ces rapports, le Canada a encouragé l'obligation pour les établissements de soins de santé de déclarer et d'informer tous les patients des EI qui surviennent pendant la prestation des soins [9]. En complément, des directives portant sur la manière d'impliquer les conseils d'administration (CA) des établissements de santé pour l'élaboration de règles et de mesures de soutien relatives à la divulgation des incidents/accidents (I/A) aux usagers, ainsi qu'à leur prise en charge ont été proposées [9]. Les CA ont aussi été amenés à superviser les mesures préventives visant à réduire la récurrence d'I/A potentiels dans le cadre de la certification.

Malgré ces rapports et ces mesures, des études mettent encore en évidence qu'au Canada, un décès toutes les 13 minutes survient à la suite d'un accident lié aux activités de soins et que ces incidents et accidents en soins actifs et à domicile entraînent des surcoûts d'environ 6 800 dollars canadiens par patient [53], ce qui entraîne en conséquence des surcoûts de 2,75 milliards de dollars canadiens chaque année [54]. Au total, on estime que les IA entraînent des dépenses de plus de 58 milliards de dollars canadiens par année à l'échelle du Canada [55].

2.1.1.2. Évolution de la gestion des risques au Québec

Fort des constats canadien et québécois, le gouvernement du Québec a confié à un comité interministériel le mandat de proposer des recommandations pour améliorer la situation en ce qui concerne la gestion des risques au Québec. C'est ainsi que le *Rapport Francœur* [75], publié en 2001, a joué un rôle essentiel pour mieux comprendre l'état de la situation dans la province en ce qui a trait à la sécurité des patients. Le rapport a alors proposé de revoir les procédures de gestion des risques et de mettre en place des mécanismes de prévention. Parmi les propositions, on retrouve la nécessité de revoir les outils de déclaration des EI, de revoir le système d'information des déclarations, de créer une banque nationale de données sur les effets indésirables et les accidents évitables afin qu'ils soient systématiquement répertoriés à des fins d'analyse, et de renforcer la formation en gestion des risques du personnel [76, 77]. Par ailleurs, des indicateurs de suivi ont été proposés pour suivre les actions de prévention recommandée dans le rapport, ainsi que pour s’assurer que les besoins des patients sont comblés en particulier en ce qui a trait à la divulgation et aux mesures mises en place pour éviter qu’un évènement se reproduise. La politique de santé et de bien-être au Québec a intégré la réduction de l’incidence de ces accidents parmi ses objectifs. Dans leur code de déontologie, les médecins et les autres professionnels de la santé se sont vus contraints de devoir déclarer les IA. Et, finalement, les établissements de santé se sont vus imposés de déclarer les IA et de rentrer dans une démarche d’agrément au cours de laquelle de nombreuses pratiques organisationnelles requises portent sur des enjeux de sécurités [77].

2.1.1.2.1. Le projet de loi 113

À la suite de la publication du *Rapport Francœur*, en décembre 2002, le projet de loi 113 a été adopté par le gouvernement du Québec pour obliger les ESSS à mettre en place un certain nombre de mesures pour rendre les lieux de soins et de services plus sécuritaires pour les patients [76].

Selon le projet de loi 113, toute personne qui reçoit un service a le droit d’être informée de tous les IA survenus au cours de la prestation du service, surtout si cela peut mettre en danger sa santé et son bien-être (divulgation)[3]. Ainsi, les fournisseurs de soins sont tenus de signaler tout IA dès que possible après en avoir pris connaissance auprès des patients et du MSSS (déclaration)[4].

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[3] Divulgation : action de porter à la connaissance d’un client ou de ses proches les informations concernant un accident survenu alors qu’il recevait des services et à l’origine des conséquences sur son état de santé ou sur son bien-être.

[4] Déclaration : action de porter à la connaissance de l’organisation, au moyen d’un formulaire prévu à cet effet, tout incident et tout accident dans le cadre d’une prestation de soins ou de services, qu’un employé, un professionnel (médecin-dentiste), un stagiaire ou une personne liée par contrat et qui donne des services aux patients a constaté, dans le but de mettre en place des mesures de prévention afin d’éviter la récurrence d’un tel incident ou accident. (LSSSS, L.R.Q., chap. S-4.2, art.2).

2.1.1.2.2. L'importance de divulguer

La divulgation (article 8 de la loi sur les services de santé et les services sociaux [LSSSS]) énonce le droit de l'usager d'être informé de tout IA survenu au cours de la prestation des services qu'il a reçu. La divulgation comporte deux étapes :

1re Étape – La divulgation initiale

Il s'agit d'une discussion avec l'usager ; celle-ci doit avoir lieu le plus tôt possible après un évènement. La divulgation initiale vise à informer le client des faits connus, cela inclut :

- les faits relatifs à l'évènement ou au préjudice connu à ce jour ;
- les mesures prises, les options recommandées et les décisions relatives aux soins du client ;
- la présentation d'excuses;
- un aperçu du processus d'enquête à venir incluant les échéanciers appropriés, et de l'information sur ce que le client pourrait apprendre à la suite de l'enquête ;
- une offre de rencontres ultérieures, y compris de l'information sur des personnes-ressources clés ;
- une période de questions et réponses ;
- une ou des offres de soutien pratique et émotionnel[5] ;
- une enquête additionnelle et un traitement, s'il y a lieu ;

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[5] Mesures de soutien : conformément à l'article 235.1 de la LSSSS, des mesures de soutien doivent être mises à la disposition de la personne victime d'un accident survenu et ayant entraîné des conséquences pour celle-ci.

- les renseignements communiqués sur les mesures proposées pour prévenir[6] ;
- la récurrence d'un accident semblable.

Le rapport de divulgation se fait à l'aide du formulaire *Rapport de divulgation (référence au formulaire AH- 223).*

2e Étape – La divulgation subséquente

C'est à cette étape que les patients sont informés des améliorations apportées, si possible pour éviter que de tels évènements se reproduisent. Les discussions doivent inclure:

- un soutien pratique et émotionnel continu, s'il y a lieu ;
- la corroboration ou la correction de l'information fournie lors des rencontres précédentes ;
- l'information factuelle additionnelle à mesure qu'elle devient connue ;
- la présentation d'excuses et la reconnaissance de responsabilité, le cas échéant, lorsque tous les faits sont établis ;
- la description des mesures prises à la suite de l'enquête interne et qui ont entraîné des améliorations du système.

2.1.1.2.3. L'obligation de déclarer

Les ESSS ont l'obligation légale de déclarer les incidents et les accidents (LSSSS, article 233.1) constatés au sein de l'établissement, par toute personne y exerçant une fonction à temps partiel ou

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[6] Mesures de prévention : l'établissement doit prendre les mesures visant à prévenir la récurrence d'un accident. La directrice générale peut désigner une personne pour identifier les mesures appropriées. Celle-ci procède à la consultation nécessaire et propose des mesures au comité de gestion des risques et de la qualité.

à temps complet. De plus, l'établissement doit assurer la mise en place d'un système de surveillance incluant la constitution d'un registre local des incidents et des accidents aux fins d'analyse des causes de ces incidents et accidents. Ce registre sert également à recommander au CA de l'établissement les mesures à prendre afin de prévenir la récurrence de ces situations ainsi que les mesures de contrôle, s'il y a lieu (LSSSS, art. 183.2, paragraphe 2). Pour déclarer ces EI, le formulaire AH-223-I[7] (Rapport de déclaration des IA) est complété par les établissements le plus tôt possible après la constatation de l'IA par toute personne du réseau qui constate un évènement. Cette déclaration est communiquée à la personne désignée en gestion des risques dans l'établissement. Ensuite, la déclaration est dénominalisée et transmise dans un rapport trimestriel et annuel envoyés au MSSS. Chaque déclaration est ensuite consignée dans un registre national (LSSS, article 278). De plus, et conformément aux pratiques organisationnelles requises (POR) d'Agrément Canada, la direction des soins infirmiers (DSI) et la direction de la qualité, de l'évaluation, de la performance et de l'éthique déclarent trimestriellement les incidents et accidents survenus dans l'établissement dans le rapport trimestriel de gestion des risques de l'établissement.

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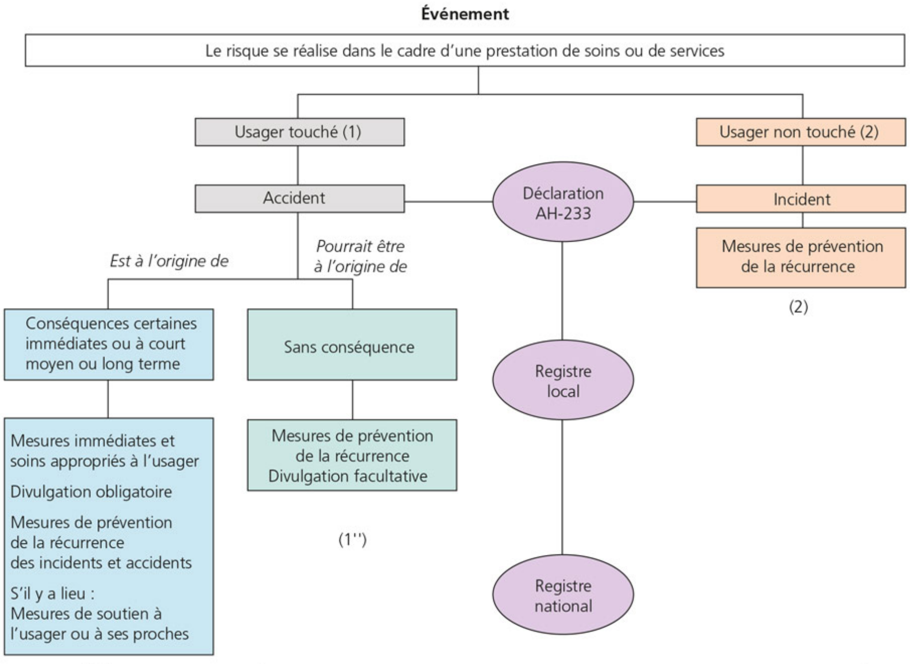
[7] Ainsi que le formulaire AH-520 pour les incidents ou accidents transfusionnels.

Figure 1 – Arbre décisionnel - Procédure de déclaration, d'analyse et de divulgation des incidents et accidents [12].

Risques & Qualité-XVI-4-Pomey

Le schéma du traitement d'un événement selon le ministère de la Santé et des Services sociaux (Québec)



1- (1) et (2) doivent être déclarés
2- C'est la présence de conséquences qui amène la divulgation obligatoire
3- (1') et (1") formulaire à verser au dossier de l'usager
4- (2) Formulaire à conserver en gestion des risques
5- (1') et (1") font l'objet d'un avis à l'assureur selon les modalités fixées par lui
6- Échelle de gravité : (1') = de E à I (1") = C et D (2) = A et B

2.1.1.2.4. La création des comités de gestion des risques

C'est en 2002 que l'article 183.2 de la LSSSS a créé le comité de gestion des risques dont le mandat est de rechercher, développer et promouvoir des moyens d'assurer la sécurité des patients et de réduire l'incidence des effets indésirables liés à la prestation des services sociaux et de santé. La mission de ce comité est de recueillir de l'information sur la gestion des risques auprès des services cliniques de l'établissement de santé, d'analyser les causes et d'élaborer des stratégies pour limiter l'occurrence d'EI liés à la prestation des soins de santé et des services sociaux [76]. Un rapport d'analyse doit être fait pour les évènements de gravité élevée (F, G, H, I) ou pour tout autre évènement de gravité moindre mais ayant un potentiel de risque élevé ou dont la récurrence s'avère problématique **(Tableau I)**.

Selon la loi 113, la composition de ce comité doit assurer « *une représentativité équilibrée des employés de l'établissement, des usagers, des personnes qui exercent leur profession dans un centre exploité par l'établissement de même que, s'il y a lieu, des personnes qui, en vertu d'un contrat de services, dispensent pour le compte de l'établissement des services aux usagers de ce dernier. Le directeur général ou la personne qu'il désigne est membre d'office de ce comité* ». Loi 113, p. 4.

Dans la composition du comité on retrouve donc un représentant du comité des usagers en complément du directeur général ou de la personne désignée par soit le directeur ou la directrice (adjointe) à la qualité ; le chef de service à la prévention et au contrôle des infections ; une pharmacienne, le directeur soit de la directrice adjointe de la DSI ; le directeur ou la directrice des services médicaux, le directeur ou la directrice des services multidisciplinaires (qui gèrent les professionnels non médicaux et non infirmiers) ; et d'autres représentants de services cliniques et services sociaux de l'établissement.

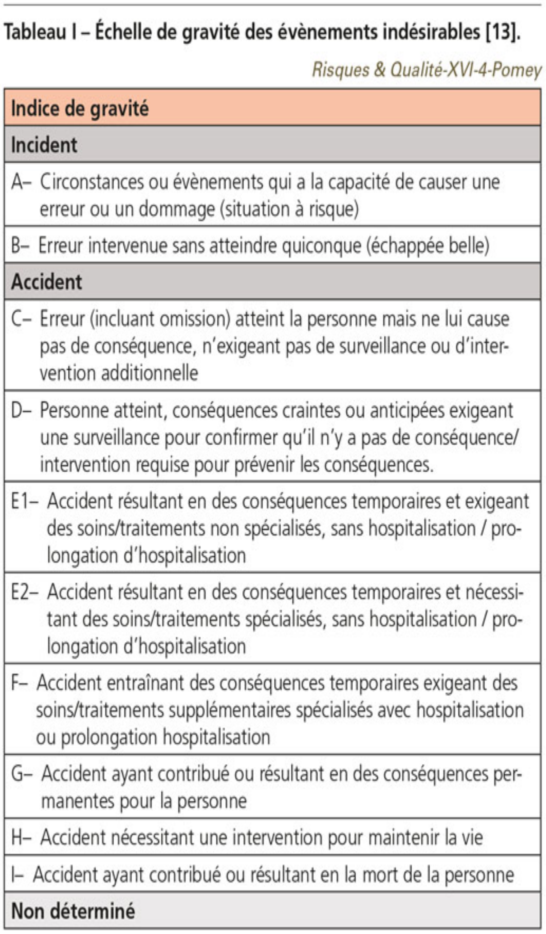


Tableau I – Échelle de gravité des évènements indésirables [13].

Risques & Qualité-XVI-4-Pomey

Indice de gravité
Incident
A– Circonstances ou évènements qui a la capacité de causer une erreur ou un dommage (situation à risque)
B– Erreur intervenue sans atteindre quiconque (échappée belle)
Accident
C– Erreur (incluant omission) atteint la personne mais ne lui cause pas de conséquence, n'exigeant pas de surveillance ou d'intervention additionnelle
D– Personne atteint, conséquences craintes ou anticipées exigeant une surveillance pour confirmer qu'il n'y a pas de conséquence/ intervention requise pour prévenir les conséquences.
E1– Accident résultant en des conséquences temporaires et exigeant des soins/traitements non spécialisés, sans hospitalisation / prolongation d'hospitalisation
E2– Accident résultant en des conséquences temporaires et nécessitant des soins/traitements spécialisés, sans hospitalisation / prolongation d'hospitalisation
F– Accident entraînant des conséquences temporaires exigeant des soins/traitements supplémentaires spécialisés avec hospitalisation ou prolongation hospitalisation
G– Accident ayant contribué ou résultant en des conséquences permanentes pour la personne
H– Accident nécessitant une intervention pour maintenir la vie
I– Accident ayant contribué ou résultant en la mort de la personne
Non déterminé

2.1.1.2.5. Le conseil d'administration

Le CA est chargé de superviser la mise en place des lois, règlements, mesures de soutien liées à la divulgation des EI auprès des patients et du MSSS. Il doit également prévoir des mesures préventives pour éviter que des AI potentiels ne se reproduisent.

2.1.2. Le projet de loi 83 et la création du rôle de commissaire aux plaintes et du comité de vigilance et de la qualité

2.1.2.1. Le commissaire aux plaintes

En complément à la loi 113, le projet de loi 83 (article 33 et 66) [78] a créé une nouvelle fonction dans les ESSS au Québec, soit le commissaire local à la gestion des plaintes dans les établissements de santé. Ce commissaire local aux plaintes relève directement du CA et a le pouvoir d'intervenir de sa propre initiative. Le commissaire local aux plaintes est chargé de faire des recommandations au CA à travers le suivi des plaintes portant sur la qualité et la sécurité des soins, l'efficacité des services rendus et le respect des droits des usagers.

L'usager insatisfait peut ainsi adresser une plainte à l'établissement. Cette plainte est traitée par le commissaire. Celui-ci enquête et fait des recommandations. S'il s'agit d'une plainte concernant un médecin, un dentiste ou un pharmacien, c'est le médecin examinateur de l'établissement qui la traitera. La conciliation est recherchée dans tous les cas.

Un mécanisme de deuxième recours permet au plaignant insatisfait des conclusions qui lui sont transmises de saisir le Protecteur des usagers ou des citoyens[8] ou le comité de révision selon le cas. Le plaignant peut en tout temps se faire accompagner par le commissaire, par le comité des usagers[9] ou par un organisme d'assistance et d'accompagnement aux plaintes. Un rapport

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[8] Selon le contexte, la personne désignée Protecteur du citoyen, un vice-protecteur ou tout membre du personnel à qui le Protecteur du citoyen a délégué l'exercice de certains de ses pouvoirs pour recevoir et examiner les plaintes des usagers ou pour procéder à une intervention de sa propre initiative. **https://protecteurducitoyen.qc.ca/sites/default/files/pdf/2011-01-25_procedure_examen_plaintes.pdf**.

[9] Le comité des usagers représente les usagers de l'établissement. Il renseigne les usagers sur leurs droits et responsabilités, ainsi que promeut l'amélioration de la qualité et des conditions de vie des usagers. Le comité des usagers est composé de membres bénévoles ne travaillant pas pour l'établissement. Ces membres sont élus par tous

d'activité est adressé au CA chaque année et celui-ci formule, au besoin, des objectifs à poursuivre. Enfin, le dossier de plaintes est régi par des règles de confidentialité.

2.1.2.2. Le comité de vigilance et de la qualité

La loi 83 a introduit aussi l'obligation pour le CA de créer un comité de vigilance et de la qualité par l'article 181.0.1 de la LSSSS. Ce comité s'inscrit « *dans la logique d'une participation accrue des usagers au sein des administrateurs des établissements et d'un meilleur suivi des services à la population* » [78].

Ce comité de vigilance et de la qualité a pour mandat de :

1. s'assurer du suivi des recommandations du commissaire local aux plaintes et à la qualité des services (ou du Protecteur des usagers) ;
2. coordonner l'ensemble des activités des autres instances mises en place au sein de l'établissement (ex. Superviser les mesures de soutien liées à la divulgation des EI aux patients) et
3. assurer le suivi de leurs recommandations [78].

La loi limite la composition du comité à cinq personnes : « *Le directeur général, dont la présence est essentielle étant donné son rôle au sein de l'établissement et auprès du conseil d'administration, le commissaire local aux plaintes et à la qualité des services est la seule personne du comité de vigilance et de la qualité qui ne soit pas membre du conseil d'administration, les trois autres membres du conseil d'administration ne doivent pas travailler*

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les usagers. Un représentant par et parmi les membres du comité des usagers est désigné pour siéger au CA de l'établissement.

pour l'établissement, ni exercer leur profession dans l'un de ses centres, ni être liés par contrat à l'établissement (familles d'accueil, ressources intermédiaires). L'un de ces trois membres doit obligatoirement être choisi parmi les deux représentants des usagers » [78].

Cependant, malgré la mise en œuvre des dispositions légales des lois 113 et 83 au Québec, la gestion des risques demeure un défi de taille, principalement en raison de l'absence d'un portrait général et des liens à tisser entre les différentes instances au sein des établissements de santé. Par exemple au Québec la gestion des infections acquises à l'hôpital est gérée à part d'autres comités. En fait, la gestion des risques est encore traitée en silos au Québec, sans tenir compte des liens et des interdépendances au sein du système de santé [30, 33].

2.1.3. Le projet de loi 10 : une tentative qui tente de tenir compte des interdépendances au sein du système de santé

En 2014, le gouvernement du Québec a décidé de revoir totalement l'organisation du réseau de la santé notamment à travers la création de nouvelles structures. C'est ainsi que sont nés les centres intégrés de santé et de services sociaux (CISSS) et les centres intégrés universitaires de santé et de services sociaux (CIUSSS) issus de la fusion de centres hospitaliers, de centres de soins de longue durée (CHSLD), de centres locaux de santé communautaires (CLSC) et de centres en charge de problèmes sociaux comme les jeunes en difficulté, la réadaptation, etc. Le but déclaré était « *de faciliter et [de] simplifier l'accès aux services pour la population, contribuer à l'amélioration de la qualité et de la sécurité des soins, de l'efficience et de l'efficacité du réseau intégré de la santé* » [67, 68]. La loi 10 fut aussi l'occasion de renforcer les dispositifs de gestion des risques au sein des établissements.

Cela s’est traduit tout d’abord par l’ajout d’un membre indépendant au CA d’un CI(U)SSS qui doit avoir des compétences en gestion des risques ce qui n’était pas le cas dans le passé mais aussi par un changement dans la composition du CA. La loi prévoit qu’il comporte:

1. le président-directeur général de l’établissement ;
2. une personne membre du conseil des médecins, dentistes et pharmaciens de l’établissement (autre qu’un médecin omnipraticien), choisie à partir d’une liste de noms fournie par ce conseil ;
3. une personne membre du conseil des infirmières et infirmiers de l’établissement, choisie à partir d’une liste de noms fournie par le conseil ;
4. une personne membre du conseil multidisciplinaire de l’établissement ;
5. un médecin du territoire exerçant sa profession hors d’une installation maintenue par un établissement ;
6. une personne membre du comité des usagers de l’établissement, choisie à partir d’une liste de noms fournie par ce comité (le nombre d’usagers au CA est réduit de deux à un, celui-ci nommé par le ministre, et non par le comité des usagers de l’établissement comme c’était fait dans le passé) ;
7. lorsque l’établissement exploite un centre hospitalier désigné centre hospitalier universitaire, une personne nommée à partir d’une liste de noms fournie par les universités auxquelles est affilié l’établissement ;
8. sept ou, lorsque l’établissement exploite un centre hospitalier désigné centre hospitalier universitaire, huit personnes indépendantes nommées conformément aux dispositions des articles 11 et 12 (selon des profils de compétences : gouvernance éthique, gestion des

risques et de la qualité ; ressources humaines ; ressources immobilières et informationnelles ; vérification et performance ; jeunesse ; services sociaux).

De plus, la loi 10 a introduit la création d'une Direction de la qualité, de l'évaluation, de la performance et de l'éthique (DQEPE) ayant comme mandat, entre autres, de mettre en place une gestion intégrée des risques et le partenariat de soins et de services avec les patients. Les mandats confiés aux DQEPE sont de mettre en place, au sein du réseau de la santé et des services sociaux, des systèmes de gestion qui permettent à un établissement :

1. d'atteindre ses objectifs en alignant ses actions sur ses objectifs organisationnels ;
2. d'améliorer constamment son accessibilité et son efficacité ;
3. d'assurer la qualité et la sécurité des soins et services offerts aux usagers [67, 68].

Le MSSS a également donné aux DQEPE une marge de manœuvre suffisante pour établir des stratégies de gestion intégrée des risques, de mise en place d'équipes et de comités, ainsi que des mesures et outils d'évaluation de l'efficience et de transfert des connaissances [67, 68]. C'est ainsi que plusieurs établissements de santé au Québec ont commencé à mettre en place (pour une meilleure gestion intégrée des risques) trois types de comités :

1. des comités de prestation sécuritaire de soins et de services par groupes-clientèle ou selon les besoins et facteurs de risques. Leurs mandats sont de:
    - collaborer au bon déroulement du programme d'audits (Pratiques Organisationnelles Requises (POR)),
    - faire les suivis d'indicateurs propres au continuum de soins et de services concernés,

    - analyser et évaluer les processus des domaines de risques propres au continuum des soins et services concernés, et
    - assurer la communication transversale avec les autres comités et veiller à l'intégration des différentes actions pertinentes afin d'assurer une meilleure gestion intégrée des risques ;
2. des comités d'experts aviseurs des domaines de risques critiques ou émergents. Les rôles et mandats de ces comités sont davantage transversaux. Ceux-ci s'assurent du développement des meilleures pratiques en gestion des risques par la recension d'écrits scientifiques, le développement de programmes, d'outils, etc. Ils se composent d'un pharmacien et des conseillers cadres de la DSI et de la direction des services multidisciplinaires et de conseillers ;
3. des comités de retour d'expérience qui consistent à identifier ce qui s'est passé à la suite d'un EI.

Cela dit, même après la réorganisation majeure issue du projet de loi 10 et les changements apportés au niveau de la qualité et la sécurité des soins et services, un plan d'action ciblé et obligatoire n'a pas encore été demandé par le MSSS pour réduire les erreurs médicales et les EI.

2.1.4. L'introduction de l'engagement des patients dans la gestion des risques pour la sécurité des patients

Le partenariat avec les patients est reconnu comme un élément clé pour développer des soins de santé de haute qualité [6, 14, 61]. L'engagement des patients (EP) peut contribuer à améliorer les résultats et réduire le fardeau des services de santé [16, 58, 2, 59], allant ainsi d'un modèle paternaliste vers un modèle inclusif [28].

Le Québec a connu d'importantes réformes mettant davantage l'accent sur la qualité, la performance et la sécurité des patients ; chose qui a été exprimée publiquement. En effet, au sein du Plan stratégique national 2015-2020 et du Cadre de référence de l'approche de partenariat entre les usagers, leurs proches et les acteurs en santé et en services sociaux [79] [27] l'engagement des citoyens et des patients y est mentionné comme l'un des principes de base pour de bons résultats de santé, la sécurité des patients et l'amélioration de la qualité [67, 68]. Dès lors, la mission intégratrice de la qualité, de la gestion des risques et du partenariat avec les patients a été confiée aux DQEPE pour favoriser une synergie entre ces trois domaines dans le but d'améliorer une vision d'ensemble de la performance des organisations.

Ainsi, les services et les comités de gestion des risques souhaitent restructurer leurs instances afin d'inviter des patients dits ressources à s'asseoir, à participer et à concevoir les cheminements, pratiques, processus et politiques des services de santé.

2.1.5. Exemples de stratégies et de mécanismes de partenariat avec les patients dans la gestion des risques pour la sécurité des soins et services

Au Québec, depuis quelques années, cette nouvelle approche d'EP a mené à la mise en place de procédures de partenariat de soins et de services dans certains établissements de santé [80]. La manifestation de l'EP au sein des organisations peut varier sur un continuum allant de l'information à la co-construction, et peut se produire tant au niveau clinique qu'organisationnel [80]. Plus spécifiquement, depuis 2010, un nouveau modèle relationnel basé sur le partenariat entre les patients et les professionnels de la santé a été développé à la faculté de médecine de l'université de Montréal et dans le réseau de la santé et des services sociaux [80]. Ce modèle qui tend vers la co-construction avec les patients repose sur la reconnaissance des savoirs expérientiels acquis par les patients qui sont amenés à être en interaction avec le système de santé. Ces savoirs sont reconnus comme complémentaires aux savoirs scientifiques et expérientiels des professionnels de la santé.

Dans le domaine de la gestion des risques et de la sécurité des patients, les études portant sur l'EP au Québec sont encore relativement bourgeonnantes. En effet, une première étude portant sur les différentes stratégies mises en place pour engager les patients au sein des établissements de santé québécois, durant laquelle les gestionnaires de risque, les responsables du partenariat de soins et des patients ont été interrogés, indique qu'il reste encore beaucoup de travail à accomplir [81].

Toutefois, certaines initiatives porteuses ont quand même été notées, que ce soit en milieu pédiatrique au CHU Sainte-Justine[10] et dans un centre de long séjour au CISSS de la Montérégie Est[11]. D'autre part, au Centre universitaire de santé McGill, plusieurs comités comprenant des patients ressources [82] ont vu le jour dans chacun des programmes afin d'améliorer la qualité et la sécurité des soins dans l'ensemble de l'établissement [82]. Ces comités sont complémentaires au comité des usagers (qui défend les droits et intérêts des usagers et évalue la satisfaction des usagers) et au comité de gestion des risques.

Au niveau canadien, l'Institut canadien pour la sécurité des patients, a publié un guide pour aider les patients/familles et les fournisseurs/organisations à travailler ensemble de manière efficace pour accélérer la sécurité des patients et améliorer la qualité des soins et services [83]. Ce guide

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[10] Voir dans ce numéro **l'article de Cousineau et al, pp 233-237**.

[11] Voir dans ce numéro **l'article de Dion-Labrie et al – pp. 250-258**.

s’appuie sur des données probantes et des pratiques exemplaires à tous les niveaux du système de santé [54]. En collaboration avec l’ICSP, Agrément Canada (l’entité d’accréditation du Canada) a déclaré dans son plan stratégique 2013-2018 que son principal objectif en matière de sécurité des patients est d’encourager l’EP afin de « *faire preuve de leadership dans l’établissement d’une stratégie nationale intégrée pour la sécurité des patients en vue de soutenir le changement transformationnel des politiques de santé, de renforcer et d’influencer la capacité (connaissances et compétences) des organismes et systèmes à assurer la sécurité des patients, de mobiliser tous les publics dans le réseau de santé pour la sécurité nationale* » [66].

Par la suite, le 1er janvier 2016, Agrément Canada a mis à jour ses normes en mettant clairement l’accent sur l’engagement des patients et de la famille. En vertu de ces normes révisées, une attention accrue est accordée à l’engagement, au partenariat et à la collaboration, ce qui signifie que les équipes d’amélioration de la qualité et de la sécurité des soins sont dorénavant considérées incomplètes sans les usagers et leurs familles. Agrément Canada s’est donc engagé à appuyer les organismes et les systèmes de santé afin d’améliorer l’EP et de jouer un rôle important dans l’amélioration de la sécurité des patients [66].

2.1.6. Conclusion

Malgré un certain nombre de réformes dans le domaine de la gestion des risques, les décideurs au Canada et au Québec ont encore du chemin à parcourir pour réduire les erreurs médicales à grande échelle, encore récemment l’ICIS publiait un rapport montrant que le Canada est en retard en ce qui a trait à la sécurité des patients par rapport aux autres pays de l’OCDE « *Un total de 553 objets* *tels que des instruments chirurgicaux ont été oubliés dans le corps de patients au Canada lors des deux dernières années* » [70].

En réponse et en concordance aux recommandations issues des rapports du groupe de vigilance pour la sécurité des soins [84], le système de santé québécois pourrait optimiser ces outils en matière de gestion des risques selon les recommandations suivantes :

1. Assurer l'évolution du formulaire de déclaration des incidents et accidents (AH-223) et du système d'information sur la sécurité des soins et des services (SISSS). Afin de bénéficier d'une vision globale des activités au sein des ESSS, une cohérence intégrée entre les systèmes de gestion clinico-administratifs et cliniques doit avoir lieu.
2. Procéder à la bonification des documents existants portant sur les responsabilités et les fonctions des comités de gestion des risques et des comités de vigilance de la qualité et faire des liens avec le comité de lutte contre les infections nosocomiales.
3. Dresser le portrait actuel de l'organe administratif de la gestion des risques au sein des établissements afin de préciser et de rehausser le profil de compétence du gestionnaire de risque et suggérer plus de travail de collaboration avec les responsables du partenariat de soins et de services. Il reste encore beaucoup de travail à réaliser afin de clarifier et spécifier les compétences requises en gestion des risques au sein des ESSS, et ce, à tous les niveaux de prestation de soins et services, particulièrement au sein des comités de gestion des risques et du CA.
4. Sensibiliser les instances d'enseignement et les ESSS à l'importance d'engager les patients dans la sécurité de leurs soins. Présentement, il y a un manque de connaissances sur les facteurs, les mécanismes et les stratégies de mise en œuvre de l'EP dans la sécurité des patients et la gestion des risques à tous les niveaux du système de santé. Il devient donc

impératif d’effectuer davantage de recherches dans ce domaine pour améliorer la sécurité des patients en matière de gestion des risques, non seulement dans le cadre de certains services, mais dans l’ensemble de l’établissement de santé. Plus récemment, cependant, des données probantes ont été produites sur la façon de mettre en œuvre l’EP dans la sécurité des patients (SP) en faisant participer les patients à leur propre prise en charge, ainsi qu’à la conception, l’évaluation ou la recherche des services de santé [7, 14]. De plus, au Québec, une étude descriptive sur l’EP pour la SP est en cours afin de comprendre les différentes stratégies d’EP dans la gestion des risques et comment améliorer l’intégration de l’EP dans la gestion des risques pour la SP [81]. Aussi, en France, le questionnaire de l’étude menée au Québec a été adapté au contexte français pour réaliser une évaluation similaire [85].

5. Prioriser la création d’un guide ou d’un portail ministériel pour partager les facteurs de succès de l’intégration des services et de la réduction des erreurs médicales afin de mieux comprendre les interdépendances entre les différentes instances impliquées.

En plus des recommandations mentionnées ci-dessus, la gestion des risques devrait évoluer davantage vers leur prévention et non simplement leur réduction. Par ailleurs, en plus de la prévention, des efforts doivent être fournis afin d’encourager une culture juste et sans blâme. Bien que plusieurs établissements de soins et services de santé au Québec y travaillent, pour progresser davantage dans cette direction, les établissements pourraient considérer l’installation d’espaces d’innovation au sein desquels des discussions à propos de projets, et de leçons apprises en lien avec des IA, sont permises avec, à la clé, des projets co-construits avec des patients partenaires. Au Québec, « les salles de pilotage » au sein des établissements de santé, qui sont des instances dans lesquelles les gestionnaires et professionnels de la santé ainsi que des patients et usagers (parfois) partagent leurs idées, sont une bonne voie pour favoriser une planification plus intégrée aux niveaux opérationnels, tactiques et stratégiques.

2.1.7. Déclaration

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2.2. Patient engagement in safety and risk management

This part of the literature review will consist of three main components relevant to this research project: 1) The Patient engagement – concepts; 2) Patient Engagement in Safety and Risk Management - concepts of safety and risk management, levels of intervention, implementation strategies; 3) Enabling and inhibiting factors of PE in safety and risk management 4) Ways to measure PE, enabling and inhibiting factors; 5) Tools and resources _ Engaging Patients in Patient Safety – a Canadian Guide**.**

2.2.1. The Patient Engagement

2.2.1.1. Concepts in patient engagement

Definitions of "Patient Engagement" (PE) vary considerably. In fact, PE gave birth to earlier concepts such as "person–centered care" and patient-centered care" (The Health Foundation, 2014). Many studies using the term "person-centred care" focused on care for older people, namely living with dementia, using mental health services or nearing the end of life [86]. Person-centred care may be slightly more common in literature from the UK and other parts of Europe compared to North America [86]. The term 'patient-centred care' was more commonly used than person-centred care, and tended to cover a much wider range of disease areas (rather than predominantly older people and mental healthcare [86]. This term has been commonly used in North America, as well as in the UK and Europe [86]. Adding to the confusion, the term "patient partnership" is also used synonymously with "patient activation" and "patient- and family-centered care". Patient activation - an "individual's knowledge, skill, and confidence for managing his/her own health and health care" - is one aspect of an individual's capacity to engage in that care [86]. But this term does not address the individual’s external context, nor does it focus on behavior. On the other hand, “patient- and family partnership” is a broader term that conveys a vision for what health care should be: “a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care” [6]. Patient partnership is an approach that enables health care professionals and patients to co-design services / programs / interventions / care pathways (e.g., The Montréal Model) [80]. Therefore, the definition this study will abide by is one of “Patient Engagement (PE)”, close to the definition of patient partnership, which is defined as patients, families, their representatives, and health professionals working in active partnership, and engaged at various levels across the health care system – clinical level, organizational level and strategic level, - to improve health care and social care as well as patient safety [80].

Engagement in care and services represent a new collaborative strategy to ensure a high level of patient and their families participation in their own care and in risk management [7]. These types of engagement can take place at several levels: at a micro level or clinical level (during individual interaction with HCWs); at a meso level or organizational level (within the organisation of care; and at a macro level (strategic level, with the creation of policies and governance of the health system) [80].

2.2.2. Patient Engagement in risk management for patient safety

2.2.2.1. Risk management for Patient safety concepts and definitions

Several definitions can be found across literature. For instance, in a systematic review authored by Duckers et al., it is mentioned that one of the definitions of Risk Management for safety put forward by National Library of Medicine's controlled vocabulary thesaurus (MeSH) was "*the process of minimizing risk to an organization by developing systems to identify and analyze potential hazards to prevent accidents, injuries, and other adverse occurrences, and by attempting to handle events and incidents which do occur in such a manner that their effect and cost are minimized. Effective risk management has its greatest benefits in application to insurance in order to avert or minimize financial liability."* [2]. Then again, a commonly recognized concept of "risk management for patient safety" was introduced in the years 2000 by the Institute of Medicine (IOM) when the report "*To err is human: Building a Safer Health System*" was released, bringing to light errors in health care organizations, as well as cost associated with those errors. The IOM described patient safety "*as the freedom from accidental injury due to medical care or from medical error"* [11]. Another definition was presented by the International Classification for Patient Safety, stipulating that "*the reduction of risk of unnecessary harm associated with healthcare to an "acceptable minimum". An acceptable minimum refers to the collective notions of given current knowledge, resources available and the context in which care was delivered weighed against the risk of non-treatment or other treatment*" [87]. Safety is thus a component of risk management and was introduced in the 1990's, according to MeSH research as "Patient safety", a concept evolving from just a risk management approach to also a risk prevention approach [2]. Moreover, the World Health Organization (WHO), in its Conceptual Framework for the International Classification for Patient Safety (ICPS), proposed the following definition of …, which is more limited to healthcare settings: "*Activities or measures taken by an individual or a health care organization to prevent, remedy or mitigate the occurrence or reoccurrence of a real or potential (patient) safety event."* [87].

Other relevant concepts relating to patient safety are “near miss”, a situation that did not cause harm to patients - but could have [88]; “Incident”, is a situation in which a harm was caused but no damage was made. “Accident”, a situation in which harm was made and damage was found. “Medical error”, “*An error is a failure to carry out a planned action as intended or application of an incorrect plan. Errors may manifest by doing the wrong thing (commission) or by failing to do the right thing (omission), at either the planning or execution phase*” [5]. Fallowfield and Jenkins (2004) suggest that medical errors should be distinguished from negligence or malpractice, insofar as the first is accidental while the second two are deliberate violations of a rule or standard of behaviour. Furthermore, medical errors do not systematically lead to observable injury to the patient [89]. “Adverse event”, is used for incidents in which the person receiving healthcare was harmed [65]. In their study, Leape et al. (2014), consider adverse events as unwanted event for the patient - or staff - which occurs during the delivery of care, as part of the prevention, diagnosis, treatment or rehabilitation, whether the event is due or not to the exposure to a health product, or any other malfunction. There are two types of undesirable events: avoidable and serious [65]. Avoidable ones can be describes as those that would not have occurred if care - or the environment in which care is being delivered – were compliant with regulations in place; whereas serious undesirable events are those that are responsible for death, immediate threat to life, hospitalisation extension, incapacitation or disability [65].

2.2.2.2. Levels of Patient Engagement: Implementation mechanisms and strategies

For a few years now, PE approach has led to the implementation of care and service partnership procedures in a certain number of healthcare institutions across the world, namely in the UK [61] and in Canada - including Quebec [80].

PE can manifest in several formats: an information continuum, consultation, collaboration / cooperation, partnerships or a co-design leadership continuum [80].

As an **information continuum**, patients can be informed and educated about their own health, while as a **consultation,** HCPs can consult patients about their experiences and potential health risks [7, 30]**.** In other PE formats, patients could be used for HCP training, or as "patient coaches" for patients in living with a common disease [30]. The **collaboration / cooperation format –** for example, in the care and services design continuum – places patients as advisors on continuous quality improvement committees, as contributors to Lean Six-Sigma processes, in developing best practice guides, or drafting documentation for patients [9, 6, 14, 15]. Finally, at the co-design / partnership **continuum, patients are engaged in governing board and committees; policy making, etc.** [7, 30]. **Patient engagement can be seen at different level of the healthcare system** [7, 30, 8]:

a) Clinical level: Direct delivery of healthcare

Engagement at this level occurs during regular meetings between HCPs and patients, but also within a team of HCPs, which includes a single patient or several patients. Building services involving PE requires [9, 30, 90, 91]:

- Educating patients on how to manage their own care. Potential strategies: patients receive information on their diagnosis, ways to manage it and available support from the healthcare institution.

- Training and education on PE (this is true for all the levels-with different degrees) - implementing training for patients, all clinicians, managers and the workforce on the value of patient engagement, ways to facilitate it, role of everyone involved, and how to create and sustain engagement. Potential strategies: creating or modifying training sessions and resources for staff and develop curriculum for patients on PE; develop PE competencies for staff; educate patients and families about their health and healthcare and support and encourage them to take an active role; support patients in managing their own health; Implement mechanisms that support clinicians' emotional well-being and ability to care compassionately for patients; implement education tools on PE. At this level, patients may also be capable of identifying risks and potential ones. The organization may also have strategies measuring patient Engagement.
- Implement a process for encouraging patients and HCP collaboration. **Potential strategies**: Building teams including patient's advisors or peer-helper / coach, patient's testimony, space availability, etc.; tools; guidelines; etc.;

Some examples of patient partnership strategies involve iin the United-States for instance, a training program aims to provide tools to patients in order to improve their abilities to better self-manage chronic pain. Other examples of PE at this level are in the UK, where Expert Patient Programs offer training sessions to develop self-management competencies for patients living with chronic diseases [61]. In France, the *Pierre and Marie Curie Faculty of Medicine* (Sorbonne

University) created a university degree and master where HCPs and patients are trained together regarding Patient Therapeutic Education. Another example would be an initiative from the World Health Organization Collaborating Centre in mental health and addiction, which aims at integrating carers to healthcare teams in clinical settings [61]. In 2007, British-Columbia, the Health Minister implemented a PE approach that fosters patient engagement and decision-making with regards to care processes, where ppatient's advisors or peer-helper / coach are encouraged to integrated clinical teams. This may also include the use of interdisciplinary care plans involving patients, so that care objectives remain focused on the patient's life plan. The approach allows patients to learn key competencies and involves them in the continuous improvement of care and service quality [92].

b) Organizational level

Patient engagement can occur within the organisation of programs and services (please refer to Appendix A for examples. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**). Ultimately, it is about co-designing and co-creating projects alongside patients, from inception to implementation (diagnostic, change management, knowledge transfers, evaluation and adjustments). At the organizational design level, mechanisms and strategies may involve: [9, 30, 90, 91]:

- Implementing a systematic process for involving patients and/or carers in the identification, planning and implementation of services, programs and interventions. As well as mechanisms that enable care and services coordination across different settings. Potential strategies: groups tasked with steering design and redesign of care organization (clinical pathway, organization of care), which include patients and/or carers (risk management committees, committees on mortality and morbidities, task group to analyze and evaluate incidents and accidents, as well as evaluating quality improvement; task group in divulgation and declaration of incidents and accidents); training design, meetings with community and patient organisations to identify opportunities for quality improvement; holding a workshop with staff and patients and/or carers to discuss opportunities for improvement and/or develop improvement approaches.

- Implementing communication mechanisms that help clinicians elicit, understand, and respect patient perspectives and concerns. **Potential strategies**: ways for patients and families to easily report adverse safety and quality events so that clinicians are aware and can take immediate action if needed.
- Measurement and research: Implementing a process for involving patients and/or carers to review and analyze organisational safety and quality performance information (measure). Potential strategies: task groups and/or committees on risk management to oversee organisational safety and quality performance information (measurement task and tools to put in place).
    - Implementing a process for involving patients and/or carers in the evaluation of patient feedback data. Potential strategies: inviting patients and/or carers to committees or groups tasked with evaluating patient feedback data.
    - Implementing a process for involving patients and/or carers in the implementation of quality activities identified through patient feedback data. **Potential strategies**: utilising patient advisory committees to provide advice on the implementation of quality improvement activities, engaging with individual patients and/or carers who

were involved in the identification of issues to develop and implement solutions to safety issues.

- Assess outcomes of patient engagement.

Some examples of patient partnership strategies involve in Quebec per example, since 2010, a new rational model based on the partnership between patients and healthcare professionals has been developed at the University of Montreal's Faculty of Medicine [80]. This patient partnership model is based on the recognition of the patient's experiential knowledge gained from living with a disease, which is complementary to the healthcare professional's scientific knowledge. The Montreal Model prescribes making executive management aware of the cultural change that is about to take place though PE and gains its official support. Then, services (willing to engage in improving their collaborative practices) implement a continuous improvement quality committee of the care and services partnership. These committees are comprised of managers, key healthcare providers (physicians, nurses, secretaries, social workers or other people) and at least two patients. Patients who integrate committees are considered as resource patients or patients' partners (PP), meaning they are no longer in an acute care and were treated in the program for which the Committee has been set up. They can provide their point of view based on their experiences and share perspectives on malfunctions or deficiencies they have identified. Therefore, they are recognized for their expertise related to their care pathways and understanding of needs. These patients are previously trained by the Patient Partnership and Collaboration Directorate (free translation of *Direction collaboration et partenariat patient*) before participating in these committees and are supported until they become autonomous.

Still in Quebec, the McGill University Health Center has created several committees with resource patients or PP [82]. These committees involve patients to address quality improvement and safety for specific programmes or for the overall healthcare facility [82]. Patient committees are complementary to patients' committees reintroduced by Bill 10 (patients committees defend rights and interests of patients, ensure proper functioning of resident committees and evaluate user satisfaction). From a tactical standpoint, this could translate to conducting partnership training by patients/healthcare providers tandems, creating continuous quality improvement committees with resource patients, or the creation of a directory of trained resource patients.

c) Strategic level [9, 30, 90, 91]:

In terms of system, patients could be part of patients' committees and board of directors, as well as be involved in training and hiring personnel (please refer to APPENDIX A - Conceptual Framework PE for PS, for examples. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**).

Here, strategies involve:

- **Policies involving patient and/or carer representatives on committees tasked with strategic and operational planning.** Many organisations undertake strategic and operational planning through the board or senior executive committees. The opposite approach would include: establishing a consumer advisory group; conducting a structured consultation process to seek patient input on key planning activities and incorporate feedback into planning (e.g., patient testimonials); involvement can also be in subcommittees in charge of quality and risk management in the organization; membership in key committees and/or boards; establishment of a patient advisory group that provides advice to the organization.

- **Policies in which patients and/or carers are involved in the governance of the health service organization**, such as user committees. Their role is to protect the right of patients, carers and families. This type of committee must ensure that patients are treated with respect for their dignity and recognizing their rights and freedoms. It is a strong advocate for patients when addressing governing bodies of the institution. Also, the rights of patients, service quality and patient satisfaction are the foundations that guide its actions. It should have a special concern for the most vulnerable patients and work to promote the safety and quality of care and services.

- **Policy strategies for communicating and/or consulting policy or strategy that describes the processes for disseminating performance information on safety and quality to the community**. This includes providing information or reports on the organisation's web site; making posters on safety and quality performance and displaying them in the organisation; developing information sheets on safety and quality performance for patients and/or carers to read while in waiting areas.

- **Policies involving patients and/or carers in the design and delivery of workforce training.** Direct strategies may include having patients and/or carers involved in committees or advisory groups tasked with developing or reviewing training materials and resources.

- **Policies that drive a culture of change. Potential strategies are: Provide transparent information about risks, benefits, and costs of care and treatment options; access and the ability to contribute to medical record; provide transparent information about organizational quality and safety (reports, etc.);** Provide recognition and rewards for care that fully incorporate patient and family engagement**. Identify potential organizational research to invest in.**

Some examples of patient partnership strategies involve PE policies, reference framework and PE strategies from Quebec [79]. These policies and reference framework help create strategic policies and plans of PE in the health institution. Strategies (as mentioned above in this section) of PE are thus integrated into these policies or strategic plans. Other examples involve guidelines from CPSI [92] and Organizational Require Practices from Accreditation bodies, such as Accreditation Canada [66] which help create strategic PE plans, and policies, as well as integrating PE performance indicators into these plans and policy, and into the performance management system of the institution.

2.2.3. Enabling and Inhibiting Factors of Patient Engagement for Patient Safety

in an article authored by Carman, Dardess, Maurer, et al., (2013), three sets general factors are highlighted with regards to the three levels. The first set factors are related to **patient characterist**ics - including values, knowledge, attitudes, beliefs and previous experiences. These factors could influence a patient's level of participation, just like other factors such as levels of education, health status, self-confidence and/or social status. **Patient participation could also depend on healthcare professionals (HCPs) and their relationship with patients** [7]. First of all, HCPs may not be incentivised to include patients in their practice, especially if it has little to no impact on their remuneration model (no financial incentives) [7]. Furthermore, there is a certain knowledge gap, or asymmetry, between HCPs and patients that may prevent both parties from addressing each other on equal terms. It has be proven that patients may not be able to express themselves with as much precision about health conditions, which may hinder their ability to assert their point of view or to retain interest from HCPs [14]. On the other hand, HCPs are not always comfortable with the notion of sharing information, or to allow input from patients to question their practice. In fact, patient participation could be perceived as a hurdle in the decision-making process [14].

At an organizational level, the second set of factors concern an **organization's culture, internal policies and practices** (whether they are open or conducive - or not - to active participation from patients) [90]. The institution must develop specific targets with clearly identified **priorities, including: safety**; effective evaluation or **effective measures**, as well as **the creation of tools to develop and adapt** the structures and processes in order to reduce dependence on individual vigilance**; technological support for the development of assessment measures** [90]. Technological support should have a number of parameters as to provide reliable, valid, real-time and useful data. It is also necessary for data to be interpretable and used in order to be integrated into decision-making; Organizations must encourage the **participation of professionals in change by creating participation areas** [30, 90], by developing a greater sense of initiative and empowerment, **by encouraging information sharing**, and by allowing decentralized decision-making [30]. The creation of a **culture that supports the recognition and flagging of dangerous acts is cruc**ial [30, 2].

And lastly, at the strategic level, a **culture that fosters change and patient engagement practices. Policies** which encourage individual and collective changes capacities and places people at the center of all preoccupations (engagement), whether they be patients or professionals [30, 90].

At the environment level, factors such as laws (regulations and policies) in place to favor patient engagement and social **norms** could be more or less in favour of patient engagement depending on how much it is valued by society or if any added value is perceived at all in their involvement in healthcare [2, 90]. Not to forget resources in place to favor patient engagement such as incentives, etc. [7].

2.2.4. Measuring patient engagement

Tools used to understand and measure the level of patient engagement can be:

Surveys or questionnaire: Surveying professionals and patient experience [93]. Some surveys have examined specific components of patient engagement, such as shared decision making, supporting self-management (e.g., chronic disease management) and communication [93]. Many surveys measure professionals' perceptions of relationships or communication [7].

- **Interviews or focus groups with patients**
- **Interviews clinicians and leaders**: There were many other examples of using interviews to collect information about staff and PE, the extent to which they believe the care provided is person-centred or barriers to implementation [93].
- **Observing interactions:** A less frequently used approach for measuring patient engagement involves observing encounters between patients and health professionals. This method tended to be used to measure specific components of PE such as communication or shared decision making rather than the broader concept as a whole [93].

Beyond the above-mentioned tools, other data sets can provide an idea of the advancement of PE within an organisation: the numbers of patient participating in the organization's intervention plan , committees; the number and the types of policies in place involving PE in safety and risk management; the types and documents designed for performance measurements made by the organization done in collaboration with patients; the integration of PE indicators in safety and risk management, booklets / documents available on patient engagement, etc.

Beyond the above-mentioned tools, other data sets (such as performance indicators) [92, 66] can provide an idea of the advancement of PE within an organisation: the numbers of patient participating in the organization's intervention plan, committees; the number and the types of policies in place involving PE in safety and risk management; the types and documents designed for performance measurements made by the organization done in collaboration with patients; the integration of PE indicators in safety and risk management, booklets / documents available on patient engagement, etc.

2.2.4.1. Tools and resources _ Engaging Patients in Patient Safety – a Canadian Guide

For several years now, numerous initiatives have been developed in Canada around patient engagement in quality and safety: health policy, organization of care and services, direct care, health research, and initial and continuing education of health professionals [80].

It is in this context that CPSI released a handbook entitled Canadian Patient Engagement Guide to Safety in May 2017 [92], to provide a model for patient engagement based on best practices in Canada in the area of patient safety.

"This guide offers an overview of promising initiatives in Canada intended to involve patients and their families in safety. It also provides a set of resources and tools, elaborated in Canada, and elsewhere, to facilitate patient engagement in safety. This guide is a useful resource to help patients and their families, health professionals, managers and all health stake- holders collaborate for patient safety improvement" [92].

2.2.4.1.1. Content of the guide

The handbook provides a synthesis of all best and innovative practices in patient and family engagement in safety in direct care (clinical level) as well as in the organization of care and services (design, delivery and evaluation), and in the health system (setting priorities and policies) in improving the safety of care and services. It also contains a collection of resources, tools and examples in this area from different provinces across Canada. Patients are seen as key players in healthcare safety, since they can help prevent or reduce risks by bringing a unique point of view, being involved throughout the care process. Healthcare professionals, having only a partial view of this process, can miss risk situations.

2.2.4.1.2. Managing adverse events

When developing patient care plans, taking into consideration their preferences and needs is a direct way to engage and involve patients in the safety of their own care. That said, this type of PE is most likely to not only occur, but succeed, in a setting which harbors a collaborative culture in which patients are encouraged and empowered to share their valued opinions, and in which HCPs are encouraged, trained, and why not required, to listen and take into consideration patient concerns as part of practice improvement processes. Examples of this include the "Safety Alert / It Ends Here" program from Saskatchewan (Canada), which was designed to enable patients and HCPs to notify and rapidly report on at-risk events, and the "You Have the Right to Ask Questions" from Manitoba (Canada), which provides tools to enable patients to boost their ability to identify, comprehend and utilize information about individual care-related risks.

Accreditation Canada offers a certification to train institutions in disclosure of adverse events to patients [94]. Moreover, disclosure guidelines (CPSI) are available for institutions that wish to bolster their efforts in that area [92]. Furthermore, knowing that Accreditation Canada has included PE in its accreditation standards (and is using patient surveyors for certification visits since 2017), health institutions are more likely to pay closer attention to PE and could use this as an opportunity to integrate patients and families in the process. Best practices include informing and training patients about the incident analysis process and integrating them within teams that conduct structured incident analysis. This also means that, at the organizational level, patients should be involved in committees that monitor incident/accident analysis, identify and implement solutions to prevent their recurrence.

2.2.4.1.3. Essential Organizational Practices

In keeping with best practices, there are essential organizational practices that could be applied at three stages of PE initiatives in PS: (1) planning, (2) implementation, and (3) Assessment.

First, when planning PE, since patient integration is a crucial step, the team must clearly define the purpose, degree and modalities of patients' involvement. "Why are we involving patients? Is it to provide a new perspective in adverse event analysis? To help change the attitudes and practices of HCPs in care safety? To enhance the risk identification process?" For each of these purposes, the degree of PE must be defined as well: information, consultation, collaboration, or partnership? The degree of engagement will then help determine the modalities of PE, as to whether surveys, focus groups, committee involvement, etc. are used to engage. These modalities will depend available human, technical and financial resources. Once those three elements are clearly defined, they must be shared (with support with the communications department if possible) with all healthcare providers responsible for safety, including patients, HCPs and managerial staff.

Secondly, at implementation, the team must prepare the recruitment and onboarding of patients to be involved in the process. This begins with a clear “job” description which highlights the desired competencies, skills and experience needed to fulfill the defined role. The recruitment itself can be done through various sources such as an internal patient database or bank, or even external sources like patient groups or associations. Once patients are recruited, proper onboarding and integration becomes crucial. Ensuring that patients have the proper support and training materials, and programs can help them gain a better understanding of their role and contribution within the safety-related initiative or structure which, in turn, makes them more effective. The other side of this equation is the HCPs. They, too, must be properly supported and trained in order to welcome patient participation, points of view and experiential knowledge.

Finally, during assessment, PE should look into the engagement process itself, its impact of decision-making, on quality and safety. Canadian literature indicated that PE can be assessed in various ways, whether through quantitative methods such as surveys, dashboards and indicators, or qualitative methods like focus groups, interviews with healthcare provider’s, or a combination of both. Regardless of the combination, the presence of indicators enables organizations to track implementation for chosen PE initiatives or activities. It is important to ensure that indicators monitor not only PE structures and resources, but also PE processes and impacts on quality and safety, as well as patient experience. For instance, indicators could include (but are not limited to): the number and type of activities, committees, initiatives in which patients were integrated; the number of patients who were integrated in each activity, committee or initiative; the number or %age of patients in the patient database or HCPS who underwent PE training programs.

In Canada, the Client Satisfaction Questionnaire developed by the Conseil Québécois d'Agrément (Quebec's accreditation body) or the Health Care Satisfaction and Experience Survey in Alberta (Canada) are examples of care experience surveys which include safety-related questions. Whereas the Public and Patient Engagement Evaluation Tool, developed by the Centre of Excellence for Patient and Public Partnership (CEPPP), assesses PE process design and planning, participatory culture within institutions, and impacts on decision-making. The CEPPP also provides a wealth of tools (questionnaires, dashboards, checklists, etc.) to evaluate PE at multiple organizational levels (clinical, organizational, research, etc.).

2.2.4.1.4. Other resources and tools available in the guide[12] ?

Table 2: Other resources and tools available in the CPSI Patient Safety guide

Types of resources in the CPSI Patient Safety Guide

Type	**Target Audience**	**Purpose**
Guide/Reading materials	Health care providers, leaders and patient engagement specialists	• Set up a patient engagement program • Include patient involvement in an existing program • Defining the role, involvement, or compensation of patients
Guide/Reading materials	Patients and families	• Inform and engage in one's own health and that of one's families • Understand the health system and the different ways to contribute to improving services and safety of care
Programs, courses (co-developed with patients, based on real-life cases)	Healthcare professionals	• Increase PE knowledge and skills • Welcoming and including patients
Guides, technical notes, evaluation tools and indicator ideas	Health care professionals responsible for patient engagement programs	• Assess PE internally • Measure planning, implementation and impact • Quantify concrete outcome
Guide/Reading materials	Health care professionals responsible for patient engagement programs	• PE in special settings (home care, long-term care and oncology)
Guide/Reading materials	Health care professionals responsible for patient engagement programs	• Engaging patients and families from diverse cultures to promote equity and diversity of perspectives • Recruiting and making information accessible (literacy)
Case studies	Health care professionals responsible for patient engagement programs	• Illustrate award-winning PE initiatives • Involving under-represented populations
Practical guides, toolkits from Canada, US and Europe	Health care professionals responsible for patient engagement programs	• Best practices from the US and Europe

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[12] Link to the resources of the guide: http://www.patientsafetyinstitute.ca/fr/toolsresources/Patient-Engagement- in-Patient-Safety-Guide/Pages/Selected-Resources-to-support-Patient-Engagement-in-Patient-Safety.aspx *(Consulté le 04-12-2017)*.

2.2.4.1.5. How can organizations take ownership of the best practices in the guide?

While the CPSI made its bilingual guide (English and French) available online through its website [92] and condensed downloadable in PDF version, the organisation also shared it directly with an exhaustive list of health institutions, patient groups, patient safety and quality groups, universities, and accreditation bodies across Canada. Interestingly, it also provided webinars and training sessions, including a Canadian adaptation of the teamwork system called Team Strategies and Tools to Enhance Performance and Patient Safety (TeamStepps), developed by the U.S. Department of Defense and the Agency for Healthcare Research and Quality. This system is designed to improve patient safety and transform healthcare culture by bettering professional and communication skills of HCPs.

Furthermore, to extend the guide's reach, the CPSI created linkages with existing programs that target multiple layers within Canadian healthcare organizations, such as: the Patient Safety Education Program - Canada for patients wanting to engage nationally; the Advancing Safety for Patients in Residency Education (Aspire) program for medical students and interns; the patient-centered simulation program of the Simulation Network and the Canadian Patient Safety Coordinators Course targeting HCPs; and the Effective Governance for Quality and Patient Safety Program geared towards senior management (including boards of directors) in Canadian health institutions.

3. CHAPTER 3: THEORETICAL FRAMEWORK

3.1. Theoretical framework

By digging into organizational change theory, institutional theory seems best suited and relevant to our research questions since it integrates all research elements, including the enabling and inhibiting factors of change, which is related to change brought about by PE in terms of practice, strategies and mechanisms implemented by **leaders** within a given health institution. Although other theories may apply, institutional and neo-institutional theory still emerges as the most applicable ones, because, according to the model of early institutional sociologist, Scott, et al., (1983), institutions provide vital functions for harmonization within society in a given context. An institution is usually the product of a process of institutionalization: a process through which something (a change: such as a concept, a behavior, a common value, etc.) anchors itself within an organization, a social system or society [3, 4]. PE for safety in care and services can be seen as a lever for organizational change management and a way to inspire and mobilize all partners for new practices and behaviours, despite difficulties linked to such a transformation. I

From an organizational point of view, change is disruptive and extrinsic by nature - in the sense that it causes stable organizations to format and/or transform their configuration [95, 96]. The complexity of a change's impact stems from the fact that it incorporates many aspects of the organization, including its values, behaviors, patterns of interaction between actors [97]. When the source of change is external to an organization, it can originate from its relationship with its environment (human, material, financial). On the other hand, when the source of change is internal to the organization, it can originate from forces produced by various organizational dynamics that can facilitate or hinder the organization's operations [97]. These forces can be retraced back to inadequate business processes, existing technologies and structures, individual and collective expectations, performance problems and lack of resources [95]. When planned, however, change can transport an organization from one stable state to another stable or desirable state, assuming that the change in question aims at the continuity and stability of the organization over time [95, 96, 97, 98].

According to institutional theory, an institutional organization can only be legitimate if it internalizes the norms of its institutional environment and preserves order via regulation. Neo-institutionalism introduced a cognitive and cultural dimension to its models, which characterizes the individual by its ability to process information and make decisions, but also integrates human shortcomings (limited rationality) by applying rules, procedures and routines. Individuals within an organization adopt values, cognitive frameworks, rules and organizational routines. Thus, the institutional environment can exercise pressure (change) through three pillars (Regulating pillar, normative pillar and Cultural-Cognitive pillar):

- Regulating Pillar: This pillar is used to preserve order via regulation and is more perceived through an economic angle (according to DiMaggio & Walter). It applies to the study of the behavior of individuals or entities (organizations) whose interests are often in conflict with each other.
- Normative Pillar: Norms are legitimate ways that allow us to achieve the objectives of our values. Together, values and norms define the roles that are socially attributed to members of an organization, which can be formally known or emerging informally with time.
- Cultural-Cognitive Pillar: An institution’s cultural and cognitive elements are, respectively, shared conceptions of social reality's nature and the frameworks through which meaning is given to things. According to Nonaka’s change theory, the creation of organizational

knowledge (by which meaning is given to things) is done through an approach that involves the observation of three basic dynamics: the creation of knowledge, its application, its preservation [99]. An organization mobilizes all its resources to "codify" the knowledge it has (to make them explicit and transferable), although some are not necessarily and / or are identified once lost. This is actually the interaction of tacit knowledge (non-communicable) and explicit that can give meaning to the environment in order to adapt to change [99].

In the institutional theory, leaders are usually the one that initiates the institutionalization. Adaptation of an organization to its environment can come from emerging, self-organized processes, and brought about by senior management that initiates and manages change [3, 97, 100]. In order for it to be successful, decision making, and the coordination of implementation activities must be done in collaboration with members of the organization and the agents concerned by the change in question. Most effective leaders appear to be those who use a portfolio of leadership approaches and are able to adapt these approaches to fit the needs of different situations, groups, and individuals. Some situations call for sharing technical expertise by showing people how to do things and exercising relatively close supervision. Others call for delegation and empowerment while still ensuring accountability for results. We understand that different kind of leadership can be needed at different level. In the work of Labelle (2014), on risk management, leaders perform distinct broad forms of institutional work as institutional carriers, depending on the level at which their work or use their strategy [101] (Labelle, 2014).

The partnership in care and services can be seen as a lever for change management and a way to inspire and mobilize all partners, despite difficulties linked to such transformation. It also allows the health and social services system to not only be motivated by the budgetary and political imperatives; but rather to build around the value created for and by people who work and are greeted there, in order to be more effective, more efficient and more responsive to citizens.

3.2. Conceptual Framework

Based on the institutional theory, the conceptual framework (APPENDIX A - Conceptual Framework PE for PS. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**) presents a more structured and illustrative display of research objectives. This framework describes the different levels of patient engagement strategies used by leaders across multiple levels (clinical level, organizational level, and strategic level). It also shows enabling and inhibiting factors of institutionalization, in accordance with institutional theory pillars (regulatory and normative pillars which are part of the environmental level, and the cultural and cognitive pillars defining the health organization – micro, meso and macro levels). These pillars apply pressure on different levels of patient engagement (micro, meso, macro levels) with regards to PE. PE engagement happens through a continuum of knowledge or institutionalization: creation, application / sharing; and preservation. For an organization to adapt to its changes and be fully institutionalized in patient engagement, knowledge has to be created, applied - shared, and preserved. The institutionalization process is initiated by institutional leaders, who give meaning to practices. The institutionalization process takes place in three steps: creation of knowledge (education, information); followed by its application by different healthcare providers (in this case: patients, HCPs and leaders) through shared leadership and decision making in process design, care design, communication, training, measurement, etc. And finally, its preservation through different policies, evaluation systems, research programs, and support system (for the purpose of continued improvement).

4. CHAPTER 4 : METHODOLOGY

4.1. Methodology: strategies and research design

The project has two research designs. The first one (part # 1), is a descriptive research design. To address research questions #1, a questionnaire was sent to all CISSS and CIUSSS, to the CHUM (Health Centre of the University of Montreal), and to the MUHC (McGill University Health Centre) (in which, all personnel in charge of patient engagement and risk management were contacted) and answered via telephone in order to index all implemented PE strategies.

The second research design (part # 2), to address the specific objective #2, is a longitudinal qualitative case study with interwoven levels of analysis (strategic, organization and clinical). The study involved one case study.

The following sections of this thesis will present part #1 (answering research question 1) and part # 2 (answering to research question 2) of the research study in order to understand the methodological implications and research design strategies used in each part.

4.1.1. Part #1 (answering research question 1)

The aim of this research study is to identify essential patient engagement (PE) mechanisms and strategies put in place by organizational leaders in leading healthcare institutions located in the province of Québec (Canada) that would allow this engagement to be fully institutionalized in the health care system for the enhancement of patient safety (PS).

Research question 1: Thus, the specific research question 1 stemming from this aim is as follows:

1. **What are the different PE strategies/mechanisms put in place by leaders in the Integrated Health and Social Service Centers (free translation of *Centre intégré de santé et services sociaux* or CISSS) or in the Integrated University Health and Social Service Centers (free translation of *Centre intégré universitaire de santé et services sociaux* or CIUSSS) to institutionalize PE for PS?**
    a. How did those PE strategies/mechanisms change overtime?
    b. What are the factors that enhance or inhibit the institutionalization of PE strategies/mechanisms for patient safety in the Integrated Health and Social Service Centers and the Integrated University Health and Social Service Centers (free translation of *Centre intégré universitaire de santé et services sociaux* or CIUSSS)?

4.1.1.1. Selecting the Research Design and Strategy

The project is a longitudinal descriptive research project by design. To address the above-described specific objective, a questionnaire was created (see Chapter 3, Article 1) then dispatched in two different times to 22 integrated health institutions and 2 university non-integrated health institutions a year after implementation of Bill 10 (2016-2017). Two different times (T1 and T2) were used because T1 represented the time after the integration of Bill 10. And T2 represented the adoption of the Reference Framework on PE created by the Minster of Health of the province of Quebec in 2018, to be integrated and adopted by the CISSS and CIUSSS's [79]. Semi-structured interviews via telephone, were also conducted to complement the data collected from the questionnaire. All personnel in charge of PE and risk management (RM) were thus contacted, first by email (in order to send the questionnaire) and then, via telephone.

4.1.1.2. Cases selection

After Bill 10, the province of Quebec counted 22 integrated health centers: 13 CISSS and nine CIUSSS, all of which were selected to participate in the research project. In addition to those 22, two major teaching healthcare networks institutions (non-integrated) affiliated to a French-speaking university or an English-speaking university (the CHUM and MUHC) were added to the sample, not only due to their leading roles and affiliations to top French and English universities respectively, but also to their advancement in PE and in quality improvements activities for PS. Hence, a total of 24 health centers in Quebec were included in the study's sample.

The research agent addressed a consent letter to DQEPE Directors of each center in order to brief them about the project's objectives and solicit their participation via email (APPENDIX B – Consent letter Part 1 research project PE for PS). The following week, the agent followed up by phone to set appointments and confirm participation and willingness to answer a questionnaire (APPENDIX C – Questionnaire PE for PS) over the telephone.

4.1.1.3. Sampling individuals

After sampling the participating health centers, the team determined which individuals, from within those centers, would be the most appropriate to answer the questionnaire. Thanks to the highly specific nature of the study's area of research, the team decided to pursue directors, head of services, middle managers or person in charge of risk management and patient engagement in each selected health center, as well as PP included in organizational teams of PE. Again, even though job titles may vary, the specific nature of that role made sampling techniques redundant in terms weeding out participants. Ultimately, the team ended up interviewing middle managers in charge of risk management and/or patient engagement (and sometimes including a PP, N = 1), DQEPE directors, and clinico-administrative managers when certain specific questions from the questionnaire could not be directly answered by DQEPE Directors.

4.1.1.4. Variables

The framework used to create the questionnaire (see APPENDIX A. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**), was based on the **Institutional Theory** revealing the importance of leadership roles and the three levels in which those leaders can act: (1) clinical level, (2) organizational level, and (3) strategic level. Additionally, Institutional Theory posits a concept of institutionalisation which enables the integration and appropriation of new knowledge (knowledge acquisition, knowledge sharing, and knowledge preservation), innovation or concepts inside an organisation by its employees, patients, and leaders.

Moreover, our literature review of PE for PS exposed that PE can be first analysed within a set of implemented norms and rules which enable its emergence and evolution. Secondly, PE can be considered as a continuum along which four types of patient and family engagement can take place, ranging from low-level engagement to a high-level engagement: (1) informing, (2) consulting, (3) collaborating and (4) co-creating. Thirdly, these four forms of engagement can occur in three different levels: (1) clinical, (2) organizational, and (3) strategic.

At a clinical level, patients can be informed, educated or consulted about their experience, potential health risks or use of healthcare services [21, 28, 30, 91, 80]. At an organizational level, a simple collaboration can be established whereby patients can become members of various committees and task groups, such as RM or mortality and morbidity committees, task groups to analyze and assess incidents and accidents, or for overseeing incident and accident disclosure and reporting [21, 28, 30, 91, 80]. At the strategic level, patients can be consulted to develop various activities that can drive change in organizational culture, such as aligning incentives and penalties to support patient and family engagement. Finally, in order to remain sustainable and transparent over time, co-design and co-creation among patients, professionals/managers and policy makers can go a long way, particularly when considering continuous educational and improvement programs or new clinical pathways to increase PS [25, 90, 91] at all levels of the healthcare system [7].

4.1.1.5. Data collection and collection instrument

The data collection tool used for this study was a questionnaire which the student researcher and the research director developed as a pilot project (APPENDIX C - Questionnaire PE for PS) (see Chapter 3, Article 1 of the thesis results for more information). They adapted the questionnaire based on existing questionnaires and literature geared towards leaders with regards to patient engagement and, more specifically, patient safety.

Questionnaires were first sent in September 2016 (T1) and in September 2019 (T2) by email to each of DQEPE Director in all the healthcare centers (CISSS/CIUSSS, CHUM, and MUHC). A week later, the research agent follow-up calls to organize a one-hour phone interview during which she went over all questions in the questionnaire to ensure that they were all answered or to complete certain answers.

4.1.1.6. The quality of the questionnaire

Since patient engagement (PE) strategies had already been pre-identified through the literature review and that the questionnaire was adapted from existing questionnaires (see Chapter 3, Article 1, for the article on the creation of the questionnaire), the questionnaire's construct validity was ensured [102]. To guarantee the questionnaire's reliability, the team designed questions to investigate strategies used at different levels of PE (clinical level, organizational level, and strategic level) based on literature review. As for validity (the ability to generalize the studied phenomenon), the 100% target sampling of risk managers and PE officers as well as PP (if available) considerably minimises that risk. In addition to the questionnaire been analyzed and discussed by the student researcher and the research director, the questionnaire was also piloted before it was sent to the different sites.

4.1.1.7. Data analysis

The research team analyzed data using Microsoft Excel and QDA Miner. Data was first compiled in an Excel sheet, indicating the different heath centers and respective strategies according to the three levels of governance (clinical level, organizational level, and strategic level) before identifying various implemented strategies at these levels. Additional qualitative data collected over the telephone, which completed the data collection and analysis by specifying why certain patient engagement strategies were implemented or not. This qualitative data analysis was done using QDA miner. The questionnaire's results have been analyzed and discussed by the student researcher and the research director to ensure the quality and alignment of the findings with the conceptual model developed in the thesis.

4.1.1.8. Validating the research strategy

Qualitative criteria were followed to ensure credibility of the results of this study. Our documentary data was chosen from multiple data sources and subjected to a rigorous critical analysis. The internal validation (is the conclusion drawn by the study warranted?) of our research part # 1 was enforced by the questionnaire (stating whether or not the health institution adopts PE strategies or not, at which level and how).

Furthermore, an explanation of how the current context affects the ability to address initial research objective was provided in the context of the present Ph.D. thesis (see Chapter 2, section 2.1). As for reliability [103], consistency or procedural accountability, a detailed and clear description of the process of the study (interviews grids, coding methods and data analysis) is provided. Finally, to ensure conformability (or neutrality), the role of researchers was defined, while ensuring that the physical presence of researchers does not alter the nature of data being collected. Throughout interviews, meanings and interpretations was clarified and verified by the student researcher and the research director to ensure that the meaning of gathered comments is truly understood. With that in mind, results are presented to the same key informants as well as to the interviewed participants for validation.

4.1.1.9. Ethics

The *Université de Montréal* Ethics Committee and the Research Center of the CHUM (CRCHUM) approved the research protocol as a multicentric research project, under approval number: MP-02-2017-6814 -- CÉR CHUM Number: 16.189 (APPENDIX D – CRCHUM research protocol approval letter - MP-02-2017-6814 -- CÉR CHUM Number: 16.189).

Study participants were informed prior to partaking in the study and signed a consent form (APPENDIX B - Consent letter Part 1 research project PE for PS), preserving anonymity and confidentiality of data.

Participants were free to withdraw at any time from the study if under any constraints. The research team followed appropriate procedures to secure the confidentiality of research data.

4.1.1.10. Timeline

The longitudinal research study lasted two years and a half on the field: From September 2016 to December 2018.

4.1.2. Part # 2 (answering to research question 2)

Research question 2: What are the innovative practices (strategies, mechanisms) as well as the limiting and enabling factors put in place by institutional leaders in one of the integrated healthcare centers in Quebec (case study) that would allow PE to be fully institutionalized[13] in risk management for the enhancement of patient safety**?**

4.1.2.1. Study design and participants

The research design is a longitudinal qualitative case study with interwoven levels of analysis (strategic, organization and clinical). The study is a qualitative case study from the Montérégie-Est Integrated Health and Social Services Center (CISSS Montérégie-Est), which started implementing strategies (pilot project of fall prevention and reduction strategy) to engage patients in risk management in a long-term care home. According to Yin (2003), a case study is particularly relevant in the context of research that focuses on understanding ("how") and explaining ("why") complex phenomena or phenomena highly influenced by external environments [104]. A qualitative approach was used to conduct semi-structured interviews for data collection and observation, as well as internal and external documents analysis.

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[13] Intitutionalization: a process through which something (a change, such as a concept, a behavior, a common value, etc.) anchors itself within an organization, a social system or society (DiMaggio & Walter, 1983; Scott, Michael & Smith, 2004).

4.1.2.2. Cases selection

The CISSS de Montérégie-Est was initially part of a research project related to PE for patient safety which involved 24 other healthcare organizations in Quebec and had taken place a couple of months prior (see Chapter 3, Article 2).

The CISSS de Montérégie-Est case was then selected out of 24 other because: (1) it had just secured a grant by the Canadian Foundation for Health Services Improvement (CFHSI) national training program for practising managers [105] to pursue a pilot project on fall prevention and reduction in their long-term care facility; (2) it had started to implement PE mechanisms for fall prevention such as involving a patient-partner in its committee, planning and modeling the desired change for fall reduction, etc.) which were identified from the part one of the research project on PE for safety (see Chapter 3, Article 2). Lastly, (3) it had a specific objective and plan on how to reach its 15% fall reduction objective in its long-term care facility.

An information and consent letter were addressed and send by mail to the Director of the CISSS in order to brief her about the project's objectives and solicit her participation (APPENDIX E – Consent letter Part 2 – research project PE for PS). A week later, the Director was contacted by telephone to confirm her willingness to participate in the study and to find out (if applicable) the names of people who would be interviewed. The interview dates (N= 7) were also set during those telephone calls.

4.1.2.3. Sampling for individual & semi-structured interviews

Participants were selected because they were already selected and included in the pilot-project of the analysis process of fall prevention and reduction at the CISSS Montérégie-Est. This selection was made by the group in charge of conducting the pilot-project (working group). Thus, participants, of the working group, the consultative committee created to guide decisions of strategies of the analysis process of fall prevention and reduction in the pilot-project (which includes the PP), were all selected for the semi-structured interviews because they were the ones responsible for the implementation (institutionalization) of PE in the analysis process of fall prevention and reduction at the CISSS Montérégie-Est.

Series of semi-structured group interviews occurred at two levels. First, at the strategic and organizational level, the research team interviewed the working group responsible for the pilot project. The members of that group included individuals from senior leadership roles such as: the General Manager, who also happened to be the Director of the Quality, Evaluation, Performance and Ethics Department (DQEPE) and of the health institution; the Quality Deputy Manager responsible for implementing the pilot project; the Chief of Service of Quality and Risk Management, as well as the executive advisor in Patient experience and ethics, and the executive advisor in quality. Secondly, at the organizational and clinical level, the research agent participated in the Consultative committee in charge of deploying the pilot project in the long-term care facility for fall prevention and reduction strategy. The committee comprised of: the working group responsible for the pilot project, 9 HCPs and managers at the clinical level, two other resources in charge of communication and complaint department, as well as a family member of a patient (as we will use the term PP here) (please refer to Table 2 for more information on the participants). These interviews lasted between 40 min to 2:30 min approximately each and took place on the premises of the CISSS from January to December 2017 (T1) and from January to October 2018 (T2).

In addition to a series of interviews, the team observed interactions between members of the risk management committee and the strategic working group on the FORCES project (project focusing on the strengths of the institutions in order to implement initiatives), as well as how they evaluate their progress and performance through indicators. Additionally, internal documents were consulted in order to corroborate on PE mechanisms and strategies put in place for fall prevention and reduction in the FORCES project.

4.1.2.4. Variables

The construction of the conceptual framework has revealed concepts related to the analysis of the objective questions. Variables include: at the strategic level - policies integrating PE, the involvement of patients in strategic working groups, norms, and regulations in place regarding PE (in risk analysis process particularly); at the organizational level - processes and practices involving PE in risk management analysis, creation of evaluation and measurement committees with PP, patient engagement in design of services, evaluation and implementation of patient safety in risk management, measurement tools used and whether they are applied to PE or not; at the clinical level - training and educational sessions on PE, on structure and processes on patient safety in risk management integrating PE and mechanisms of collaboration between patients and HCPs (roles of the different interest groups such as patients and families / health care professionals / managers) – (Please refer to APPENDIX A - Conceptual Framework PE for PS for more details. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**).

4.1.2.5. Data collection – and collection instruments

In order to obtain a fuller picture of the context [102, 106], the research team completed **data collection** using different methods: semi-structured group interviews and discussions; external and internal documents; and group interaction observation.

Since the research study is a longitudinal case study, data collection was completed according to a specific timeline (T). T0 marked the implementation of Bill 10, Quebec's health care reform of April 2014, and T1 was part one of the research project in which the CISSS de Montérégie-Est was identified (see Chapter 3, Article 2 for more information). Hence, data collection for this specific case study began in T2, according to the following timeline: T2 (March 2017 – December 2017) – Series 1 of group interviews; (January 2018- October 2018) –Series 2 of group interviews. (January 2018- October 2018).

Moreover, data contained in the CISSS' internal documents allowed the team to review and confirm variables and methodology, whereas Field observation help refine the contextual environment and dynamics between health professionals and support triangulation.

The measuring instruments used for the semi-structured interview guides were based on the importance of context and strategies/mechanisms of PE for safety. The interview guides were pre-approved by the student research and the research director, based on the conceptual model of the institutionalization of PE for safety (APPENDIX A - Conceptual Framework PE for PS. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**). This conceptual model addressed indicators used to measure PE for safety, mechanisms and strategies used by leaders to implement PE for patient safety, as well as factors influencing the engagement of patients, health professionals and / leaders.

4.1.2.6. Interview guide quality and measurement analysis

Our measuring instruments were based on the importance of context. In order to get a full picture of the context [102, 106], group interviews and discussion, internal document consultation and field observation were conducted. Meaning was derived from these different sources. The interview guides were pre-approved by the research director even though the questions within the guides are adapted from existing interview guides. The impact of the participant-researcher relationship, the potential for participant bias, and the potential for researcher bias will also be documented for potential interpretation bias (see Chapter 3, Article 3 for more information).

4.1.2.7. Data analysis

The approach to data analysis was based largely on the qualitative analysis of collected data. Semi-structured interviews were recorded digitally by the student-researcher. Data transcription was also completed by the same student-researcher who encoded it using qualitative software (QDA miner). Coding was performed using different themes contained in the study's conceptual framework. Two people analyzed and discussed the results (the student researcher and the research director). Moreover, these themes focused on the mechanisms and strategies used by institutional leaders at the different levels of the institution; factors influencing PE for PS; and measurement indicators of PE for PS. Finally, data triangulation was completed and confronted with documentary and field observation.

4.1.2.8. Validating the research strategy

Qualitative criteria were followed to ensure credibility of the results of this study. Our documentary data was chosen from multiple data sources and subjected to a rigorous critical analysis. In part # 2, the conclusion drawn was enforced by tool triangulation: the combined use of documents observation and interviews (group interviews and discussions). And for transferability, a clear and detailed description of each case (in-depth narrative, group discussion interview, data collection, and observation) and their context, as well as the context of Quebec's reform (Bill 10) affecting the study was provided (see section Chapter 2, 2.1 for more information). According to techniques explained by authors like Simon (2015) and Creswell (2013), they explain how to generalize findings of a single case study by way of in-depth narrative and case particularity [102, 106]. They argue that qualitative studies of psychological empowerment based on collaborative methods and communal narratives analyzed at multiple levels can be used to advance knowledge of the processes by which social and personal change occurs [102, 106]. They continue by saying that that contextual data is very important in order to get a full picture. In that same sense, in addition to interviewing different contextual actors, observation data was collected, and internal documents consulted in order to corroborate with the findings.

As for reliability [103], consistency or procedural accountability, a detailed and clear description of the process of the study (interviews grids, coding methods and data analysis) is provided. Finally, to ensure conformability (or neutrality), the role of researchers was defined, while ensuring that the physical presence of researchers does not alter the nature of data being collected. Throughout interviews, meanings and interpretations was clarified and verified with key informants (research director and interview participants) to ensure that the meaning of gathered comments is truly understood. With that in mind, the results of the data analysis are presented to the same key informants as well as to the interviewed participants for validation.

4.1.2.9. Ethics

The *Université de Montréal* Ethics Committee and the Research Center of the CHUM (CRCHUM) approved the research protocol as a multicentric research project, under approval number: MP-02-2017-6814 -- CÉR CHUM Number: 16.189 (APPENDIX D - CRCHUM research protocol approval letter - MP-02-2017-6814 -- CÉR CHUM Number: 16.189).

Study participants were informed prior to partaking in the study and signed a consent form (APPENDIX E - Consent letter Part 2 – research project PE for PS), preserving anonymity and confidentiality of data. Participants were free to withdraw at any time from the study if under any constraints. The research team followed appropriate procedures to secure the confidentiality of research data.

4.1.2.10. Timeline

The longitudinal research study lasted two years and a half on the field: From September 2016 to December 2018.

5. CHAPTER 5: RESULTS

5.1. ARTICLE 1

Title: An Evidence-Based Tool (PE for PS) for Healthcare Managers to Assess Patient Engagement for Patient Safety in Healthcare Organizations

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Abstract: 250 words

Background: In 1999, the Institute of Medicine had already warned that medical errors caused between 44,000 and 98,000 avoidable deaths per year in the United States. A similar situation was subsequently in 2000, documented in Canadian hospitals. According to a Canadian Patient Safety Institute report (2016), incidents in both acute and home care settings resulted in additional costs of $2.75 billion each year. Research suggests that patient engagement (PE) for patient safety (PS) can help address this issue. However, the use of PE in various strategies to promote PS has yet to be fully integrated across healthcare systems in OECD countries.
Goal: The aim of this study was to develop a tool for managers to assess PE strategies implemented at a health system level to enhance PS.
Methodology: Developing the tool involved 3 phases: (1) creating a framework; (2) building a first version of the tool; (3) validating the tool by an expert committee of PS and PE managers.
Discussion & Conclusion: The final tool consists of 82 questions, divided into four sections: (1) describing the healthcare organization (n=14); (2) gathering general information on PE strategies (n=15); (3) assessing different PE strategies for PS (n=50); and (4) describing the respondent's involvement in PS committees (n=3). The tool is currently being used (by healthcare professionals working in RM or PS, or, by task groups that include patients) in a research study in Canada and France, to assist healthcare managers in monitoring the evolution of PE for PS at a system level.

Keywords: Patient engagement / partnership / participation / risk / risk management / patient safety / institutionalization / strategies / mechanism / factors / tools / change / patient partnership

5.1.1. Introduction

According to the Institute of Medicine (IOM), risk management (RM[14]) is part of patient safety (PS) and can be thought of as "*freedom from accidental injury due to medical care or from medical error"* [11]. Already in December 1999, the IOM's report entitled "*To Err is Human: Building a Safer Health System*" revealed that medical errors[15] caused between 44,000 and 98,000 avoidable deaths per year in the USA [11]. In Canadian hospitals, similar evidence has been found, revealing that "*one in fourteen patients suffer from some form of harm, with a third of such cases being preventable"* [72]. Moreover, deaths related to incidents[16] occur every 13 minutes [53], and medical errors in both the acute and home care settings can cost $6,800 per patient, resulting in additional costs of $2.75 billion each year in Canada [54]. Estimated costs related to incidents and accidents[17] in hospitals represent the costliest form of care, accounting for over $58 billion per year across the country [55].

That said, according to the "Safety is Personal" report from the Institute of the National Patient Safety Foundation, patients and families can play a primary role in the prevention of medical errors and harm reduction [18]. Indeed, studies related to both patient engagement (PE) and shared decision-making reflect the evolving and shifting role of patients and families in healthcare as they become more active, informed, and influential [14]. A growing body of evidence supports that PE

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[14] The World Health Organization (WHO) and its conceptual framework for the International Classification for Patient Safety (ICPS), define risk management (RM) as "*activities or measures taken by an individual or a healthcare organization to prevent, remedy or mitigate the occurrence or reoccurrence of a real or potential (patient) safety event*." [87, 2]

[15] A "medical error" (or simply *error* here*) is a failure to carry out a planned action as intended or an application of an incorrect plan. Errors may occur through doing the wrong thing (commission) or by failing to do the right thing (omission), at either the planning or execution phase* [39].

[16] An "incident" is a situation in which harm was caused but no damage occurred [39].

[17] An "accident" is a situation in which harm was caused and damage occurred [39].

can lead to better health outcomes [9, 14], contribute to improvements in quality and PS [25, 23, 24, 90, 26], and help control healthcare costs [16, 28]. For example, in a mixed method study by Taber et al. [62], a multidisciplinary quality improvement initiative concluded that engaging patients in follow-up analysis of their medication (e.g. reviewing discharge medication with patients) intake reduced medication safety issues by 40%, and was associated with 100 % adherence with reconciliation[18], while seven-day readmission rates decreased by 50 % [62]. Moreover, a systematic review summarizing the evidence from 55 studies [58] concluded that "Patient experience is positively associated with self-rated and objectively measured health outcomes, adherence to recommended medication and treatments; preventative care such as use of screening services and immunisations, appropriate healthcare resource use such as hospitalisation and primary-care visits, technical quality-of-care delivery and fewer adverse events" [58].

Hence, patient engagement (PE) – and that of the patient's family and loved ones – is becoming a cornerstone for improving quality of care, so much so that healthcare institutions wanting to build safer systems and control costs are increasingly setting PE goals [14, 9, 16, 6, 8]. In other words, PE in healthcare and social services are part of a new collaborative strategy, whose aim is to ensure higher levels of engagement from patients with regard to managing their own care and overall risk management in healthcare and social services [7].

In addition to the evidence above, Accreditation Canada (Canada's healthcare institution accreditation body), in collaboration with the Canadian Patient Safety Institute (CPSI), stated in

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[18] The process of comparing a patient's **medication** orders to all of the **medications** that the patient has been taking. This **reconciliation** is done to avoid **medication** errors such as omissions, duplications, dosing errors, or **drug** interactions. https://www.ncbi.nlm.nih.gov/books/NBK2648/

its 2013-2018 strategic plan that the organization's main goal in PS is to encourage PE in order to "provide leadership on the establishment of a National Integrated Patient Safety Strategy in order to sustain healthcare policy transformational change, to build and influence patient safety capability (knowledge and skills) at organizational and system levels, and, to engage all audiences across the health system in the national patient safety agenda" [107, 66]. Thereafter, on January 1st, 2016, Accreditation Canada standards were updated and clearly focused on the patient and family partnership approach. For instance, quality improvement teams and care safety are now deemed as incomplete without patients and their families being involved [66].

Despite these great strides and intentions, risk and PS managers in Canada have little to no evidence-based guidance on how to plan, implement, promote, evaluate and improve (thus, institutionalize) PE in healthcare establishments, particularly as related to PS at a system level. In this context, our research team performed an environmental scan in order to identify existing tools which capture strategies and mechanisms of PE for PS in healthcare organizations at a system level. The results found were scanty, as will be described, with no tools being found which captured an overall « system » strategy of PE in PS in an entire healthcare organization.

Our research team thus decided to build a tool to assist healthcare managers in assessing system-wide integration of PE for PS practices, incorporating concepts of "Safety I" (situations that can go wrong) and "Safety II" (what goes right and the system's ability to succeed despite conflicts, uncertainties and risks) [108]. The tool was also intended to track change over time based on organizational practices. Further validating the rationale for our research is the fact that, after the creation of our PE for PS assessment tool, in 2018, the CPSI released a guide to assist both patients/families and providers/organizations effectively partner to accelerate PS and quality efforts (in accreditation, regulations, etc.) [109].

The aim of this article is to present the development of the PE for PS assessment tool at a system level by describing its creation process, and then discussing how it can be used by PS managers, risk managers or a task group in which patients are included, who wish to assess their PE strategies. The first part presents the methodology used to create the tool in three phases. We then discuss the results and limits of our research, before making our conclusions.

5.1.2. Methodology

In order to build the PE in PS diagnostic tool, the research team followed a validated process to ensure relevance, acceptability and reliability [110] according to a three-phased triangulation of: 1) structuring and identify themes (framework building); 2) creating a first version of the tool; 3) testing the validity and usability of the tool.

Phase 1: Structuring and Identifying Themes

Phase 1 firstly involved building a conceptual framework to anchor the tool around guiding principles of institutional theory (theory of change) [99, 4] for better integration and institutionalization of PE for PS. Published and grey literature were reviewed in order to better structure the conceptual framework around (i) PE best practices in healthcare institutions, (ii) factors enabling and inhibiting PE for PS, and (iii) available tools to measure PE for PS. Pertinent literature was identified through systematic searching of English-language published and grey literature covering the 2000 – 2016 time period. Our search targeted health management and social science literature using key words such as ‘patients OR users’ AND ‘engagement OR involvement

OR participation' AND 'institutionalization or integration' AND 'patient safety OR risk management'. In addition to these resources, the research team reviewed internal documents on PE for PS from international organization websites such as CPSI, Accreditation Canada, the Institute for Healthcare Improvement (IHI), and the Health Foundation, because of their potential to influence PE for PS across healthcare organizations.

Phase 2: Creating a First Version with support from two PS/PE experts

Phase 2 involved taking into consideration the conceptual framework's structure and guiding principles with support from two PS/PE experts (one each working for the ministries of health in Quebec and France). Both experts commented on and reviewed all proposed questions in the tool by considering their respective governments' priorities.

Phase 3: Testing Validity and Usability

Phase 3 consisted of testing the tool's validity and usability by sending its second version to selected PS/PE experts. These experts came from three different types of healthcare organizations in Quebec: (1) integrated university health and social service centres (free translation of *Centre intégré universitaire de santé et services sociaux* or CIUSSS); (2) non-university integrated health and social service centres (free translation of *Centre intégré de santé et services sociaux* or CISSS); and (3) university healthcare centres (UHC) which offer tertiary and quaternary care.

A total of five organizations (2 CIUSSS, 2 CISSS and 1 UHC) were selected based on their recognized work on PE and PS in the province. The proposed tool was sent to each selected organization via email, and, more specifically, to a management duo (active at the management level) comprised of one person in charge of PE strategy and the other responsible for PS and RM. The expert duos were asked to answer all questions by keeping in mind (see Table 3): 1) the relevance and usability of questions pertaining to their? organization (question and tool relevance); 2) the tool's layout and whether it was easy to navigate and understand; 3) question comprehension; 4) whether important questions were missing or elements needed to be adapted; 5) the clarity of instructions as formulated in the tool; 6) the time spent answering the questions; and, 7) whether they had any other comments to improve the tool. A conference call was then carried out to collect the experts' comments and responses. All of their suggestions were taken into consideration in finalizing the tool.

Table 3: Questions asked to the duo of PE/PS experts

- Were the objective of the tool and the instructions for use clearly stated and helpful?
- Was the tool easy to use?
- Was the layout easy to follow?
- Were the questions easy to understand?
- Were there important questions missing or needing to be adapted?
- Do you think this tool will be useful for your organization? How long did it take you to complete the tool?
- Do you have any other comments on how to improve the tool?

5.1.3. Results

5.1.3.1. Phase 1: Structuring and Identifying Themes (Conceptual framework)

5.1.3.1.1. Theoretical framework and conceptual model based on a theory of change: the institutional theory

For this research project, the institutional theory was used not only to enable the construction of a conceptual framework (APPENDIX A - Conceptual Framework PE for PS. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**), which sets out the different themes, principles and sections to be included in the tool for PE in PS [4, 95, 96, 97, 98, 99] Such an instutionalization process is initiated by establishment leaders [4, 99], who give meaning to practices, and follows three steps. Knowledge acquisition (education, information) is followed by knowledge application and sharing by different healthcare providerss (in this case, patients, healthcare professionals [HCP] and managers) through shared leadership and decision-making on key elements such as process design, care design, communication, training, and measurement [99]. Finally, knowledge preservation is accomplished through various policies, evaluation systems, research programs, and support systems for the purpose of continued improvement [99].

In sum, the theoretical framework used to build our PE for PS assessment tool describes the different levels of strategies used by risk or PS managers across not only a continuum of knowledge but also multiple levels (strategic, organizational or tactical, and clinical). In addition, it shows enabling and inhibiting factors of institutionalization (integration) of PE for PS, in accordance with institutional theory pillars (regulatory and normative pillars, which are environmental elements, and the cognitive-cultural pillar defining the health organization) [99, 97, 3, 100].

5.1.3.1.2. Literature review

A total of 85 articles and internal documents were found which related to PE for PS. Many of these articles concerned PE in specific health conditions or areas such as prenatal care [111] or PE in research [112]. In addition to these resources, the research team identified grey literature and internal documents (government articles and reports) on PE in PS from renowned Canadian and international groups.

Our literature review uncovered three main areas relevant to this project: i) implementation mechanisms and approaches for PE for safety; ii) enabling and inhibiting factors for PE for PS; and iii) available strategies for measuring PE for PS and RM at the organizational level. The research team placed particular focus on articles which included organizational level strategies, factors, tools, and were peer reviewed or systematic reviews. In total, 18 articles were retained related to strategies used for PE for PS at an organizational level [55, 9, 24, 26, 58, 6, 7, 112, 113, 114] [30, 61, 86, 91, 93, 115, 116].

Implementation mechanisms and approaches

Our review of PE for PS revealed that PE can be considered as a continuum along which can be placed four types of patient and family engagement: informing, consulting, collaborating and co-creating. These four forms of engagement can occur in three different areas: clinical level, organizational level and strategic level [7, 21, 61]. At the clinical level, patients can be informed and educated about risks related to medical procedures by HCPs [9, 90, 30, 91], managers or policymakers. They can also be consulted about their experience, potential health risks or use of healthcare services [7, 30]. At the organizational level, patients can collaborate to simply report adverse safety and quality events so that clinicians are made aware and can take immediate action if needed. Patients can also become members of RM or mortality and morbidity committees, task groups to analyze and evaluate incidents and accidents, and task groups overseeing incident and accident disclosure and reporting [14, 9, 6, 15]. At the strategic level, patients can be consulted to develop various activities that can drive change in organizational culture, such as: reports providing transparent information on risks, benefits, and costs of care and treatment options; appreciation and rewards for care that fully incorporates patient and family engagement; identifying potential organizational research in which to invest; aligning incentives and penalties to support patient and family engagement; requiring patient and family engagement competencies for certification or accreditation; advancing patient and family participation through legislation; etc. Finally, co-creation between patients and professionals/managers and policy makers involves co-designing, for example, educational programs at all levels or new clinical pathways to increase patient safety [9, 7, 30, 91, 90].

Enabling and Inhibiting Factors

Carman et al., [7] propose three sets of general factors that affect PE at the direct care or clinical level, organizational and strategic levels. The clinical level factors include patient characteristics such as values, knowledge, attitudes, beliefs and previous experiences. These factors can influence a patient's level of participation, just like others such as levels of education, health status, self-confidence and/or social status. Moreover, PE may also depend on HCPs and their relationships with patients [7]. Indeed, HCPs may not have the incentive to include patients in their practice, especially if this has little to no impact on their remuneration model (no financial incentive), for instance [7]. Additionally, there is a certain knowledge gap, or asymmetry, between HCPs and patients that may prevent both parties from addressing each other on equal terms. Patients may not be able to express themselves with as much precision about health conditions, which can hinder their ability to assert their point of view or to retain the interest of HCPs [14]. For their part, HCPs are not always comfortable with the notion of sharing information or allowing input from patients to question their practices. In fact, some may perceive patient participation as a hurdle in decision-making processes [14].

The second set of factors, operating at the organizational level, concern its culture, internal policies and practices [90]. Developing specific targets with clearly identified priorities (including: safety;

effective evaluation or measures; tools to develop and adapt structures and processes to reduce dependence on individual vigilance; technological support for developing assessment measures, etc.) can help enable PE within healthcare organizations (HCOs) [90]. Furthermore, when HCOs encourage the participation of relevant professionals by creating participation areas [90, 30], this leads to a greater sense of initiative and empowerment, encourages information sharing, and allows decentralized decision-making [30]. Creating a culture that supports partnership, as well as recognizing and flagging dangerous acts, is crucial [2, 30].

The third set of factors at the strategic level, concern the existence of influencing factors such as laws, regulations, policies and social norms, as well as available resources to support PE initiatives [90, 26, 30, 2].

Measuring PE at the organizational level

There are many ways to collect general PE information [112, 113, 114, 115, 116, 86, 92] (see Table 4). The literature revealed four main strategies to assess PE.

Survey-type tools examine specific components of PE, such as shared decision-making, supportive self-management (e.g., chronic disease management) and communication [7, 93, 115] that can impact PS. Such tools have captured the development of PE in prenatal care [111]. They have provided a framework to describe PE in PS, to gain insight into patients' perspectives about their knowledge, comfort level and behaviors in promoting their safety while receiving health care in hospital [113]. They have also been used to assess the impact of engagement in research [114] or to evaluate patient and public involvement in health research [112]. These tools do not focus on

PE for PS per se, but rather on self-management. Other survey tools at the organizational level assess the quality of PE or organizational culture which enables PE, trust, putting PE structures in place, etc. [115]. The Public and Patient Engagement Evaluation Tool (PPEET), an organizational measure of its capacity for, and culture of, public and patient engagement [115], does not specifically assess PE for PS despite the tool's evaluation of engagement more broadly.

Furthermore, although these survey tools incorporate concepts of PE, none include the two concepts of PS [108, 117], that is, Safety I and Safety II, which are both necessary for a higher quality, safer and preventive healthcare organization [30]. For the Safety II, attention is also given to performance variability and adaptations that led to successful outcomes in the face of risk [108]. Thus, the existing survey tools found were not specific to PS.

The second strategy includes *interviews or focus groups* with patients, clinicians or managers to collect information about how PE is implemented by staff, as well as barriers to appropriate PE implementation [93]. Existing approaches were, again, not specific to PS.

Observing interactions is a third way to measure PE. This involves watching encounters between patients and HCPs to measure specific components of PE, such as communication or shared decision-making, rather than the broader concept of PE as a whole [93]. Once again, this strategy is mostly used to observe general interactions in PE, but not necessarily PE for PS.

The last approach involves *performance indicators*, such as the numbers of patients participating in intervention plans or on committees; the number and types of implemented policies involving PE for safety and RM; the types and documents designed for RM measurement created in collaboration with patients; the integration of PE indicators for safety and RM; and booklets / documents available on PE [93].

Table 4: Tools to evaluate PE in PS at the organizational level

Title / Author / Year	Aim	Brief description	Where	Level
A 5-facet framework to describe patient engagement in patient safety / Duhn et al./ 2018	To gain insight into patients' perspectives about their knowledge, comfort level and behaviours in promoting their safety while receiving healthcare in hospital.	Open-ended questions were based on professional knowledge and common sense. The topics of some questions were informed by existing patient safety strategies and the study site's patient information booklet, as well as common clinical processes (e.g., administration of medication; diagnostic testing; staff hand washing). The questions were written at a Flesch-Kincaid grade level 5 to reduce the need for clarification and as part of best practice to facilitate patient understanding. The demographic questions included age; gender; reason for admission; length of hospitalization; health status; previous hospitalizations; and previous personal experience with adverse events in healthcare.	Kingston, Ontario, Canada	Organizational
Public and patient engagement evaluation tool (PPEET) version 2.0/ McMaster University / 2018	1) an Organization tool to assess the organization's capacity for, and culture of, public and patient engagement; 2) a Participant tool to obtain participants' assessments of key features of the engagement activity that they have participated in; 3) a Project tool to assess the planning, execution and impact of the engagement activity after it has been completed.	The Public and Patient Engagement Evaluation Tool (PPEET) includes three tools: the organization tool, the participant tool, and the project tool. When used together, the PPEET tools provide a comprehensive evaluation of public and patient engagement within a project and/or organization.	Hamilton, Ontario, Canada	Strategic, organizational and clinical
Methods and impact of engagement in research, from theory to practice and back again: early findings from the Patient-Centered Outcomes Research Institute (PCORI) / Forsythe et al./ 2017	To present PCORI's evaluation framework for assessing the short- and long-term impact of engagement; to describe engagement in PCORI projects (types of healthcare providers engaged, when in the research process they are engaged and how they are engaged, contributions of their engagement); and to identify the effects of engagement on study design, processes, and outcomes selection, as reported by both PCORI-funded investigators and patients and other stakeholder research partners.	An evaluation framework, as part of PCORI's evaluation plan, was developed with input from several groups representing diverse healthcare health care providers, including the PCORI Board of Governors, Methodology Committee, and its Advisory Panel on Patient Engagement. The full framework addresses all aspects of PCORI's work and operationalizes questions about PCORI's work in practice. The section focusing on the impact of engagement in research is the source of the research questions addressed and is organized into four areas: (1) description of engagement approaches; (2) effect of engagement on research processes and intermediate outcomes reflective of studies that matter to patients; (3) longer-term effects of engagement on achievement of PCORI's strategic goals; (4) impact of engagement in research on health.	Washington, DC, USA	Strategic and organizational
Evaluating patient and public involvement in health research: from theoretical model to practical workshop / Gibson A, et al./ 2017	To explore the practical utility of the theoretical framework as a tool for mapping and evaluating the experience of patient and public involvement (PPI) in health services research.	Three workshops were conducted with different PPI groups in which participants were invited to map their PPI experiences on wall charts representing the four dimensions of the framework. The language used to describe the four dimensions was modified to make it more accessible to lay audiences. Participants were given sticky notes to indicate their own positions on the different dimensions and to write explanatory comments if desired. Participants' responses were then discussed and analyzed as a group.	Bristol, England	Organizational

This literature review revealed four tools to evaluate PE at the clinical level in specific disease management areas and at the organizational level [86, 92, 110, 112, 113, 114, 115, 116] (Table 3). That being said, there is a lack of tools which collect information on strategies / mechanisms at the system level of an entire healthcare institution, particularly in PE for PS integrating Safety I approach (incorporating RM practices), and safety II approach (incorporating preventative practices as well as practices in PE in RM for PS).

5.1.3.2. Phase 2: Building a First Version

Following our conceptual framework, the first version of our tool contained **91 questions, separated in four sections:**

(1) Section 1 (n=16 questions) is related to the healthcare organization characteristics. It describes knowledge preservation policies, and the structure of RM and PS inside the organization;

(2) Section 2 (n=16 questions) includes general questions on PE strategies and mechanisms in the healthcare organization. This section describes knowledge acquisition among the different task groups and structures in place to engage patients and their families;

(3) Section 3 (n=56 questions) includes specific questions on PE strategies and mechanisms for PS in the healthcare organization. The section pertains not only to knowledge acquisition, but also knowledge application and sharing within the different task groups and structures in place to engage patients and their families for RM and PS. The second part deals with knowledge preservation within PE policies for PS, as well as indicators and

structures in place (regarding support systems, transparency and indicators used to maintain and institutionalize PE for PS);

(4) Section 4 (n=3 questions) includes questions on the general appreciation of PS and the involvement of the respondents in PS committees in the organization. This section relates to knowledge acquisition, knowledge application and sharing and knowledge preservation (see table 5 for more information).

Table 5: Theoretical framework sections based on institutional theory

(1) Knowledge acquisition Knowledge is created for patients, HCPs, and different strategic managers (e.g., through workshops, training and education on disease management, RM / safety, and on PE in risk management / safety);
(2) Knowledge application and sharing Managers involve and engage patients in different task groups, committees and teams for shared decision-making on process design, care design, communication, training, and measurement (e.g., reporting and disclosure process for medical errors, PE in PS and quality improvement plans, processes, monitoring, etc.). Patients could also be engaged in incident management (immediate response, disclosure, analysis, follow-up, shared learning, engagement in quality and safety committees, assurance reviews, implementing recommendations, etc.) [14].
(3) Knowledge preservation Managers and the healthcare institution not only engage patients in the creation of different PE policies, evaluation systems, research programs, and support systems, but also create a culture of safety, transparency, and collaboration among teams (which include patients). An evaluation framework containing measures and indicators is developed as well.

During the month of September 2016, this first version of the tool was sent to the Ministry of Health and Social Services of Quebec (MSSS), the quality and ethical directorate, and to the Ministry of Health and Solidarity of France (the General Directorate of Healthcare Services (free translation of *Direction Générale de l'offre de soins)*). The objective was to align the tool's questions with government priorities and to be sure that an important element had not been omitted. Both governments advised to integrate more questions related to PE-sensitive performance indicators for health outcomes and costs. In total, 55 questions were modified with respect to their wording, 6 were deleted and 3 questions on indicators were added. Thus, the second version of the tool had 88 questions instead of the initial 91.

5.1.3.3. Phase 3: Testing validity and usability

During September 2016, a second version of the tool was sent to five duos of experts on PE/PS, each from five different HCOs in Quebec. One duo even filled out and analyzed the tool alongside a patient who was part of their team. After one week, a conference call was organized with each site to discuss the questions. One researcher (UAG) led all calls with the expert duos, which lasted between 45 and 60 minutes. In terms of the results:

(i) <u>Relevance of the tool and questions</u> and <u>question comprehension:</u> All respondents mentioned that the tool helped guide actions and could be used as a self-assessment tool for healthcare institutions. The tool is best used as a team of health care professionals (an expert in PE, RM and or PS and a patient advisor): "*The tool helps us really frame our strategies and could be used as a self-assessment tool for healthcare institutions [...] It will be used for sure*".

(ii) <u>The tool's layout:</u> The layout was reworked by adding specific titles to sections and spaces for comments underneath each question.

(iii) <u>Important questions missing or to be adapted:</u> Questions were added and adapted to word questions and use certain terms that were more appropriate for the Quebec context (e.g., using the term "users" instead of "patients"). Other advice was to include questions associated to policies, training, simulations, and collaboration strategies with different departments, community organizations or other entities such as an internal user committee in relation to implementation of PE in RM.

(iv) Clarity of instructions: The tool's instructions were said to be clear and well understood by the team of PE professionals and patients, or PS professionals and patients, or both.

(v) Time spent answering questions: The average time to complete the tool was 55 minutes. Based on the above comments, a third version of the tool (see Table 6), totalling 88 questions, was resubmitted for final approval to the committee of experts composed of the 5 Québec duos of PE and PS managers.

Table 6: Final layout of the tool

Section 1	**General questions (Number of questions = 14)**
Knowledge preservation* -- Descriptive questions about the organization	› People working in patient engagement (PE) in patient safety (PS) › Number of years employed › Training received › Structure of PE in PS: e.g., department responsible for PE in PS
Section 2	**Questions related to PE strategies in general (Number of questions = 15)**
Knowledge acquisition*	› PE activities › Structure and strategies used to engage patients › Organization and committees
Knowledge application and sharing*	› Training › *Simulations* › *Collaboration with different departments or community organizations* › User committee
Knowledge preservation*	› Indicators: implementation, planning and performance › Transparency › *Policies*
Section 3	› **Questions related to RM and PS (Number of questions = 50)**
Knowledge acquisition*	› PE activities › Structures used to engage patients › *Organization and committee*
Knowledge application and sharing*	› Training › *Simulations* › *Collaboration with different departments or community organizations* › User committee
Knowledge preservation*	› *Indicators (implementation, planning and performance)* › Transparency › *Policies*
Section 4	› **General information of the implication of the people answering the tool (Number of questions = 3)**
Knowledge application and sharing & knowledge preservation*	› *Participation of management in PS committees* › *Additional comments*

*These titles do not appear in the tool; they are intended to provide structure to the reader of this article, according to the guiding principles of the institutional theory of change within the conceptual framework for the integration of PE for PS.

5.1.4. Discussion and limits

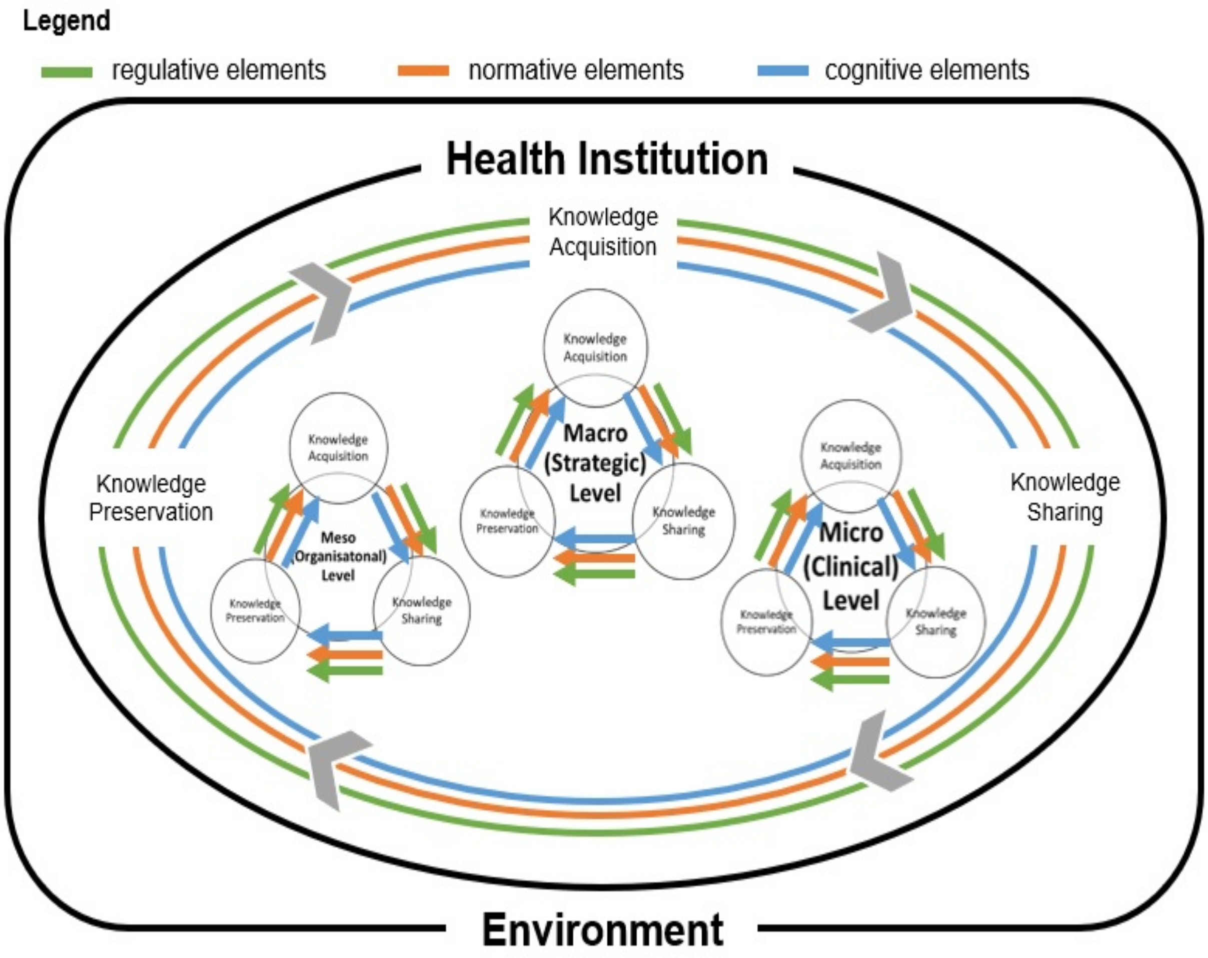
5.1.4.1. A patient engagement tool for patient safety

This tool is the first to be dedicated to managers or task groups (which could include patients) to assess different strategies meant to enhance PS, as well as to track change over time. The tool finds its originality in the fact that risk/PS managers, in collaboration with patients, can assess PE, and then support and deploy strategies and mechanisms based on emerging practices in order to optimize efforts for PS and results within the organization and inter-organizations. It integrates PE strategies for PS at different governance levels of the organization, supported by a change management theory which helps decision makers / leaders / managers integrate strategies into their organizational practices over time. Additionally, the tool can help accreditation organizations assess institutions' PE for PS over time. Moreover, the tool also exposes positive deviants or emerging innovative practices (using not only a "Safety I" but also a "Safety II" approach) [108] through its data collection on factors, mechanisms and strategies implemented in the HCO which help fully institutionalize (integrate) PE for the enhancement of PS.

Figure 4 presents the framework of the tool.

Figure 4: framework for the implementation of PE in risk management for safety based on the institutional theory (see APPENDIX A - Conceptual Framework PE for PS **for more information. In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study)**

PS: the regulative, normative and cognitive elements are presented in this article as factors influencing the PE in PS.



5.1.4.2. Updated with complementary tools

In fact, since the tool was created in 2016, our research team has been able to adapt and integrate into the tool many points and themes mentioned in the literature review (from 2016 to 2018) such as the literature on "Engaging Patients in Patient Safety – a Canadian Guide" which came out in 2018 [109] (p. 63), and other contemporary tools such as that used by the American Institute for Research [118], which contains an inventory of PE measures at the organizational level. According to the latter organization, key elements for measuring PE at the organizational level include leadership support, participation of patients and families in organizational partnership, having policies in place, and the type of structures set up to enable patient and family participation. This Institute also mentions tools available to measure and collect data, ongoing initiatives, and how to recruit patient partners and health professionals who support PE structures. Indeed, all of the above-mentioned elements were incorporated in our PE in PS assessment tool. Despite not being specific to PE in PS at the organizational level, such elements assisted our validation of various sections of our assessment tool.

5.1.4.3. The preliminary user testing and confirmation of tool's face validity

To ensure that the tool fulfilled its intended objective, the research team followed and met a set of qualitative criteria [102]. As a first qualitative criterion, the project's internal validity (i.e., whether conclusions drawn through the tool's questions are warranted or not) was enforced through the tool's questions: 1) their relevance for the HCO (i.e. did the questions help HCOs structure PE initiatives in PS; and did the tool help risk and safety managers track change and initiatives of PE in PS?); and 2) whether solicited experts were able to understand and answer questions posed by the tool and felt that all important components were present. Moreover, data from the literature review which informed the tool's development were drawn from multiple international data sources and were subjected to a rigorous critical analysis. The construction of the tool was carried out by triangulation of: (1) the combined use of a conceptual framework and a literature review; (2) the construction of a first version of the tool and its alignment with cross-jurisdictional priorities; and (3) mobilizing experts in PE and PS to test the tool and its usability.

As for transferability, the tool is currently being used in a province-wide research project and was sent to all integrated healthcare institutions in Quebec (n=24).

5.1.4.4. The tool’s limits

One of the limits of our PE for PS tool is the fact that, as created, it was not intended to be used by patients alone but rather by healthcare professionals and managers working in RM or PS or by a task group (on which patients might be present). However, if a patient were to be part of a working group, he or she would be capable of answering the tool alongside healthcare professionals as a team or as part of a trio. In fact, one of the expert teams in Quebec who tested the tool during phase 3 involved a patient advisor.

Secondly, our tool does not address the quality and culture of PE within the organization in detail, nor how PE could instill trust in an organization. Rather, it focuses more on what should be done in order to institutionalize PE in PS. The tool can be used in a complementary manner alongside other tools in order to evaluate such aspects in more detail. These other tools include the American Institute for Research inventory of PE measures at the organizational level [118], and the Evaluate Team Collaboration Skills tool, a toolkit for not only engaging patient and families at the planning level, but also assessing collaboration over time by taking into consideration diversity, structure of participation, and trust [119]. Other complementary tools are the Engaging Patients in Patient Safety guide which provides strategies for organizations that need to implement PE in PS [109], and the PPEET [115] which assesses the quality of PE at the organizational level through “integrity of design and process”.

Thirdly, the tool’s focus on PE for PS assessment in Quebec’s integrated healthcare context may limit its applicability to non-Canadian settings and to healthcare organizations that focus on smaller and more specific populations. While the tool principally relies on Canadian experience, we attempted to balance this aspect with an extensive review of the international literature, which also informed our work, and by diversifying the groups testing the tool through participating partner organizations (e.g., from major urban centres as well as regional referral centres). Also, by involving a counterpart from France, an international setting was included in our research. Participating practice partners in France have already begun to use our PE for PS assessment tool. The tool could potentially be used, in translation, by any healthcare organization in the world.

Fourthly, The PE in PS tool will be sent to the 24 integrated health care and social care organizations in the Quebec province of Canada to be able to have more robust psychometric analysis.

Finally, in addition to the identified limits and comments by the participants from the pilot project, and because the pilot project also enabled us to observe that PE in PS strategies were not well known at the three organizational levels by all PE in PS leaders. Thus, healthcare institutions should ask themselves if they put the effort to identify and collect information on PE in PS strategies within their organization? How do they ensure that these strategies are communicated throughout the organization? And how does the organization value these strategies?

The limits identified above reflect a balance between the application of rigorous methods and relevance to practitioner needs. In light of the considerable investment being made in PE for PS in HCOs around the world, this early step is critical for ensuring that this rapidly evolving field is supported by a strong foundation of evidence. As we continue to experiment with this tool, we expect it to be not only used by managers in PE and for PS, but also by teams that bring together PE/PS managers and patient advisors. Understanding how the tool is perceived by managers, patients and the public will contribute to its improvement over time. You can access the assessment tool here: (**APPENDIXE B1-** Questionnaire PE for PS -French version; **APPENDIXE B2-** Questionnaire PE for PS – Translated _ English version).

5.1.5. Conclusion

The fairly preliminary user testing and confirmation of the PE for PS tool face validity by experts gave birth to the development of a tool which has implications for practice and research. This tool which assesses for the first time PE strategies in patient safety supports decision-making by healthcare leaders and updates existing PE for PS modalities. There is no other such tool available at present to collect this type of information at the organizational or system level. The tool also offers an opportunity to allow managers in collaboration with patient's advisors in health care organizations to track PE changes in safety strategies over time by repeated assessments within the organization. PS/RM and PE Managers can use this tool to gain an important PE perspective on safety, capturing areas of weakness that might otherwise go unreported or unidentified. Furthermore, such a tool can be used to compare results and to develop standards or best practices for PE in safety improvement. Currently, as part of its "Global Patient Safety Challenge", the WHO encourages healthcare institutions around the world to "*reduce the level of severe, avoidable harm related to medications by 50% over the next five years"* [120]. Our tool could be adapted and adopted by healthcare institutions taking on the WHO's challenge, and could be integrated into international standards or even innovative practices of PE for safety. While the PE for PS assessment tool is currently in French (**APPENDIXE B1-** Questionnaire PE for PS - French version), an English version has been created by translating the French version (**APPENDIXE B2-** Questionnaire PE for PS – Translated _ English version).

Furthermore, an English adaptation will be soon available after a pilot project is completed in English-speaking provinces in Canada by Fall 2020 as well as a psychometric analysis of the tool. As evidenced by existing research, patient (and family) engagement offers a promising pathway towards better, safer healthcare, as well as improved population health.

Declarations

- **Ethics approval and consent to participate:** The research protocol was approved by the University of Montreal ethics committee and the *Centre de Recherche du Centre Hospitalier de l'Université de Montréal*: Approval number: MP-02-2017-6814 -- CÉR CHUM Number: 16.189. [30]

- **Consent for publication:** We received a signed consent form from all 5 duos participants who took part in our study, and who are also involved in ongoing research projects.

- **Availability of data and material:** All data generated or analyzed during this study are included in this article, and the end result is the assessment tool which is available in French. You can access the assessment tool here (**APPENDIXE B1-** Questionnaire PE for PS -French version; **APPENDIXE B2-** Questionnaire PE for PS – Translated _ English version)

- **Conflicts of interest:** None to declare

- **Funding:** No funding was provided

❖ **Authors' contributions:** Both of the first authors (UAG and MPP) were involved in building the tool. UAG performed data analysis, interpreted the literature review and carried out the interviews. MPP assisted with identifying themes and elements which were important to consider. MPP connected the team with experts in RM / safety and PE. UAG was responsible for writing the study protocol, assisted by MPP.

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❖ **Authors' information (optional):** Not applicable

5.2. ARTICLE 2

Title: Health Organization Strategies in Patient Engagement for Safety (HOSPES): Research Results from a Longitudinal Case Studies in Quebec

Article to be submitted to BMC-Health service research- Research article

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ABSTRACT

Background: Worldwide, four out of 10 patients are harmed while receiving health care in a hospital setting, of which 80 % could have been prevented (WHO, 2009; WHO, 2002; Slawomirski, 2017; WHO, 2019). Recent evidence demonstrates that 15 % of total hospital expenditure and activities in OECD countries is a direct result of adverse events, amounting to trillions of US dollars every year (Slawomirski, 2017). Therefore, it is no surprise that investing in the cost of prevention is much lower than the cost of care due to harm. Today, it is widely recognized that patient engagement (PE) can help improve outcomes and reduce the burden on health organizations.

The aim of this research study is to identify emerging PE mechanisms and strategies put in place by organizational leaders in leading healthcare institutions in the province of Québec (Canada), that would allow the institutionalization of PE in the health care system for patient safety (PS).

Methods: The project is a longitudinal descriptive research project by design. A questionnaire was created then dispatched to the 26 health centers (including 22 integrated one) followed by a second dispatch a year later (2017-2018). All personnel in charge of PE and risk management (RM) were contacted to complete the questionnaire in addition to a one-hour phone interview to understand participants reasoning of certain strategies and mechanisms.

Results: In total, 24 organizations participated and 43 HOSPES have been identified and discussed through the institutionalization process of knowledge acquisition, knowledge sharing, and knowledge preservation at the three levels of governance: clinical, organizational and strategic.

Conclusion: The research study is the first of its kind at a provincial level. Future work should focus on comparative studies between provinces, nations, and their evolution. There is currently an ongoing Pan-Canadian and a Brazilian research project based on the original research project from Quebec's. In addition, France, have also conducted this study to describe their PE for PS strategies. Furthermore, moving from a hospital setting, future research we should evolve into Citizen's engagement for safety, especially during these pandemic periods (e.g., Covid-19).

Keywords: Health organizations/institutions; risk management/patient safety; patient engagement; strategies/mechanisms

5.2.1. Background

Care and service delivery remain a focal point of our health systems, but just like good and evil, whenever care takes place, potential harm is never far away. Unfortunately, in healthcare settings, a substantial amount of harm still occurs, despite a huge %age being preventable [5].

Specifically, among countries in the Organisation of Economic Co-operation and Development (OECD), one in 10 patients are harmed while receiving hospital care [32, 34, 35, 36], with nearly 50 % of these harms considered preventable [38]. Worldwide, four out of 10 patients are harmed while receiving health care in a hospital setting, of which 80 % could have been prevented [38].

In Canada, deaths related to incidents occur every 13 minutes [53]. A new report called "Measuring Patient Harm in Canadian Hospitals" reveals that, in 2014–2015, harm was experienced by patients during one of every 18 hospital stays, or 138,000 hospitalizations. Of those, 30,000 (or one in five) involved more than one form of harm [54].

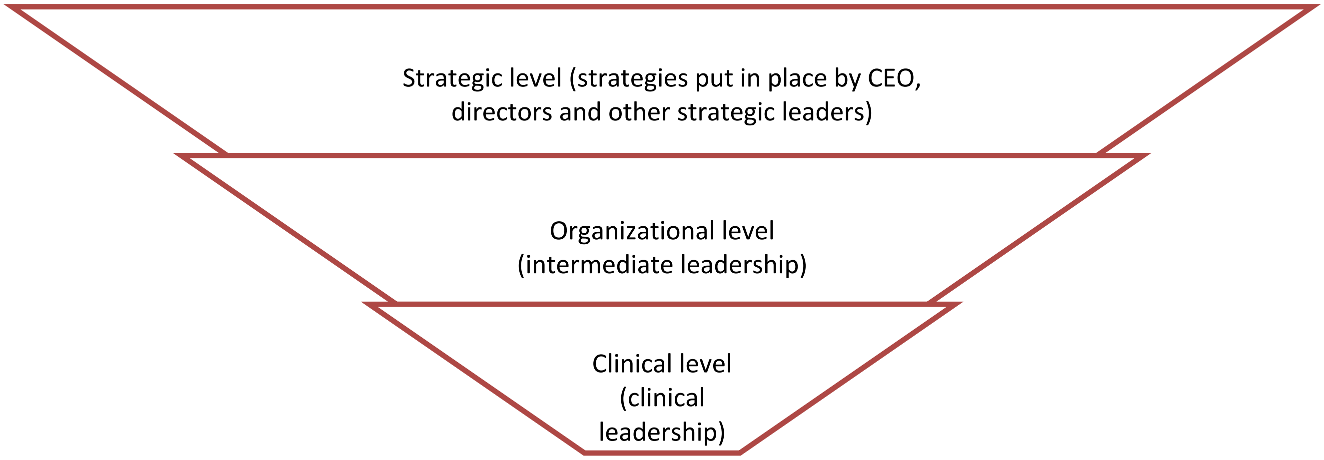
Moreover, incidents in both acute and home care settings can cost CA$6,800 per patient, resulting in additional costs of CA$2.75 billion each year [53]). Recent evidence demonstrates that 15 % of total hospital expenditure and activities in OECD countries is a direct result of adverse events. Estimates show that the total cost of harm in these countries alone amounts to trillions of US dollars every year [36]. One out of every seven Canadian dollars is spent treating the effects of patient harm in hospital care [56]. Therefore, it is no surprise that investing in the cost of prevention is much lower than the cost of care due to harm [36].

Today, it is widely recognized that patient engagement (PE) can help improve outcomes and reduce the burden on health services [9, 58, 2, 16, 59, 28, 22, 21, 20, 60]. Indeed, partnering with patients for the sake of their own health and care is known to be a key component for developing the highest quality of healthcare [6, 14, 20, 21, 22, 61]. This is why implementing PE strategies offers undeniable value to health care systems by helping them reduce by up to 15 % the burden of patient harm in hospital care, saving billions of dollars each year along the way [36].

Hence, it becomes increasingly essential for healthcare organisations to be able to assess their strategy and implementation status of PE within their organisations to gain a better understanding of their PE performance, specifically regarding risk management (RM) in patient safety (PS).

In Canada, and around the world, patient engagement (PE) has become a key strategy to ensure the quality of care and patient safety (PS). Nowadays, the unique perspective brought by patients can help prevent or reduce risks missed by healthcare professionals (HCPs) due to blind spots. As such, patients can be considered as key players in PS and prevention and be involved at various level of the care process.

Figure 2: Key levels inside a healthcare institution



To see the big picture, it is worth noting that PE in PS and risk management (RM) can occur at **three different key levels** of healthcare institutions (Figure 1): (1) the clinical level, (2) the organizational level and (3) the strategic level [7, 8, 30, 92, 91] (see APPENDIX A - Conceptual Framework PE for PS for more information on strategies at these three different levels. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**). Within the three key levels (Figure

1), PE can manifest in several formats: an information continuum, consultation, collaboration, partnerships or a co-design leadership continuum [80].

Figure 3: Formats of patient engagement [6]

1- INFORMATION **2- CONSULTATION** **3- COLLABORATION / COOPERATION** **4- CO-DESIGN**

Karazivan P, Dumez V, Flora L, Pomey M-P, Del Grande C, Ghadiri D. P, Lebel P, «The Patient advisor approach in health care: a conceptual framework for a necessary transition. » Acad Med, pp. p. 437-41., 2015. 90(4).

As an **information continuum**, patients can be informed and educated about their own health, while as a **consultation,** HCPs can consult patients about their experiences and potential health risks [7, 30]**.** In other PE formats, patients could be used for HCP training, or as "patient coaches" for patients in living with a common disease [30]. The **collaboration/cooperation format** – for example, in the care and services design continuum – places patients as advisors on continuous quality improvement committees, as contributors to Lean Six-Sigma processes, in developing best practice guides, or drafting documentation for patients [9, 14, 6, 15]. Lastly, the **partnership/leadership co-design format** enables the participation of patients in governing boards, committees, policy making, etc. [7, 30].

5.2.1.1. Patient Engagement in Risk Management for Patient Safety in Quebec

In 2014, the Government of Québec decided to completely overhaul the organization of its health network, namely through the creation of new integrated structures. This is how integrated university and non-university health and social services centers – known as *Centres intégrés de santé et de services sociaux* (CISSS) and *Centres intégrés universitaires de santé et de services sociaux* (CIUSSS) – came to life as a result of merging hospital centers, long-term care centers (CHSLDs), local community health centers

(CLSCs) and social services centers. The stated goal was to "facilitate and simplify access to services for the population, contribute to improving the quality and safety of care and the efficiency and effectiveness of the integrated health network" [67, 68].

A new bill, Bill 10, also strengthened risk management (RM) mechanisms within these massive centers through the creation of Departments of Quality, Evaluation, Performance and Ethics (DQEPE). One of the mandates of these new departments is to implement “integrated risk management and care and services partnerships with patients” in order to help health centers: (1) achieve objectives by aligning actions with organizational objectives; (2) constantly improve accessibility and effectiveness; (3) ensure the quality and safety of care and services offered to patients [67, 68]. In addition, the Quebec Health Ministry (*Ministère de la Santé et des Services sociaux* (MSSS)) provided the DQEPEs with sufficient leeway to develop strategies for integrated RM, set up teams and committees, as well as establish measures and tools for assessing efficiency and knowledge transfer [67, 68].

Shortly after Bill 10, the government released the 2015- 2020 Quebec National Strategic Plan which mentioned, for the first time, the importance of patient engagement (PE) as part of its basic principles for “good health outcomes”, patient safety (PS) and quality improvement [67, 68]. Three years into the strategic plan, in 2018, a Reference Framework for the Partnership Approach between Patients, Their Families and Health and Social Service Actors [79] was published, calling for citizens to support healthcare leaders and institutions implementing new PE structures and initiatives in quality improvement projects (including PS).

In other words, DQEPEs were given the mission to foster synergy in the areas of quality, RM and patient partnership with the aim of enhancing the comprehensive notion of organizational performance. Healthcare leaders and institutions started restructuring their bodies in order to invite patients, known as resources or partners, to sit down, participate and design health service pathways, practices, processes and policies.

However, despite existing PE initiatives, significant strides and intentions in Quebec's healthcare system and worldwide [32], RM is still dealt within silos, while ignoring connections and interdependencies [33, 30]. Health centers still struggle to obtain a general portrait of PE for PS across the entire organisation, which is why this research project, as a Quebec case study, seeks to identify strategies that would allow for its overall assessment and implementation.

5.2.2. Objective

The aim of this research study is to identify essential patient engagement (PE) mechanisms and strategies put in place by organizational leaders in leading healthcare institutions located in the province of Québec (Canada) that would allow this engagement to be fully institutionalized in the health care system for the enhancement of patient safety (PS).

Thus, the specific objectives stemming from this are as follows:

1. What are the strategies/mechanisms put in place by leaders in the Integrated Health and Social Service Centers (free translation of *Centre intégré de santé et services sociaux* or CISSS) or in the Integrated University Health and Social Service Centers (free translation of *Centre intégré universitaire de santé et services sociaux* or CIUSSS) to institutionalize PE for PS?

c. How did those PE strategies/mechanisms change overtime?

d. What are the factors that enhance or inhibit the institutionalization of PE strategies/mechanisms for patient safety in the Integrated Health and Social Service Centers and the Integrated University Health and Social Service Centers (free translation of *Centre intégré universitaire de santé et services sociaux* or CIUSSS)?

The next sections of the article show the methodology behind the tool (a questionnaire) that was developed, then used, to assess PE strategies in this case study. After presenting research results and discussion points, the article concludes by showing how this case study is already being used in similar studies outside of Quebec and suggests how it could be deployed at a global scale.

5.2.3. Methodology

5.2.3.1. Selecting the Research Design and Strategy

The project is a longitudinal descriptive research project by design. To address the above-described specific objectives, a special questionnaire was created (see Chapter 3, Article 1) then dispatched to the CHUM, the MUHC, and all CISSS and CIUSSS in Quebec (N= 24) a year after implementation of Bill 10 (2016-2017), followed by a second dispatch a year later (2017-2018). Two different times (T1 and T2) were used because T1 represented the time after the integration of Bill 10. And T2 represented the adoption of the Reference Framework on PE created by the Minster of Health of the province of Quebec in 2018, to be integrated and adopted by the CISSS and CIUSSS's [79]. All personnel in charge of PE and risk management (RM) were contacted, first by email (in order to send the questionnaire) and then via telephone to index all implemented PE strategies in the questionnaire.

The framework used to create the questionnaire (see Appendix A - Conceptual Framework PE for PS. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**), was based on the **Institutional Theory** revealing the importance of leadership roles and the three levels in which those leaders can act: (1) clinical level, (2) organizational level, and (3) strategic level. Additionally, Institutional Theory posits a concept of institutionalisation which enables the integration and appropriation of new knowledge (knowledge acquisition, knowledge sharing, and knowledge preservation), innovation or concepts inside an organisation by its employees, patients, and leaders.

Moreover, our literature review of PE for PS exposed that PE can be first analysed within a set of implemented norms and rules which enable its emergence and evolution. Secondly, PE can be considered as a continuum along which four types of patient and family engagement can take place, ranging from low-level engagement to a high-level engagement: (1) informing, (2) consulting, (3) collaborating and (4) co-creating. Thirdly, these four forms of engagement can occur in three different levels: (1) clinical, (2) organizational, and (3) strategic [21, 30, 28, 91].

At a clinical level, patients can be informed, educated or consulted about their experience, potential health risks or use of healthcare services [21, 30, 28, 91]. At an organizational and strategic level, a simple collaboration can be established whereby patients can become members of various committees and task groups, such as RM or mortality and morbidity committees, task groups to analyze and assess incidents and accidents, or for overseeing incident and accident disclosure and reporting [21, 30, 28, 91, 20, 25, 90]. At the policy level, patients can be consulted to develop various activities that can drive change in organizational culture, such as aligning incentives and penalties to support patient and family engagement. Finally, in order to remain sustainable and transparent over time, co-design and co-creation among patients, professionals/managers and policy makers can go a long way, particularly when considering educational programs or new clinical pathways to increase PS [21, 30, 28, 91, 20, 25, 90]. At all levels of the healthcare system.

5.2.3.2. Cases selection

After Bill 10, the province of Quebec counted 22 integrated health centers: 13 CISSS and nine CIUSSS, all of which were selected to participate in the research project. In addition to those 22, two major teaching healthcare networks institutions (non-integrated) affiliated to a French-speaking university or an English-speaking university (the CHUM and MUHC) were added to the sample, not only due to their leading roles and affiliations to top French and English universities respectively, but also to their advancement in PE and in quality improvements activities for PS. Hence, a total of 24 health centers in Quebec were included in the study's sample.

The research agent addressed a consent letter to DQEPE Directors of each center in order to brief them about the project's objectives and solicit their participation via email (APPENDIX B - Consent letter Part 1 research project PE for PS). The following week, the agent followed up by phone to set appointments and confirm participation and willingness to answer a questionnaire (APPENDIX C1 - Questionnaire PE for PS -French version) over the telephone.

5.2.3.3. Sampling individuals

After sampling the participating health centers, the team determined which individuals, from within those centers, would be the most appropriate to answer the questionnaire. Thanks to the highly specific nature of the study's area of research, the team decided to pursue directors, head of services, middle managers or person in charge of risk management and patient engagement in each selected health center. Again, even though job titles may vary, the specific nature of that role made sampling techniques redundant in terms weeding out participants. Ultimately, the team ended up interviewing middle managers in charge of risk management and/or patient engagement, DQEPE directors, and clinico-administrative managers when certain specific questions from the questionnaire could not be directly answered by DQEPE Directors.

As a result, the research agent made 24 phone calls to answer a total of 24 questionnaires from all 22 integrated health centers of Quebec (13 CISSS, 9 CIUSSS), the CHUM, and the MUHC. Participants were questioned in November 2016, and one year later in order to describe the evolution of their PE strategies in RM (T1: November 2016 – December 2017; and T2: November 2017 – December 2018), enabling the team to reach its 100 % target sample of health centers in Quebec, allowing for better generalization of study findings.

5.2.3.4. Data collection and collection instrument

The data collection tool used for this study was a questionnaire which the student researcher and the research director developed as a pilot project (Appendix C1 - Questionnaire PE for PS -French version) (see Chapter 3, Article 1 of the thesis results for more information). They adapted the questionnaire based on existing questionnaires and literature geared towards managers with regards to patient engagement and, more specifically, patient safety in risk management.

Questionnaires were first sent in September 2016 by email to each of DQEPE Director in all the healthcare centers (CISSS/CIUSSS, CHUM, and MUHC). A week later, the research agent follow-up calls to organize a one-hour phone interview during which she went over all questions in the questionnaire to ensure that they were all answered or to complete certain answers.

5.2.3.5. The quality of the questionnaire

Since patient engagement (PE) strategies had already been pre-identified through the literature review and that the questionnaire was adapted from existing questionnaires (see Chapter 3, Article 1 of the thesis results for more information), the questionnaire's construct validity was ensured (Creswell, 2003). To guarantee the questionnaire's reliability, the team designed questions to investigate strategies used at different levels of PE (micro level, meso level, and macro level) based on literature review. As for validity (the ability to generalize the studied phenomenon), the 100% target sampling of risk managers and PE officers considerably minimises that risk. In addition to the questionnaire been analyzed and discussed by the student researcher and the research director, the questionnaire was also piloted before it was sent to the different sites.

5.2.3.6. Data analysis

The research team analyzed data using Microsoft Excel and QDA Miner. Data was first compiled in an Excel sheet, indicating the different heath centers and respective strategies according to the three levels of governance (clinical level, organizational level, and strategic level) before identifying various implemented strategies at these levels. Additional qualitative data collected over the telephone, which completed the data collection and analysis by specifying why certain patient engagement strategies were implemented or not. This qualitative data analysis was done using QDA miner. The questionnaire's results have been analyzed and discussed by the student researcher and the research director to ensure the quality and alignment of the findings with the conceptual model developed in the thesis.

5.2.3.7. Ethics

The *Université de Montréal* Ethics Committee and the Research Center of the CHUM (CRCHUM) approved the research protocol as a multicentric research project, under approval number: MP-02-2017-6814 -- CÉR CHUM Number: 16.189 (APPENDIX D - CRCHUM research protocol approval letter - MP-02-2017-6814 -- CÉR CHUM Number: 16.189).

Study participants were informed prior to partaking in the study and signed a consent form (APPENDIX B - Consent letter Part 1 research project PE for PS), preserving anonymity and confidentiality of data. Participants were free to withdraw at any time from the study if under any constraints. The research team followed appropriate procedures to secure the confidentiality of research data.

5.2.3.8. Timeline

The longitudinal research study lasted two years and a half on the field: From September 2016 to December 2018.

5.2.4. Results and analysis of the questionnaire

This section presents the results and the analysis of the questionnaire as well as the qualitative data collected during the semi-structured interviews.

5.2.4.1. Results

5.2.4.1.1. Participating institutions and respondents

Table 7 provides a detailed look into the questionnaire's results which reflect the current patient engagement (PE) structures and implemented strategies in Quebec's 22 Integrated Health Centers (CISSS, CIUSSS), the CHUM and the MUHC. Results are presented according to the structure of the questionnaire.

Table 7: Section 0_ Description of participating institutions and individual participants

	T1	**T2**
GENERAL DATA ABOUT THE QUESTIONNAIRE		
Collection dates	From Mai 2017 until December 2017	From March 2018 until December 2018
Frequency	22	22
%	100%	100%
Total questionnaires answered	22	22
DESCRIPTION OF THE PARTICIPATING INSTITUTIONS* (PLEASE REFER TO APPENDIX F FOR A DESCRIPTION OF THE INSTITUTIONS)		
Number of solicited organizations	24	24
Number of participating organizations	22	22
# participating CIUSSS	9	9
# participating CISSS	11	11
Others: (major teaching healthcare networks institutions affiliated to a French-speaking university or an English-speaking university)	2	2
Does the institution make reference to user engagement? (see APPENDIX G for detail information on the type of documents mentioning PE)	**N (%)**	**N (%)**
In strategic plan + other documents	13 (45.5%)	19 (86.4%)
In other documents only	9 (40.9%)	2 (9.1%)
No mention of PE at all	3 (13.6%)	1 (4.5%)
DESCRIPTION OF THE INDIVIDUAL PARTICIPANTS		
# of individual participants in total	49	38
Average of participants per institutions	2	2
Minimum	1	1
Maximum	4	4
Median	2	2
Number of patient's resources participating in the research project	1	**0**
Job title of the participants (see APPENDIX H - Description of participating institutions and individual participants, for more details on the job titles of the participants	49 answered	38 answered
Upper management	15	15
Upper and middle Management	11	8
Healthcare Professional: APPR or executive advisor in quality and safety	18	13
Others = (patient safety officer, ethical advisor, program evaluator, patient partner)	5	3
Departments in which participants work	49 answered	38 answered
DQEPE	44	34
DSM	4	2
Direction of multidisciplinary services, quality, evaluation, performance and ethic	1	1
DSP	0	1
Date the participants were hired	37 answered	33 answered
2011-2014	6 (16%)	5 (15%)
2015	17 (46%)	15 (45.5%)
2016	8 (21.7%)	8 (24.2%)
2017	6 (16.3%)	2 (6.1%)
2018	0	3 (9.2%)
In the past month, how much time, on average, did you spend on patient engagement?	49 answered	38 answered
More than 50% of your time	16 (32.6%)	12 (31.6%)

Less than 50% of your time	33 (67.4%)	26 (68.4%)
In the past month, how much time, on average, have you spent on risk management?	49 answered	38 answered
More than 50% of your time	24 (49%)	21 (55.3%)
Less than 50% of your time	25 (51%)	17 (44.7%)
How long have you been working in the health care system?	35 answered	28 answered
Less than 5 years	6 (17%)	4 (14.3%)
Less than 10 years	4 (11.4%)	5 (18%)
Less than 20 years	8 (23%)	4 (14.2%)
Between 20-30 years	12 (34.2%)	9 (32%)
Between 31-35 years	4 (11.4%)	5 (18%)
More than 35 years	1 (3%)	1 (3.5%)
SECTION 4- OTHER GENERAL QUESTIONS ABOUT THE INSTITUTION'S PARTICIPATION IN PE AND IN RISK MANAGEMENT STRUCTURES		
Participation of institutions in structures related to user engagement?		
For T1 and T2 alike, 85% of the participants have participated in structures related to patient engagement. 15% have not.		
Committees related to risk management in which the institution has participated in (* T1 and T2 responses are combined for this question because the answers are alike.)		
100% of the institutions participated in "Risk management Committees" and in Vigilance and quality committees"		
68% of the institutions participate in Infection Prevention and Control Committee		
58% of the institutions participate in Committee on the Appropriate Use of Drugs		
28% of the institutions participate in Committee on Medical Devices		
16% of the institutions participate in Control measures and prevention of falls		
9% of the institutions participate in Prevention and suicides as well as Restraint committees		
7% of the institutions participate in Continuous improvement committee and Information Security Committee		
4.6% of the institutions participate in Audit Committee, Preventive Withdrawal Program, obstetrics' Team, Abuse 4.6%, White Code[19], Committee (Behavioural Emergencies)		
2% of the institutions participate in Committee on Pain Control; Committee for safety in continuing assistance resources, Run away committee, Regional food committee, Code blue (cardiac arrest), Evaluation committee of the board of directors (by invitation), Health and safety		
To note that, only 40% of the institutions have Integrated Risk Management Committees. And 60% have the conventional Risk Management Committee dealing with healthcare risks.		
Overall, how would you rate the safety of care and services in your facility?		
For T1 and T2 alike, 70% of the participants score their appreciation of safety in their institutions "very good"; 20% rated it "acceptable"; 5% rated it "excellent", and 5% rated it "weak".		

5.2.4.1.2. Section 1_Governing structure of Patient engagement/Patient experience/Risk management

Table 8 explains the PE, patient experience and risk management governing structures in participating healthcare institutions, as well as collaboration mechanisms between different departments.

It is also worth noting that two questions were eliminated from this study: (question 4) “Which departments have patient engagement projects and how many projects are being carried out in each of these services (specify the number of projects per department)?” and (question 7) “Which service(s) uses patient experience questionnaires?”. For both questions, too many institutions were not in a position to answer due to a lack of an overall portrait of ongoing projects on PE in PS.

Table 8: Section 1_Governing structure of Patient engagement/Patient experience/Risk management

Questions	**PE structure**		**User Experience structure**		**Risk management structure**	
	T1	**T2**	**T1**	**T2**	**T1**	**T2**
Which directorate(s) is/are responsible for supporting the implementation of PE / PExp or RM in care and services? (number of institutions)						
DQEPE (including DSM, quality, evaluation, performance and ethic directorate)	11	16[20]	18	18	22	22
DQEPE + other clinical directorates (multiplying agents in DSM, DSI, DSP, long-term-care)	6	2	1	1		
DQEPE + other type of collaborations (PP's office + PH + DSI/ User's experience office[21]	2	2	2	2		
DQEPE in collaboration with Population and partnership assistant directorate / and DQEPE + PH	1	1	1	1		
DSM (in collaboration with PP office and PP coordinating committee)	2	1				
Questionnaire done by the institution internally or by an external agency (T1 and T2 combined since the results were alike)						
Internal			85%	85%		
External			15%	15%		
Frequency of use of the questionnaire: (T1 and T2 combined since the results were alike)						
Ongoing			70.6%	70.6%		
More than one time per year			17.7%	17.7%		
Once a year			11.7%	11.7%		
Identification of people, who at management level, contributes to the deployment of PE / PExp?						
Initial training (including graduate degree in *QEOPSI[22] (n=2))						
Nurse*	13		10			
Social worker	7		6			
Communication	6		3			
Bioethics and ethics*	4		2			
Others[23]	24		9			
Date hired (year)	N =32	N = 28	N=18	N=25		
2010-2014	5	3	4	4		
2015-2016	23	17	11	13		
2017	4	2	3	4		
2018	0	6	0	4		
% of time spent on PE / PExp or / Risk management in care and services	N= 27	N= 29	N=21	N=25		
100%	3	3	1	5		
70-90%	3	1	2	3		
50-69%	6	6	2	4		
20-49%	7	16	7	9		

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[20] One institution with: DQEPE + respondent quality in every department (multiplying agent)

[21] Which comprises 1 user's committee + 1 PP committee. $ chief of services, one of them been the chief of the volunteer's office

[22] *QEOPSI : Master's in quality and PS

[23] Others: Sociology, Psychoeducation, Psychology, Physiotherapy, Nutritionist, Anthropology, Criminologist, sociologist, archivist, Political science, Law, Program evaluation, Public health, Occupational therapist, Care experience and clinical sciences, Medical technologist, Physical activity education, Administration

10-20%		1	8	3		
0-9%	8	2	1	1		
Number of people, who at management level contributes to the deployment of PE / PExp?	# institution		# institution			
9 or more people: DQEPE + Patient experience office + PP committee	1[24]			1[25]		
5 or 6 people	1[26]	2[27]				
4 people	3[28]	1	1	1[29]		
2 and sometimes 3[30] people	2	2				
3 people (mostly executive advisors)	3	4	1	4		
2 people[31]	3	4	4	4		
1 person	2[32]	5	7[33]	6[34]		
User engagement training (yes, no)? (See APPENDIX I for more details on the type of training)	N (%)	N (%)				
Yes	28 (57%)	27 (70%)				
No	20 (41%)	11(30%)				
Don't know	1 (2%)					
Is there collaboration between directorates to improve user engagement to enhance risk management?						
Yes					16 (73%)	17 (77.3%)
No (Several transfers of managers since the creation of the CISSS; Or the PE approach is not developed)					4 (18%)	3 (13.7%)
Other (volunteer's office, DSI, DSP, PH, DSM, complaint department, etc.)					2 (9%)	2 (9%)
Are there coordination mechanisms (bodies, procedures, situation analysis, etc.) between user involvement, risk management and the Patients' committee?						
Yes					18 (82%)	20 (91%)
No					3 (13.5%)	1 (9%)
Other					1 (4.5%)	0

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[24] We have a Care and Service Partnership Office and a Care and Service Partnership Coordinating Committee with one representative from each of the directorates

[25] We are 9 people: 1 Deputy Assistant Director for vision, 1 Technical support for the database, 2 Consultants and 4 administrative officer who send the survey)

[26] One executive counsellor and 4 professionals working with her (APPR)

[27] When a project is submitted, the person is then identified to follow the PP. We have a committee in which, we have 6 people from each direction that gravitates around the PP. The HCP who is identified follows the and supports him/her in the committee.

[28] One chief of Department and 3 HCPs (DQEPE)

[29] Including Multiplying agents in clinical departments

[30] This is the PP office, (we help support the deployment of user engagement. We're not going to deploy but we're going to create tools, training, etc.). The DQEPE deploys the PE approach

[31] One department Head, and one HCP. Only one institution has multiplying agents (at T1 and T2 for PE structures), and Interdisciplinary teams are involved: PS, DSM, DSI, long term care.

[32] One institution: Mainly carried by the Patient Partnership Program Coordinator (DQEPE). But, all the management (N=52), is responsible for PE institutionalization.

[33] One HCP + (collaboration with Patient Committee or PP's office in two institutions)

[34] One HCP + (collaboration with Patient Committee or PP's office in two institutions)

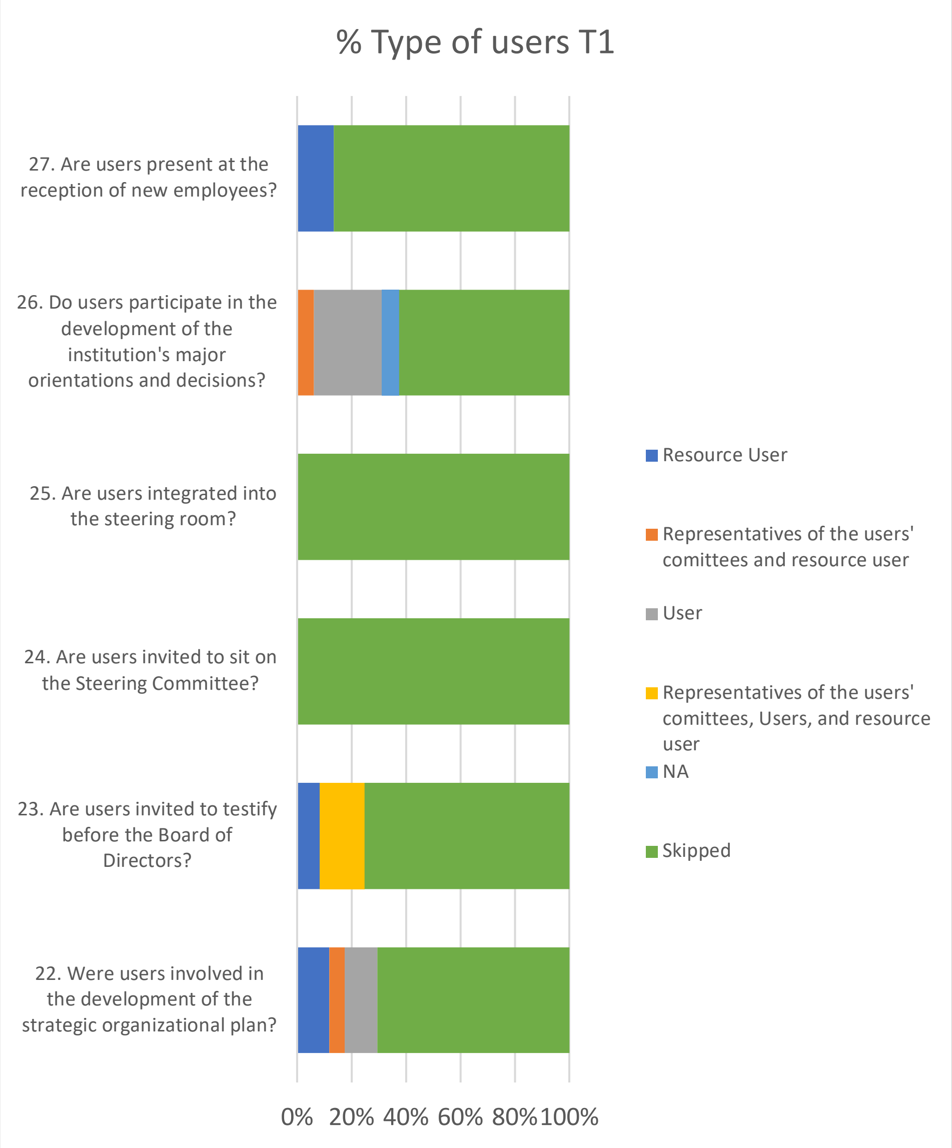
5.2.4.1.3. Section 2: questions related to patient engagement (in general)

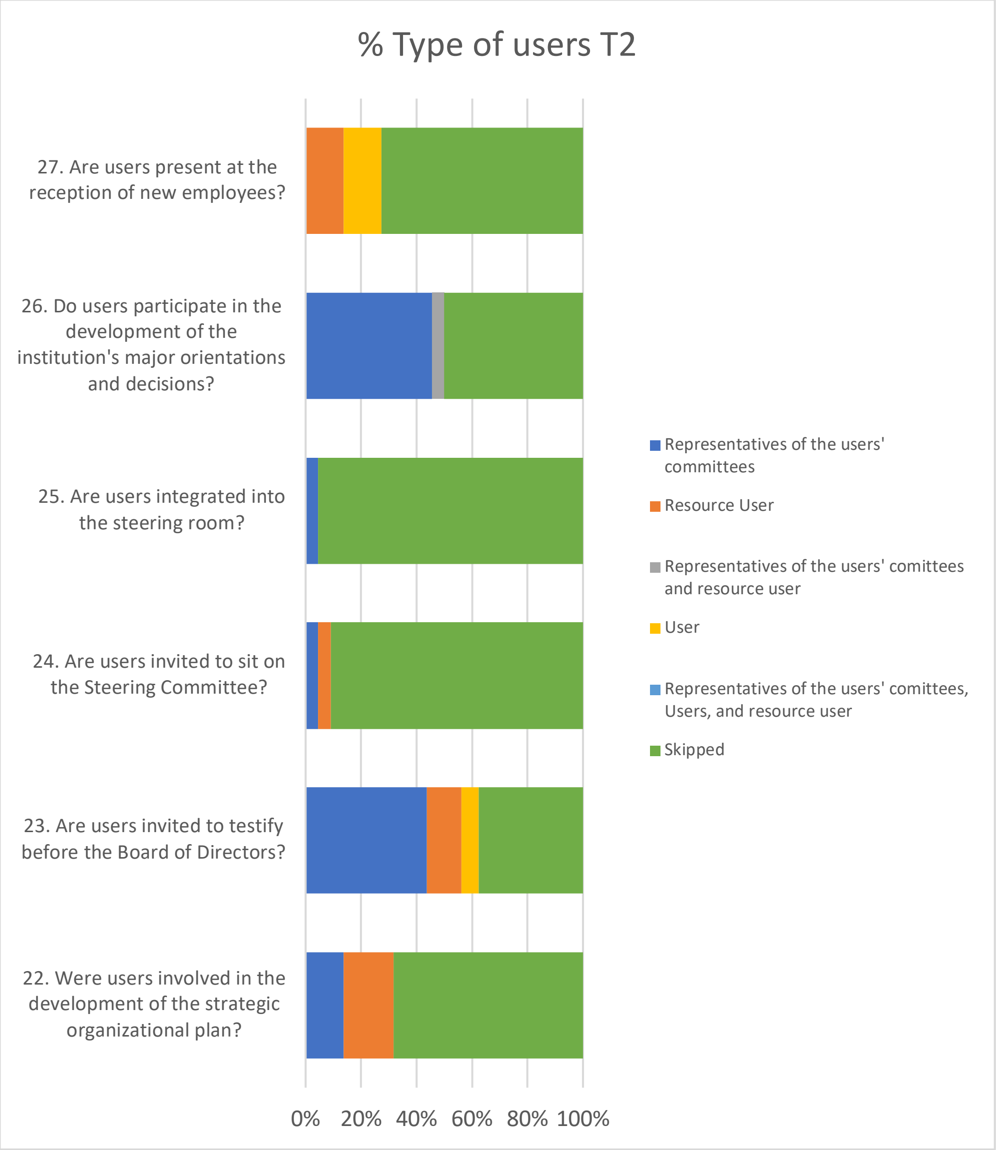
Table 9 explains the evolution of various PE general areas (and not specific to PS) in which patients could be involved in healthcare institutions in Quebec, using a scale ranging from “Never”, “Sometimes”, “Always”, “in Progress”, “NA-Non-applicable”, or “Skip” (if the respondent did not know the answer). The following topics will be covered in this section: patient engagement strategy or policy (question 15); patient recruitment tools (questions 16 to 18); PE awareness tools (questions 19 to 21); patient involvement in strategy and decision making (questions 22 to 27); and senior leadership involvement (questions 28, 29, 30 and 31).

Table 9: Section 2: questions related to patient engagement (in general)

Section 2 _Questions related to patient engagement (in general)

Section 2 _Type of patients



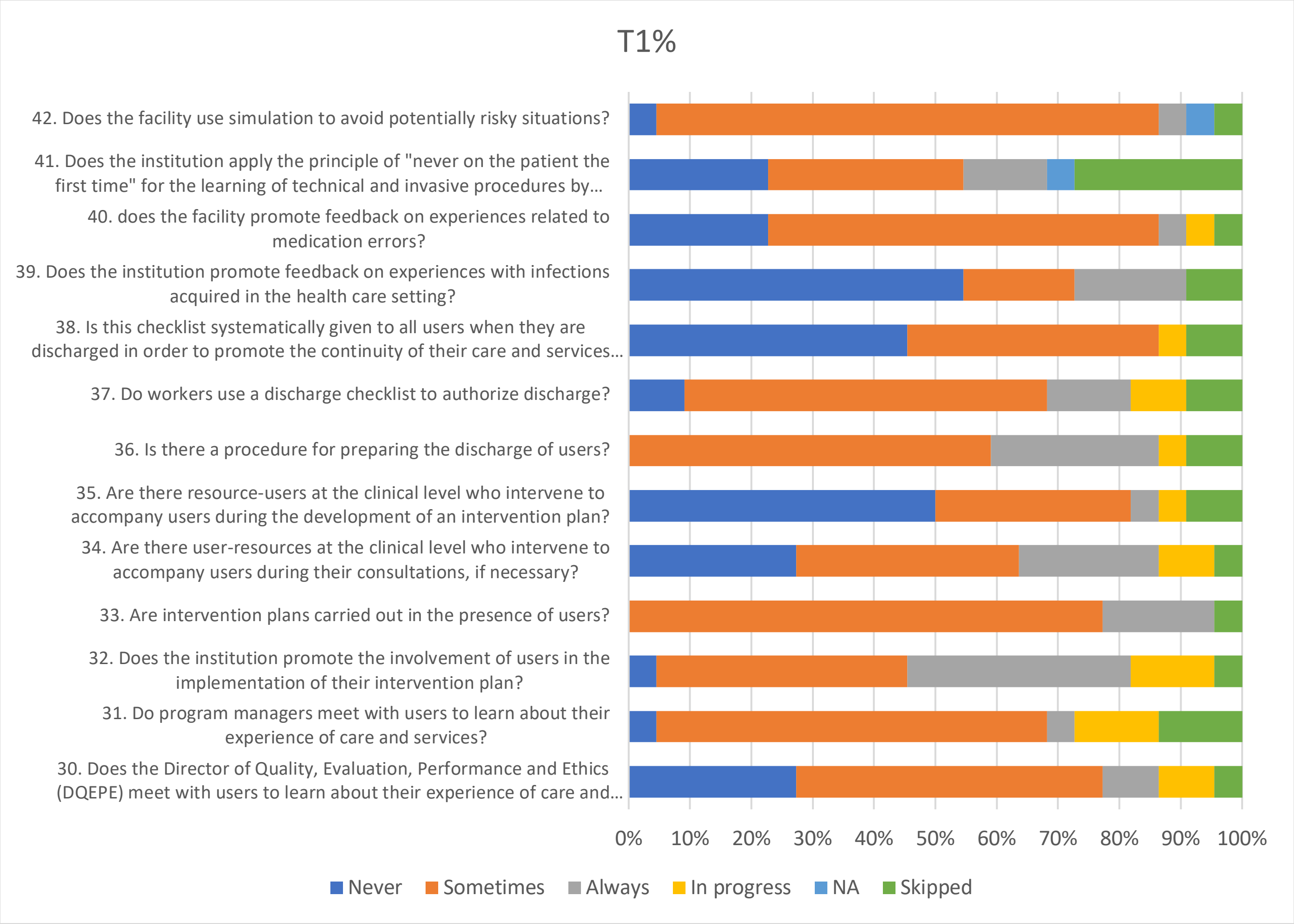


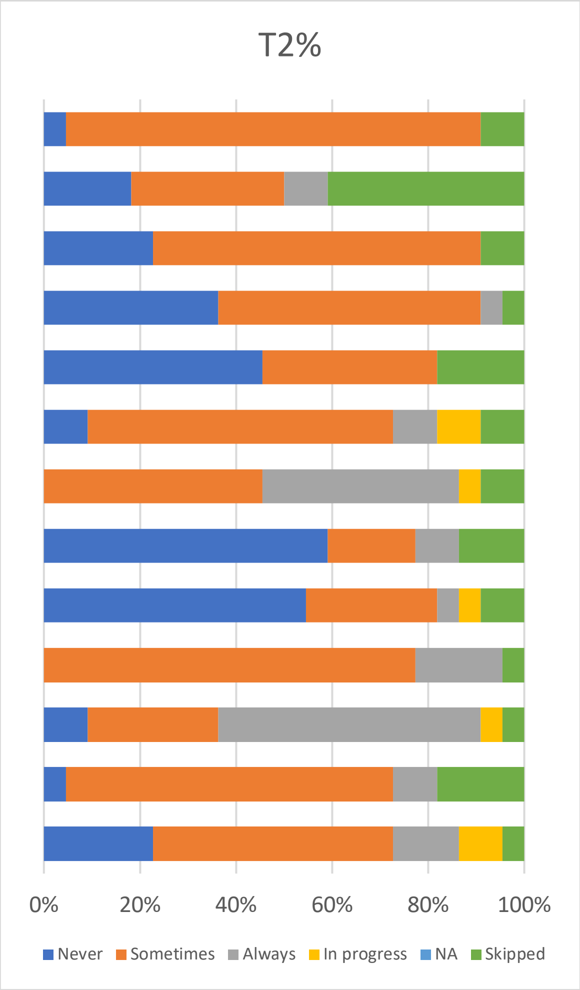
5.2.4.1.4. Section 3. Questions related to PE for safety

In a similar fashion to Table 9, Table 10 (below) explores how institutions address patient engagement for safety through five areas: risk management (questions 30-42); safety policies, strategies and mechanisms (questions 43-52); training (questions 53-60), involvement in committees (questions 61-66), in Family medicine groups (FMG) (questions 67-75), and indicators (questions76-78).

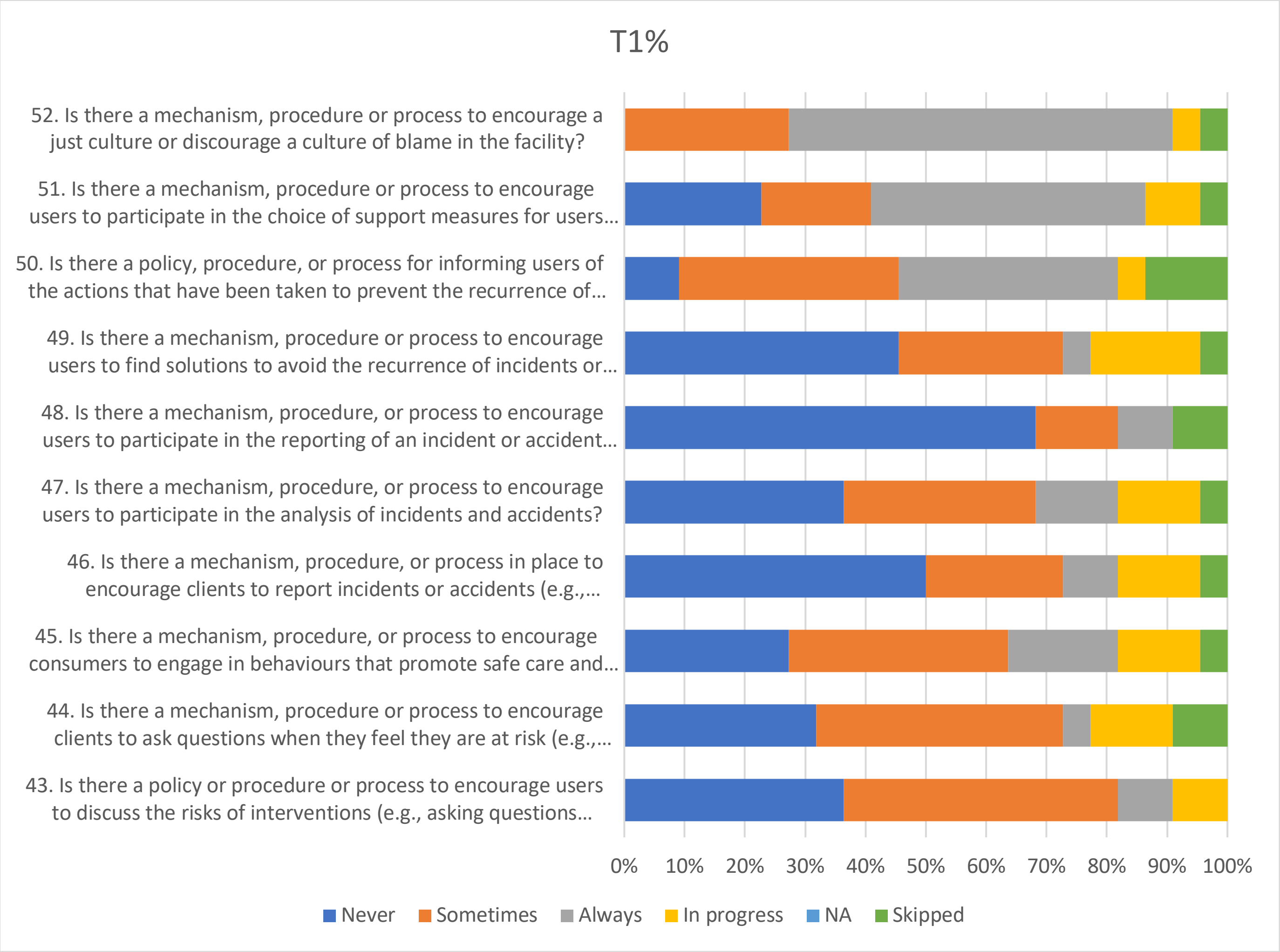
Table 10: Section 3. Questions related to PE for safety

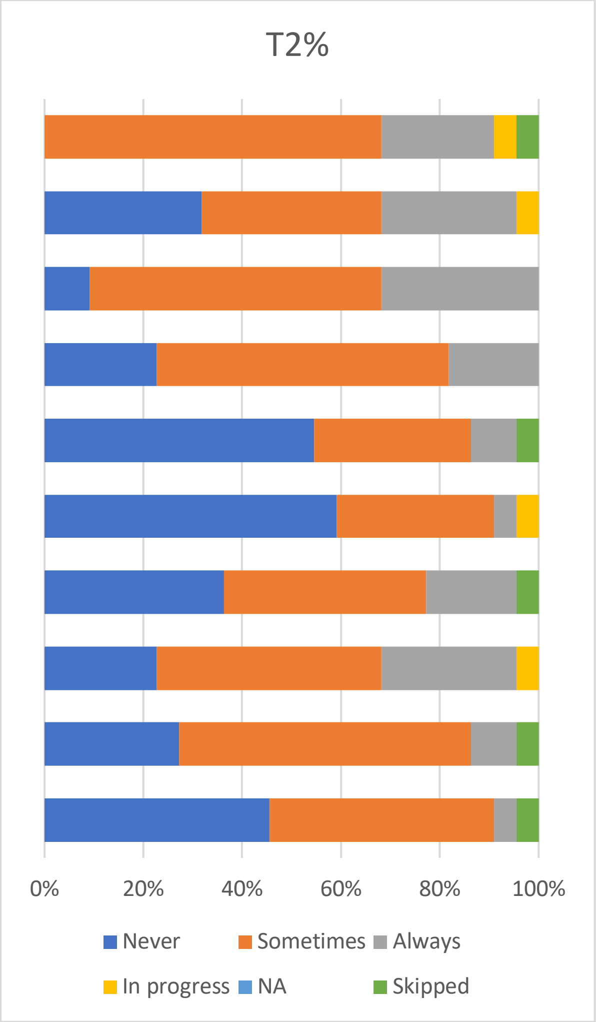
Section 3: Related to risk management

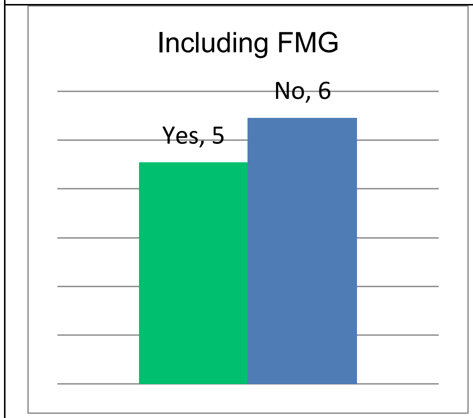
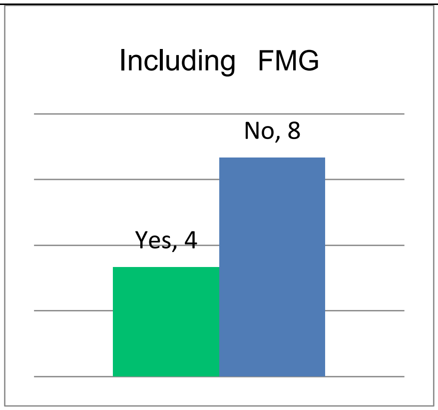
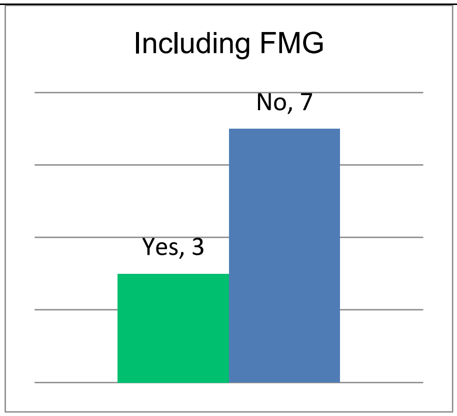
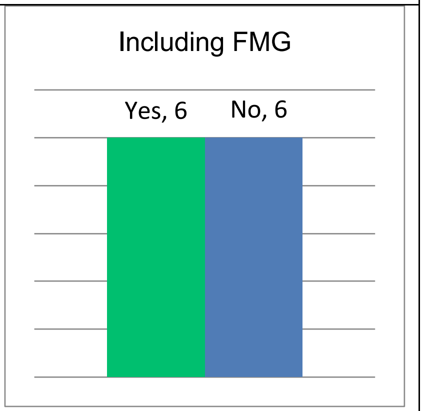




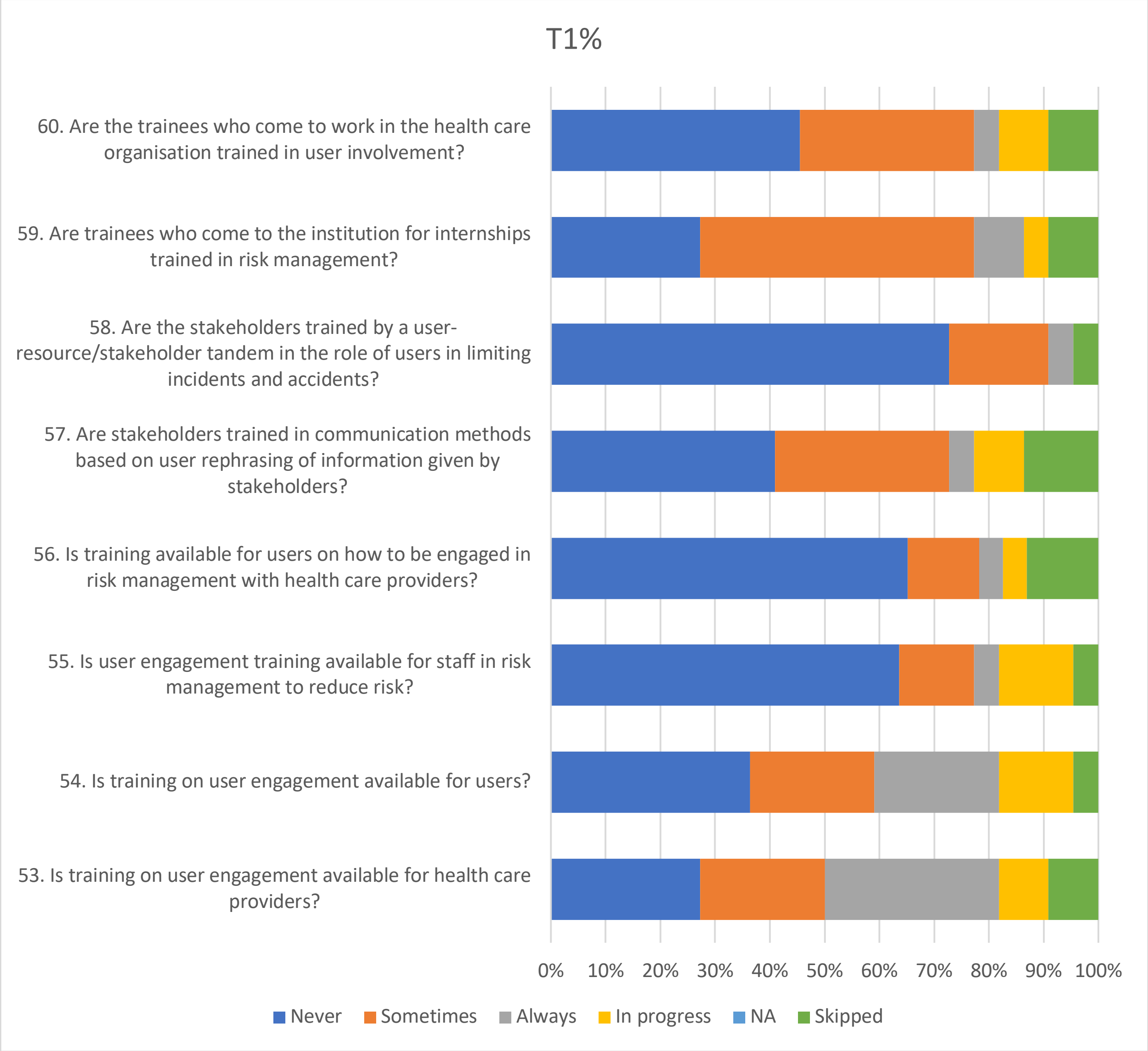
Related to the institutions’ patient safety policy and mechanisms

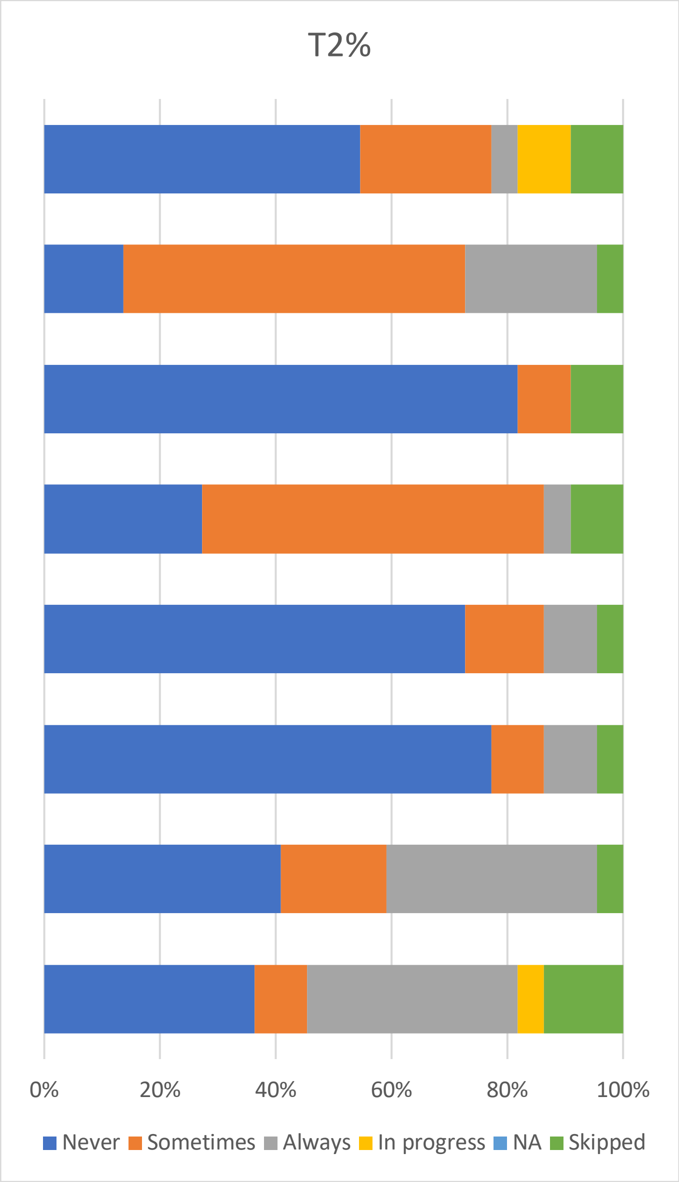




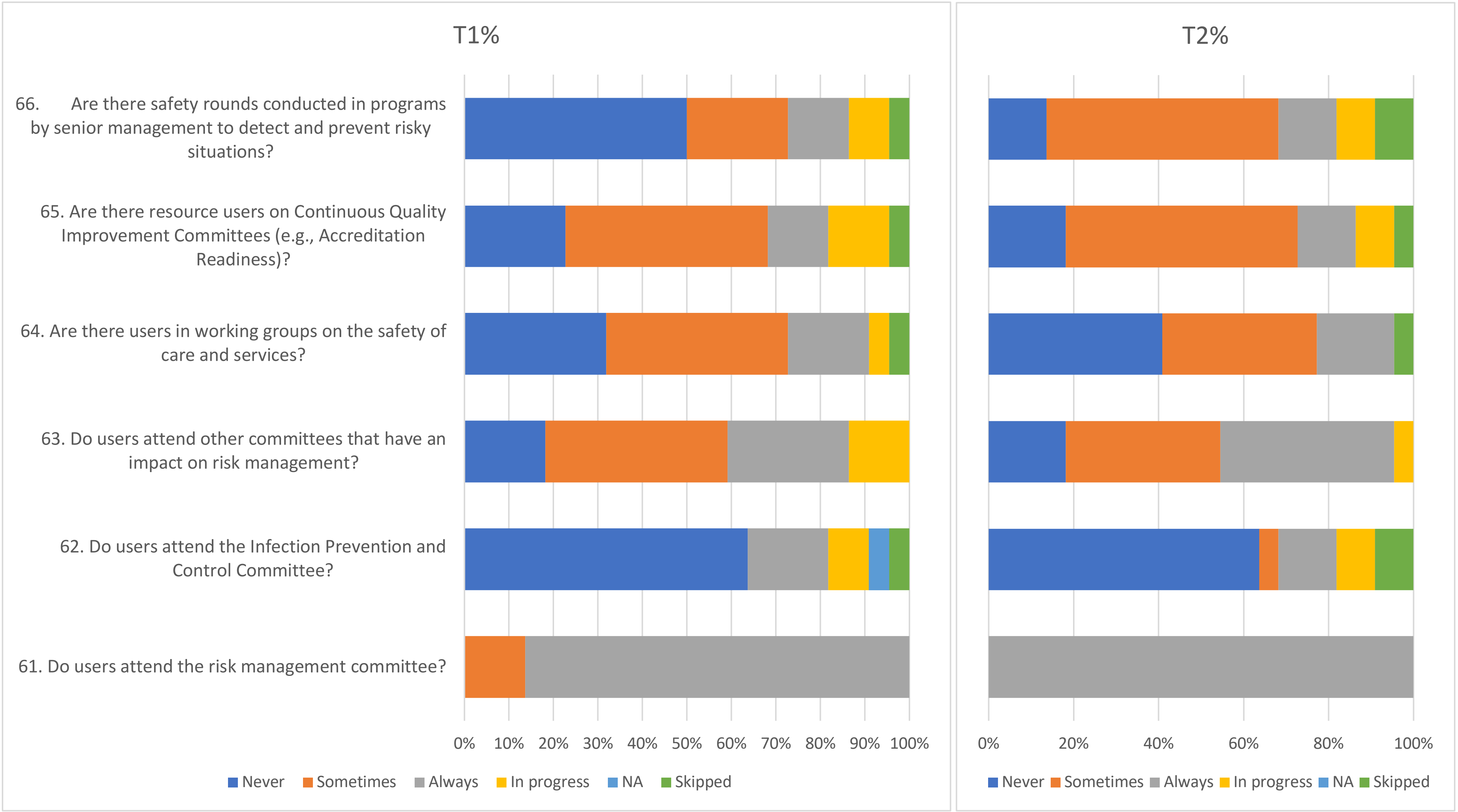
#46	#47	#49	#50
 Including FMG Yes, 5 No, 6	 Including FMG Yes, 4 No, 8	 Including FMG Yes, 3 No, 7	 Including FMG Yes, 6 No, 6

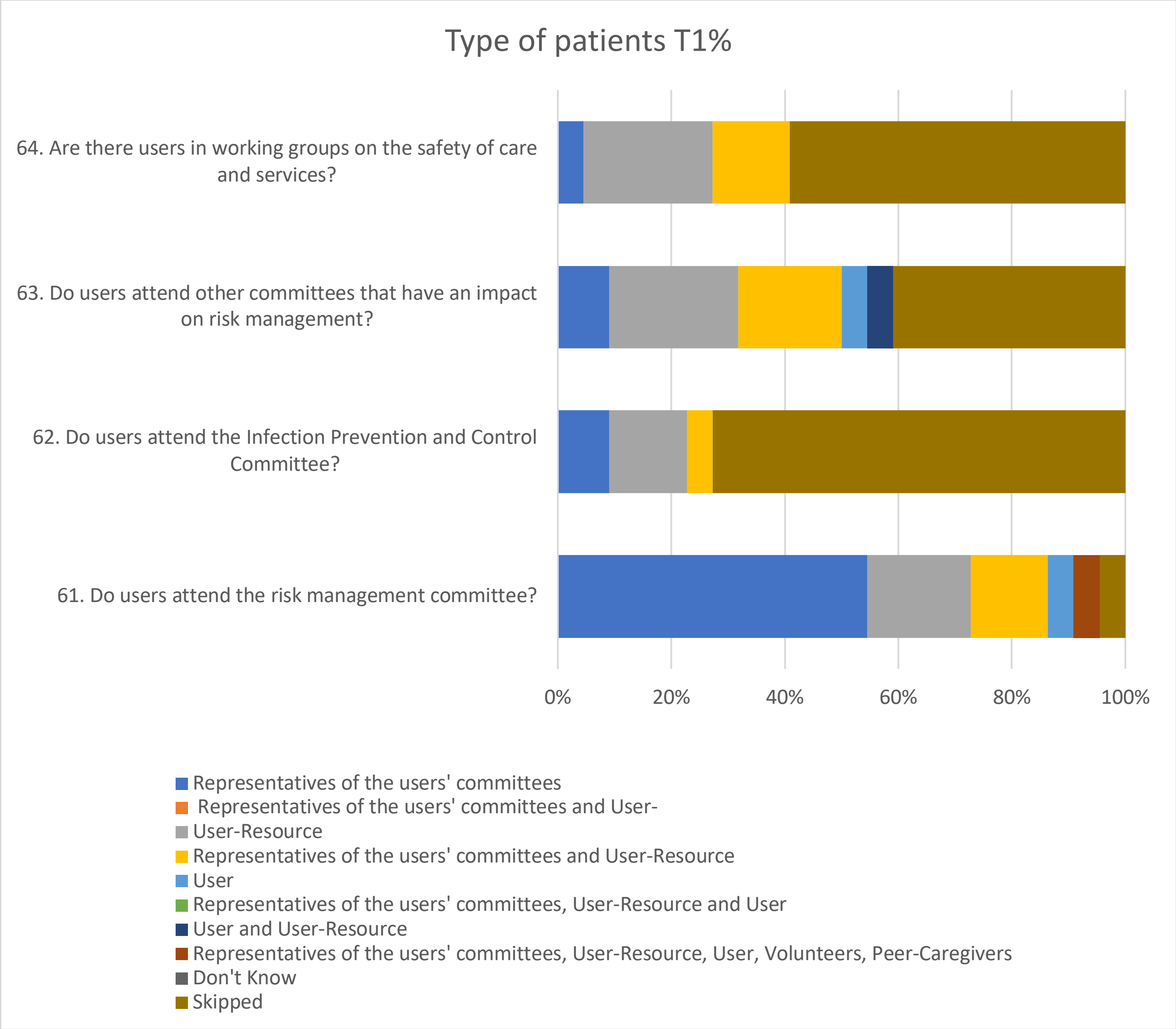
Related to training

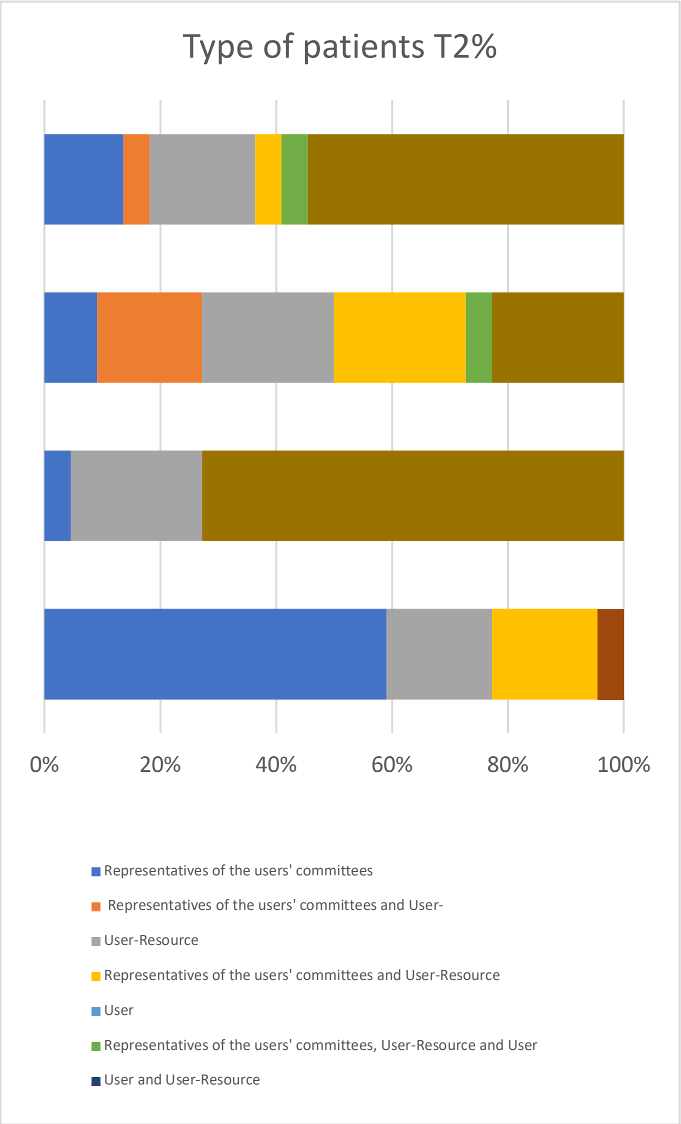

T1%


T2%

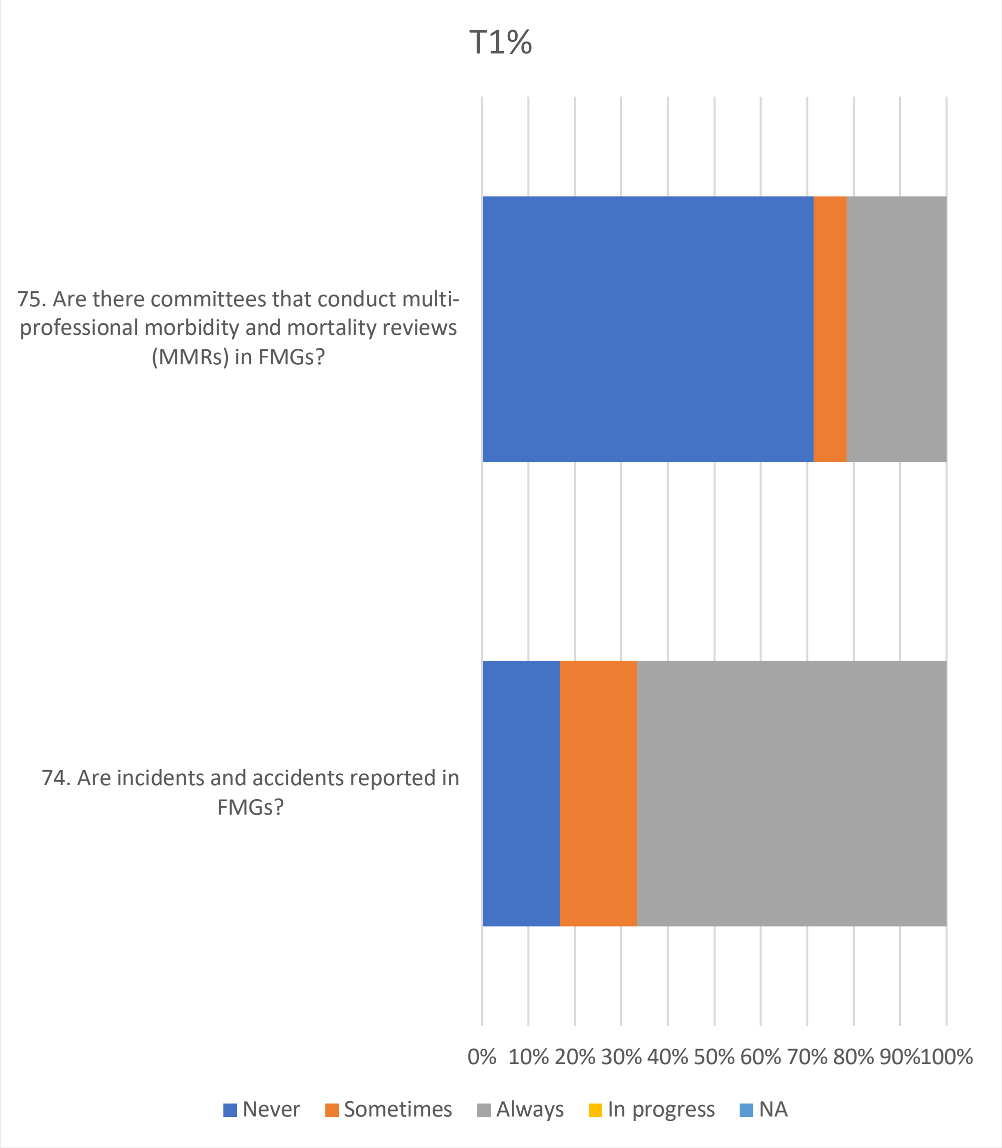
Related to the organization of committees

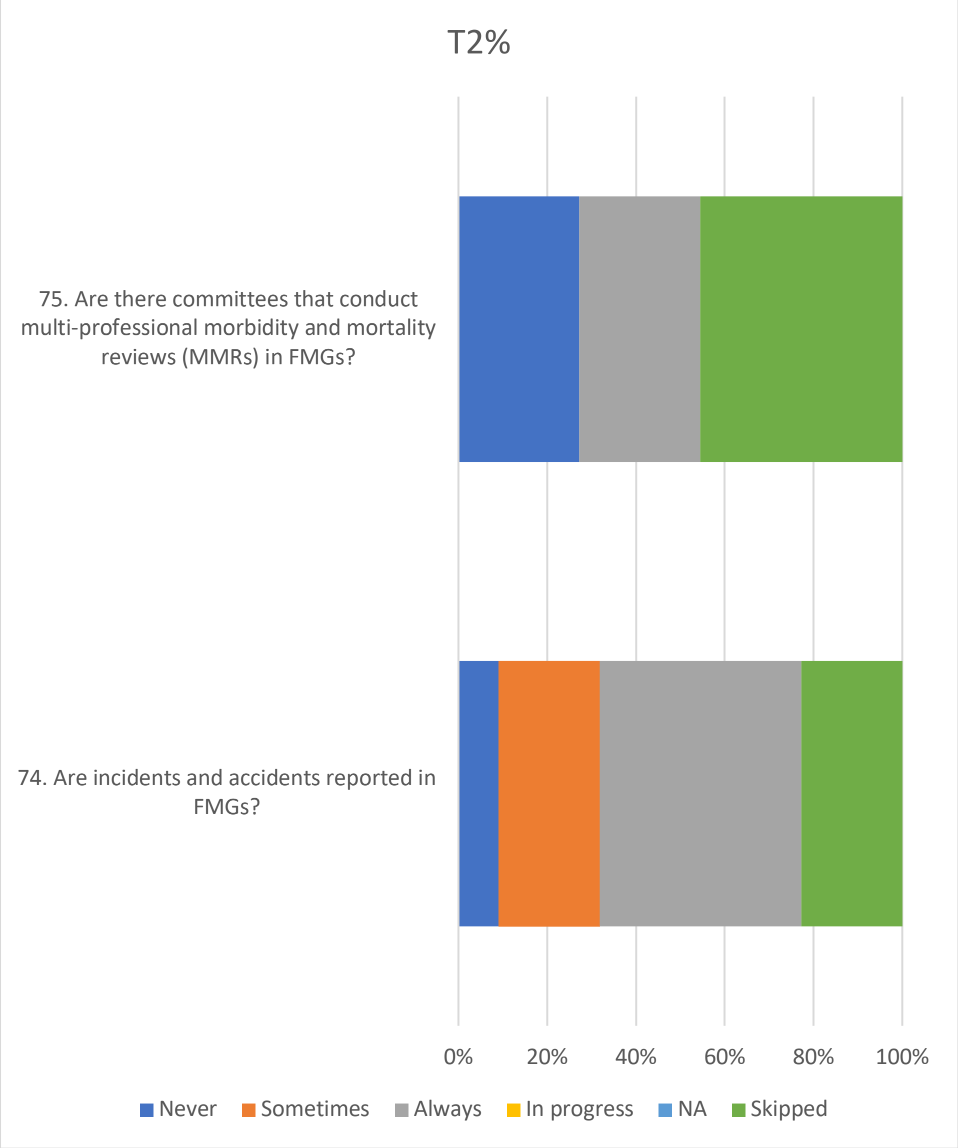



Type of patients T1%
64. Are there users in working groups on the safety of care and services?
63. Do users attend other committees that have an impact on risk management?
62. Do users attend the Infection Prevention and Control Committee?
61. Do users attend the risk management committee?
0%
20%
40%
60%
80%
100%
Representatives of the users' committees
Representatives of the users' committees and User-
User-Resource
Representatives of the users' committees and User-Resource
User
Representatives of the users' committees, User-Resource and User
User and User-Resource
Representatives of the users' committees, User-Resource, User, Volunteers, Peer-Caregivers
Don't Know
Skipped

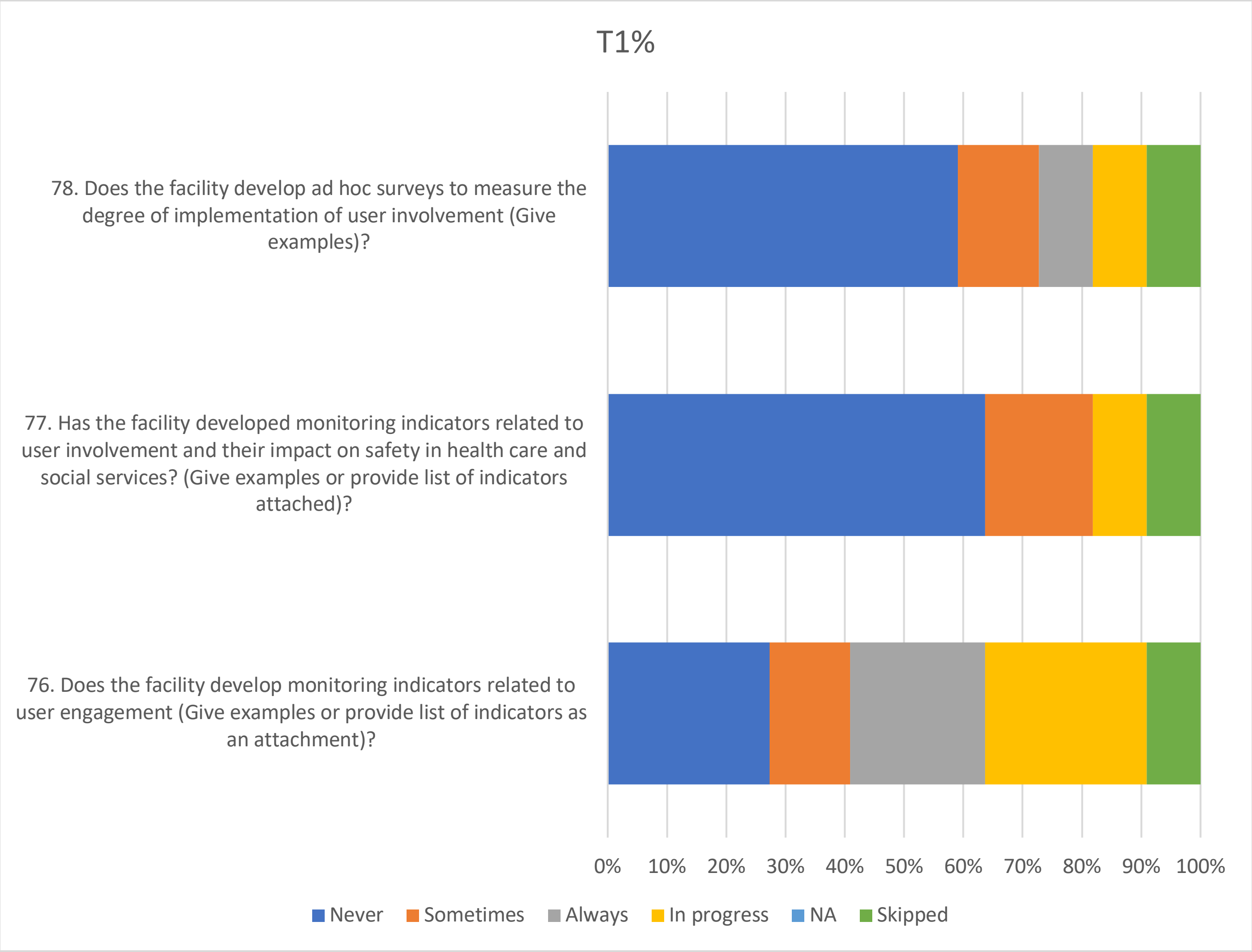

Type of patients T2%
0%
20%
40%
60%
80%
100%
Representatives of the users' committees
Representatives of the users' committees and User-
User-Resource
Representatives of the users' committees and User-Resource
User
Representatives of the users' committees, User-Resource and User
User and User-Resource

Related to FMG





Related to indicators



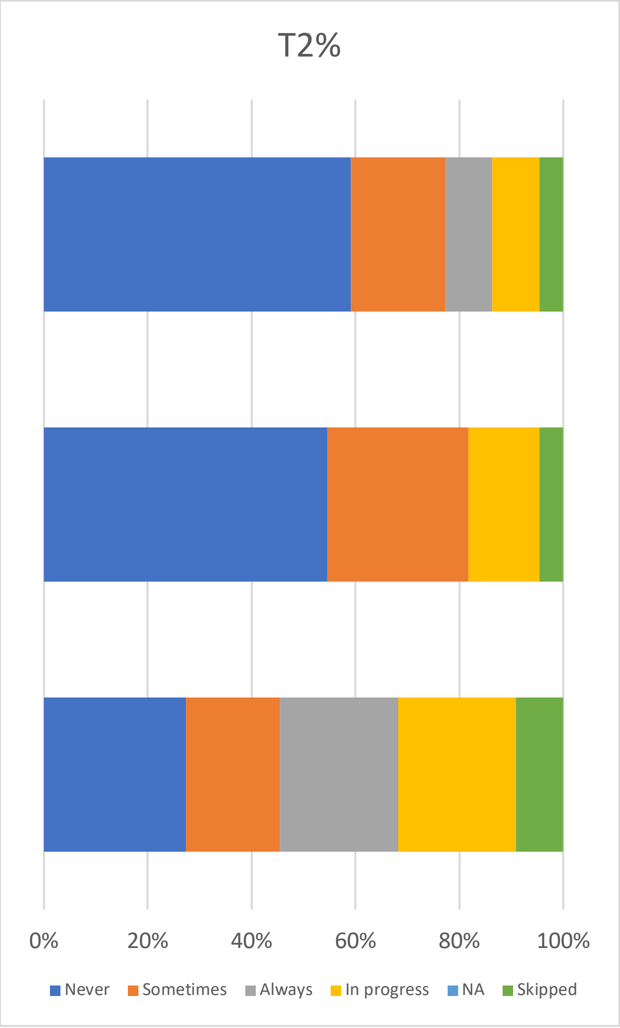


Table 11: Indicators

Table 11 shows the different indicators identified through the research project in regard to PE and PE in risk management for safety.

	Indicators of PE in general
1	Number of projects involving patients
2	Active patient in the bank
3	Rate of patients involved in pilot projects (because the aim is not to involve them everywhere without results, but to make them into pilot projects before and see the added value)
4	Number of pp integrated into teams per year
5	Level of satisfaction of patients with their care and services
6	Increase the number of initiatives and bodies that integrate patient participation in the organization of care and services.
7	Increase the rate of implementation of the partnership with the community and service trajectory
8	Increase the rate of compliance with hand hygiene best practices
9	Number of patient involvement in the creation of tools or participation in a committee
10	Evaluation of patient-resource satisfaction
11	% of sectors with data on their patient experience.
12	Assessment of manager satisfaction
13	Number of requests
14	Number of resource patients
15	Number of queries per direction
16	Number of queries by geographical area
17	Number of patients seen for the recruitment process,
18	Number of patients actually recruited as patient partners,
19	Number of partnership applications received.
20	Indicators monitored in the strategic steering room: % sectors (in which accreditation standards are in place) where a patient or a close partner is involved; Number of projects involving patients or close partners.

	Indicators of PE in risk management for safety
1	Number of PP engaged in the evaluation of adverse events (incidents and accidents)
2	Double ID’s *“Double I.D.'s help us identify other patients (2-3 pp on the board); by putting the bracelets on. They also played a role in raising awareness of the cause, as patients were aggressive when asked their names too often. They made a poster that said, "it's better to be asked your name many times than to be asked for your name in error...".*
3	Number of security committees or teams that have a Patient advisor

Table 12: Factors

Finally, **Table 12** describes (with the help of verbatims from the analysis of the qualitative data collected from the complementary interview conducted during the questionnaire completion) the types of factors influencing PE for PS.

TYPE OF FACTORS	FACTORS AND VERBATIMS
ENVIRONNEMENTAL (+++)[35]	**Policies or reference framework from governmental bodies (+++):** - Reference framework: “*The MSSS reference framework came out couple of months ago. And we developed a procedure and guide”* - Accreditation bodies: PE concepts and practices embedded in accreditation, ROPS, indicators, etc. *“We use Accreditation’s Canada’s ROPs as our PE indicators”* - Other health organization’s guides. For example, CPSI: A Guide to PE in Public Services. *“We used CPSI’S and AC’S resources to build our training tools and procedure for PE for PS”.*
LEADERSHIP (++)	**Visionary leadership (++):** - *Global vision: "It takes a global vision. It takes a person who has a global vision of CISSS. Of what's going on throughout.* - *IF one wants to have a global vision of what is being done in risk management engagement".* **Implementation Strategies (-/+):** - Awareness strategies: link between vision and operations (managers and coordinators) - Communication plan, that people (managers) are skilled (competencies, trained, be aware through a communication plan, activities) - Validated tools and processes (to plan, prepare and sustain, measurement (measure progress) *“Start with pilot projects involving patients in projects”. – and measure impact* *“Involve patients in the conception and design of the structure, services, not just participation on committees after the event has arrived”.* - It also takes a strategy of accompaniment (“*people need to have experts, an advisory role, to be more involved at the beginning and over time less. Identify key multipliers beforehand and accompany them by projects, etc.*”. - Partnership strategies with management and across the territory with organizations: “*We have fewer managers; we have many other responsibilities. We have to manage to develop and deploy a structure. We need to make allies in the clinical departments and throughout the territory”.* - *“We are going to start a community of practice with all our multiplying agents from all directions (virtual), - 2-3 meetings per year to keep the link”.*

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[35] (+++): Very positive factors

	- *“We are also setting up a collaborative space to review population responsibility across the health continuum and actions taken”.* - *“We are also putting together the citizen health council for collaboration with the community”.*

ORGANIZATIONAL CULTURE - FAIR, BLAME-FREE AND TRANSPARENT (+/-)	**Communication of transparency and continuous education training (-)**:
	- *“We need to be able to understand and practice a blame-free, fair and transparent culture. With concrete examples / cases and identify the practices brought forward by management / staff / and patients.*
	- *“We are accompanied by the university of Montreal, and the DCEPP, to help us with our PE implementation approach”.*
	
	Integration of performance indicators and continuous evaluation (-/+):
	- Control room and simulation: “*We try not to work in silo. The tool that allows all of this is our control rooms, on our walls, people can see the boards. The team then solicits the colleagues and takes it back to the cockpit. We treated it as culture change and performance. We have an operational, tactical, and strategic control room”.*
	    - Ex: “F*or the prevention of infection. We monitor nosocomial infection rates. The indicator is applied at the operational level. At the POR level. At the tactical level, we apply it to hand hygiene (the manager puts indicators on the board, does he have processes that prevent you from working; after that, we look at the monitoring, what does it say in our sectors of activity, is there a risk that it will come back? yes, we'll work on that and we monitor it over time. We've added it on a map. If the card is red, what's on the protocol has not been followed.......Just the fact that the employees see that they are heard by the management, makes a difference…the means of communication flow”.*
	    - *“We work our indicators in cascade and_escalation. One that has an effect on another. From the strategic level to the clinical level or vice-versa”.*
	
	- **Collaboration and recognition of employees and PPs (-):** *"Barrel Institute presents posters on safe care at Barrel Institute. We're doing Planetree, and at the same time, we recognize our employees this way by sending them to these conferences. It's the best way to recognize. By doing that, we're taking knowledge from everywhere. There are resource patients who are on Accreditation Canada (AC), and CPSI, Vigilance, medication safety, self-medication, surgery, psychiatry, SM, etc.".*

ORGANIZATIONAL STRUCTURE (+)	In risk management specifically, we need: - **Governance body (++):** “*A governance body such as the DQEPE. But also, an office of PE or staff to take care of PE on a full-time basis and not on a part-time basis*.” - **Tools, Resources and Supporting Technology:** - *"Put in place documents, tools and support (personal resources, technological resources (simulation, innovation room, etc.), etc.) structuring to support the implementation of patient engagement".* - **Pilots projects:** *“Start with pilot projects involving patients in projects”.*

	o *"Involve patients in the conception and design of the structure, services, not just participation on committees after the event has arrived".* o Involvement of patients in Accreditation and ROPs**-** - **Ongoing support and training for staff: "***Staff should participate in the Committee of Practice".* - **Integration of Performance Indicators: «** *With respect to indicators and performance, we will put them in place following the implementation of the structuring documents in the fall, as well as following the more official launch of the approach to all executives at a leadership day in October ».*
INTERNAL POLITICS / STRATEGY ON PE (++)	**Internal policy (++):** - *"Policy of patient involvement in the institution (e.g., the policy favouring the presence of family and friends in the hospital environment) helped put in place an action plan for PE".*
PERSONAL (-)	**Well-being of patients (-):** - *"The challenge with regard to patient involvement in our structures: it is obvious that patients feel comfortable in the role they are asked to play".* **Staff Wellness (-):** - *« We have to pay attention to the workload and know how to recognize our employees through our good practices".* - **Ongoing support and training for staff: "***Staff should participate in the Committee of Practice" and have more ongoing continuous education training for PE competencies".*
RESOURCES (+)	**Human Resources (+)** o ***Involvement of staff in PE projects and availability of staff for these projects (+):*** *"The person in risk management, is not involved in PE structures".* o **Definition of the roles of the patient committee, the PP and the patient (-)**: « *Let's say there's work to be done to better define roles. The Patient Committee has no idea what the Patient Partner is doing. It is a complementary role that both have ».* o **Recruitment of patients for PE (+)**: ▪ *"Recruitment is done through our multiplying agents, on our websites, or referenced from a physician, an HCP or staff at reception, or again, from application forms found at the reception/waiting area"* ▪ The choice of patient partner is very important". • Experienced patients: e.g., *"a patient who has experienced a Risk situation (accident or incident), but who has enough distance either directly or through a relative. Challenges: recruitment and the length of time required for meetings".* • Competence profile of patients in Risk management: *"1- knowledge of how to be; 2- knowledge; 3- motivation. Within our project on Acting and with the patient we use the competence profile".* • Recruitment and integration process. A guide will be available in the fall to support the process. o **Job Description (-): "***Reading the questionnaire: I liked to put them on the job and task descriptions".*

	o **Tacit multiplying agents (++)**. *« We identified people who have collaborated with the DQEPE. But are not officially mandated. They are often the managers ».* o **Use of volunteers (+): «** *We use the existing volunteer structure to integrate PPs. Often, they become our PPs. And they have their access card, and volunteer compensations ».*
	Financial investment (-) - Reflexion: o "However, we *do not to professionalize the role of the resource patient"* o *Patient compensation? "We also have peer helpers (they get paid a small fee) in psychiatry (in the primacy of the person framework). We are going to create their own committee of PPs.".* - *"We need funding for these types of projects, especially as pilot project to evaluate the impact and their outcome properly".*
	Training in PE for safety and tools for patients and health care workers (-): - "We don't have any training in patient safety engagement yet".
	Research (+): o **A door to PE integration**: *Research Projects a Gateway to PE "* o **To demonstrate the value of patients in committees and projects** • *"At the clinical level, managers do not yet see the added value of organizing interdisciplinary IP, studies do not show that it is effective. It takes time and resources. We need studies to show effectiveness. The added value in the committees has not yet been demonstrated. It has to be people who understand the system »*

Legend:

(+++): Presence of that factor (very positive influence on the institutions during the research project)

(++): Factors are present and have an average positive influence

(+): Factors are present and have an ok positive influence

(-/+): Factors are presents in some cases. If so, they have a positive influence

(-): Factors are not present. Or, they have a negative influence

5.2.4.2. Analysis of the data collected

Please consult Appendix M for a detailed explanation of the data analysis of the different tables and figures in the results' section.

5.2.5. Discussion

To our knowledge, the current research project is the first of its kind in Quebec. Its main objective was to make an initial assessment of the state of patient engagement (PE) structures and strategies in most major healthcare institutions in the province. It was also a means to spark, within those institutions, a reflection about self-assessing their PE practices and pondering about the various ways in which patients are – and could be – involved at different levels.

Overall, in Quebec, PE in healthcare institutions seems to be picking up pace. Indeed, since the 2015 heath system reform, which included the entry into force of Bill 10; the merger of healthcare institutions and creation of Departments of Quality, Evaluation, Performance and Ethics (DQEPE) within each newly Integrated Health Center, led to the implementation of various PE initiatives and projects, in addition to revised PE policies and guidelines. New PE structures have also emerged, not only thanks to DQEPEs entering partnerships with patients' groups, patient committees or clinical departments, but also thanks to accreditation bodies strongly recommending PE as part of their standards and Required Organisational Practices (ROPs), as well as the release of the Quebec PE Reference Framework by ministry of health and social services [79] in 2018. This, in turn, helped healthcare institutions obtain a better understanding of how to improve their implementation of PE strategies (see Chapter 3, Article 2). In fact, 45.5% of institutions in T1 had a PE policy or strategy compared to 86% in T2. That might be because of many factors, one of them being the Quebec PE Reference Framework by the ministry of health and social services [79] which came out in 2018.

Furthermore, even though healthcare institutions were already measuring patient experience in various departments, by hiring personnel specifically for PE and patient experience roles or by partnering with patient committees, departments of volunteers, patient groups or the DQEPE complaints department, the focus on PE became stronger and efforts in that regard more coordinated. Along the way, this led to the burgeoning of new PE structures, ways to collaborate by factoring in the voice of patients (with clinical instances, Public health instances-for the citizen's voice, the complaint department at the DQEPE, etc.), the assessment of patient experience through various tools (such as service-specific patient experience surveys co-designed with patients), greater attention to existing in-house tools or tools made externally (by accreditation bodies, for instance), as well as new ways to engage patients.

Based on the data collected and on evidence [99], the following section provides the evolution of PE strategies and mechanism over time, factors influencing the institutionalization of PE for PS, and some recommendations (at the clinical, organizational and strategic level) to help organizations create, develop/share, and preserve in order to institutionalize PE for safety.

5.2.5.1. Evolution of PE strategies and mechanisms over time (from T1 to T2)

5.2.5.1.1. Slight PE strategies and mechanisms change over time

Results from the study highlight different paces of evolutions between T1 and T2 in different areas of PE in risk management for safety. For example, in terms of CEO involvement, in T1, only 4.5 % of institutions claimed that their CEO meets with patients to understand their experiences. In T2, that %age grew slightly to 9.1 %. As for the patient involvement in new employee onboarding, and incident and accident reporting, the percentages increased respectively from 21% in (T1) to 32% in (T2), and 32% (T1) to 45.5% (T2).

More significant positive results were noted in areas such as encouraging a "no-blame culture" (91% in T1 and T2); developing indicators in PE for safety (18% in T1, 27% in T2), and making PE for safety training available for patients (35% in T1, 27% in T2).

Significant growth was also observed in specific areas of PE promotion and governance. First, in terms of promotion (questions 21 and 19), while only 9 % of surveyed institutions "always" had PE promotional materials geared towards patients, in T2, the %age tripled to 27 %. And regarding PE training for healthcare providers, institutions that claim to "always" offer them, increased from 23 % in T1 to 36 % in T2. Secondly, in terms of governance, a larger portion of institutions claims to "sometimes" or "always" invite patients to share their patient experiences with the board of directors (59% in T1 vs. 77% in T2). Such advances, though not generalized across the entire areas of PE promotion and governance, indicate that there is at least some progress being made and willingness to promote and involve patients in those areas.

That said, growth did not only concern positive evolutions, as there were also indications of persistent challenges. For example, with regards to PPs interventions at a clinical level to accompany patients during the development of their care plans (question 35), half of surveyed institutions said that it "never" happens. In T2, this % age grew to 59 %. Another example is the fact that over a quarter of institutions in T1 said the PPs "never" intervened during consultation phases (27%), which doubled to 54.5 % in T2. With regards to the participation of patients in the analysis of incidents and accidents, 64% in T1 said that patients participated, and 41% in T2 of respondent, said that patients participated in the analysis.

These types of evolutions, which typically go against the idea of more PE approach in healthcare settings, point to the difficulties of an overall knowledge of PE initiatives in the institution by the respondents.

Factors that might have been at play are discussed further in the "factors" section of the discussion, but here is one worth mentioning: human resource changes in upper/ middle management. Thus, the person answering the questionnaire in T2, may have not known the answer to the question and assumed the answer:

> "It is difficult to answer some of the questions sometimes, because we do not know, in this case, if interns are trained in PE. They usually learn that in their training at university".

5.2.5.1.2. Presence and creation of governance structures / bodies

The importance of governance bodies is to plan, develop, evaluate and support PE implementation for safety with the different instances and departments [92].

For most of the institutions (T1 = 90, T2= 95%), PE structures emerged within the DQEPE or some type of collaboration between the DQEPE and other clinical or PP's office. In 5-10% of the cases, PE structures emerged from the DSM department. In the case of PExp structures, 100% of the institutions, emerged from the DQEPE in which, 18% is a form of collaboration between the DQEPE and other instances. One of these instances is a separate entity called the Patient Experience Office in collaboration with the DQEPE. Collaborations here are mostly between the DQEPE Complaints Department, and the Patient Committee for patient experience data collection (surveys) and data analysis.

Regarding the RM structures, 100% of them emerged from the DQEPE. Here, collaborations are between the risk management committee, the patient committee and sometimes, the presence of a PP.

What we can deduct from our results analysis is that while the DQEPE is the central structural piece driving PE (more than 90%), patient experience 100%) and risk management 100%) within institutions, the nature of collaborations is heterogenous among institutions (i.e., the DQEPE does not necessarily partner with the same departments in all institutions). For instance, collaborations can be with one or more clinical departments or public Health departments, the Patient Committee, or with the PP office.

The variety of collaboration prompts the desire to figure the determinants of those collaborations, whether they are related to simple leadership preferences, predominant disease areas within institutions (mental health, cancer, etc.), or whether these collaborative structures could be studies to identify innovative practices which could, later, be harmonized across institutions [14].

Moreover, as much as PE structures are important, without dedicated human resources (based on how PE is valued, PE awareness, and core PE competencies), part of sufficiently staffed teams (number of people in PE structures / Pexp structures and the time allowed for these projects) it will be difficult for the PE governance to support the institutionalization of PE for patient safety (PS). In fact, in seven institutions in T1, compared to 6 institutions in T2, only one person is responsible for putting in place the PExp approach in the organization. In the PE structure, two institutions put one person in charge of the PE office in T1, and in T2, 5 institutions put one person in charge. The average number of people working in PE structures are two to three people, with 8 institutions in T1, and 10 institutions in T2. In regard to PExp structures, there were 5 institutions in T1, compared to 8 institution sin T2 with two- to three people working in these structures. With only 5% in T1 compared to 20% in T2, of HCP actually spending 100% of their time on PE, and % on Pexp.

Most importantly, as a key component, Institutions have a hard time finding qualified patients to work with and to add in their patient bank [121, 122].

> “The choice of the PP is very important. We are looking for “experienced patients”. Per example, *a patient who has experienced a Risk situation (accident or incident), but who has enough distance either*

directly or through a relative. Other challenges to recruitment are the length of time required for meetings".

"The competence profile of patients in Risk management should include: *1- knowledge of how to be; 2- general knowledge; 3- motivation…Within our project on Acting and with the patient, we use this competence profile to select our patients".*

That being said, having a bank of PP is part of building a PE governance or structure, and is crucial for PE CPSI [92]. Most banks are currently at the institutional level (50% at T1 and 54.5% at T2), while others are at the directorate level (27% at T1, and 9% at T2), or even ad hoc at the moment. Regardless, proper strategies must be in place to add more PPs into those banks. Some of the strategies used by the respondents of the research project to identify PPs for their PP's bank can be achieved through the office in charge of volunteers, the Patient's Committee, patients and families who had received a service or care in the institution and have been referred by a physician, a HCP, or a manager. Patient could also apply online via the institution's website

"Recruitment is done through our multiplying agents, on our websites, or referenced from a physician, an HCP or staff at reception, or again, from application forms found at the reception/waiting area".

5.2.5.1.3. Health Organization Strategies in Patient Engagement for Safety (HOSPES)

PE in care and services is a lever for change management and a way to inspire and mobilize all institutional partners for patient safety, despite difficulties linked to such a meaningful transformation [7, 25, 30]. As many slight and significant changes were observed throughout this study, in order to identify the strategies and mechanisms of institutionalized changes, we used a framework (Appendix A - Conceptual Framework PE for PS. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**) based on the Institutional Theory and Nonaka's change theory. This framework helped to analyse our results for the institutionalization of PE in risk management for safety.

According to the model of early institutional sociologist, Scott, et al., (1983), an institution is usually the product of a process of institutionalization: a process through which something (a change: such as PE in risk management for safety) anchors itself within an organization, a social system or society [3, 4].

Based on Institutional Theory, as explained in the methodology section of this article, an institutional organization can only be legitimate if it (1) internalizes the norms of its institutional environment (e.g. PE Reference Framework from the MSSS; accreditation bodies ROPs; etc.), (2) preserves order via regulation (internal policies and strategies in PE, procedures and mechanisms in declaring/analysing adverse events, etc.), and (3) integrates a cognitive and cultural dimension (no-blame culture, training, competencies and continuous improvement activities, etc.) to its models in which meaning is given to things. The cognitive and cultural dimension characterize the individual by its ability to process information and make decisions (personal characteristics, etc.), but also integrates human shortcomings (limited rationality) by applying rules, procedures and routines. Individuals within an organization adopt values, cognitive frameworks, rules and organizational routines. Thus, the institutional environment can exercise pressure (change) through three pillars (regulating pillar, normative pillar and Cultural-Cognitive pillar). An organization does the above through its different organisational levels: clinical, organizational and strategic.

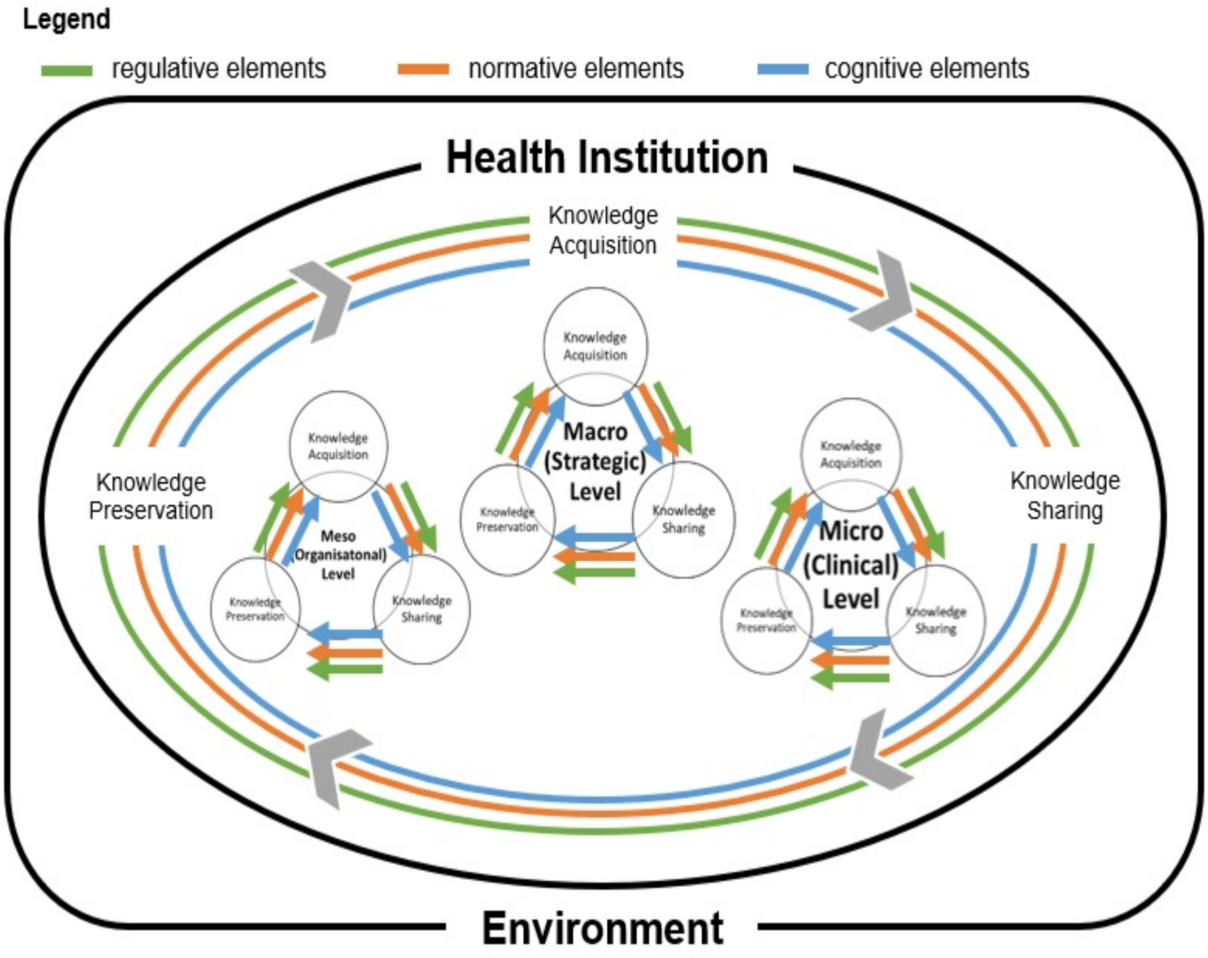
5.2.5.1.3.1. The role of the institutional leader

According to Nonaka's change theory and institutional theories, the creation of organizational knowledge (institutionalization) is done through an approach that involves the observation of three basic dynamics: the creation of knowledge, its application, and its preservation [99].

That said, leaders are usually the ones who initiates the institutionalization process. Adaptation of an organization to its environment can either come from emerging, self-organized processes, or brought about by senior management which initiates and manages change [3, 100, 97]. In order for it to be successful, decision making, and the coordination of implementation activities must be done in collaboration with members of the organization and the agents concerned by the change in question. Most effective leaders appear to be those who use a portfolio of leadership approaches and are able to adapt these approaches to fit the needs of different situations, groups, and individuals. Some situations call for sharing technical expertise by showing people how to do things and exercising relatively close supervision. Others call for delegation and empowerment while still ensuring accountability for results. We understand that different kinds of leadership can be needed at different levels. In the work of Labelle (2014) on risk management, leaders perform distinct broad forms of institutional work as institutional carriers, depending on the level at which they work or use their strategy (clinical, organizational and strategic level) [101]. Figure 3 (below) describes the institutionalization process of PE for safety within an organization.

Figure 4: framework for the implementation of PE in risk management for safety based on the institutional theory (see APPENDIX A - Conceptual Framework PE for PS **for more information. In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study)**

PS: the regulative, normative and cognitive elements are presented in this article as factors influencing the PE in PS.



Based on the data collected, on evidence [99], and on the conceptual model (figure 4), the following section presents the identified themes of this research study influencing the institutionalization of PE for PS, as well as the identified emerging strategies and mechanisms of PE for PS.

5.2.5.1.3.2. Identified themes and emerging strategies / mechanisms of PE for PS (see Appendix M for more detailed information)

Based on the empirical results of this thesis, we were able to identify three main types of strategies, and seven sub-strategies, which we discuss in relation to the conceptual framework based on the Institutional Change Management theory (see Figure 4).

Strategy 1: Knowledge acquisition (preparation phase)

Article 2 highlights that leaders are engaged in practices aimed at initiating, designing and structuring partnership approaches with patients in safety. In this respect, leaders at the strategic, organizational and clinical levels play a key role in creating a shared vision of the approach between healthcare professionals (HCPs) and patients.

Sub-strategy 1: Initiate through adoption of framework, guidelines, as well as identified institutional priorities [4]

At the **strategic level**, for a more structured approach to PE, decision-makers should ensure that institutions formally adopt (1) reference frameworks or guidelines such as the PE Reference Framework from the Quebec Ministry of Health and Social Services (MSSS) [79], as well as PE policy recommendations and Required Organizational Practices from of accreditation bodies (i.e. Accreditation Canada, Quebec Accreditation Council, ISQUA, and other national or international accreditation bodies) [66, 92]. Then, those references should be used by institutional leaders to (2) initiate an official PE action plan which formally describes PE / Patient Experience structures. The action plan should include regulations and strategies to ensure the inclusion of expert patients in work/task groups, particularly those responsible for reviewing/developing internal policies on safety, care pathways, training tools and documents. Lastly, (3) training and awareness campaigns about the PE action plan should be developed internally so that patients, HCPs and managers become familiar.

Sub-strategy 2: Structure and support through governance bodies, tool creation/data collection and analysis methodology, and human resources [92, 143, 144, 145]**.**

At the **organizational level,** leaders/healthcare providers in risk management/ PE / and Patient Experience (PExp), should be (1) identified and hired to oversee and coordinate PE projects in the organization on a full-time basis, preferably with a (2) PE team. This team would help implement the type of (3) PE and PExp structure, in addition to (4) developing and managing PE for safety resources, tools and material for patients and staff (HCPs, Senior Managers, Managers), and (5) setting up an patient-partner (PP) bank to recruit patients for PE initiatives. This usually involves developing a recruitment form, a database for PPs, etc.).

Sub-strategy 3: Define and identify moments of PE integration in teams as well as defining PP core competencies for particular initiatives in PS [14]

Finally, at the **clinical level**, based on the PE action plan, and with support of the appropriate directorate overseeing PE (in Quebec, it is usually under the purview of the Quality, Evaluation, Performance and Ethics Directorate (DQEPE)), (1) create task groups (involving patients and professionals) to review clinical practices and pathways to clearly define the scope and moments of patient engagement, as well as (2) develop strategies and tools to identify and recruit potential PPs based on co-developed criteria and co-defined competencies [121]

Strategy 2: Knowledge sharing (implementation phase)

Strategies put in place by strategic, organizational and clinical leaders can be viewed as disseminators of information to patients and clinical teams [138]. Articles 2 and 3 highlight the important role of leaders in creating collaborative strategies for communication, regulation revision and processes purposes. These strategies relate to informing and training HCPs and patients integrating teams, as well as evaluating or assessing employee and patient's satisfaction.

Sub-strategy 4: Promote and inform the institution on PE policies and strategies, as well as safety culture through videos, pamphlet, presentations, etc. [146].

At the **strategic level,** upper management overseeing PE should implement and promote (in collaboration with patients and the communications department for message adaptation and increased visibility and awareness) (1) PE policies (i.e., integrated risk management with patients involved) and culture (no-blame, transparency and empowerment regarding adverse events, complaints, etc.). In addition, (2) a task group (involving PPs) should be created to review the mission, vision, ethical governance of the institution as well as (3) identify, at least, one sector where a pilot project be conducted within the organizational as a whole (clinical, organizational and strategic).

Sub-strategy 5: Collaborate, train leaders, HCPs and patients integrating organizational or clinical teams, and assess satisfaction and safety culture for decision-making [92] [147].

At the **organisational level,** middle/program managers implement (1) collaboration strategies with Patients Committees, complaint departments, risk management, volunteer departments, public health departments, clinical departments, multiplying agents at different departments of the institution, community organizations, universities, and other patient groups, etc. Moreover, they should (2) develop training (PE for PS training adapted to managers, patients, HCPs and other staff), and assessment programs for PE in risk management for safety. As they report back to senior management, they will also (3) implement an approach or methodology for the data collection and evaluation plan in order to collect data for decision making.

Other elements of collaboration and training include:

- (4) Collaboration with the Human Resources Department to develop a clear and detailed description of staff, patients, volunteers, and other patient group job descriptions;
- (5) Collaboration with different directorates/departments to hire patients for the PP database from different sources such as patients, associations, volunteers and citizens;
- (6) Development of a continuous training program for PE in risk management for safety;
- (7) A No-blame culture procedure and methodology within management and HCP's practices to capture experiences and practices;

Lastly, at the **clinical level** [25, 148] in collaboration with the organizational level or the structure in charge of PE in the institution, (1) pilot projects in PE should be implemented while capturing patient and family experiences and satisfaction with decision-support tools, as well as outcomes of shared decision making via, for example, the use of a direct feedback loop (surveys, committees, patient groups and complaint departments, comments and analysis). (2) Mechanisms should also be in place to empower and enable patients and families to report, analyse adverse safety and quality events (rapid response teams, etc.), health risks and incidents/accidents related to their health in collaboration with the clinical team. This also means being involved in the selection of support measures for patients after an incident or accident, coming up with solutions and being informed of measures taken by the organization to reduce or eliminate the risk. In terms of training, patients should be (3) integrated in clinical teams to educate and develop patient and family engagement sections in the training curriculum of HCPs (i.e. role learning), as well as (4) help HCPs develop standardized patient and family engagement competencies. Both patients and families should be (5) invited to coach/train other patients in disease management and risks identification, and (6) patients should be involved in different safety, risk management and other local safety committees, and task group (e.g. Fall prevention, suicide, etc.). HCPs should also be trained to work in teams alongside patients and vice versa.

Strategy 3: Knowledge preservation (sustainability)

Knowledge preservation strategies are put in place to sustain PE for PS practices. To do so, strategies aimed at transparency policies / mechanism and continuous education (on patient's rights, and contributions) are used to raise awareness about PE for PS among leaders, HCPs, and patients at all levels of the institution [146, 149, 150, 151]. Moreover, strategies for developing a culture of innovation and continuous improvement are utilized to create spaces for discussion and collaboration with internal departments and external organizations which enable knowledge transfer, enhanced visibility, simulations and thinking, as well as continuous improvement of competencies for PPs, and HCPs. In addition, a management system process (or methodology) for data collection and analysis should be integrated to support decision-making and increase knowledge regarding the added value of PE in risk management for safety [148]. Finally, a strategy of well-being for HCPs (e.g. recognition programs, etc.), leaders, and patients should be implemented to foster a safe and just culture [92].

Sub-strategy 6: Sustain and support a culture of ongoing evaluation, transparency (raising awareness), safety, well-being, and innovation

As for knowledge preservation, at the **strategic level**, (1) Human Resource departments should include PE competencies in job descriptions of HCP and staff, as well for PPs [121], while (2) senior management incorporates performance indicators into organizational practices (quantitative and qualitative data (e.g. complaints data, patient committee, patient's groups, etc.), while (3) setting up communication methods and technology to coordinate activities in-between departments. (4) Producing quarterly reports on PE in risk management / ongoing activities, etc., (5) encouraging and structurally empowering patients and families to officially and regularly attend board meetings and patient committees, as well as take part in shared decision-making through organizational communications (videos, pamphlet, Patients Committees, etc.) is also suggested. Furthermore, (6) developing organizational policies that specify families as full members of the healthcare team. To (7) encourage patients to participate (and professionals to welcome their participation), senior management should design and provide recognition and reward programs for care that fully incorporates patient and family engagement. Empowerment also goes by (8) developing policies that define access and transparency regarding information related to risks, benefits, costs of care, treatment options, medical records in the annual report. Moreover, the institution should (9) develop strategies and policies for the well-being of staff and patients [92], as well as strategy and mechanisms for interdisciplinary collaboration (which include the patient), collaboration with universities (such as the university of Montreal-department of DCPP, which supports institutions in the implementation of their PE approach), but also collaboration with national and international organizations (through conferences, communities of practices, etc.) [92, 152].

Sub-strategy 7: Sustain and support a culture of collaboration, and continuous improvement /education [143, 145, 153, 154]

At the **organization level**, PE teams should (1) continuously develop a PE curriculum and PE training programs in risk management which explain roles, organizational structure, quality and risk management improvement processes to key stakeholders (patients, HCPs, etc.). PE teams should also (2) develop a sustainable methodology or system to capture and assess patient experience (PExp) in risk management for safety at an institutional level (reviewing surveys and creating or adapting new ones, collaborating with other departments (complaint department, patient committee, PPs, clinical departments, citizen's forum, CEO/upper management or other HCPs or PP's safety rounds, and other data collected through consultations, and focus groups, etc.). In addition, to capture PExp data, it is also important to capture PE initiatives in the institution, and measure PE degree of integration in different sectors of the institution. (3) should there be a sub-structure to the PExp office, to be the assessment / evaluation of projects in PE/ PExp bureau?

Finally, at the **clinical level,** there should be (1) documents available to elicit structured care processes to support patient and family involvement in care planning and self-management. For example, dedicated full-time staff and the creation of departments to oversee work with patient and family advisors; as well as safety and quality improvement committees co-led with patients, etc.). To support HCPs in PE, (2) mechanisms should be in place which help clinicians elicit, understand, and respect patient perspectives and concerns (active listening, patient coach, etc.). (3) In terms of recruitment, not only should clinician tasks and job descriptions be updated to account for PE-related tasks, but also recruitment tools and tactics should enable the ongoing identification and selection of effective patient and family advisors for an interdepartmental PE databank (institution-wide).

5.2.5.2. Enabling and Inhibiting Factors (regulating, normative and cognitive elements)

Seven groups of different types of factors are found influencing PE in risk management for safety in this research project: Structural factors: (1) Environmental factors (or system wide barriers), (2) Leadership, (3) organizational culture, (4) organizational structure (including governance, interpersonal relationships or collaboration and partnership, etc.), (5) internal politics / mechanisms, etc., (6) personal characteristics (or intrapersonal), and (7) resources. In the systematic review of Park and Giap [122], Howe et al. categorized factors to patient engagement in patient safety initiatives as interpersonal, intrapersonal and cultural. Others categorized factors as resources (e.g., time and cost), service patient or patient issues, organizational issues, or system wide factors [122]. Other authors such as Each Kovacs Burns and Frankish et al. identified broad factors to participation in health care decision-making [122].

The following paragraphs describe and explain how the seven types of factors identified in our research project influenced PE in Risk management for safety in our research project.

Regulating elements

5.2.5.2.1. Environmental

The lack of or poor political commitment to patient engagement at all levels in the healthcare system and especially at the policy decision level is one of the strongest barriers. Luckily, in Quebec, in 2018, a reference framework on PE was published and strengthened PE initiatives and implementation in healthcare institutions [79].

"The MSSS reference framework came out couple of months ago. And we developed a procedure and guide".

"We used CPSI'S and AC'S resources to build our training tools and procedure for PE for PS".

5.2.5.2.2. Leadership

Trusting in the competence, abilities and collaboration of our leadership is important to instill trust in one another within the organization. The leader [4], also is a vector to bring and deploy a vision at each level of the institution. Leaders initiate partnership between departments, or community organizations, pilot projects, etc., and exists within the organization as clinical leaders, organizational leaders and strategic leaders [122]. In our research project, many leaders had shared values of PE, without necessarily having the right approach to PE institutionalization (which is starting with the knowledge acquisition, then the knowledge sharing, and knowledge preservation). Many did underestimate the knowledge acquisition phase and went directly into the knowledge sharing phase of involving patients directly into committees, etc. without first understanding the value of integrating a PP into any of their committees or ongoing projects. As leaders implement PE for safety, a best practice would be to support **pilot projects** and involve patients into the conception/part of the team of the decision-making and design of structures and services/documents and procedures revision, before implementing the later across the institutions.

"Start with pilot projects involving patients in projects".

"Involve patients in the conception and design of the structure, services, not just participation on committees after the event has arrived".

5.2.5.2.3. Internal policies and legal aspect

Policies and strategies articulating the PE approach is necessary for the personnel and patients to understand the institution's priorities and philosophy. Similar to policies of well-being (which was find missing in most of the institutions), transparency, etc., designing a set of policies can help structural elements of barriers [122].

"Policy of patient involvement in the institution (e.g., the policy favouring the presence of family and friends in the hospital environment) helped put in place an action plan for PE".

Normative elements

5.2.5.2.4. Cultural

Integrating a transparent communication and awareness of a blame-free culture is crucial to creating and maintaining a safety culture [123]. Professional culture, particularly in the healthcare space can be highly technical, which would require training in health literacy and terminology to address this barrier of HCP-patients communication. As well as training and accompanying managers on the innovative practices for a non-blame culture.

"We need to be able to understand and practice a blame-free, fair and transparent culture. With concrete examples / cases and identify the practices brought forward by management / staff / and patients".

Communication may also be hindered by work silos, which is why institutions should cultivate collaboration [109] between departments as demonstrated in the research project. This is a must in order to diminish risks especially between the patient committee, the complaints department and PE and patient experience offices in order to collect and analyse the patient's voice.

Another type of collaboration is inter-institution collaboration in order to share knowledge (through a community of practice for example or being accompanied by universities to support implementation of PE's approach).

"We are also setting up a collaborative space to review population responsibility across the health continuum and actions taken".

"We are also putting together the citizen health council for collaboration with the community".

"We are accompanied by the university of Montreal, and the DCEPP, to help us with our PE implementation approach".

Innovation [109] is also a key vector for a safety culture (e.g., control rooms or spaces for innovation and collaborations). Many studies demonstrated the benefits for patients and decision-makers at various levels to have patients engaged in face-to-face discussions and decisions concerning healthcare and health product decisions or issues [25, 20, 22]. Sharing information, experiences and concerns between patients and decision makers was more than educational; it was also informative for healthcare recommendations. One of the overarching benefits of patient engagement is enabling the health system to address the right issues in an appropriate way, design programs, policy and planning activities closely tailored to the needs of both individuals and special populations; achieve better results; and validate outcomes [92, 20]. Knowing that, healthcare institutions creating spaces (committees, innovation spaces, etc.) for patients to raise their voice are central to sharing information and experiences for patient safety.

"*We try not to work in silo. The tool that allows all of this is our control rooms, on our walls, people can see the boards. The team then solicits the colleagues and takes it back to the cockpit. We treated it as culture change and performance. We have an operational, tactical, and strategic control room. …We work our indicators in cascade and_escalation. One that has an effect on another. From the strategic level to the clinical level or vice-versa".*

E.g.: "F*or the prevention of infection. We monitor nosocomial infection rates. The indicator is applied at the operational level. At the ROP level. At the tactical level, we apply it to hand hygiene (the manager puts indicators on the board, does he have processes that prevent you from working; after that, we look at the monitoring, what does it say in our sectors of activity, is there a risk that it will come back? yes, we'll work on that and we monitor it over time. We've added it on a map. If the card is red, what's on the protocol has not been followed.......Just the fact that the employees see that they are heard by the management, makes a difference…the means of communication flow".*

5.2.5.2.5. Organization structure of PE in risk management

A need for a governance body (PE office and patient's experience office) is essential to implement PE for safety. Not only to oversee activities, but to support, evaluate and train personnel. In order to achieve this, performance indicators must be integrated in performance measures (including quantitative and qualitative measures, patients' experience measures).

Cognitive elements

5.2.5.2.6. Personal characteristics

Furthermore, despite progress towards acceptance of a more important role for patients, attitudes of health professionals remained a strong barrier [122]. Negative attitudes might manifest through professionals disengaging, not sharing information or resources, or exerting their power [122]. Much of this negativity could stem from professionals feeling threatened if they had to seek advice from expert patients; that it was a significant change from the medical model they were used to; or that it might question the role of health professionals [124].

> *"At the clinical level, managers do not yet see the added value of organizing interdisciplinary IP, studies do not show that it is effective. It takes time and resources. We need studies to show effectiveness. The added value in the committees has not yet been demonstrated. It has to be people who understand the system ".*

Characteristics of patients like knowledge of healthcare institutions, disease or health condition (e.g., mental health issues) and other relevant aspects might lead to discrimination, and therefore lower opportunities for involvement [122]. Other considerations for patient and family involvement included their willingness to participate, commitments and time, transportation, wellness and health, language and communication, and fear of health care being jeopardized [125].

Other barriers to PE for safety include well-being strategies for patients (e.g., presence of patient's right, patient's group or committee for support, compensation?) (and wellness strategies for healthcare professionals (e.g., support for leadership, employee recognition, mental health support, workload management, etc. [92].

> *"We present posters on safe care at the Barrel Institute. We're doing Planetree, and at the same time, we recognize our employees this way by sending them to these conferences. It's the best way to recognize. By doing that, we're taking knowledge from everywhere. There are resource patients who are on Accreditation Canada (AC), and CPSI, Vigilance, medication safety, self-medication, surgery, psychiatry, SM, etc.".*

5.2.5.2.7. Resources

Human resources / tools and training

Creating a governance structure of PE and PExp structure as we saw in the study helped many institutions with their PE institutionalization. In addition to those structures, having a PP bank is necessary in order to have the PPs ready when needed.

> "Recruitment is done through our multiplying agents (managers in other departments), on our websites, or referenced from a physician, an HCP or staff at reception, or again, from application forms found at the reception/waiting area"

"The choice of patient partner is very important. Experienced patients: e.g., "a patient who has experienced a Risk situation (accident or incident), but who has enough distance either directly or through a relative. Challenges: recruitment and the length of time required for meetings".

"The competence profile of patients in Risk management should have is: "1- knowledge of how to be; 2- knowledge; 3- motivation. Within our project on Acting and with the patient we use the competence profile".

While there is support for volunteer engagement with a wide range of activities for volunteers, several barriers to volunteer engagement were identified. These barriers relate to unionization, patient safety and confidentiality, volunteer attendance, and lack of collaboration between clinical and volunteer resource department. Interpreting the results with an interprofessional practice lens. These barriers could be addressed through improving role clarity of status for volunteers.

Methods and tools, and HR competencies and hiring process should be reviewed and aligned with PE in safety. For instance, inappropriate or lacking administrative procedures, reporting and technical skills required for some engagement activities [122] can become difficult barriers to overcome. Health institutions should invest to hire the right type of human resource with the right number of hours spent on PE projects. PExp personnel should definitely have an evaluation background as a competency, as they may encounter project evaluations and mostly qualitative data evaluation as well as quantitative.

As much as the institution should focus its attention on engaging patients, it should also consider engaging organizational leaders and healthcare providers as “multiplying agents” of PE for PS in their departments.

« We identified people who have collaborated with the DQEPE. But are not officially mandated. They are often the managers ».

« People who have collaborated with. But are not officially mandated. They are often the organizational leaders ».

Creating and developing PE for PS modules, presentations, training, promotional documents as well as recruitment form, guides, for patients and HCP competencies, are all essential tools that are needed at the knowledge acquisition phase of the PE institutionalization [92]. But only few institutions had put these in place before moving on to the sharing knowledge phase.

“We don't have any training in patient safety engagement yet”.

In addition to creating new knowledge strategies and resources of continuous education tools should be created for patients and HCPs as well as for managers, as many organizations, were not yet at that phase.

Financial & Research resources

Investing in pilot projects for PE in risk management for safety is a determining factor at the “knowledge acquiring phase” (see Chapter 3, Article 3 of the research thesis). Without the proper preparation and understanding of factors influencing PE institutionalization in specific areas, the institution risk to lose HCPs and manager's interest by integrating PP in every instance without properly understanding its value.

"We need funding for these types of projects, especially as pilot project to evaluate the impact and their outcome properly".

" To demonstrate the value of patients in committees and projects, *research projects are a Gateway to PE".*

"At the clinical level, managers do not yet see the added value of organizing interdisciplinary IP, studies do not show that it is effective. It takes time and resources. We need studies to show effectiveness. The added value in the committees has not yet been demonstrated. It has to be people who understand the system ".

There is a revolving question regarding patient compensation in patient engagement. While the compensation need not be financial, perhaps other useful or health-related services could be included as a compensation package:

"For example, peer helpers could get paid a small fee in psychiatry, or again, have funding for Patient Partner projects?".

"However, *we do not need to professionalize the role of the PP"*

One institution came up with an innovative way to tackle the structure of the compensation of PP in their organization:

« *We use the existing volunteer structure to integrate PPs. Often, they become our PPs. And they have their access card and volunteer compensation".*

Indicators resources

The added value of patient involvement has not been quantified and qualified in economic terms and, thus, patients have not been adequately compensated for their contribution. Further, meaningful indicators associated with health outcomes following patient engagement would be required for more involvement of both the patients and healthcare professionals [92]. Some indicators or evaluation processes for levels of satisfaction are measures of success. That said, other indicators include participation or response rates of patients, Patient influence on decisions, health care outcomes or resource utilization, patients' or professionals' satisfaction with the engagement process or resulting products, cost, critical factors for success, and limitations of methods or processes. Rather than assessment being a step that happens at the end of the engagement opportunity, healthcare institutions should integrate a methodology evaluating each process into the planning at the outset. Which will save time and frustration at the end and enable better learning from the process as it is taking place.

Finally, table 11 shows the different indicators identified through the research project. Three specific indicators related to PE for PS have being identified: 1- Number of PP engaged in the evaluation of sentinel events/incidents/accidents, 2- Double Identification of patients with a bracelet, 3- Number of security committees or teams that have a PP. Other type of indicators are more general to PE and include, the number of PP existing in the institution, the presence of a PP bank, number of PP integrated in teams, etc. (see table 11 for more information).

5.2.5.3. Limitations

The biases of this survey are primarily related to its declarative nature. Furthermore, respondents may have overestimated the actual level of patient involvement in their institution or, on the contrary, may not be aware of all the initiatives and practices in many of the services and departments. Thus, healthcare institutions should ask themselves if they put the effort to identify and collect information on PE in PS strategies within their organization? How do they ensure that these strategies are communicated throughout the organization? And how does the organization value these strategies?

Another limitation of the questionnaire is related to the difficulty in differentiating between the involvement of patient representatives and other patients in the responses, as well as personnel changes within surveyed institutions. Finally, this survey also enabled us to report on pioneering experiences developed by certain institutions that involve their patients in, for example, analysing sentinel events, disease pathways, incidents and accidents, finding solutions or informing other patients.

5.2.6. Conclusion

The Quebec's case study on emerging strategies and mechanisms of PE for safety is a first in its kind. This original research project on PE in risk management is more important than ever before because of the pressing issues in PS. As the first of its kind in Quebec, this original research project on patient engagement in risk management for safety is more important than ever. Whether Quebec's healthcare system allows for generalizations that could be applied to other national or international jurisdictions still needs to be examined in more detail. In line with this idea, there is currently an ongoing Pan-Canadian research project [126] modeled after this project, in addition to a project in France, [85] where this study was used (the framework and questionnaire) to describe their PE strategies for safety. An upcoming study is under way in Brazil as well. With enough jurisdictions covered, it would be interesting to assemble a global case study in partnership with the World Health Organization. This would help oversee and prevent a broader set of risks, which it would be essential to define risk according to those different contests from around world. Future comparative studies will also be conducted between provinces, nations, including their evolution over time. Moreover, additional research should focus on the role of patient groups, volunteers for better PE for safety, as well as compensation models for PE. This type of analysis could support the development of strategies to reduce and remove barriers to PE in safety optimization.

Lastly, from an even broader perspective, PE could be viewed as a window to Citizen Engagement, inside and outside health institutions, with regards to their own health and safety, especially during health crises such as pandemics (e.g., Covid-19).

5.3. ARTICLE 3

TITLE: Innovative practices used in the institutionalization of Patient Engagement in risk analysis process: A Qualitative Longitudinal Case Study of a fall reduction and prevention strategy from an Integrated Healthcare Centers in Quebec

To be submitted to BMJ- Quality and safety journal

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ABSTRACT = 345 words

Context: Injurious falls are the most prevalent in-hospital adverse event, and hospitalized patients are at greater risk of falling than the general population. Patient engagement in hospital fall prevention could be a promising approach to help reduce falls and fall-related injuries.

Objective: Analyse a concrete example (case study) put in place by organizational leaders in one of Quebec's Integrated Health and Social Service Centers in order to identify (1) emerging innovative practices, mechanisms / strategies, and (2) limiting and enabling factors that would allow patient engagement to be fully institutionalized[36] (implemented) in risk management for the enhancement of patient safety. In this case, fall prevention and reduction.

Methodology: The research design is a longitudinal case study with interwoven levels of analysis (strategic, organization and clinical). The case study is from the CISSS Montérégie-Est, which started implementing strategies (fall prevention and reduction pilot project) to engage patients in risk management in a long-term care facility. A qualitative approach was used to conduct semi-structured interviews (N = 7) of 40 min to 2 h 30 min for data collection and observation, as well as internal and external documents analysis.

Results: Analyzing PE in fall prevention and reduction with the center's clinical interdisciplinary team was a success as the rate of falls evolved from 10 falls per week (2016-2017) to 4-6 per week (2017-2018). Other related results include: family and friends involved in finding solutions to fall prevention and reduction; patient-partners (PP) involvement in the communication strategy towards patients and their family, as well as training to read a viewing board that presents the number of falls in the residential unit and potential prevention strategies.

Conclusion: To be able to prevent and reduce falls, engaging patients and their family / friends as co-designers/collaborators could be the answer. This means engaging patients not only in their own health at the clinical level with healthcare professionals, but also at the organizational and strategic level for care, service design and process revision and development. Moreover, PE in fall prevention and reduction save costs from fall related injuries (Wong et ah, 2011).

KEYWORDS: Patient engagement, safety, institutionalization, fall prevention / reduction, strategies/mechanisms, innovative practices, emerging practices

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5.3.1. Background

According to WHO [1], falls[37] are the second leading cause of accidental or unintentional injury deaths worldwide. Each year, an estimated 646,000 individuals die from falls globally, of which over 80% are in low- and middle-income countries, and 37.3 million falls are severe enough to require medical attention. Falls are a significant cause of preventable injury and death, particularly among the elderly. In 2010, in the United States (U.S.), 31.7% of adults aged 65 years or older fell and experienced injury within that year [71]. Hospitalized patients are at a greater risk of falling than the general population and it is estimated that nearly 1 million patients fall during their hospital stay annually in the United States, while up to half of these falls result in an injury [127]. Tzeng & Yin (2015) emphasized that the risk of falling can rise from multiple factors including mobility problems (e.g., due to surgery), medications for sedation and pain relief, aging (e.g., older adults), and mental status changes (e.g., delirium) [128]. In U.S. hospitals, patients with fall injuries stay in the hospital an average of 6.3 extra days longer and their care costs $13,000 more compared with patients who do not fall during hospital stays [128].

To successfully prevent harm, past research indicates how vital it is to partner with patients and provide them with a role in their own safety and safety planning [129, 130]. Patient engagement (PE) can lead to better health outcomes, contribute to improvements in patient safety, and help control health care costs [129, 7]. However, this has not been tested empirically on inpatient fall prevention in long-term care settings. PE in patient safety requires a culture shift from

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[37] A fall is defined as an event which results in a person coming to rest inadvertently on the ground or floor or other lower level. Fall-related injuries may be fatal or non-fatal *(1)* though most are non-fatal. For example, of children in the People's Republic of China, for every death due to a fall, there are 4 cases of permanent disability, 13 cases requiring hospitalization for more than 10 days, 24 cases requiring hospitalization for 1–9 days and 690 cases seeking medical care or missing work/school [1].

a “paternalistic” approach – where physicians and healthcare providers are the experts – to a coproduction approach, where patients and healthcare professionals, physicians and administrators work as team to generate value by fostering partnership in fall prevention and reduction [128, 131, 132]. Coproduction identifies patients as experts in their own preferences and values and recognizes clinicians as medical science experts [131].

Many strategies used to reduce falls in elderly care facilities involve fall risk assessment and screening tools, use of bed alarms, patient and family education, increased frequency of patient rounds, patient involvement and engagement with the nurses for education on fall prevention [128]. However, the sustainability of these effects obtained mixed success, and a consistent trend of reduced inpatient fall incidents has not been noticed [128].

An innovative fall prevention approach is needed to reduce and sustain reductions in inpatient falls and injurious falls in acute inpatient care settings. However, very little research has been done on PE in planning and design of care and services leading to fewer patient falls and injurious falls during hospital stays. Further, the level of PE in current fall prevention initiatives has not been established [133]. This is why strategies of fall prevention and reduction should include PE at the organizational and strategic level of care and service design in long-term care facilities in order for patient voices to be

heard and seen through all levels of governance. Moreover, evidence in a systematic review shows that multicomponent interventions can reduce risk for in-hospital falls by as much as 30% [134]. Most common strategies used involve risk assessment for patients, patient and staff education, bedside signs and wristband alerts, footwear advice, scheduled and supervised toileting, and a medication review [134].

While the literature has identified some limiting and enabling factors to the implementation of PE in fall prevention and reduction, there are still some innovative emerging practices that leaders in healthcare organizations are creating. Therefore, the aim of this article is to analyse one concrete example (case study) of PE institutionalization (becoming embedded) in risk management for patient safety (fall prevention and reduction) implemented by leaders in one of the Integrated Health and Social Service Centers of Québec (Canada) in order to identify (1) emerging innovative practices, mechanisms / strategies, as well as (2) limiting and enabling factors that would allow PE to be fully institutionalized in risk management for the enhancement of patient safety.

5.3.1.1. Context of the case: the CISSS Montérégie-Est

The CISSS of Montérégie-Est is a semi-rural health and social services organization the 4th biggest one out of 24, located on the South Shore of Montreal serving a population of 510,000 people with 12000 employees and 800 physicians [135]. Over the years, fall declarations increased at the CISSS [136]. In fact, in Quebec, fall declarations are one of the main causes of adverse events reported by health and social service institutions [135].

This is why, in an attempt to reduce these events, the integrated health center decided to work on a fall prevention and reduction project through its Quality Department [136]. This decision came about after the department had analyzed the situation and concluded that patients, as a co-evaluators/coproducers/collaborators, were missing from the interdisciplinary team carrying out the analysis as well as from the design of care and services related to adverse events such as falls [136].

5.3.1.1.1. The FORCES[38] project

In light of the above observation, a team from the Quality Department of the CISSS in Montérégie-Est executed a 14-month continuous improvement project called FORCES, as part of the Canadian Foundation for Health Services Improvement (CFHSI) national training program for practising managers [105].

The objective of the FORCES project was to reduce by 15% the rate of falls and fall-related injuries at the Du Palais residence unit of the Hôtel-Dieu Long-Term Care Center (CHSLD Hôtel-Dieu) in Saint-Hyacinthe between (January 15th and November 10th, 2018 [136].

For this continuous improvement project, the Quality Department of the CISSS of Montérégie-Est decided to develop three strategies to achieve the project's 15% reduction objective : (1) PE in the analysis process of a fall; (2) partnering with the interdisciplinary team in the analysis process by setting up a visual board comprising of the use of the (i) safety cross[39]; (ii) a communication section; and section for the objective of the year and value of the institution. (3) Engaging a patient/family or friend as a partner in the design and revision of care and services for fall prevention and reduction solutions [136]. Moreover, the visual boards are discussed during a (i) quality/safety caucus (ii). Another intervention put in place are, the intentional tours[40] . For more information's on the visual board and the intentional tours, please consult APPENDIX J – Visual board, and APPENDIX K – Intentional tours.

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[38] FORCES : project focusing on the strengths of the institutions in order to implement initiatives

[39] Safety cross: Part of the visual board in which safety indicators are integrated

[40] Intentional tours: Before entering the room of a Patient, any person should ask four questions. (see Appendix K – Intentional tours for more information's on the type of questions that are asked)

5.3.1.1.2. The Du Palais Residence Unit

The Du Palais residence unit (*Unité de vie Du Palais*) is a housing unit which contains a total of 84 beds, 19 of which are in prosthetic units (a living environment adapted to the needs of elderly people living with various types of dementia which could lead to disruptive behaviour). The average age of the unit's residents is 80 years old (mainly elderly people in loss of autonomy) [136]. And in between 2016-2017, the residence unit reported an increase in falls (N=446) [136].

5.3.2. Methodology

The following section will first explain the conceptual framework used in the research project. It will then provide a description of the study design, participants, case selection, data collection and analysis, ethics and timeline.

5.3.2.1. Theoretical framework

According to the model of early institutional sociologists Scott, et al., (1983), institutions provide vital functions for harmonization within society in a given context. An institution is usually the product of a process of "institutionalization": a process through which something (a change, such as a concept, a behavior, a common value, etc.) anchors itself within an organization, a social system or society [3, 4].

PE for safety in care and services can be seen as a lever for organizational change management and a way to inspire and mobilize all partners for new practices and behaviours, despite difficulties linked to such a transformation. It also allows the health and social services system to not only be motivated by budgetary and political imperatives; but rather to build around the value created for and by people who work and are greeted there, in order to be more effective, more efficient and more responsive to citizens.

Based on change theories (institutional theory and the creation of organizational knowledge), the conceptual framework (APPENDIX A - Conceptual Framework PE for PS. **In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study**) describes the different levels of PE strategies used by leaders across multiple levels (strategic level, organizational level, and clinical level) in order to institutionalized PE for safety.

According to Nonaka's change theory, the creation of organizational knowledge (by which meaning is given to things) is done through an approach (institutionalization/internalization) that involves the observation of three basic dynamics: the creation of knowledge, its application, and its preservation [99]. But, according to Institutional Theory, an institutional organization can only be legitimate if it internalizes it resources (its norms, regulations, and its ability to process information and make decisions, also known as the cognitive-cultural dimension) by exercising pressure (change) through three pillars:

- Normative Pillar: Norms are legitimate ways that allow us to achieve the objectives of our values. Together, values and norms define the roles that are socially attributed to members of an organization, which can be formally known or emerging informally with time.
- Regulating Pillar: This pillar is used to preserve order via regulation and is more perceived through an economic angle (according to DiMaggio & Walter) [3]. It applies to the study of the behavior of individuals or entities (organizations) whose interests are often in conflict with each other.

- Cultural-Cognitive Pillar: An institution’s cultural and cognitive elements are, respectively, shared conceptions of social reality's nature and the frameworks through which meaning is given to things.

These three pillars (normative, regulating, and cultural-cognitive) in return, apply pressure on different levels of PE (strategic, organizational, clinical) with regards to PE for safety.

For an organization to adapt to PE-related changes and to fully institutionalize PE for safety, engagement (new knowledge) must be produced through a continuum of institutionalization: knowledge must be created (education, information); then applied by different stakeholders (in this case: patients, Health Care Professionals (HCPs) and leaders) through shared leadership and decision making in process design, care design, communication, training, measurement, etc. And finally, knowledge preservation must occur through different policies, evaluation systems, research programs, and support systems (for the purpose of sustainability and continued education / improvement).

5.3.2.1.1. Study design and participants

The research design is a longitudinal case study with interwoven levels of analysis (strategic, organization and clinical). The study is a case study from the Montérégie-Est Integrated Health and Social Services Center (CISSS Montérégie-Est), which started implementing strategies (pilot project of fall prevention and reduction strategy) to engage patients in risk management in a long-term care home. According to Yin (2003), a case study is particularly relevant in the context of research that focuses on understanding ("how") and explaining ("why") complex phenomena or phenomena highly influenced by external environments [104]. A qualitative approach was used to conduct semi-structured interviews for data collection and observation, as well as internal and external documents analysis.

5.3.2.1.2. Cases selection

The CISSS de Montérégie-Est was initially part of a research project related to PE in risk management for safety which involved 24 other healthcare organizations in Quebec and had taken place a couple of months prior [81].

The CISSS de Montérégie-Est case was then selected out of 24 other because: (1) it had just secured a grant by the Canadian Foundation for Health Services Improvement (CFHSI) national training program for practising managers [105] to pursue a pilot project on fall prevention and reduction in their long-term care facility; (2) it had started to implement PE mechanisms for fall prevention such as involving a patient-partner in its committee, planning and modeling the desired change for fall reduction, etc.) which were identified from the part one of the research project on PE in risk management for safety. Lastly, (3) it had a specific objective and plan on how to reach its 15% fall reduction objective in its long-term care facility.

An information and consent letter were addressed and send by mail to the Director of the CISSS in order to brief her about the project's objectives and solicit her participation (APPENDIX E - Consent form Part 2 – research project PE for PS). A week later, the Director was contacted by telephone to confirm her willingness to participate in the study and to find out (if applicable) the names of people who would be interviewed. The interview dates (N= 7) were also set during those telephone calls.

5.3.2.1.3. Sampling for individual & semi-structured interviews

In this longitudinal study, a series of in-depth group interviews took place. The group interviews occurred at two levels. First, at the strategic level, the research team interviewed the working group responsible for the pilot project. The members of that group included individuals from senior leadership roles such as: the General Manager, who also happened to be the Director of the Quality, Evaluation, Performance and Ethics Department (DQEPE) and of the health institution; the Quality Deputy Manager responsible for implementing the pilot project; the Chief of Service of Quality and Risk Management, as well as the executive advisor in Patient experience and ethics, and the executive advisor in quality. Secondly, at the organizational level, the research agent participated in the Consultative committee in charge of deploying the pilot project in the long-term care facility for fall prevention and reduction strategy. The committee comprised of: the working group responsible for the pilot project, 9 HCPs and managers at the clinical level, two other resources in charge of communication and complaint department, as well as a family member of a patient (as we will use the term PP here) (please refer to Table 1 - **Description of the different teams in charge of the institutionalization of PE in falls prevention and reduction,** for more information).

In addition to a series of interviews, the team observed interactions between members of the consultative committee and the strategic working group on the FORCES project, as well as how they evaluate their progress and performance through indicators. Additionally, internal documents were consulted in order to corroborate on PE mechanisms and strategies put in place for fall prevention and reduction in the FORCES project.

5.3.2.1.4. Data collection – and collection instruments

In order to obtain a fuller picture of the context [102, 106], the research team completed **data collection** using different methods: individual semi-structured interviews; group discussions; external and internal institutional documents (please refer to Box 1 - **Internal documents evaluated in the pilot-project,** for more information on the type of documents consulted); and group interaction observation.

Since the research study is a longitudinal case study, data collection was completed according to a specific timeline (T). T0 marked the implementation of Bill 10, Quebec's health care reform of April 2014, and T1 was part one of the research project in which the CISSS de Montérégie-Est was identified (ref, article on questionnaire). Hence, data collection for this specific case study began in T2, according to the following timeline: T2 (March 2017 – December 2017) – Series 1 of group interviews; (January 2018- October 2018) –Series 2 of group interviews. (January 2018- October 2018).

Moreover, data contained in the CISSS' internal documents allowed the team to review and confirm variables and methodology, whereas Field observation help refine the contextual environment and dynamics between health professionals and support triangulation. Among the documents collected are: organisations' annual strategic plans; codes of ethics; risk management process and procedure; minutes of working group of the DQEPE, and of the consultative committee meetings; final presentations on results made to the external body (N= 2), tools explaining visual board, safety caucus, safety cross, surveys tools for patients, and for HCPs, and risk management dashboards and indicators.

Table 13: Internal documents evaluated in the pilot-project

Internal documents collected	Number of documents collected
Organisations' annual strategic plans	1
Codes of ethics action plan	1
Codes of ethics	1
Risk management process and procedure	1
Minutes of working group of the DQEPE meetings	4
Minutes of the consultative committee meetings	4
Final presentations on results made to the external body	2
Tools explaining visual board, safety caucus, safety cross, intentional visits (refer to Appendix xx to view these tools)	3
Surveys tools for patients, and for HCPs, (refer to Appendix xx to view these tools)	2
Risk management dashboards and indicators.	1

The measuring instruments used for the semi-structured interview guides were based on the importance of context and strategies/mechanisms of PE for safety. The interview guides were pre-approved by the student researcher and the research director, based on the conceptual model of the institutionalization of PE for safety (APPENDIX D – Interview guide – Part 2 research study PE for PS). This conceptual model addressed indicators used to measure PE for safety, mechanisms and strategies used by leaders to implement PE for patient safety, as well as factors influencing the engagement of patients, health professionals and / leaders.

5.3.2.1.5. Data analysis

The approach to data analysis was based largely on the qualitative analysis of collected data. Semi-structured interviews were recorded digitally by the student-researcher. Data transcription was also completed by the same student-researcher who encoded it using qualitative software (QDA miner). A double coding was performed with the Director of research using different themes contained in the study's conceptual framework. These themes focused on the mechanisms and strategies used by institutional leaders at the different levels of the institution; factors influencing

PE for PS; and measurement indicators of PE for PS. Finally, data triangulation was completed and confronted with documentary and field observation.

5.3.2.1.6. Ethics

The *Université de Montréal* Ethics Committee and the Research Center of the CHUM (CRCHUM) approved the research protocol as a multicentric research project, under approval number: MP-02-2017-6814 -- CÉR CHUM Number: 16.189 (APPENDIX F - CRCHUM research protocol approval letter - MP-02-2017-6814 -- CÉR CHUM Number: 16.189).

Study participants were informed prior to partaking in the study and signed a consent form (APPENDIX E - Consent form Part 2 – research project PE for PS), preserving anonymity and confidentiality of data. Participants were free to withdraw at any time from the study if under any constraints. The research team followed appropriate procedures to secure the confidentiality of research data.

5.3.2.1.7. Timeline

The longitudinal research study lasted two years and a half on the field: From September 2016 to December 2018.

Table 14: timeline

	# of interviews	T1 (January - December 2017)	T2 (January – October 2018)
Group interviews with the strategic /tactical support internal working group of the DQEPE	3	22 June 2017 (1h35) 22 September 2017 (45 min)	10 October 2018 (35 min)
Group interview of the consultative committee (including the clinical interdisciplinary team and the PP)	4	22 November 2017 (2 :30 min)	8 February 2018 (2:30 min) 26 April 2018 (1:00) 6 June 2018 (2:30)

5.3.3. Results

In this longitudinal study, a series of semi-structured group interviews took place. These interviews lasted between 40 min to 2:30 min approximately each and took place on the premises of the CISSS from January to December 2017 (T1) and from January to October 2018 (T2). Below, are five tables presenting the results collected from the semi-structured group interviews, the documents and observation made on the field.

Table 15: Description of the different teams in charge of the institutionalization of PE in falls prevention and reduction

Table 15 describes the various teams in charge of deploying the pilot project in which the institutionalization of PE in fall prevention and reduction project is taking place at the CISSS Montérégie-Est.

	Working group at the DQEPE (strategic internal support team)	**Clinical teams on falls prevention**	**Consultative committee - including the PP**	**Other resources**
# of people (N= 17 in total)	4	9	15	2
Title of people involved				
Quality director	X			
Deputy director of Health	X			
Chief of integrated services in quality and risk management	X			
Senior Advisor – Client Experience and Ethics	X			
Executive advisor in quality	X			
Advisor in communication				X
Advisor in services to the elderly		X		
Executive advisor in long-term care		X		
Coordinator of patient services and environment of HCPs		X		
2 Chiefs of service (one from the pilot project and another one from another unity)		X		
Deputy director of services to the elderly		X		
Coordinator of services to the elderly and long-term-care services		X		
Registered Nurse		X		
Long-term care operator		X		
Complaint commissioners				X
Professional Development and Executive Services Assistant		X		
# of group meetings	Twice per week (3 hours every time)	4 times during the year (2-3hours each time)		

Table 16: Innovative practices identified in the institutionalization of Patient Engagement in risk analysis process

Table 16 describes the Innovative practices identified in the institutionalization of Patient Engagement in risk analysis process in fall prevention and reduction pilot-project at the CISSS Montérégie-Est. (from knowledge creation to knowledge preservation).

Strategy I: Knowledge creation			
1	**Pilot project**		Identification of the pilot project site based on the number of falls, and leadership and unit experience in order to lead the project
			Literature review and identification of innovative practices in fall prevention
2	**PDCA Cycle**		
		Identification of needs	Integration of a PP and making the fall analysis process more clinical and interdisciplinary by involving the clinical team in the fall analysis.
		Identification of strengths	Viewing station tools, fortress tool, security caucus, security cross, Form H-223
		Identification of indicators	Patient engagement in fall analysis process; HCP engagement in the interdisciplinary fall analysis clinical team; Leadership engagement in fall analysis reduction
		Objective	Objective for fall reduction and prevention in fall analysis which involves an interdisciplinary clinical team and a PP
3	Communication plan		Awareness of management
			Personnel awareness
4	Tool adaptation (refer to APPENDIX J and K to view tools related to the visual board, tracking tool, safety caucus, Intentional tours questions, H-223, and safety cross)		Working committee working on the tracking tool
			The safety cross and choosing the theme of the year (reduction in falls of severity F by 15%)
			The Quality/Safety Caucus
			H-223
			Visual board
			Intentional tours
5	Creation of the advisory committee		Committee comprising 15 members (clinicians, managers and tactical and strategic members)

6	Representation of our interdisciplinary clinical teams in falls analysis	Creation of the Interdisciplinary Team
7	Representativeness of a PP in the fall analysis process	Identification and hiring a PP
8	Identifying the Support of the interdisciplinary team	The DQEPE Working Group team
9	Measuring satisfaction	Surveys
		Safety culture survey
10	Developing procedures and policies	Fall analysis procedures and policies within an interdisciplinary clinical team with the PP
Strategy II: Knowledge development and sharing		
1	Daily support for the unit’s team	By the DQEPE Work Group
2	Communication Plan	Communication and transparency
3	Implementation of tools	Satisfaction survey
		Intentional tours
		Viewing stations
4	Raising awareness and training HCPs	Video clips on organizational safety
		Video clips on patient and resident safety
		Training the Du Palais unit’s personnel on how to moderate a visual board
		Next step: involve registered nurses and nurses
5	Engagement of PP, friends and families	Creating a viewing board with help from a PP – Communication with the family
		Training families and loved ones in finding fall reduction solutions
		Advisory committee
		Involvement of the PP in the interdisciplinary clinical team for fall analysis with H-223
6	Assess satisfaction surveys regarding participation in the process and safety culture	Accreditation Canada (AC) safety culture survey, and employee knowledge survey on the Adverse Event Declaration Process, how they experience it on in the unit; if it is difficult; and they are involved
7	Follow-up assessment	Meet the unit's professional team about the visual board, meet with a PP
		Creating a decision algorithm
		Visual board (20 min instead of an hour)
		After 4 months assessment
		Creation of the Great Fallers committee thanks to the visual board

Strategy III: Knowledge preservation		
1	Designing sustainability from the start	Conceptual framework "National health services model"; 3 pillars: 1-the staff, 2- the process, 3- the organization “”
2	Collaboration	Collaboration with different departments (Multiplying agents)
3	Vision alignment	Aligning vision with strategic and tactical plans
4	Adapting the tools	Viewing station and Project fortresses
5	Transferability plan to other units (N=16)	Communication and awareness plan - managers
6		Train HCPs and nurses
7		Training plan- Patients, residents and families
8	Human resources for transferability of the project to other long-term care in the institution	Project manager
		Involvement of all directorates and involvement of clinical managers in residential services, PP,
		Support change management by the DQEPE team
9	Visibility	Presenting the pilot project to the MSSS and transferring knowledge outside the organization

Table 17: Factors (regulating, normative and cognitive elements)

Table 17 describes the enabling and limiting factors identified from the qualitative and observational data collected that influence the institutionalization of Patient Engagement in risk analysis process in fall prevention and reduction pilot-project at the CISSS Montérégie-Est.

Type of factors	Definition	Quotes +
Regulating		
Environmental	MSSS recommendations on falls	**Incidents and accidents report form the MSSS**
	Accreditation bodies	“We received training from Accreditation Canada on patient- and family-centered care. And training with DCEPP with UdeM”.
	External support organization	“we are supported they give us webinars, 3 sessions in-person (Toronto, August in Mont Tremblant, February in Banff and in Ottawa). Eventually, it creates a university fellowship. They are great change management mentors”
	Universities	“We must train a PP team. We must be affiliated to the UdeM and DCEPP, etc.”
Leadership	Vision and strategic and tactical alignment of objectives	Strategic and tactical room and true objective which are in line with the project. The CEO is open to PE. And the Board, via the user committee, vigilance, etc. also asks us about it.
	Unity/clinical -open to innovation, trained in lean management and has past experience with a viewing station	“Open to innovation” “The manager, before, completed lean (green belt) before coming to work here, also she had worked on a viewing station which was being deployed as part of this project.
	Internal support team at the DQEPE	“We are a very competent small team. Our mobilizing force is the Deputy GM (visionary), and she is very good ambassador”.
Normative		
Organizational culture	Trust value	“We used to work together before. We also tried to bring different skills from different sectors, but we worked in the same center (CSSS) before. Everyone has their strengths: methods, relationships, etc. But basically, we have the same values. That way, we think differently with a great cognitive diversity, age, profession, etc. Which makes people enjoy working here. We laugh a lot. And we work very hard. There is no hierarchy. We all have lunch together”
	Collaboration between directorates (DSM, DSI, and SAPA)	“During the year, we created collaborations with the DSI, DSM, DSP, CU, residents' committee”
	Passionate and having fun	“We are passionate about what we do. We have lots of fun”

	Credibility of the DQEPE’S projects has been demonstrated throughout the years	“What helps us here, at the DQEPE, is that the undertaken projects are very successful: e.g., Accreditation Canada, ethical approach (massive consultation: conceptual framework for ethics, etc.; and now the FORCES project. Which means we have successes, major transformations, and recognition. So, we have established our credibility and can present PE as it is will be well accepted”
Blame culture perceived by employees	Tool used: survey by AC on safety culture: use of this survey to identify employees’ fears and areas of improvement	“fear to lose their job or to declare when they see something, etc.)” “Safe culture expressed by 48% of employees and 43% in the unit and 43% in the organization “We provide feedback on site visits and present main elements of what has been reported. We don't want it to happen within a blame culture, but in a culture of continuous improvement. So, we anonymize. Problems like “we hear noise from carts at night, etc.” We immediately report this to the manager in order to manage noise at night in the center. But for bigger problems, we complete the analysis first so as not to contribute to a blame culture”.
	Fall analysis process: Knowledge about H-223 (Is the form administrative, clinical, or administrative AND clinical?)	“The form is much more administrative” “Satisfaction regarding the overall process is 37% in T0” “The analysis contribution is not sufficiently present” "The analysis must be done on a daily basis, but it is not yet; it is not fluid yet "
	Clinical process of the nurse	Factors: "analysis took 1 hour when first set up. Because the nurse is not involved enough, and she does not know how to do an analysis. We must involve and train nurses" “We came up with a decision support guide for nurses"
Just culture	Recognition system	“We also want to put in place an employee recognition system, for employees who make a difference. Because a positively perceived employee makes a difference to others and contaminates" "We made the WOW employee (which is immediately reported to the manager so that he recognizes the employee)" And we send a letter which added to the employee's file. "
Cognitive		
Human Resources	Graphic designer	“Make these tools usable for all institutions since they are now integrated. This explains graphic designer and why vocabulary must be reviewed."
	Credibility of the PP	“Mobilizing Forces: PE, Staff Engagement and Manager Engagement” “He was at the unit every day. The care team brought him great credibility. That's why we also chose him. He has good analytical skills. His wife had been here for two years and was well integrated”
	Choosing the right PP	“Because the institutions are bigger now, being disconnected from the field does not work. It’s just about finding the right patient who will be able to verbalize his/her observations and experiences. ”

	HCPs	“We need to involve the PP at the clinical level for him/her to find meaning, or else, we will lose them” “We have a hard time freeing up our resources”
	Practitioner and registered nurses	Less participation for registered nurses because of cultural factors? They usually work individually and not within groups?
	Management	Resistance to change. 2 levels: colleagues and managers. Involvement of clinical managers also and not just members of the professional team
	Clerks	Added value of the viewing station: "Clerks report these comments to Julie" Promoting the employee's role in solution-finding.
	Multiplying agents for sustainability	Multiplying agents: SAPA, DSM, DSI, DSP, as well as willingness of the general administration, involvement of beneficiaries.
Tools	- AC safety survey - Patient experience survey - Employee experience survey -	“Interviews with patients, focus groups with families and loved ones, customer satisfaction questionnaires, and employee experience to go full circle” “Questionnaires: customer experience interviews; employee questionnaire... HR takes care of it ”
	- Change management concept to conceptualize the FORCES project	We utilize change management.
	- - Diagram of engagement forces and improvement charts	“We must produce several tools at the moment, such as: Diagram of engagement forces and improvement charts ”.
	- Awareness resource on risk management policies and procedures (declaration and disclosure, etc.)	Pecha Kucha: transmit all our knowledge on 20 illustrations that we publish within the organization, so that even the plumbers see them and say, "I know this exists" Each illustration takes 7 seconds to view and describes a very specific risk management concepts, policies and procedures.
	- Awareness video	the FORCES project requested that the center create a one-minute video on the objective and involvement of the team in charge, etc. to be used as a promotional tool.
	- Viewing Station	The viewing station has been recognized as good practice by Accreditation Canada (AC).
Training	Analysis Training for nurses	“Development of a decision support guide for fall analysis”
	Online training content and Guide to Good Disclosure	“We developed e-learning training content, a support guide for managers, video clips about proper and improper disclosure that we are going to do with the UdeM (we will perhaps involve patients as actors) ”.

	Clinical team competency in fall analysis	“Managing the viewing station. We also need experienced people who bring back good information”
Data analysis	Literature review	“We use the document center as a resource for evidence” "We're looking for literature not just in health, but other areas that apply." “We look at marketing literature a lot because customer experience comes from marketing. We connect it to perceived and actual experience to the 4 concepts of quality which creates a delight effect” ”.
	Scientific approach	“We have a very scientific approach because our person in ethics has a PhD” “We have a codification system for interviews, plus the questionnaire, create themes using analysis software (SPSS). The strategy is to recover the themes on which we want to work and explain that this was how we evaluated in the user experience ”.
Workload	Adding to tasks	It is not an additional task. It's about a 15-min daily task. We insert the indicator we are following. The objective is not to collect problems, but to find solutions together and solve them as a team.

Table 18: Indicators

Table 18 presents indicators and tools used during the implementation of strategies in risk analysis process in fall prevention and reduction pilot-project at the CISSS Montérégie-Est.

INDICATORS	
Organizational measurements related to PE for PS (quantitative data)	PP participation in the advisory committee Participation rate of the clinical team and PP in the analysis falls of F-severity Management engagement in fall reduction analysis Create a PP bank Integration of HCPs and PP in the identification, adaptation and development of existing or new tools
Organizational measurements related to PE for PS (qualitative data)	Surveys: Satisfaction/dissatisfaction relative to the process (team, manager, patient): Assessment of employee, patients, management and professional satisfaction in team analysis of an adverse event the engagement of patients, families and friends in the identification of solutions for fall prevention and reduction measures after a fall had happened to their loved ones Identify the right PP according to the literature
Organizational measurements related to falls (PS)	Non-Injury Falls Rate Cost of falls leading to hospitalization Safety culture satisfaction rate
Other (Unit measurements)	Controlled pain and uncontrolled pain management End of life Behavioral symptoms and difficult baths Skin integrity Food / choking Restraints and alternative measures
TOOLS (see APPENDIX B AND C for more information)	
Visual board (Appendix B)	Safety caucus Safety cross Daily indicators Improvement ideas / innovative practices Communication of the day Mission-Vision-Value of the health institution Memory-aid on the causes related to an accident
Intentional rounds (Appendix C)	The goal is to ensure the safety of the residents by means of four questions that any person validates verbally or by observation, can ask after a care, service or visit (see Appendix C for more information).

Table 19: Local results of the fall reduction and prevention pilot project

Table 19 presents the local results of the risk analysis process in fall prevention and reduction pilot-project at the CISSS Montérégie-Est.

	2015-2016 %	2016-2017 %	2017-2018 %	Other comments
# of total falls	447	446	492 (10% increase instead of 15% decrease). The spike is related to seasonal flu	4 points out of 6 are below target.
Rate of falls per week by removing peak weeks (seasonal flu) (17-week project)	10	8	4-6	In weeks 15, 16 and 17: there were more falls because of disorders and terminal phases for multiple fallers.
Non-Injury Falls			74%-87% (augmentation de 2%).	There were fewer risks

5.3.4. Discussion

The FORCES pilot project is a first of its kind in Quebec, where the process of fall analysis in risk management is conducted through a clinical and interdisciplinary team which involves a patient-partner (PP) [136].

To successfully prevent harm, past research indicates how vital it is to partner with patients and provide them with a role in their own safety and safety planning [129, 130]. Patient engagement (PE) can lead to better health outcomes, contribute to improvements in patient safety, and help control health care costs [128, 14]. However, this has not been tested empirically on inpatient fall prevention in long-term care settings. Many strategies employed to reduce falls in elderly care facilities involve fall risk assessment and screening tools, use of bed alarms, patient and family education, increased frequency of patient rounds, patient involvement and engagement with the nurses for education on fall prevention [128]. However, the sustainability of these effects obtained mixed success, and a consistent trend of reduced inpatient fall incidents has not been noticed [128]. This is why, in the FORCES pilot project, the process of fall **analysis migrates** from an administrative process (involving only management) to a wider process done by an interdisciplinary clinical team which involves a PP (see table 1 for more information on the description of the clinical team members) [136].

5.3.4.1. Identified strategies for PE for PS in the fall prevention and reduction initiative

In light of empirical findings in this research study, three sub-strategies and practices designed to reduce and prevent falls through PE were identified (see Table 2 for more information).

5.3.4.1.1. Strategy 1: Knowledge creation

Sub-strategy 1: Initiate, design and structure PE for PS

Organizational leaders were essentially involved in designing and structuring approaches to better engage [137, 138] patients in clinical teams for process analysis in risk management for PS. They (a) initiated the process with strategic leaders in identifying institutional priorities as well as adopting national or international guidelines and introduced the project through a (b) pilot project. Organizational leaders, then, structured and designed the pilot project by (c) creating implementation structures (such as an advisory committee comprised of organizational and clinical leaders to participate and collaborate around one goal: fall reduction and prevention), and created a (d) support team for clinical teams, as well as (e) recruiting a PP to be integrated in the clinical team for risk analysis process.

(f) Action plans were created to review and develop processes, procedures and guidelines, and (g) tools were also identified for adaptation as gaps were reviewed in case new tools were required.

5.3.4.1.2. Strategy 2: Knowledge sharing and development

Sub-strategy 2: Inform adjust and train in collaborative and partnership practices

The organizational team (a) informed and raised awareness among leaders at all levels of the institution, in addition to (b) training HCPs and the PP working within clinical teams. The organizational team, in collaboration with the clinical team, trained and adapted training modules for HCPS, (c) according to satisfaction surveys and other collected qualitative and quantitative data to understand the safety culture and barriers to PE in RM for safety. Data collection tools included: satisfaction survey geared towards PP, employees and managers, complaints documents, and a literature review on innovative practices. (d) The literature agrees that measurement indicators should put in place in order to follow progression and adjustment or continuous improvement plan which must be implemented and taken into consideration [92]. Moreover, (e) competence training were also adjusted and provided to HCPs, patients and management if needed, and (f) results were also communicated to not only instances that were involved, but to the organization as a whole for better clinical governance and leadership of PE for safety [139].

5.3.4.1.3. Strategy 3: Knowledge preservation (sustainability)

Sub-strategy 3. Sustain and support a culture of ongoing evaluation, transparency (raising awareness), safety, well-being, innovation collaboration, and continuous improvement/education

To preserve knowledge generated in Strategy 1, the literature suggests the integration of a management system which will support its sustainability, such as: a real-time data analysis system; a structure to support implementation and continuous evaluation of data and improvement of competencies and training [92]. In other words, this means (a) creating improvement plans and (b) follow-up systems, (c) transparency procedures and (d) continuous work on the safety culture through different strategies of well-being, recognition, identification of innovative practices, and (e) communication of results in a positive manner [92]. (f) A bank of qualified patients and (g) continuous education/training for patients and HCPs are also needed to be created and offered on a regular basis [92].

5.3.4.2. Indicators

In this case study, **seven main indicators** in PE for PS were followed (see table 4 for more information): (1) Patient engagement in fall analysis process and in advisory committee; (2) HCPs engagement as well as management engagement in the interdisciplinary clinical fall analysis team (integrating the PP); (3) the integration of HCPs and PP in the identification, adaptation and development of existing or new tools; (4) the evaluation of satisfaction / dissatisfaction of the process of fall analysis by the interdisciplinary clinical team (which involves the PP) : Assessment of employee and professional satisfaction as well as patients and management satisfaction in team analysis of an adverse event; (5) the engagement of patients, families and friends in the identification of solutions for fall prevention and reduction measures after a fall had happened to their loved ones; (6) the analysis of the safety culture in the health institution in order to identify places of resistance and instances of improvement (competency training, awareness campaign, collaboration mechanisms, human or financial resources, etc.); and (7) Intentional rounds: are a recognized practice for improving care and service quality. The goal is to ensure the safety of the residents by means of four questions that any person validates verbally or by observation, can ask after a care, service or visit.

Other indicators or factors which emerged as important for future projects are: (a) the creation of a PP bank, (b) Identifying the right PP according to the literature, (c) doing a cost analysis of falls leading to hospitalization, and (d) the analysis of Non-injury falls rate.

At the end of the 17-week long project, there was an increase in falls (10% increase) within the unit mainly because of a spike in flu cases. This could officially mean that the targeted 15% reduction rate in falls was missed (see table 5 for more information). However, the rate of falls decreased from 10 falls per week to 4-6 per week. Which definitely showed the success of the project.

5.3.4.3. Tools

Tools which were created in order to support the implementation of the analysis of the process of fall prevention and reduction at the CISSS Montérégie-Est are (see Appendix B and C for more information): (1) the **visual board** which integrates: (a) the safety caucus section which helps the interdisciplinary clinical team as a memory-aid on questions to ask on identified AE (see Appendix B – Element 1 for more information); (b) the safety cross section which identifies i- the day with falls with injuries, ii- the days with falls without injuries, iii- the day without falls (see Appendix B – Element 2 for more information); (c) a daily indicators section (such as : is it a new problem, has data being collected, etc.) are assessed at the unit level (Appendix B – Element 3); (d) an improvement ideas / innovative practices section that the interdisciplinary team can come up with or through the consultation with family and friends of the patients who have lived a fall (see Appendix B- Element 4 for more information); (e) a section in which the communication of the day (or other pertinent information) are written (see Appendix B- Element 5 for more information); (f) a section in which the mission-vision-values of the health institution are written (see Appendix B- Element 5 for more information); and lastly, (g) a section with a memory-aid on the causes related to an accident is visible on the visual board (see Appendix B- Element 5 for more information).

Appendix C, shows, the other tool or practice which were created in this project (2) the Intentional rounds. Which is a recognized practice for improving care and service quality. The goal is to ensure the safety of the residents by means of four questions that any person validates verbally or by observation, can ask after a care, service or visit (see Appendix C for more information).

5.3.4.4. Innovative practices

Some innovative practices behind that result involved (a) integrating the PP in the advisory committee in charge of deploying the pilot project, (b) contacting families and friends when a fall occurs to ask about fall prevention measures for their loved ones, (c) using the PP to adjust communication and training towards friends and families, (c) videos clips to raise fall prevention awareness among patients, (d) installing a viewing board for patient to promote transparency and elicit comments.

Furthermore, results expand beyond quantitative results and include qualitative results such as the added value for clerks to participate and add their voices to the fall reduction project; the PP's sense of involvement in fall reduction, etc. At the end, the role of the PP is to make sure the voice of the patient is integrated in the initiatives and pathways created for the patients by the organization. And the way that it was done in this study, was through the creation of a multidisciplinary team which integrated a PP.

5.3.4.5. Factors

In terms of **enabling factors** which contributed to the success of the fall reduction strategy (see table 3 for more information), this case study mainly points to: (a) the vision and implication of leadership, (b) support from external bodies in change management and (c) that of the internal strategic and tactical team of the Quality, Evaluation, Performance and Ethics Directorate (DQEPE) during the execution of the pilot project. In addition, (d) the creation of the consultative committee comprising of multidisciplinary HCPs, a PP, and all levels leaders (strategic, organizational, and clinical), helped guide the pilot project to success. Moreover, (e) the involvement of the PP to adjust the communication and add an extra point of view to fall analysis, the involvement of clerks when communicating with nurses, in addition to the identification of the viewing board as an effective communication tool, formed innovative practices for the organization to adapt and implement within the unit. Another enabling factor is the (f) use and analysis of surveys to assess the security culture within the unit and the organization, as well as PP and employee satisfaction in the fall analysis process. Ensure the presence of a just culture appears to make a significant difference as well, which includes identifying innovative practices from evidence which enables a just culture within organisations. Furthermore, (g) using a conceptual framework which integrates change management theory for sustainability to frame the pilot-project, (h) pilot-testing the strategy, (i) setting up a recognition system to reinforces a just culture, (j) as well as the interdepartmental collaboration which, in turn, creates multiplying agents capable of implementing survey findings in their units.

On the other hand, **barriers that act as limiting factors** to PE in fall reduction and prevention include: the difficulty of identifying the right PP with the right competencies suited for fall analysis, as well as resistance of management staff and HCPs in the process [140, 141, 142]. This combines with a perception, from certain HCPs, that involving a PP and adding time for fall analysis to the tasks of the clinical team may adversely increase their workload [140]. Another barrier lays in the financial constraint of investing for data management systems, or human resources, or again, to create or complete training modules [140] Moreover, the lack of use of information technology systems to provide in-real time data about falls can act as a limiting factor [134]. However, in this case, the visual board used by the interdisciplinary clinical team (also integrating a PP), was completed every day and can act as "in-real time system to provide data about falls.

To counter those limiting factors, evidence from PE institutionalization and international literature suggest that to create knowledge (planning), the organization must train and raison the awareness among management, patients and HCPs, in addition to creating and adapting tools and procedures, and developing collaboration mechanisms with important departments. Furthermore, having the right resources along with the right skillset and training (including formal/academic training) remains necessary as well as a robust support body or system backed by a solid methodology to evaluate and assess indicators [134].

Regarding knowledge creation and development, the literature agrees that measurement indicators should be put in place in order to follow progression, adjust or continuously improve. Thus, a plan must be set up which takes into consideration [14, 92, 25] competence training for HCPs, patients and management (if needed), as well as communicating results to instances that are involved and within the entire organization [25].

Then, to preserve the above knowledge, the literature suggests the implementation of a management system which will support the knowledge's sustainability, such as a real-time data analysis system; a structure to support implementation and continuous evaluation of PE and creating an improvement plan with a follow-up mechanism. Procedures within that structure would have to be transparent, and in the spirit of developing a safety culture that includes well-being strategies, recognition, identification of innovative practices, and communication of results in a positive manner) [92]. Last but not least, a bank of competent patients and continuous education programs for patients and HCPs also need to be created and offered on a regular basis [92].

In a systematic review, evidence shows that successful implementation of fall prevention and reduction strategies were positively influenced by "leadership support, engagement of front-line staff in program design, guidance of the prevention strategy by a multidisciplinary committee, pilot-testing interventions, use of information technology systems to provide data about falls, staff education and training, and changes in nihilistic attitudes about fall prevention" [134].

5.3.4.6. Limits

Some limits identified in the research project were related to the non-observation or participation on-site, at the Du Palais unit to witness live interventions and dynamics of the PP within the interdisciplinary clinical team, as well as an actual viewing board for the fall analysis process. However, the research team managed to watch a video of the viewing board for research purposes. Another limit of this pilot project is the engagement of only one PP. Indeed, the literature mentions the need to engage at least two patients just in case one is absent or to exchange ideas with greater cognitive diversity, or give each other confidence to talk during the committees meetings [90]. Additionally, the research agent did not participate in the meetings created by the external support body which was in charge of supporting the implementation of a change management framework in the pilot project. Lastly, the research team did not participate in the transferability of the successful pilot project into other units (n=16) of the of the long-term care center.

5.3.4.7. Lessons learned

To be able to reduce falls and prevent them, one needs to involve not only the "right" PP integrated in the interdisciplinary clinical team, but also clinical management in fall analysis. In order to achieve this, organizations would need the support of leadership at the strategic, organizational and clinical levels. In addition, organizations must make time for preparation (knowledge creation) before the deployment of a pilot project, In fact, a pilot project is recommended for easier buy-in by internal stakeholders (senior management, middle management, professionals, nurses, etc.) , which will facilitate the creation of a support body (external or internal expert body) to manage a project in change management, and support the clinical teams and engaged leaders at the strategic level during the pilot project (in this case, the team (body) in charge of FORCES project was located in the quality directorate).

5.3.5. Conclusion

Preventing falls and fall-related injuries continues to be challenging for health care organizations, which requires a shift from clinician-centric decision-making to a collaborative/co-production model. While one of the answers is to engage patients to become more active participants in fall prevention during hospitalization, venturing in the land of coproduction with healthcare professionals as well as in care and service design is an avenue worth exploring and developing for healthcare organizations. In order to better examine fall risks as a whole (as per integrated risk management) hosting the patient as a coproducer could be the answer. This would mean engaging patients not only in their own health, at the clinical level alongside healthcare professionals, but also at the organizational and strategic level for care, service design and process revision/development. In fact, the World Health Organization recommends that additional prevention strategies in reducing and/or preventing falls should emphasize patient education for greater engagement in their own health; training for patients and healthcare professionals; creating safer environments for organizations; prioritizing fall-related research and establishing effective policies to reduce risk [1]**.** In that same framework, a systematic review, identified eleven studies in which leadership support, engagement of front-line staff in program design, guidance of the prevention program by a multidisciplinary committee, pilot-testing interventions, use of information technology systems to provide data about falls, staff education and training, and changes in nihilistic attitudes about fall prevention were associated with successful implementation [134].

Moreover, according to that same review, future research should rely on the mix of implementation (institutionalization) strategies for optimal fall prevention and relative risk reduction by as much as 30% [134]. The beauty of it all is that PE, even in fall prevention, can help health organisations and the health system save costs given the additional financial burden of fall related injuries [128, 134].

6. CHAPTER 6: DISCUSSION

The discussion of this thesis is organized into six main sections. The first section highlights the main findings and the scientific and practical contributions that emerge from the three article papers (6.1). The next section (6.2) identifies emerging and innovative practices at the strategic, organizational, and clinical levels of PE for PS drawn from general results collected from the questionnaire (6.2.1) (article 1 and 2 of the thesis results), followed by a case study which highlights the innovative strategic, organizational, and clinical strategies used in a PE pilot project part of a fall prevention and reduction program (6.2.2) (article 3 of the thesis results). Section (6.3) discusses the factors that supported the institutionalization of PE in risk management for safety at different levels. Section (6.4) presents the identified indicators of PE for PS as discussed in the research study. Section (6.5) discusses, based on strategies identified in previous sections, the most relevant emerging innovative strategies at the strategic, organizational and clinical level used by leaders to institutionalize PE in risk management for safety. Ultimately, patient engagement poses challenges and gives rise to paradoxes that managers face and must try to respond to; these are discussed in section 6.6. Finally, this discussion ends by synthetizing the overall findings of the research thesis (6.7) and identifying the limits of the research (6.8).

6.1 Main findings and scientific and practical contributions

In Canada, and around the world, patient engagement (PE) has become a key strategy to ensure the quality of care and patient safety (PS). Indeed, partnering with patients for the sake of their own health and care is known to be a key component for not only developing the highest quality of healthcare, but also improve outcomes and reduce the burden on health services [6, 9, 14, 20, 21, 22, 28, 7, 2, 59]. This is why implementing PE strategies offers undeniable value to healthcare systems by helping them reduce by up to 15 % the burden of patient harm in hospital care, saving billions of dollars each year along the way [36].

However, despite existing PE initiatives, significant strides and intentions in Quebec's healthcare system and worldwide [32] risk management (RM) is still dealt within silos, while ignoring connections and interdependencies [33, 30].

Health institutions still struggle to obtain a general portrait of PE for PS across the entire organisation, which stands in the way of identifying practical strategies, mechanisms and practices to institutionalize (or embed) PE for PS, as well as addressing factors hindering the institutionalization process.

The three thesis papers identify and analyze the emerging strategies used by strategic, organizational and clinical leaders in health institutions to ensure the institutionalization of PE in risk management for safety. It also contributes to developing knowledge in the field of PE in risk management for safety at an institutional level. Beyond a scientific contribution, results of this research help support health institutions and their leaders in implementing strategies to foster PE by highlighting key practices/mechanisms and strategies as wells as the challenges associated with them.

We will discuss the two questions of the thesis in light of the results presented in the last two articles:

Question 1: What are the different approaches put in place by leaders in Quebec's Integrated Health and Social Service Centers (CISSS), Integrated University Health and Social Service Centers (CIUSSS), the *Université de Montréal* Heath Center (CHUM), and the McGill University Health Centre (MUHC) that would allow patient engagement (PE) to be fully institutionalized in the health care system for the enhancement of patient safety (PS)?

- **a)** How did those PE approaches evolve overtime?
- **b)** What are the factors that enable or inhibit the implementation of PE approaches for PS in those health centers? (Articles 1 and 2)

Question 2: Using a concrete example (case study) of fall prevention and reduction, what could be emerging innovative practices, mechanisms / strategies, as well as limiting and enabling factors that would allow PE to be fully institutionalized for the enhancement of patient safety? (Article 3)

To answer the first question, we used a questionnaire (Article 1) to survey healthcare institutions on their emerging strategies / mechanisms and practices used for the institutionalization of PE for safety at the institution's strategic, organizational and clinical levels, as well as semi-structured interviews to collect data on factors and emerging indicators in PE for PS (Article 2). To answer the second question, Article 3 focuses on the analysis of a case study taking place in a Quebec Integrated Health and Social Services Center (CISSS Montérégie-Est). This case study regards the implementation of a fall prevention and reduction pilot project which helps identify emerging strategies used by strategic, organizational and clinical level leaders to institutionalize PE in risk management for safety.

Table 20: Synthesis of thesis articles (title, objective, scientific contribution and contribution for practice)

Table 20 provides a synthesis of the three articles, highlighting their objective, as well as their scientific and practical contributions.

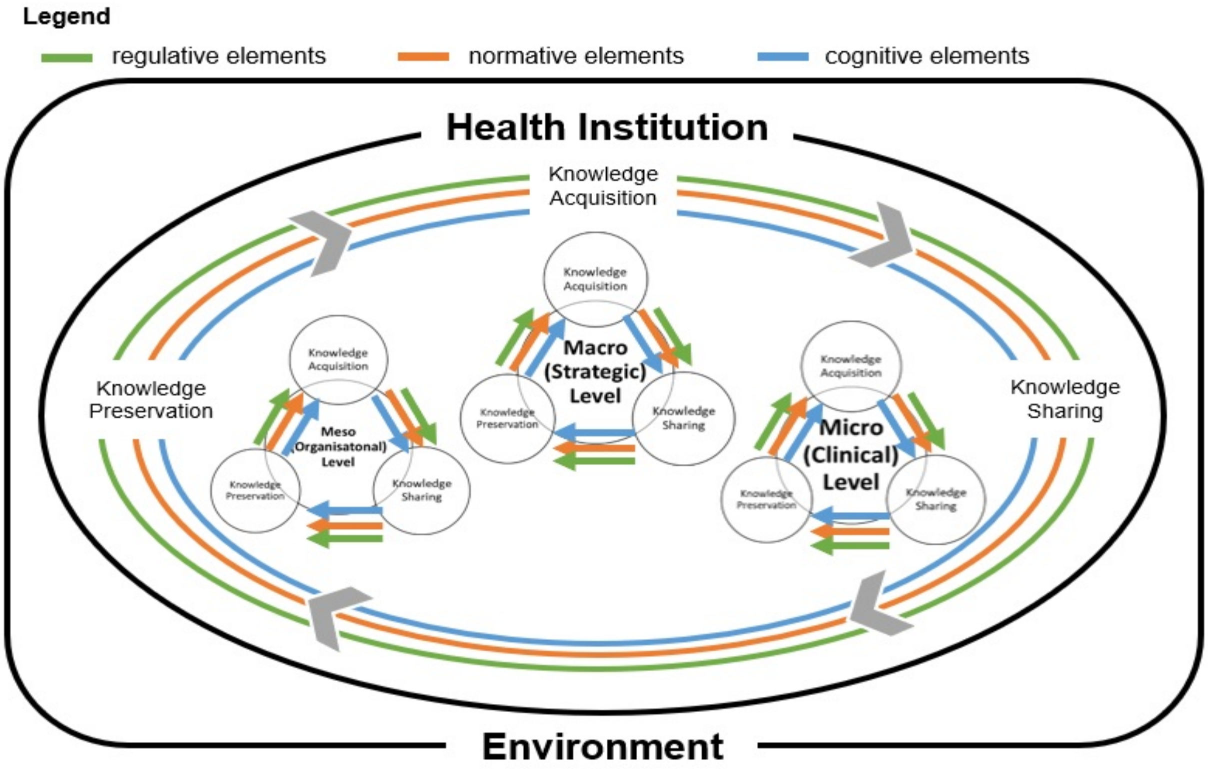
Articles	**Article 1**	**Article 2**	**Article 3**
Title	**An Evidence-Based Tool (PE in PS) for Healthcare Managers to Assess Patient Engagement in patient Safety in Healthcare Organizations**	***Health Organization Strategies in Patient Engagement for Safety (HOSPES): Research Results from a Longitudinal Case Study in Quebec***	**Strategies used to Institutionalize Patient Engagement (PE) in Fall Reduction and Prevention: A Qualitative Longitudinal Case Study from an Integrated Healthcare Center in Quebec**
Main objective	Develop a tool for managers to assess PE integration strategies implemented in healthcare organizations to enhance PS.	Identify emerging PE mechanisms and strategies put in place by organizational leaders in leading healthcare institutions after the enactment of Bill 10 in 2015 (which modified the organization and governance of the health and social services network, by integrating them into 24 integrated organizations in the province of Québec (Canada)), which would allow the institutionalization of PE in the health care system for patient safety (PS).	Analyse a concrete example (case study) put in place by organizational leaders in one of Quebec's Integrated Health and Social Service Centers in order to identify (1) emerging innovative practices, mechanisms / strategies, as well as (2) limiting and enabling factors that would allow patient engagement to be fully institutionalized in risk management for the enhancement of patient safety. In this case, fall prevention and reduction.
Scientific contribution	Contributes to the creation of tools which can be used by managers and leaders at the strategic, organizational and clinical levels to identify and assess innovative practices / strategies implemented in their healthcare organizations to enhance PS.	Contributes to the international knowledge of emerging practices and strategies of PE for PS used by healthcare leaders.	Contributes to the international knowledge on conducting a pilot project in order to implement a PE initiative in risk management for safety (particularly in the context of fall prevention and reduction) at the clinical level.
Practical contribution	Use of a standardized tool based on evidence to collect data on emerging practices and guide PE implementation in risk management for PS.	Identifies emerging innovative practices and strategies (e.g., potential pilot projects) put in place by leaders in healthcare organizations for PE for PS.	Supports healthcare leaders in the implementation (institutionalization) of PE in risk analysis by integrating the PP into the clinical team.

6.2. Emerging practices at the strategic / organizational / clinical levels of PE for PS

In order to institutionalize or fully integrate a new concept or approach (in this case, PE in risk management), the empirical studies presented in this thesis highlight the interconnectivity and interdependency strategies used by leaders of the three different levels of the health institution (strategic, organizational and clinical) as an important lever for patient safety.

Figure 5: Framework for the implementation of PE in risk management for safety based on the institutional theory (see APPENDIX A - Conceptual Framework PE for PS **for more information. In APPENDIX A, strategies in blue are the new emerging identified strategies from this research study)**

Figure 5 presents the different types of strategies needed to be implemented by an institution in order for its PE initiative be fully integrated in risk management for patient safety.



6.2.1. Emerging PE practices in risk management at the strategic, organizational and clinical levels for safety, based on questionnaire results

Institutionalizing PE for PS relies on a variety of strategies put in place by strategic, organizational and clinical leaders (Articles 1 and 2). Based on the empirical results of this thesis, we were able to identify three main types of strategies, and seven sub-strategies (see table 21), which we discuss in relation to the conceptual framework based on the Institutional Change Management theory (see Figure 4).

6.2.1.1. Strategy 1: Knowledge acquisition (preparation phase)

Article 2 highlights that leaders are engaged in practices aimed at initiating, designing and structuring partnership approaches with patients in safety. In this respect, leaders at the strategic, organizational and clinical levels play a key role in creating a shared vision of the approach between healthcare professionals (HCPs) and patients.

Sub-strategy 1: Initiate through adoption of framework, guidelines, as well as identified institutional priorities [4]

At the **strategic level**, for a more structured approach to PE, decision-makers should ensure that institutions formally adopt (1) reference frameworks or guidelines such as the PE Reference Framework from the Quebec Ministry of Health and Social Services (MSSS) [79], as well as PE policy recommendations and Required Organizational Practices from of accreditation bodies (i.e. Accreditation Canada, Quebec Accreditation Council, ISQUA, and other national or international accreditation bodies) [66, 92]. Then, those references should be used by institutional leaders to (2) initiate an official PE action plan which formally describes PE / Patient Experience structures. The action plan should include regulations and strategies to ensure the inclusion of expert patients in work/task groups, particularly those responsible for reviewing/developing internal policies on safety, care pathways, training tools and documents. Lastly, (3) training and awareness campaigns about the PE action plan should be developed internally so that patients, HCPs and managers become familiar.

Sub-strategy 2: Structure and support through governance bodies, tool creation/data collection and analysis methodology, and human resources [92, 143, 144, 145]**.**

At the **organizational level,** leaders/healthcare providers in risk management/ PE / and Patient Experience (PExp), should be (1) identified and hired to oversee and coordinate PE projects in the organization on a full-time basis, preferably with a (2) PE team. This team would help implement the type of (3) PE and PExp structure, in addition to (4) developing and managing PE for safety resources, tools and material for patients and staff (HCPs, Senior Managers, Managers), and (5) setting up an patient-partner (PP) bank to recruit patients for PE initiatives. This usually involves developing a recruitment form, a database for PPs, etc.).

Sub-strategy 3: Define and identify moments of PE integration in teams as well as defining PP core competencies for particular initiatives in PS [14]

Finally, at the **clinical level**, based on the PE action plan, and with support of the appropriate directorate overseeing PE (in Quebec, it is usually under the purview of the Quality, Evaluation, Performance and Ethics Directorate (DQEPE)), (1) create task groups (involving patients and professionals) to review clinical practices and pathways to clearly define the scope and moments of patient engagement, as well as (2) develop strategies and tools to identify and recruit potential PPs based on co-developed criteria and co-defined competencies [121]

6.2.1.2. Strategy 2: Knowledge sharing (implementation phase)

Strategies put in place by strategic, organizational and clinical leaders can be viewed as disseminators of information to patients and clinical teams [138]. Articles 2 and 3 highlight the important role of leaders in creating collaborative strategies for communication, regulation revision and processes purposes. These strategies relate to informing and training HCPs and patients integrating teams, as well as evaluating or assessing employee and patient's satisfaction.

Sub-strategy 4: Promote and inform the institution on PE policies and strategies, as well as safety culture through videos, pamphlet, presentations, etc. [146].

At the **strategic level,** upper management overseeing PE should implement and promote (in collaboration with patients and the communications department for message adaptation and increased visibility and awareness) (1) PE policies (i.e., integrated risk management with patients involved) and culture (no-blame, transparency and empowerment regarding adverse events, complaints, etc.). In addition, (2) a task group (involving PPs) should be created to review the mission, vision, ethical governance of the institution as well as (3) identify, at least, one sector where a pilot project be conducted within the organizational as a whole (clinical, organizational and strategic).

Sub-strategy 5: Collaborate, train leaders, HCPs and patients integrating organizational or clinical teams, and assess satisfaction and safety culture for decision-making [92] [147].

At the **organisational level,** middle/program managers implement (1) collaboration strategies with Patients Committees, complaint departments, risk management, volunteer departments, public health departments, clinical departments, multiplying agents at different departments of the institution, community organizations, universities, and other patient groups, etc. Moreover, they should (2) develop training (PE for PS training adapted to managers, patients, HCPs and other staff), and assessment programs for PE in risk management for safety. As they report back to senior management, they will also (3) implement an approach or methodology for the data collection and evaluation plan in order to collect data for decision making.

Other elements of collaboration and training include:

- (4) Collaboration with the Human Resources Department to develop a clear and detailed description of staff, patients, volunteers, and other patient group job descriptions;
- (5) Collaboration with different directorates/departments to hire patients for the PP database from different sources such as patients, associations, volunteers and citizens;
- (6) Development of a continuous training program for PE in risk management for safety;
- (7) A No-blame culture procedure and methodology within management and HCP's practices to capture experiences and practices;

Lastly, at the **clinical level** [25, 148] in collaboration with the organizational level or the structure in charge of PE in the institution, (1) pilot projects in PE should be implemented while capturing patient and family experiences and satisfaction with decision-support tools, as well as outcomes of shared decision making via, for example, the use of a direct feedback loop (surveys, committees, patient groups and complaint departments, comments and analysis). (2) Mechanisms should also be in place to empower and enable patients and families to report, analyse adverse safety and quality events (rapid response teams, etc.), health risks and incidents/accidents related to their health in collaboration with the clinical team. This also means being involved in the selection of support measures for patients after an incident or accident, coming up with solutions and being informed of measures taken by the organization to reduce or eliminate the risk. In terms of training, patients should be (3) integrated in clinical teams to educate and develop patient and family engagement sections in the training curriculum of HCPs (i.e., role learning), as well as (4) help HCPs develop standardized patient and family engagement competencies. Both patients and families should be (5) invited to coach/train other patients in disease management and risks identification, and (6) patients should be involved in different safety, risk management and other local safety committees, and task group (e.g., Fall prevention, suicide, etc.). HCPs should also be trained to work in teams alongside patients and vice versa.

6.2.1.3. Strategy 3: Knowledge preservation (sustainability)

Knowledge preservation strategies are put in place to sustain PE for PS practices. To do so, strategies aimed at transparency policies / mechanism and continuous education (on patient's rights, and contributions) are used to raise awareness about PE for PS among leaders, HCPs, and patients at all levels of the institution [146, 149, 150, 151]. Moreover, strategies for developing a culture of innovation and continuous improvement are utilized to create spaces for discussion and collaboration with internal departments and external organizations which enable knowledge transfer, enhanced visibility, simulations and thinking, as well as continuous improvement of competencies for PPs, and HCPs. In addition, a management system process (or methodology) for data collection and analysis should be integrated to support decision-making and increase knowledge regarding the added value of PE in risk management for safety [148]. Finally, a strategy of well-being for HCPs (e.g., recognition programs, etc.), leaders, and patients should be implemented to foster a safe and just culture [92].

Sub-strategy 6: Sustain and support a culture of ongoing evaluation, transparency (raising awareness), safety, well-being, and innovation

As for knowledge preservation, at the **strategic level**, (1) Human Resource departments should include PE competencies in job descriptions of HCP and staff, as well for PPs [121], while (2) senior management incorporates performance indicators into organizational practices (quantitative and qualitative data (e.g. complaints data, patient committee, patient's groups, etc.), while (3) setting up communication methods and technology to coordinate activities in-between departments. (4) Producing quarterly reports on PE in risk management / ongoing activities, etc., (5) encouraging and structurally empowering patients and families to officially and regularly attend board meetings and patient committees, as well as take part in shared decision-making through organizational communications (videos, pamphlet, Patients Committees, etc.) is also suggested. Furthermore, (6) developing organizational policies that specify families as full members of the healthcare team. To (7) encourage patients to participate (and professionals to welcome their participation), senior management should design and provide recognition and reward programs for care that fully incorporates patient and family engagement. Empowerment also goes by (8) developing policies that define access and transparency regarding information related to risks, benefits, costs of care, treatment options, medical records in the annual report. Moreover, the institution should (9) develop strategies and policies for the well-being of staff and patients [92], as well as strategy and mechanisms for interdisciplinary collaboration (which include the patient), collaboration with universities (such as the university of Montreal-department of DCPP, which supports institutions in the implementation of their PE approach), but also collaboration with national and international organizations (through conferences, communities of practices, etc.) [92, 152].

Sub-strategy 7: Sustain and support a culture of collaboration, and continuous improvement /education [143, 145, 153, 154]

At the **organization level**, PE teams should (1) continuously develop a PE curriculum and PE training programs in risk management which explain roles, organizational structure, quality and risk management improvement processes to key stakeholders (patients, HCPs, etc.). PE teams should also (2) develop a sustainable methodology or system to capture and assess patient experience (PExp) in risk management for safety at an institutional level (reviewing surveys and creating or adapting new ones, collaborating with other departments (complaint department, patient committee, PPs, clinical departments, citizen's forum, CEO/upper management or other HCPs or PP's safety rounds, and other data collected through consultations, and focus groups, etc.). In addition, to capture PExp data, it is also important to capture PE initiatives in the institution, and measure PE degree of integration in different sectors of the institution. (3) should there be a sub-structure to the PExp office, to be the assessment / evaluation of projects in PE/ PExp bureau?

Finally, at the **clinical level,** there should be (1) documents available to elicit structured care processes to support patient and family involvement in care planning and self-management. For example, dedicated full-time staff and the creation of departments to oversee work with patient and family advisors; as well as safety and quality improvement committees co-led with patients, etc.). To support HCPs in PE, (2) mechanisms should be in place which help clinicians elicit, understand, and respect patient perspectives and concerns (active listening, patient coach, etc.). (3) In terms of recruitment, not only should clinician tasks and job descriptions be updated to account for PE-related tasks, but also recruitment tools and tactics should enable the ongoing identification and selection of effective patient and family advisors for an interdepartmental PE databank (institution-wide).

Table 21: Management practices and roles to support patient engagement at the organizational level

Strategies/mechanisms/practices	Institution Levels
Sub-strategy 1: Initiate through adoption of framework, guidelines, as well as identified institutional priorities	Strategic level (CEO and general managers)
Sub-strategy 2: Structure and support through governance bodies, tool creation/data collection and analysis methodology, and human resources	Organizational level (Quality directors, or deputy quality directors)
Sub-strategy 3: Define and identify moments of PE integration in teams as well as defining PP core competencies for particular initiatives in PS	Clinical and organization levels as well as patient committees and PP committees (clinical managers in collaboration with the quality team or the directorate in charge of implementing PE in the institution)
Sub-strategy 4: Promote and inform the institution on PE policies and strategies, as well as safety culture through videos, pamphlet, presentations, etc.	Strategic and organizational levels (CEO and quality directors as well as deputy quality directors)
Sub-strategy 5: Collaborate, train leaders, HCPs and patients integrating organizational or clinical teams, and assess satisfaction and safety culture for decision-making	Organizational and clinical levels as well as patient committees and PP committees (Organizational leaders or the directorate in charge of implementing PE in the institution in collaboration with clinical managers)
Sub-strategy 6: Sustain and support a culture of ongoing evaluation, transparency (raising awareness), safety, well-being, and innovation	Strategic level (CEO and general managers) in collaboration with the organizational level (Quality directors, or deputy quality directors)
Sub-strategy 7: Sustain and support a culture of collaboration, and continuous improvement/education	Organizational and clinical levels as well as patient committees and PP committees (Organizational leaders or the directorate in charge of implementing PE in the institution in collaboration with clinical managers)

6.2.2. Case study: Innovative strategies used in a pilot project to institutionalize PE in RM fall prevention and reduction

In light of empirical findings (Article 3), in addition to findings in section (5.2.1, Articles 1 and 2), three sub-strategies and practices designed to reduce and prevent falls through PE were identified (see Table 21).

6.2.2.1. Strategy 1: Knowledge creation

Sub-strategy 1: Initiate, design and structure PE for PS

Organizational leaders were essentially involved in designing and structuring approaches to better engage [137, 138], patients in clinical teams for process analysis in risk management for PS. They initiated the process with strategic leaders in identifying institutional priorities as well as adopting national or international guidelines and introduced the project through a pilot project. Organizational leaders, then, structured and designed the pilot project by creating implementation structures (such as an advisory committee comprised of organizational and clinical leaders to participate and collaborate around one goal: fall reduction and prevention), and created a support team for clinical teams, as well as recruiting a PP to be integrated in the clinical team for risk analysis process.

Action plans were created to review and develop processes, procedures and guidelines, and tools were also identified for adaptation as gaps were reviewed in case new tools were required.

6.2.2.2. Strategy 2: Knowledge sharing and development

Sub-strategy 2: Inform adjust and train in collaborative and partnership practices

The organizational team informed and raised awareness among leaders at all levels of the institution, in addition to training HCPs and the PP working within clinical teams. The organizational team, in collaboration with the clinical team, trained and adapted training modules for HCPS, according to satisfaction surveys and other collected qualitative and quantitative data to understand the safety culture and barriers to PE in RM for safety. Data collection tools included: satisfaction survey geared towards PP, employees and managers, complaints documents, and a literature review on innovative practices. The literature agrees that measurement indicators should put in place in order to follow progression and adjustment or continuous improvement plan which must be implemented and taken into consideration [92]. Moreover, competence training were also adjusted and provided to HCPs, patients and management if needed, and results were also communicated to not only instances that were involved, but to the organization as a whole for better clinical governance and leadership of PE in RM for safety [139].

6.2.2.3. Strategy 3: Knowledge preservation (sustainability)

Sub-strategy 3. Sustain and support a culture of ongoing evaluation, transparency (raising awareness), safety, well-being, innovation collaboration, and continuous improvement/education to preserve knowledge generated in Strategy 1, the literature suggests the integration of a management system which will support its sustainability, such as: a real-time data analysis system; a structure to support implementation and continuous evaluation of data and improvement of competencies and training [92]. In other words, this means creating improvement plans and follow-up systems, transparency procedures and continuous work on the safety culture through different strategies of well-being, recognition, identification of innovative practices, and communication of results in a positive manner [92]. A bank of qualified patients and continuous education/training for patients and HCPs are also needed to be created and offered on a regular basis [92].

Table 22: Innovative emerging strategies and practices to engage patients and their families/friends in RM for PS

Strategies / practices	**Institutional levels**
Sub-strategy 1: Initiate, design, structure and define PE for PS	Strategic and organizational levels (CEO and quality directors as well as deputy quality directors) + Clinical and organization levels as well as the PP (clinical managers in collaboration with the quality team or the directorate in charge of implementing PE in the institution)
Sub-strategy 2: Inform adjust and train in collaborative and partnership practices	Consultative committee (implementation committee): Organizational leaders or the directorate in charge of implementing PE in the institution in collaboration with clinical managers, as well as the PP
Sub-strategy 3. Sustain and support a culture of ongoing evaluation, transparency (raising awareness), safety, well-being, innovation collaboration, and continuous improvement/education	**Working group in charge of the pilot project:** Strategic level (general managers) + Organizational and clinical levels as well as patient committees and PP committees (Organizational leaders or the directorate in charge of implementing PE in the institution in collaboration with clinical managers)

6.3. Factors enabling strategies, mechanisms and practices of PE for PS

In this current research project, based on articles 2 and 3, seven groups of different types of factors influence PE in risk management for safety. First, structural barriers: (1) Environmental factors (or system wide barriers), (2) leadership, (3) organizational culture, (4) organizational structure (including governance, interpersonal relationships or collaboration and partnership, etc.), (5) internal politics / mechanisms, etc., (6) personal (or intrapersonal), and (7) resources.

(1) Environmental factors (in both Articles 2, and 3) are linked to the presence or absence of, for example, reference frameworks and guideline on PE. In Quebec, a national reference framework

[79], as well as guidelines and policies such as the POR of Accreditation Canada and the CPSI guide for PE in PS [92, 66] strengthened PE initiatives and their implementation in healthcare institutions in across the province.

(2) Leadership factors and organizational structure (in both Articles 2, and 3) identify leaders at different levels of the institution who initiate the institutionalization of PE for PS, as well as managers who actively participate and offer their competence and values to PE.

(3) With regards to cultural factors (such as a no-blame culture or a just culture), integrating a transparent communication and awareness of a blame-free culture is crucial to creating and maintaining a safety culture (ref, safe culture). Professional culture, particularly in the healthcare space, can be highly technical, which would require training in health literacy and terminology to address HCP-patient communication barriers. Training and supporting managers on the innovative practices for a no-blame culture are essential as well. On the other hand, factors enabling a just or no-blame culture are found in the leaders' practices related to innovation, creation of collaborative spaces, and collaboration strategies with other directorates and external entities such as universities, conferences, and with community of practice to exchange knowledge and support continuous education and improvement. Moreover, strategies of wellbeing such as recognition strategies also influence positively the fostering of a safe culture.

(4) Articles 2 and 3 also mentioned the creation of structures such as specific bodies to support the implementation of PE for PS. In Quebec, those structures tend to be under the directorate overseeing PE (the DQEPE) with a dedicated resource, or team, collaborating with other directorates internally.

(5) While Internal policies and processes were cited briefly (article 3) with regards to the revision of procedures (in that case, the fall analysis process), that same factor was more significantly

stressed in article 2, when referring to the revision of procedures, pathways and processes with a PP involved in clinical teams or organizational teams.

(6) Moreover, personal (or intrapersonal) factors such as patients characteristics – including (knowledge of healthcare institutions (Article 2, and 3), disease or health condition (e.g. mental health issues) and other relevant aspects – might lead to discrimination, and therefore lower opportunities for involvement [122], other considerations for patient and family involvement included their willingness to participate, commitments and time, transportation, wellness and health, language and communication, and fear of health care being jeopardized.

(7) Finally, resources [122] factors such as human resources, competent staff and PPs, as well as available tools and training, not only support continuous education, and investment in PE for PS, but also its integration in RM in terms of PS performance indicators within the management system. All these elements positively contribute to influencing PE for PS. Last but not least, the presence of a structure and a methodology or data collection and analysis management system is essential in order to sustain PE for PS.

6.4. Identified PE for PS Indicators in the overall findings of the thesis

The added value of patient involvement has not been quantified and qualified in economic terms and, thus, patients have not been adequately compensated for their contribution. Further, meaningful indicators associated with health outcomes following patient engagement would be required for more involvement of both the patients and healthcare professionals [92]. Some indicators or evaluation processes for levels of satisfaction are measures of success. That said, to institutionalize PE for safety strategies, performance indicators must be integrated into performance measures (including quantitative and qualitative measures, patients' experience measures).

General indicators include, participation or response rates of patients, Patient influence on decisions, health care outcomes or resource utilization, patients' or professionals' satisfaction with the engagement process or resulting products, cost, critical factors for success, and limitations of methods or processes. Rather than assessment being a step that happens at the end of the engagement opportunity, healthcare institutions should integrate a methodology evaluating each process into the planning at the outset. Which will save time and frustration at the end and enable better learning from the process as it is taking place.

Table 23 shows the different indicators identified through the research project. 1- Number of PP engaged in the evaluation of sentinel events/incidents/accidents, 2- Double Identification of patients with a bracelet, 3- Number of security committees or teams that have a PP, 4- Integration of a PP in risks analysis process and in advisory committee, HCPs engagement as well as management engagement in the interdisciplinary clinical risks analysis team (integrating the PP), 5- the integration of HCPs and PP in the identification, adaptation and development of existing or new tools, 6- the evaluation of satisfaction / dissatisfaction of the process of risks analysis by the interdisciplinary clinical team (which involves the PP) : Assessment of employee and professional satisfaction as well as patients and management satisfaction in team analysis of an adverse event, 7- the engagement of patients, families and friends in the identification of solutions for risks management, prevention and reduction measures after an incident or accident had happened to their loved ones, 8- the analysis of the safety culture in the health institution in order to identify places of resistance and instances of improvement (competency training, awareness campaign, collaboration mechanisms, human or financial resources, etc.), and, 9- integrate “intentional rounds” for all personnel (which are a recognized practice for improving care and service quality. The goal is to ensure the safety of the residents by means of four questions that any person validates verbally or by observation, can ask after a care, service or visit. Personnel are: HCPs, patients, friends and family, managers, etc.).

Other indicators or factors which emerged as important for future projects are: (a) the creation of a PP bank, (b) the number of PP existing in the institution, (c) Identifying the right PP according to the literature, (d) doing a cost analysis of risks or falls leading to hospitalization, and (e) the analysis of Non-injury falls rate, or analysis of risk prevention due to a PE for PS initiative.

Table 23: Identified PE for PS Indicators in the overall findings of the thesis

#	**Indicators**
1	Number of PP engaged in the evaluation of sentinel events/incidents/accidents
2	Double Identification of patients with a bracelet
3	Number of security committees or teams that have a PP
4	Integration of a PP in risks analysis process and in advisory committee, HCPs engagement as well as management engagement in the interdisciplinary clinical risks' analysis team (integrating the PP)
5	Integration of HCPs and PP in the identification, adaptation and development of existing or new tools
6	Evaluation of satisfaction / dissatisfaction of the process of risks analysis by the interdisciplinary clinical team (which involves the PP): Assessment of employee and professional satisfaction as well as patients and management satisfaction in team analysis of an adverse event
7	Engagement of patients, families and friends in the identification of solutions for risks management, prevention and reduction measures after an incident or accident had happened to their loved ones
8	Analysis of the safety culture in the health institution in order to identify places of resistance and instances of improvement (competency training, awareness campaign, collaboration mechanisms, human or financial resources, etc.)
9	Integration of "intentional rounds" for all personnel
10	creation of a PP bank,
11	Number of PP existing in the institution
12	Identifying the right PP according to the literature
13	Cost analysis of risks or falls leading to hospitalization
14	Analysis of Non-injury falls rate, or analysis of risk prevention due to a PE for PS initiative

6.5. Innovative PE strategies for PS

Integrating patient perspectives at different levels of health institutions contributes to safer care and services. In article 2, several strategies were identified such as: involving a PP into the analysis, declaration, disclosure and discharge processes of a risk situation. Moreover, patients were engaged in training (building modules, or supported by a manager), supporting another patient in their patient intervention or their care, reviewing and creating tools, process, or even guidelines. In addition, patients were also engaged in welcoming new employees for their training, simulation initiatives in the organization.

Furthermore, article 3 highlights innovative practices by leaders, particularly organizational and clinical level leaders to engage patients, their families and friends into the analysis of risk processes (fall prevention and reduction). These strategies involved: integrating a PP into the advisory committee (implementation committee) which involved collaboration with directorates at all levels. Other strategies pertained to integrating the PP into an interdisciplinary clinical team to analyse risks (in this case falls risks) using a visualization board and contacting family and friends of patients when a fall happens to discuss potential fall prevention and reduction measures and mechanisms. A last strategy identified from that research study regarded the participation of the PP in adapting communication strategies to reach patients and their families. This also concerned training tools geared towards patients to raise awareness about fall prevention and reduction, as well as knowing how to read a visualization board to provide feedback for improvement or potential solutions to personnel. This strategy further supported transparency in terms of informing patients, their families and friends about current measures taken by the organization.

Finally, patients are becoming a new essential partner in quality improvement processes. Patient integration into teams must be managed and evaluated [14] in order to benefit from the experiential knowledge of patients and avoid mere symbolic and superficial participation [25] [148]. For that reason, there are innovative institutional strategies in place to integrate not only quantitative data for decision making, but also qualitative data such as patient experience through various data sources. The patient's voice can be captured from various tools and sources, including organization-wide patient satisfaction surveys, complaints data [146, 155], user committee surveys, and accreditation body surveys. Ultimately, employee and leader satisfaction surveys which collect qualitative and quantitative indicators for PE in RM performance measurement should also be integrated to obtain a full picture of the situation, especially when it comes to assessing the satisfaction of HCPs working in teams alongside a PP.

6.6. Challenges in identifying and analysing strategies, mechanisms, and practices put in place by institutional health leaders in PE for PS

Managing patient engagement in health organizations poses a number of challenges. One of the big challenges identified in article 2 is the collaboration challenge. Leaders at the strategic and organizational level have a hard time connecting with the clinical level. However, in article 3, to simplify collaboration, the organizational team created an advisory committee comprised of strategic, organizational, and clinical members, all collaborating together to find solutions for a particular problem (in this case, fall prevention and reduction). Multiplying agents in each directorate were identified and integrated into the process as well [92].

When integrating the PP within the multidisciplinary clinical team, as demonstrated in Article 3, ongoing collaboration with patients in decision-making is not always feasible in situations where patients do not have the right competence and ability to analyze risks [121].

Another challenge faced by HCPs is the fact that their time is limited, and that integrating a PP in their clinical team could be viewed as extra workload, especially when the PP is not properly trained or integrated with through appropriate support and training programs. These challenges require managers to think about degrees and modalities of patient participation which would be most compatible with available resources in clinical settings and most adapted to clinical situations and patient needs.

In terms of data challenges, qualitative data must be better integrated into the decision-making process by collecting data from the complaint department [156, 157] and surveying not only patients, employees and management for satisfaction in teams but also in more RM-specific areas such as risks analysis [14] .

One of the overarching challenges for leaders is to better integrate all approaches to patient engagement into an integrated management system for the entire organization [158]. In that regard, attention needs to be given to creating an integrated real-time management system (which will help decision-making) for data collection and data analysis for PE for PS which captures ongoing strategies, results from satisfaction surveys, data from the complaints department as well as ad-hoc data from focus groups, consultation and group discussions. Another important challenge mentioned by HCPs is to not “professionalize” the PP. If this were to occur, the PP could lose its independence and become influenced or biased by an “employee” status. PPs needs to keep their independence from the institution and not feel obligated to mold their responses to fit into expected or desired responses from the organisation.

6.7. Synthesis of overall findings of the thesis

The synthesis of overall findings of the thesis highlights six key messages presented in Table 22 that contribute to the advancement of scientific and practical knowledge in the field of patient engagement in risk management for safety. Of note, the phase one (Articles 1 and 2) of the thesis helped identify emerging strategies and practices in PE for safety. These identified strategies and practices in the questionnaire (part 1) validate not only the pilot project (case study) investigated in phase two of the research project (Article 3), but also illustrate the emerging strategies of PE for PS identified in phase 1. Thus, the questionnaire used to identify emerging strategies (Articles 1 and 2) in phase one of the research study helped in identifying ongoing innovative practices, and part two (Article 3) of the research project, and helped look deeper at innovative strategies used by leaders to illustrate a concrete example of PE in risk management for safety (in this case, fall prevention and reduction). The case study confirmed the use and identification of a pilot project (as identified in phase one, the questionnaire) to initiate the implementation of PE in risk management for safety at the clinical level. The case study also confirmed the important role played by the DQEPE as a support structure to implement PE for PS.

Table 24: Cross-synthesis of thesis papers, key results from the thesis

Key results	Thesis articles
Strategies used by health leaders are crucial for institutionalizing PE for PS.	Articles 1, 2 &3
The implementation of PE strategies for care and service safety requires initiating the initiative as a pilot project first, before considering at large implementation in order to understand the added value.	Articles 2, 3
PE strategies requires enhanced inter-directorate/department collaboration at different levels of the health institution (strategic, organizational and clinical). Without these active collaborations, the institutionalization of PE will not fully succeed, only partly at best.	Articles 1, 2, 3
PE for PS initiatives are supported by sustainability strategies such as a culture of safety, transparency, collaboration, innovation and continuous improvement / education as well as a well-being strategy. Ultimately, strategies and practices are supported by a set of contextual factors conducive to the integration of patient engagement.	Articles 2, 3
The institutionalization of PE for PS creates challenges that must be addressed, such as compensation strategies and challenges when engaging a patient (the identification and the choice of the "right" patient, patient competencies).	Articles 2, 3

6.8. Research Limitations

This thesis contributed to identifying, exploring and analysing strategies, mechanisms and practices that leaders in health institutions use to institutionalize PE for PS. This first study on the subject opens a way towards developing a new field of research on emerging or ongoing PE practices in RM for PS.

The identification of emerging strategies and practices are mainly based and limited to the biases of the declarative nature of the participants. Further, there are limits due the paper version and length of the questionnaire. In fact, a shorter and electronic version of the questionnaire is being created to launch in other Canadian provinces [92]. Furthermore, respondents may have overestimated or underestimated the actual level of patient involvement in their institution or may not be aware of all ongoing or potential PE initiatives and practices in many of the services and departments. Another limitation of the questionnaire used to identify emerging strategies in phase one (Articles 1 and 2) pertains to the limited distinctions among patients (patient-partners, patient-experts, etc.) in PE responses. The questionnaire also does not account for personnel changes (human resources) within surveyed institutions.

However, the questionnaire enabled the research team to report on pioneering experiences developed by certain institutions that involve their patients in, for example, analysing sentinel events, disease pathways, incidents and accidents, finding solutions or informing other patients.

Regarding phase 2 of the research study (Article 3), some limits identified in the research project are related to the limit in field observation and participation, as well as interviews with clerks and HCPs (nurses) involved in the field, including during a live demonstration of a visualization board part of the fall analysis process (article 3). This would have provided insight on the dynamics of the interdisciplinary clinical team vis-à-vis the PP at. That said, the team managed to watch a video of the visualization board activity, which was taken into consideration for research purposes. Additionally, the fact that only one (1) PP was involved in the pilot project points to another limitation. Indeed, the literature mentions the need to have two patients involved just in case one is absent, or even to exchange ideas and simply give each other confidence to voice their opinions during committee meetings [90]. Finally, the fact that research team did not participate in the transferability process of the successful pilot project into other units (n=16) of the case study organization constitutes another limitation.

7. CHAPTER 7: CONCLUSION AND FUTURE RESEARCH

The main objective of this thesis was to identify emerging strategies and mechanisms as well as to analyse how organizational leaders at the strategic, organizational and clinical levels institutionalize patient engagement (PE) in risk management (RM) for patient safety (PS). While many initiatives exist in PE for PS, no research to-date has been able to account for the interconnectivity of the three levels of health institutions (strategic, organizational and clinical). Thus, having an overall picture of PE for PS in the institution, as opposed to having silos results and outcomes, helps managers better understand the state of PE within their organizations. Many studies have focused on the organizational and contextual factors that enable or limit the implementation of PE at separate levels, without necessarily understanding the collaboration mechanisms and interconnectivity among the different organizational levels and how this interconnectivity influences the institutionalization of PE for PS. For that reason, it is up to the leaders of these three organizational levels to initiate collaboration in order to hope for the institutionalization of PE for PS. The last two thesis papers highlighted key emerging PE strategies and practices that leaders of health institutions put in place in RM for PS, as well as innovative practices used to engage patients and their families or friends in the analysis of organizational risk processes. The first thesis paper helped create a tool for institutional leaders to use in order to capture emerging and /or innovative ongoing practices and strategies in their institution and compare/benchmark them with other institutions.

Findings from this first paper provided an initial basis for building innovative practices in the field of PE for PS for decision makers and health leaders. The identified strategies could support the development of training programs and competency frameworks for leaders and patients developed by the DCPP [152], as well as review structures in place to welcome PE for PS and PE investment opportunities.

7.1. Main messages of the thesis

The results of this thesis can be summarized into six main messages. Strategies used by health leaders are crucial for institutionalizing PE for PS. The implementation of PE strategies for the safety of care and services requires initiating a pilot project first, before considering at large implementation. This is to understand the added value and kick-start or enhance inter-directorate/department collaboration at different levels of the health institution (strategic, organizational and clinical). Without these active collaborations, the institutionalization of PE will not fully succeed, only partly at best.

Moreover, the integration of patient engagement demands the emergence of innovative and renewed strategies in institutions. Therefore, PE for PS initiatives are supported by sustainability strategies such as a culture of safety, transparency, collaboration, innovation and continuous improvement / education, as well as a well-being strategy. Ultimately, these strategies and practices are supported by a set of contextual factors conducive to the integration of patient engagement.

Finally, the institutionalization of PE for PS creates challenges that must be addressed, such as compensation strategies and challenges when engaging patients, identifying and selecting the “right” patient (in terms of qualifications and competence) at different levels of governance. Moreover, attention needs to be given to the creation of an integrated real-time management system (which will help decision-making) for data collection and data analysis for PE for PS, which captures ongoing strategies, results from satisfaction surveys and data from the complaints department, as well as ad-hoc data from focus groups, consultation and group discussions.

7.2. Further researches

In the meantime, further research is required at national or international levels to capture more emerging PE strategies and practices in RM for PS. In line with this idea, there is currently an ongoing Pan-Canadian research project [126] modeled after this project, in addition to a project in France [85] in which the framework and questionnaire from this study was used to describe PE strategies for safety. An upcoming study is under way in Brazil as well. With enough jurisdictions covered, it would be interesting to assemble a global PE for PS case studies in partnership with international institutions, including the World Health Organization. This would help oversee and prevent a broader set of risks, for which it would be essential to define risk according to respective contests from around world. Thus, future comparative studies should be conducted between provinces, nations, including their evolution over time. Furthermore, additional research should focus on collaboration mechanisms and strategies used in the institutionalization of concrete initiatives / innovative practices (case studies) of PE for PS, the role of patient groups, volunteers, the role of patients in the implementation of a just culture, as well as compensation models in those collaboration mechanisms. In addition, more research on innovative leadership practices to instill a no-blame culture by way of concrete examples (case studies) will be required to implement a safe culture based on practical leadership experiences. This type of analysis could support the development of strategies to reduce and remove barriers to PE in safety optimization. Lastly, from an even broader perspective, PE could be viewed as a window to Citizen

Engagement, inside and outside health institutions, with regards to their own health and safety, especially during health crises such as pandemics (e.g., Covid-19).

8. CHAPTER 8: BIBLIOGRAPHY

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APPENDIX A - Conceptual Framework PE for PS: How leaders use strategies to implement Patient engagement for PS

Regulating pillar	**Cognitive-cultural pillar**			**Normative pillar**
	Knowledge acquisition	**Knowledge application and sharing**	**Knowledge preservation (culture is installed)**	
Clinical level of engagement	- Educate and inform patient on PE in risk management (structure-process, roles). Educate about culture of no-blame and risk management; organization structure, tools available, etc. - Educate and Integrate patient and family engagement into the healthcare professions curriculum (role learning) - Develop standardized patient and family engagement competencies - Develop a clinical action plan integration PE for PS - Create task groups involving PPs to review clinical practices - Develop tools and mechanisms to identify and recruit potential PPs	- Patients report adverse safety and quality events (rapid response teams, etc.) - Patients and families are invited to coach / train other patients with their disease management and risks identification Patients and families are able and capable to report health risks and incidents / accidents related to their health. - Patients are part of clinical teams for risk process analysis and pathways analysis. But as well to educate and develop patient and family engagement sections in the training curriculum of HCPs (i.e., role learning), and help HCPs develop standardized patient and family engagement competencies - Mechanisms to support communication of adverse events are created - Patients are involved in the choice of support measures for patients after an incident or accident, come up with solutions and be informed of measures taken by the organization to reduce or eliminate the risk - Direct feedback loop surveys are used to collect patient's satisfaction	- Develop continuously curriculum / training programs in PE in risk management. Develop training programs that explain roles, explain organizational structure, quality and risk management improvement processes - Support systems in communication. Mechanisms that help Clinicians elicit, understand, and respect patient perspectives and concerns (active listening, patient coach, etc.) - Resources are available in PE for PS for patients, HCPs and management (booklet, guide, jobs in PE, etc.) - Clinicians task and job description integrate PE - Develop recruitment that enable the ongoing identification and selection of the "right patients" and family advisors - Develop mechanisms to integrate in safety and quality improvement committees' the "right patients" - Develop mechanism to integrate in clinical teams, the "right patients" - To support HCPs in PE, mechanisms should be in place which help clinicians elicit, understand, and respect patient perspectives and concerns (active listening, patient coach, etc.).	
	Role learning, health literacy & knowledge, education, competency of HCPs, **and of PPs (PP's personal characteristics and competencies are integrated in the choice of the patient)**			**Factors**
	Measurement: 1- Implement additional measures of patient-level experiences, goals, and outcomes. 2- Patient-reported outcome measures. 3- Capture patient and family experiences and satisfaction with Decision-support tools and the outcomes of shared decision making via, for example, the use of a direct feedback loop (consultation, focus groups, citizen's forum, complaints data, user committees, patients' groups, clinical management rounds, employees, satisfactions, etc.). 4- Double Identification of patients with a bracelet. 5- Number of security committees or teams that have a PP. 6- Integration of HCPs and PP in the identification, adaptation and development of existing or new tools. 7- Engagement of patients, families and friends in the			Indicators

	identification of solutions for risks management, prevention and reduction measures after an incident or accident had happened to their loved ones. 8- Integration of "intentional rounds" for all personnel			
Organizational level of engagement	- Create an Action plan on PE for PS - Identify and hire PE coordination project personnel or team which includes PPs (governing structure) - Create a PE pool bank to recruit patients - Creation of tools to recruit, train, inform patients, managers and HCPs) - The organisation asks patients about their experiences when tackling services, planning, design in risk management (surveys are used)	- Patients are engaged on different group work tasks, committees in risk management. - Managers implement collaboration strategies with user committees, complaint departments, risk management, and other clinical or organizational departments - Managers and CEOs are doing safety rounds to collect patient feedback and to assess environmental risks - Managers collect patient feedback trough citizen's forum, consultation, focus groups, etc. - Identify multiplying agents for the collaboration strategy - Continuous training in PE for PS is developed for HCPs, managers, and PPs - The PE governing structure implements an approach or methodology for data collection, evaluation for decision making	- Documents exist in eliciting structure care processes to support patient and family involvement in care planning and self-management (E.g., Dedicate staff and create departments to oversee work with patient and family advisors Patients co-lead safety and quality improvement committees) - Communication and technology to coordinate activities in-between departments are created - Quarterly reports on PE in risk management / ongoing activities, etc. are developed - Creation of an organizational plan for continuously develop a curriculum and training programs in PE in risk management which explain roles, organizational structure, quality and risk management improvement processes to key stakeholders (patients, HCPs, etc.), - Develop a sustainable methodology or system to capture and assess Patient experience in risk management for safety at an institutional level - Create a system that capture Patient experience and PE for PS initiatives - Dedicated full time staff for the governing PE for PS structure are available	
	Leadership Practice, safety culture (risk management, culture of no blame, continuous learning culture, transparency culture, **collaboration culture**), governing structure, **data collection and data evaluation methodology and system**			**Factors**
	Measurement: 1- Implement measures that assess the process of patient and family engagement—how and to what extent engagement occurs. 2- Create feedback mechanisms (using measures) to help plan patient care, provide real-time, personalized feedback to clinicians, patients and organizations, and drive changes. 3- Conduct research on how engagement leads to outcomes, including improved health, quality, cost, or staff satisfaction. 4- A no-blame culture procedure and methodology in management and HCP's practices to capture experiences and practices. 5- PP bank is created and number of PP. 6- Governing structure of PE is created. 7- Safety culture is measured, and improvement points are integrated in action plan. 8- Cooperation with different departments for data collection and measurement Is created (complaint department, user committee, PE governing structure, clinical department, etc.). 9- Number of PP engaged in the evaluation of sentinel events/incidents/accidents. 10- Number of security committees or teams that have a PP. 12- Integration of a PP in risks analysis process and in advisory committee, HCPs engagement as well as management engagement in the interdisciplinary clinical risks' analysis team (integrating the PP). 13- Evaluation of satisfaction / dissatisfaction of the process of risks analysis by the interdisciplinary clinical team (which involves the PP): Assessment of employee and professional satisfaction as well as patients and management satisfaction in team analysis of an adverse event. 14- Analysis of the safety culture in the health institution in order to identify places of resistance and instances of improvement (competency training, awareness campaign, collaboration mechanisms, human or financial resources, etc.). 15- Analysis of risk prevention due to a PE for PS initiative. 16- Number of ongoing pilot projects. 17- Number of successful pilot project (fully implemented and evaluated). 18- Number of pilot projects on PE for PS that have being transferred to other departments and are successful vs. non-successful. 19- Identification of management and teams Practices of no-blame culture. 20- Simulation rooms are used for HCPs training (integrating PPs).			Indicators

Strategic level of engagement	- Use reference frameworks, policies, ROP, or guidelines on PE, and/or PE for PS - Develop strategic plan on PE for PS - Training and awareness campaign for PE are created and offered - Provide access and transparency on annual report concerning information about risks, benefits, and costs of care and treatment options	- Promote PE for PS policies, safety culture, transparency culture and collaboration culture - Task group involving a PP to review the mission, vision etc. is created - A pilot project is identified for a PE for PS project and integrated in the strategic plan - Patients and families are on the board of Directors and user committees for share decision	- Develop organizational policies that specify families as full members of the healthcare team. - Policies about transparency are created (information about risks, benefits, cost of care and treatment options, access to medical record) - Provide recognition and rewards for care that fully incorporate patient and family engagement - Require patient and family engagement competencies for certification or accreditation are created. Human Resource departments should include PE competencies in job descriptions of HCP and staff, as well for PPs - Senior management incorporates performance indicators into organizational practices (quantitative and qualitative data (e.g., complaints data, patient committee, patient's groups, etc.) - Senior management sets up communication methods and technology to coordinate activities in-between departments as well as produce quarterly reports on PE in risk management / ongoing activities, etc. - Senior management should also encourage and structurally empower patients and families to officially and regularly attend board meetings, patient committees, and take part in shared decision-making through organizational communications (videos, pamphlet, Patients Committees, etc.). - The institution should develop strategies and policies for the well-being of staff and patients as well as strategy and mechanisms for interdisciplinary collaboration (which include the patient), collaboration with universities, but also collaboration with national and international organizations (through conferences, communities of practices, etc.)	
	PE for PS Policies, **leadership training and competency,** transparency of data, access to information (report, board of directors), **follow-up and preventive measures to patients and families. Investment budget or portfolio allocated to PE for PS pilot projects**			**Factors**
	Measurement: 1- Policies in place, 2- measures that evaluate number of decisions taken with patients and families, 3- availability and access of risk management report. 4- Cost analysis of risks or falls leading to hospitalization. 5- Evaluation and decision-making system integrated with data collection methodology. 6- CEO do safety rounds. 7- Collaboration spaces and innovative spaces are created. 8- strategic rooms are created and used for strategic, tactical and clinical planning.			Indicators

APPENDIX B - Consent letter Part 1 research project PE for PS

CHUM

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

Phase 1

Titre du projet:	Construire un système de santé sécuritaire: les stratégies utilisées dans l'institutionnalisation de la participation des patients dans la gestion des risques.
Chercheuse responsable au CHUM et direction de recherche:	Marie-Pascale Pomey, MD, Msc, PhD Professeure titulaire, Département d'administration de la santé École de santé publique, Université de Montréal
Étudiante-chercheuse:	Ursulla Aho-Glele Candidate au doctorat Département d'administration de la santé École de santé publique, Université de Montréal
Identifiant multicentrique:	MP-02-2017-6814 (MP)
No de projet au CHUM:	16.189

PRÉAMBULE

Nous sollicitons votre participation à un projet de recherche parce que vous êtes à la direction d'un Centre intégré universitaire de santé et des services sociaux (CIUSSS) ou d'un Centre intégré de santé et des services sociaux (CISSS), ou du Centre Universitaire de santé de McGill (CUSM), ou que vous y travaillez en tant que gestionnaire en gestion des risques, gestionnaire en partenariat-usager, gestionnaire en expérience-usager, ou encore, gestionnaire en qualité. Dans le cas échéant, vous êtes un professionnel de la santé.

Cependant, avant d'accepter de participer à ce projet et de signer ce formulaire d'information et de consentement, veuillez prendre le temps de lire, de comprendre et de considérer attentivement les renseignements qui suivent.

Ce formulaire peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles à la chercheuse responsable du projet, à l'étudiante-chercheuse, ou aux autres membres du personnel affecté au projet de recherche et à leur demander de vous expliquer tout mot ou renseignement qui n'est pas clair.

NATURE ET OBJECTIFS DU PROJET

L'engagement des patients et de leurs familles au sein de l'organisation de soins de santé et des services sociaux reconnaît le patient comme faisant partie intégrante de l'équipe de soin et des services sociaux. Le patient est donc reconnu comme un expert qui possède des connaissances uniques. Cette étude a pour but de contribuer à l'avancement des connaissances dans le domaine de l'engagement des patients en gestion des risques pour la sécurité des patients. Les résultats contribueront à identifier les mécanismes et stratégies de l'organisation que les gestionnaires mettent en place dans l'institution de santé afin de permettre l'engagement des patients.

Actuellement, il existe peu d'études publiées qui évaluent l'engagement des patients et de leurs familles sur la gestion des risques dans l'ensemble de l'institution de santé. La présente étude sera la première à le faire.

Plus spécifiquement, les objectifs principaux sont de :

- Décrire les différentes stratégies d'engagement des patients et de leurs familles mises en place par les établissements de santé; et expliquer si les stratégies mises en œuvre dans les établissements de soins de santé et services sociaux sont axées davantage sur la gestion des risques à des niveaux cliniques, organisationnels ou stratégiques.
- Identifier les facteurs qui favorisent ou inhibent l''engagement des patients et de leurs familles en ce qui concerne la sécurité des patients;
- Analyser les indicateurs mis en place par les établissements pour évaluer l'impact de l'engagement des patients et de leurs familles conçues pour l'amélioration de la sécurité des patients.

L'étude s'effectuera en deux phases. La première–consistera en une étude descriptive des stratégies en engagement des patients en gestion des risques à travers les CISSS, CIUSSS et le CUSM du Québec afin de décrire un portrait de la situation avant et après deux ans.

La deuxième phase–consistera en une analyse longitudinale du cas unique du CIUSS de la Mauricie et centre-du-Québec. Trois niveaux d'analyses seront privilégiés (clinique, organisationnel et stratégique) afin d'aller plus en profondeur dans la compréhension des mécanismes et stratégies mis en place par l'établissement pour engager les patients et leurs familles dans la sécurité des soins et services de santé.

NOMBRE DE PARTICIPANT(E)S ET DURÉE DE LA PARTICIPATION

Nous contacterons les directeurs des neuf CIUSSS, du CUSM, et treize CISSS du Québec afin de répondre à un questionnaire à deux temps différents soit en 2017 et en 2018 en utilisant le même questionnaire.

NATURE DE LA PARTICIPATION DEMANDÉE ET DÉROULEMENT DU PROJET

En acceptant de participer à ce projet de recherche et après avoir signé le présent formulaire, la participation consistera à répondre à un questionnaire via téléphone d'une durée de 60 minutes, portant sur l'avancement de l'engagement des patients et de leurs familles au sein de votre organisation.

Ce questionnaire sera administré par Madame Ursulla Aho-Glele, étudiante-chercheuse, à un moment qui vous conviendra. De même afin de respecter le moment le plus propice de la journée pour vous, l'heure de l'entrevue sera fixée à votre convenance. Si une question s'avère plus difficile, vous n'aurez pas à y répondre. Il n'y a pas de bonnes, ni de mauvaises réponses.

Pour faciliter la collecte et l'analyse des données, l'entrevue téléphonique durant laquelle vous complèterez le questionnaire sera enregistrée sur support audionumérique.

L'entrevue peut se faire sur plusieurs rencontres téléphoniques si vous le désirez.

La participation à ce projet de recherche est **confidentielle.**

RISQUES ET INCONVÉNIENTS

À notre connaissance, la participation à cette étude comporte peu de risque. Toutefois, le temps requis pour remplir le questionnaire, peut représenter un inconvénient pour certain(e)s participant(e)s. Vous pourrez décider de cesser l'entrevue en tout temps et sans aucun préjudice.

Risque lié au bris de confidentialité :

Il existe un risque lié à un possible bris de confidentialité concernant vos informations personnelles qui pourrait se traduire par une atteinte à votre vie privée. Ce risque est cependant minime. Puisque les participants comprennent les directeurs des CUSM, CIUSSS et des CISSS du Québec, il serait possible que vous soyez identifiable indirectement lors des publications en raison de la fonction unique que vous occupez. Toutefois, tous les efforts seront déployés pour protéger votre identité et assurer la confidentialité de nos échanges afin d'éviter une telle identification, tel que décrit dans la section «Confidentialité».

AVANTAGES

Il se peut que vous retiriez un bénéfice personnel de votre participation à ce projet de recherche, mais on ne peut vous l'assurer. À tout le moins, les résultats obtenus contribueront à l'avancement des connaissances dans ce domaine.

CONFIDENTIALITÉ

Durant votre participation à ce projet de recherche, la chercheuse responsable de ce projet ainsi que *l'étudiante-chercheuse* recueilleront, dans un dossier de recherche, les renseignements vous concernant et nécessaires pour répondre aux objectifs scientifiques de ce projet de recherche.

Ces renseignements peuvent comprendre le nom de votre établissement et le titre de votre fonction.

Tous les renseignements recueillis demeureront confidentiels dans les limites prévues par la loi. Vous ne serez identifié(e) que par un numéro de code. La clé du code reliant votre nom à votre dossier de recherche sera conservée par la chercheuse responsable de ce projet de recherche.

Ces données (transcriptions et questionnaires remplis) de recherche seront conservées pendant 7 ans sous clé, après la fin de l'étude par Mme Marie-Pascale Pomey dans un classeur de son département universitaire à l'Université de Montréal et sous son unique responsabilité. Après ce délai, les données seront totalement détruites.

Les données de recherche pourront être publiées ou faire l'objet de discussions scientifiques, mais il ne sera pas possible de vous identifier.

À des fins de surveillance, de contrôle, de protection et de sécurité, votre dossier de recherche pourra être consulté par des représentants de l'établissement et du comité d'éthique de la recherche. Toutes ces personnes et ces organismes adhèrent à une politique de confidentialité.

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis et les faire modifier au besoin.

COMMUNICATION DES RÉSULTATS GÉNÉRAUX

Un résumé des résultats vous sera envoyé par courriel dans un langage compréhensible pour les participants à la fin de la recherche.

COMPENSATION

Vous ne recevrez aucune compensation financière pour votre participation à ce projet de recherche.

EN CAS DE PRÉJUDICE

En acceptant de participer à ce projet de recherche, vous ne renoncez à aucun de vos droits et vous ne libérez pas l'équipe de recherche et l'établissement de leur responsabilité civile et professionnelle en cas de préjudice.

PARTICIPATION VOLONTAIRE ET DROIT DE RETRAIT

Votre participation à ce projet de recherche est volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner de raisons, en informant la personne-ressource de l'équipe de recherche et ce, par simple avis verbal.

Si vous vous retirez du projet ou êtes retiré(e) du projet, l'information et le matériel déjà recueillis dans le cadre de ce projet seront néanmoins conservés, analysés ou utilisés pour assurer l'intégrité du projet.

Toute nouvelle connaissance acquise durant le déroulement du projet qui pourrait avoir un impact sur votre décision de continuer à participer à ce projet vous sera communiquée rapidement.

IDENTIFICATION DES PERSONNES-RESSOURCES

Si vous avez des questions ou éprouvez des problèmes en lien avec le projet de recherche, ou si vous souhaitez vous en retirer, vous pouvez communiquer avec la chercheuse responsable, Madame Marie-Pascale Pomey, professeure titulaire au département d'administration de la santé (Université de Montréal) au numéro suivant :

- Madame Marie-Pascale Pomey : 514-xxx-xxxx poste xxxx (du lundi au vendredi de 8h00 à 16h00) ou par courriel : marie-pascale.pomey@umontreal.ca.

Vous pourriez aussi contacter l'étudiante-chercheuse au :

- Madame Ursulla Aho-Glele, étudiante-chercheuse : 514-xxx-xxxx (du lundi au vendredi de 8h00 à 17h00) ou par courriel : ursulla.aho-glele@umontréal.ca.

Pour toute question concernant vos droits en tant que participant(e) à ce projet de recherche ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec le commissaire local aux plaintes et à la qualité des services de l'Hôpital Notre-Dame du CHUM, au 514-xxx-xxxx, poste xxxx.

SIGNATURE

J'ai pris connaissance du formulaire d'information et de consentement. On m'a expliqué le projet de recherche et le présent formulaire d'information et de consentement. On a répondu à mes questions et on m'a laissé le temps voulu pour prendre une décision. Après réflexion, je consens à participer à ce projet de recherche aux conditions qui y sont énoncées. Je signe ce document et le fait parvenir à l'équipe de recherche par courrier/courriel ou j'envoie un accord écrit par courriel à l'équipe de recherche pour confirmer ma participation.

Nom (en lettres moulées) Signature du/de la participant(e) Date

SIGNATURE DE LA PERSONNE QUI OBTIENT LE CONSENTEMENT

J'ai expliqué au/à la participant(e) le projet de recherche et le présent formulaire d'information et de consentement et j'ai répondu aux questions qu'il/elle m'a posées.

Nom (en lettres moulées)	Signature de la personne qui obtient le consentement	Date

ENGAGEMENT DE LA CHERCHEUSE RESPONSABLE AU CHUM

Je certifie qu'on a expliqué au/à la participant(e) le présent formulaire d'information et de consentement, que l'on a répondu aux questions que le/la participant(e) avait.

Je m'engage, avec l'équipe de recherche, à respecter ce qui a été convenu au formulaire d'information et de consentement et à en remettre une copie signée et datée au/à la participant(e).

Nom (en lettres moulées)	Signature de la chercheuse responsable	Date

APPROBATION PAR LE COMITÉ D'ÉTHIQUE DE LA RECHERCHE

Le comité d'éthique de la recherche du CHUM a approuvé le projet et assurera le suivi du projet pour les établissements du réseau de la s

APPENDIX C1- Questionnaire PE for PS - French version

CRCHUM
CENTRE DE RECHERCHE
Centre hospitalier
de l'Université de Montréal

ESPUM
L'ÉCOLE DE SANTÉ PUBLIQUE
DE L'UNIVERSITÉ DE MONTRÉAL

Construire un système de santé sécuritaire :

stratégies utilisées pour institutionnaliser la participation des usagers dans la gestion des risques.

4.

5. QUESTIONNAIRE

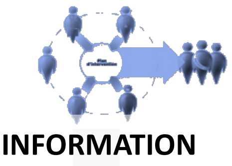
6. Portant sur l'engagement des usagers[41] à la sécurité des soins et services dans les établissements de santé et de services sociaux du Québec

Nous remercions chaleureusement la Communauté de Pratique sur l'expérience et le partenariat de soins et de services pour leur contribution à l'élaboration de ce questionnaire.

<u>Objectif du questionnaire</u>

Ce questionnaire s'adresse aux établissements de santé et services sociaux du Québec et plus spécifiquement aux **directions concernées par l'engagement des usagers** (partenariat de soins et de services[42]) ainsi qu'à celles qui sont responsables de la **prestation sécuritaire des soins et des services**.

Ce questionnaire cherche à évaluer les stratégies et les mécanismes mis en place dans votre établissement **en matière d'engagement des usagers** et plus particulièrement sur la manière dont ils sont mobilisés pour **améliorer la sécurité des soins et des services**. Par engagement, nous entendons le moyen qui permet de solliciter des usagers et ce, à différents niveaux de l'organisation (clinique (opérationnel), organisationnel (tactique) et stratégique) pour arriver à une meilleure gestion des risques et, donc, à une sécurité des soins et services optimale pour les usagers. L'engagement des usagers peut prendre 4 formes différentes : 1) ils peuvent être **informés** par les intervenants; 2) ils peuvent être **consultés** pour donner leur avis; 3) ils peuvent **collaborer** afin que leur besoin soit pris en compte; 4) ils peuvent participer à **co-construire** des interventions en partenariat[2] avec les intervenants.



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[41] Le terme « usagers » comprend les patients et les proches (comprenant la famille).

[42] Partenariat de soins et de services : une relation entre le patient, ses proches et les intervenants de la santé et des services sociaux (cliniciens, gestionnaires ou autres) qui s'inscrit dans un processus dynamique d'interaction et d'apprentissage et qui favorise l'autodétermination du patient et l'atteinte de résultats de santé optimaux. Pour y parvenir, le patient s'engage à travers sa participation, sa collaboration, ou encore par une co-construction à un soin, programme, service ou politique de santé**Invalid source specified.**.

La compilation des résultats servira à documenter les pratiques et à suivre les changements en matière d'engagement des usagers dans la sécurité des soins et services au cours du temps au Québec.

Les questions incluses dans le questionnaire ont été choisies à partir de ce que l'on retrouve dans la littérature internationale mais aussi à partir des activités en cours au Canada et au Québec.

Sommaire du questionnaire

Au cours du questionnaire, nous aborderons des questions générales sur l'engagement des usagers et sur la gestion des risques, puis, des questions spécifiques sur la manière dont s'actualise l'engagement des usagers dans la sécurité des soins et de services (politique, formation, organisation, modalités d'implication et indicateurs).

Instructions

- Le questionnaire est à remplir par les personnes responsables du développement de l'engagement des usagers dans les soins et services et par celles en charge de la gestion des risques. Et donc, le **questionnaire peut être rempli par plus d'une personne**. **Le responsable de l'engagement des patients (ou le responsable du partenariat de soins et de services) pourra ainsi répondre aux questions des pages 3 à 12 du questionnaire ; et le responsable de la gestion des risques (en collaboration ou non avec les directions des services professionnels/ infirmiers/ multidisciplinaires) pourra répondre aux questions des pages 3, et 13 à 26 du questionnaire.**
- Le questionnaire est composé d'énoncés pour lesquels il est demandé un niveau d'accord ou de désaccord.
- Nous ne nous attendons pas à ce que vous puissiez répondre à toutes les questions de ce questionnaire.
- Pour certaines questions, nous ne voulons savoir que ce que vous pensez et ce que vous percevez. Il n'y a donc pas de bonne ou de mauvaise réponse.
- Pour certains énoncés, des commentaires ou précisions supplémentaires sont requises.
- Des documents complémentaires sont à joindre aux questionnaires (cf page 25).
- Les informations sont dé-nominalisées et confidentielles.
- L'utilisation du genre masculin a pour objectif d'alléger le texte.
- Le temps approximatif nécessaire pour remplir le questionnaire est de 45 minutes à 1 heure.

Merci infiniment pour votre participation !

1. Nom de l'organisation : ____

2. Identification des personnes qui ont contribué à répondre au questionnaire :
(À cet effet, remplir la section ci-dessous)

Personne no 1

Titre d'emploi :

Date d'embauche à cette fonction :

Nom de la direction où vous travaillez :

Depuis combien de temps travaillez-vous dans le réseau de la santé ? ____________________

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à l'engagement des patient

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à la gestion des risques ?

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Personne no 2

Titre d'emploi :

Date d'embauche à cette fonction :

Nom de la direction où vous travaillez :

Depuis combien de temps travaillez-vous dans le réseau de la santé? ____________________

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à l'engagement des patient

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à la gestion des risques ?

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Personne no 3

Titre d’emploi :

Date d’embauche à cette fonction :

Nom de la direction où vous travaillez :

Depuis combien de temps travaillez-vous dans le réseau de la santé? ______________________________

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à l’engagement des patient

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à la gestion des risques ?

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Personne no 4

Titre d’emploi :

Date d’embauche à cette fonction :

Nom de la direction où vous travaillez :

Depuis combien de temps travaillez-vous dans le réseau de la santé? ______________________________

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à l’engagement des patient

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à la gestion des risques ?

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Personne no 5

Titre d’emploi :

Date d’embauche à cette fonction :

Nom de la direction où vous travaillez :

Depuis combien de temps travaillez-vous dans le réseau de la santé? ______________________________

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à l’engagement des patient

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Au cours du dernier mois, combien de temps, en moyenne, avez-vous accordé à la gestion des risques ?

○ Moins de 50 % de votre temps de travail ○ Plus de 50 % de votre temps de travail

Section 1 : Questions générales

Introduction

1. Est-ce que l'établissement fait référence à l'engagement des usagers ?
    a. Dans son plan stratégique : ○ Oui ○ Non

    b. Dans d'autres documents : ○ Oui ○ Non
        Préciser : ______________________

2. Si oui, de quelle manière ? (inscrire ici le libellé utilisé) ______________________

    ____

    ____

    ____

Description de l'organisation de l'engagement des usagers

3. Quelle(s) direction(s) est/sont responsable(s) de soutenir la mise en œuvre de l'engagement des usagers dans les soins et services ? Cocher la ou les directions concernées :
    - ○ Direction de la qualité, de l'évaluation, de la performance et de l'éthique
    - ○ Direction des services professionnels
    - ○ Direction des services multidisciplinaires
    - ○ Direction de la santé publique
    - ○ Autres (précisez) : ______________________________________

4. Quels sont les directions qui ont des **projets portant sur l'engagement des usagers** et combien de projets sont menés dans chacun de ces services ? (À cet effet, remplir le tableau ci-dessous)

Nom de la direction	**Précisez les programmes dans lesquels se trouvent ces projets**	**Nb de projets menés**
a. Direction de la qualité, de l'évaluation, de la performance et de l'éthique		
b. Direction des services professionnel		
c. Direction des services multidisciplinaires		
d. Direction des soins infirmiers		
e. Direction soutien à l'autonomie des personnes âgées		

f. Direction de l’enseignement, des relations universitaires et de la recherche
g. Direction des programmes jeunesse
h. Direction des programmes en déficience intellectuelle, déficience physique et trouble du spectre de l’autisme
i. Direction de la santé publique
j.
k.
l.

* possibilité de rajouter des lignes

5. Identification des personnes, qui au niveau des directions contribue au déploiement de l’engagement des usagers ? (À cet effet, remplir le tableau ci-dessous)

#	**Formation initiale** **(infirmière / travailleur social/ autres)**	**Formation à l’engagement des usagers**	**Titre d’emploi**	**% de temps consacré à l’engagement des usagers**	**Date d’embauche à cette fonction** JJ/MM/AA
1.	○ Infirmière ○ Travailleur social ○ Autres (précisez) : ______________________	○ Oui ○ Non			
5.*	○ Infirmière ○ Travailleur social ○ Autres (précisez) : ______________________	○ Oui ○ Non			

* possibilité de rajouter des lignes

Description de l’organisation de l’évaluation de l’expérience usager

6. Quelle(s) direction(s) est(sont) en charge de coordonner l’évaluation de l’expérience usager ?

o Direction de la qualité, de l’évaluation, de la performance et de l’éthique
o Direction des services professionnels
o Direction des services multidisciplinaires
o Direction de la santé publique
o Autres (précisez) : ____

7. Quel(s) service(s) utilise(nt) des questionnaires sur l’expérience usager ?

Nom du service	**Questionnaire fait par l’établissement à l’interne ou par un organisme externe**	**Nom du questionnaire**	**Fréquence d’utilisation du questionnaire**	**Utilisation pour l’agrément**
1.	○ Interne ○ Externe		○ En continue ○ Plus d’une fois par an ○ Une fois par an ○ Moins d’une fois par an	○ Oui ○ Non
2.	○ Interne ○ Externe		○ En continue ○ Plus d’une fois par an ○ Une fois par an ○ Moins d’une fois par an	○ Oui ○ Non
3.	○ Interne ○ Externe		○ En continue ○ Plus d’une fois par an ○ Une fois par an ○ Moins d’une fois par an	○ Oui ○ Non
4.	○ Interne ○ Externe		○ En continue ○ Plus d’une fois par an ○ Une fois par an ○ Moins d’une fois par an	○ Oui ○ Non
5.	○ Interne ○ Externe		○ En continue ○ Plus d’une fois par an ○ Une fois par an ○ Moins d’une fois par an	○ Oui ○ Non

* possibilité de rajouter des lignes

8. Identification des personnes porteuses du dossier sur l'expérience usager? (À cet effet, remplir le tableau ci-dessous)

# de Personnes	Formation initiale (Infirmière / Travailleur social / Autres)	Formation à l'engagement des usagers ou à l'expérience usager	Titre d'emploi	% de temps consacré à l'expérience usager	Date d'embauche à cette fonction JJ/MM/AA
1.	○ Infirmière ○ Travailleur social ○ Autres (précisez) : ____________________	○ Oui ○ Non			
2.	○ Infirmière ○ Travailleur social ○ Autres (précisez) : ____________________	○ Oui ○ Non			
3.	○ Infirmière ○ Travailleur social ○ Autres (précisez) : ____________________	○ Oui ○ Non			
4.	○ Infirmière ○ Travailleur social ○ Autres (précisez) : ____________________	○ Oui ○ Non			
5.	○ Infirmière ○ Travailleur social ○ Autres (précisez) : ____________________	○ Oui ○ Non			

* possibilité de rajouter des lignes

Description de l'organisation au regard de la gestion des risques

9. Dans quelle(s) direction(s) la gestion des risques est coordonnée ?

   - Direction de la qualité, de l'évaluation, de la performance et de l'éthique

- o Direction des services professionnels
- o Direction des services multidisciplinaires
- o Direction de la santé publique
- o Autres (précisez) : ____

10. Est-ce qu'il existe une collaboration entre les directions pour améliorer l'engagement des usagers en vue d'améliorer la gestion des risques ?

    ○ Oui ○ Non

11. Si oui, quels mécanismes ou travaux communs sont mis en place pour favoriser cette collaboration (participation à des comités conjoints, projets menés ensemble, etc.) ?

    ____

    ____

12. S'il n'existe pas de mécanismes de collaboration, pourquoi ?

    ____

    ____

    ____

13. Est-ce qu'il existe des mécanismes de coordination (instances, procédure, analyse de situation, etc.) entre l'engagement de l'usager, la gestion des risques et le comité des usagers ?

    ○ Oui ○ Non

14. Si oui, lesquels ? ____

Section 2. Questions en lien avec l'engagement des usagers (en général)

Activités réalisées en ce qui concerne l'engagement de l'usager - En général	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
15. Est-ce que votre établissement comporte une **stratégie ou une politique** sur l'engagement des usagers dans l'établissement ?	○	○	○	○
16. Est-ce qu'il existe une **banque d'usagers-ressources**[43] au niveau de l'ensemble de l'établissement ? Autre type de banque d'usagers ? Précisez : ______________________ ______________________	○	○	○	○
17. Est-ce qu'il existe un **formulaire pour l'ensemble de l'établissement pour** solliciter des **usagers-ressources** par les programmes ? Lesquels ? ______ ______________________ ______________________	○	○	○	○
18. Est-ce qu'il existe une **banque d'usagers-ressources par direction** ? Lesquelles ? ______________________ ______________________	○	○	○	○
19. Est-ce qu'il existe une **formation portant sur l'engagement des usagers** disponible **pour les intervenants ?** ____ ______________________ ______________________	○	○	○	○
20. Est-ce qu'il existe des **documents promotionnels** portant **sur l'engagement des usagers** disponibles **pour les intervenants** ? ______________________ ______________________ ______________________	○	○	○	○

---

[43] Un usager-ressource est un ancien patient qui a terminé sa réadaptation / traitement, etc. et qui désire maintenant aider d'autres patients à retrouver, eux aussi, leur pleine autonomie / santé. L'usager-ressource est un partenaire à part entière de l'équipe de soins. Il s'assure que l'équipe est à l'écoute des besoins des patients et il aide, par exemple, à bien comprendre les plans de traitement qui sont proposés**Invalid source specified.**.

Activités réalisées en ce qui concerne l'engagement de l'usager - En général	**Jamais/non**	**Parfois**	**Toujours/oui**	**En cours**
21. Est-ce qu'il existe des **documents promotionnels** portant **sur l'engagement des usagers** disponibles **pour les usagers** ? (Si oui fournir le document) ________________________	○	○	○	○
22. Est-ce que des usagers ont participé à l'élaboration du **plan organisationnel stratégique** ? **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1- Représentants des comités des usagers 2- Usager-ressource 3- Usager	○	○	○	○
23. Est-ce que des usagers sont invités à témoigner au **Conseil d'administration** ? **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1. Représentants des comités des usagers 2. Usager-ressource 3. Usager **Si *parfois*,** % du temps ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
24. Est-ce que des usagers sont invités **au comité de direction**? **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1- Représentants des comités des usagers 2- Usager-ressource 3- Usager **Si *parfois*,** % de réunion ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
25. Est-ce que des usagers sont intégrés **à la salle de pilotage** ? **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1- Représentants des comités des usagers 2- Usager-ressource 3- Usager **Si *parfois*,** % de réunion ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○

Activités réalisées en ce qui concerne l'engagement de l'usager - En général	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
26. Est-ce que des **usagers** participent à l'élaboration des **grandes orientations et décisions** de l'établissement ?	○	○	○	○
Si *parfois*, à quelles occasions ? _____________ ____				
27. Est-ce que des usagers sont présents lors **de l'accueil des nouveaux employés ?** **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1- Représentants des comités des usagers 2- Usager-ressource 3- Usager **Si *parfois*,** % du temps ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
28. Est-ce que le **PDG** rencontre des usagers pour connaître leur expérience de soins et de services ?	○	○	○	○
Si *parfois*, nombre de fois par an que le PDG rencontre les usagers : _____ __________________________				
29. Est-ce que le **PDGA** rencontre des usagers pour connaître leur expérience de soins et de services ?	○	○	○	○
Si *parfois*, nombre de fois par an que le PDGA rencontre les usagers : _______________________________				

Section 3. En lien avec la gestion des risques

Activités réalisées en ce qui concerne l'engagement de l'usager – Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
30. Est-ce que le **Directeur de la qualité, de l'évaluation, de la performance et de l'éthique (DQEPE)** rencontre des usagers pour connaître leur expérience de soins et de services ?	○	○	○	○
Si *parfois*, nombre de fois par an que le directeur de la DQEPE rencontre les usagers : ____				
31. Est-ce que des **chefs de programmes** rencontrent des **usagers** pour connaître leur expérience de soins et de services ?	○	○	○	○
Si *parfois*, nombre de fois par an que des chefs de programmes rencontrent des usagers : ________________________________				
32. Est-ce que **l'établissement** fait la promotion de l'implication des **usagers** dans la **réalisation de leur plan d'intervention** ?	○	○	○	○
Si *parfois*, dans quel % des directions ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)				
33. Est-ce qu'il y a **des plans d'intervention** réalisés en présence des **usagers ?**	○	○	○	○
Si *parfois*, dans quel % des directions ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)				
34. Est-ce qu'il existe des **usagers-ressources au niveau clinique** qui interviennent pour accompagner, au besoin, des usagers lors de leur c**onsultation** ?	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)				

Activités réalisées en ce qui concerne l'engagement de l'usager – Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
35. Est-ce qu'il existe des **usagers-ressources au niveau clinique** qui interviennent pour accompagner des usagers lors de l'élaboration d'un **plan d'intervention** ?	○	○	○	○

Si *parfois*, dans quel % des programmes ?

0- 25 %   25-49 %   50 %   51-75 %   75 -99%

(encercler la réponse)

36. Est-ce qu'il existe **une procédure** pour préparer **le congé des usagers ?**	○	○	○	○

Si *parfois*, dans quel % des programmes ?

0- 25 %   25-49 %   50 %   51-75 %   75 -99%

(encercler la réponse)

37. Est-ce que les intervenants utilisent une **liste de vérification** pour autoriser le **congé** (« discharge check-list ») ?	○	○	○	○

Si *parfois*, dans quel % des programmes ?

0- 25 %   25-49 %   50 %   51-75 %   75 -99%

(encercler la réponse)

38. Est-ce que **cette liste de vérification** est remise systématiquement à tout **usager** lors de son congé dans le but de favoriser la continuité de ses soins et services, et limiter les risques ?	○	○	○	○

Si *parfois*, dans quel % des programmes ?

0- 25 %   25-49 %   50 %   51-75 %   75 -99%

(encercler la réponse)

Activités réalisées en ce qui concerne l'engagement de l'usager - Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
39. Est-ce que l'établissement favorise **un retour sur les expériences vécues** dans le cadre des infections acquises en milieu de soins ? **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
40. Est-ce que l'établissement favorise **un retour sur les expériences vécues** liées **aux erreurs médicamenteuses ?** **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
41. Est-ce que l'établissement applique **le principe de « jamais sur l'usager la première fois »** pour l'apprentissage des actes techniques et gestes invasifs **par les intervenants en formation ?** **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
42. Est-ce que **l'établissement utilise la simulation pour éviter des situations potentiellement à risque** ? **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○

Activités réalisées en ce qui concerne l'engagement de l'usager - Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
Politiques				
43. Est-ce qu'il existe **une politique ou une procédure ou un processus** pour **encourager les usagers à discuter des risques des interventions** (ex. : poser des questions sur les traitements) ? (Si oui fournir le document) ________________________	○	○	○	○
44. Est-ce qu'il existe **un mécanisme, ou une procédure ou un processus** pour **encourager l'usager à poser des questions** quand celui-ci se sent dans **une situation à risque** (ex. : demander aux professionnels de se laver les mains) ? (Si oui fournir le document) ________________________	○	○	○	○
45. Est-ce qu'il existe **un mécanisme, une procédure, ou un processus** pour **encourager les usagers à avoir des comportements qui favorisent la sécurité des soins et des services ?** (ex. : signaler qu'un médicament n'est pas le bon) ? Si oui, quels sont les outils utilisés (dépliant, etc.) : ____	○	○	○	○
46. Est-ce qu'il existe **un mécanisme, une procédure, ou un processus pour encourager** les usagers **à déclarer des incidents ou des accidents** (ex. : signaler à l'administration des incidents ou accidents) ? Si oui, quels sont les outils utilisés (dépliant, etc.) : ____ ____	○	○	○	○
47. Est-ce qu'il existe **un mécanisme, une procédure, ou un processus pour encourager** les usagers **à participer à l'analyse des incidents et accidents** ? Si oui, lesquels : ____	○	○	○	○

48. Est-ce qu'il existe **un mécanisme, une procédure, ou un processus pour encourager les usagers à participer à l'annonce d'un incident ou accident qui est arrivé à une autre personne** ?

Si oui, lesquels :

○ ○ ○ ○

____

____

____

49. Est-ce qu'il existe **un mécanisme, une procédure, ou un processus pour encourager** les usagers **à trouver des solutions pour éviter la récurrence d'incidents ou d'accidents** ?

○ ○ ○ ○

Si oui, lesquels :

50. Est-ce qu'il existe une **politique, une procédure, ou un processus pour mettre au courant les usagers des actions qui ont été mises en place pour éviter que des incidents ou accidents se reproduisent ?**

Si oui, lesquels :

○ ○ ○ ○

____

51. Est-ce qu'il existe **un mécanisme, une procédure, ou un processus pour encourager** les usagers à **participer aux choix des mesures de soutien pour les usagers ayant subi un accident** ?

○ ○ ○ ○

Si oui, lesquels :

____

52. Est-ce qu'il existe **un mécanisme, une procédure, ou un processus pour encourager une culture juste ou décourager une culture de blâme dans l'établissement ?**

Si oui, lesquels :

○ ○ ○ ○

____

Activités réalisées en ce qui concerne l'engagement de l'usager - Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
Formation				
53. Est-ce qu'il existe **une formation portant sur l'engagement des usagers** disponible pour les **intervenants** de la santé ? ______________________________ ______________________________	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)				
54. Est-ce qu'il existe une **formation portant sur l'engagement des usagers** disponible pour les **usagers** ? ______________________________ ______________________________	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)				
55. Existe-t-il de la **formation en engagement des usagers pour le personnel en gestion des risques** afin de réduire les risques ?	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)				

Activités réalisées en ce qui concerne l’engagement de l’usager - Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
Formation (suite)				
56. Existe-t-il de la **formation pour les usagers sur comment être engagé dans la gestion des risques** avec les intervenants de la santé ? **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
57. Est-ce que les intervenants sont formés **aux méthodes de communication s’appuyant sur la reformulation par l’usager** de l’information donnée par les intervenants ? **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
58. Est-ce que les intervenants sont **formés par un tandem usagers-ressources/intervenants** au **rôle des usagers** pour limiter les incidents et les accidents ? **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
59. Est-ce que **les stagiaires** qui viennent en stage dans l’établissement sont **formés à la gestion des risques** ? **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
60. Est-ce que les **stagiaires** qui viennent en stage dans l’établissement sont formés à **l’engagement des usagers ?** **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○

Activités réalisées en ce qui concerne l'engagement de l'usager - Questions liées à la gestion des risques	**Jamais/non**	**Parfois**	**Toujours/oui**	**En cours**
Organisation et comités				
61. Est-ce que des **usagers** assistent **au comité de gestion des risques ?** **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1- Représentants des comités des usagers 2- Usager-ressource 3- Usager **Si *parfois*,** dans quel % de réunions sont-ils présents ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
62. Est-ce que des **usagers** assistent au **Comité de prévention et contrôle des infections ?** **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1- Représentants des comités des usagers 2- Usager-ressource 3- Usager **Si *parfois*,** dans quel % de réunions sont-ils présents ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
63. Est-ce que des **usagers** assistent à **d'autres comités** qui ont un impact sur la **gestion des risques** ? **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1- Représentants des comités des usagers 2- Usager-ressource 3- Usager **Si *oui***, lesquels ? ____________ ____ ____	○	○	○	○

Activités réalisées en ce qui concerne l'engagement de l'usager - Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
Organisation et comités (suite)				
64. Existe-t-il des **usagers** dans **des groupes de travail sur la sécurité des soins et des services** ? **Spécifiez le type d'usager (encerclez la bonne réponse) :** 1. Représentants des comités des usagers 2. Usager-ressource 3. Usager **Si *oui*,** lesquels ? ______________________________ ______________________________	○	○	○	○
65. Existe-t-il des **usagers-ressources** sur les **comités d'amélioration continue de la qualité (ex. : préparation à l'agrément) ?** **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
66. Est-ce qu'il existe des **rondes de sécurité**[44] faites dans les programmes par la haute direction afin de détecter des situations à risques et de les prévenir ? **Si *parfois*,** % de programmes : 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○

---

[44] La ronde de sécurité est un examen visuel et auditif des éléments / facteurs susceptibles de causer un accident, qui permet : de déceler le plus tôt possible les situations à risques probables et possibles ; d'informer les personnes responsables de la gestion des risques et d'empêcher ces situations avant qu'elles n'arrivent (SAAQ, 2017).

Activités réalisées en ce qui concerne l’engagement de l’usager - Questions liées à la gestion des risques	**Jamais/non**	**Parfois**	**Toujours/oui**	**En cours**
Implication des usagers				
67. Est-ce qu’actuellement les **usagers sont incités à discuter des risques des interventions** qu’ils vont recevoir **avec les intervenants** (ex. : poser des questions sur les risques liés à une endoscopie) ?	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse) Les usagers auxquels vous pensez, comprennent-ils ceux suivis dans des Groupes de médecine de famille (GMF) ? ○ Oui ○ Non				
68. Est-ce qu’actuellement les **usagers** sont **encouragés à poser des questions quand ils identifient une situation à risque** (ex. : demander aux professionnels de se laver les mains) ?	○	○	○	○
Si *oui* ou *parfois*, quels sont les mécanismes mis en place ? ______				
69. Est-ce qu’actuellement les **usagers** sont **encouragés à avoir des comportements qui favorisent la sécurité des soins et des services** (ex. : signaler qu’un médicament n’est pas le bon) ?	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse) Les usagers auxquels vous pensez, comprennent-ils ceux suivis dans des Groupes de médecine de famille (GMF) ? ○ Oui ○ Non				

Activités réalisées en ce qui concerne l’engagement de l’usager - Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
Implication des usagers (suite)				
70. Est-ce qu’actuellement **les usagers** sont amenés à **déclarer des incidents ou des accidents** (ex. : signaler à des intervenants ou à l’administration des incidents ou accidents) ?	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse) Comprenant les GMF ? ○ Oui ○ Non				
71. Est-ce qu’actuellement les usagers sont amenés à **participer à l’analyse des incidents et accidents ?**	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse) Comprenant les GMF ? ○ Oui ○ Non				
72. Est-ce qu’actuellement **les usagers** sont amenés à **participer à trouver des solutions pour éviter la récurrence d’incidents ou d’accidents ?**	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse) Comprenant les GMF ? ○ Oui ○ Non				

Activités réalisées en ce qui concerne l'engagement de l'usager - Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
Implication des usagers (suite)				
73. Est-ce qu'actuellement les **usagers** sont **mis au courant des actions qui ont été mises en place pour éviter la récurrence des incidents ou accidents** ? Comment ? ____ ____ ____ ____ **Si *parfois*,** dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse) Comprenant les GMF ? ○ Oui ○ Non	○	○	○	○
Dans les soins donnés en Groupe de médecine de famille (GMF)				
74. Est-ce que les **incidents et accidents sont déclarés en GMF ?** **Si *parfois*,** dans quel % des installations ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○
75. Est-ce qu'il existe des **comités qui réalisent des revues de morbi-mortalité (RMM) pluri professionnelles en GMF ?** **Si *parfois*,** dans quel % des installations ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)	○	○	○	○

Activités réalisées en ce qui concerne l'engagement de l'usager - Questions liées à la gestion des risques	**Jamais/ non**	**Parfois**	**Toujours/oui**	**En cours**
Indicateurs				
76. Est-ce que l'établissement développe **des indicateurs de suivi** en lien avec **l'engagement des usagers** (Donnez des exemples ou fournissez la liste des indicateurs en pièce jointe) ? ____ ____	○	○	○	○
77. Est-ce que **l'établissement a développé des indicateurs de suivi en lien avec l'engagement des usagers** et leur impact **sur la sécurité dans les soins et services sociaux** ? (Donnez des exemples ou fournissez la liste des indicateurs en pièce jointe) ? ____ ____	○	○	○	○
Si *parfois*, dans quel % des programmes ? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (encercler la réponse)				
78. Est-ce que l'établissement développe **des enquêtes ponctuelles pour mesurer le** degré d'implantation de l'engagement des usagers (Donnez des exemples) ? ____ ____	○	○	○	○

Section 4 : Informations générales

79. Participez-vous ou avez-vous participé dans votre établissement à des structures ou des comités de gestion des risques ?

a. Comité de vigilance et de la qualité	○ Oui ○ Non
b. Comité de gestion des risques	○ Oui ○ Non
c. Comité de gestion intégrée des risques	○ Oui ○ Non
d. Comité portant sur la prévention et le contrôle des infections	○ Oui ○ Non
e. Comité portant sur la lutte contre la douleur	○ Oui ○ Non
f. Comité portant sur le bon usage des médicaments	○ Oui ○ Non
g. Comité portant sur les dispositifs médicaux	○ Oui ○ Non
h. Autre (précisez) :	

80. Participez-vous ou avez-vous participé dans votre établissement à des structures en lien avec **l'engagement des usagers** ?

○ Oui ○ Non

81. Globalement, quelle est votre appréciation de la sécurité des soins et des services dans votre établissement ?

○ Excellente ○ Très bonne ○ Acceptable ○ Faible ○ Défaillante

Liste des documents à joindre si possible

Politique d'engagement des usagers dans l'établissement

Définition de l'engagement

Grille projets partenariat / engagement des usagers du ministère de la Santé et des Services sociaux

Liste des indicateurs utilisés pour suivre l'engagement des usagers dans les soins et services

Liste des indicateurs utilisés pour suivre l'impact de l'engagement des usagers sur la sécurité des soins dans les soins et services

Dernier rapport d’incidents / accidents envoyés au MSSS

Commentaires?

NOUS VOUS REMERCIONS pour votre temps précieux qui sera très utile pour promouvoir la sécurité des usagers dans le système de santé et de services au Québec

APPENDIX C2- Questionnaire PE for PS – Translated _ English version

"The Institutionalization of Patient Engagement in Risk Management and Patient Safety: Building a questionnaire for the assessment of strategies used by healthcare managers at every level of governance."

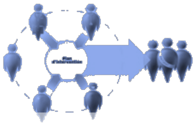
7.

8. Questionnaire on Patient[45] Engagement in Risk Management and Safety in Healthcare and Social Health Services within Quebec's Integrated Healthcare Institutions

This English version of the questionnaire has been translated from the original French version.

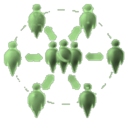
Objective of the Questionnaire

This questionnaire is intended for healthcare and social health service institutions concerned with patient engagement (patient-as-partners[46] in care and health services) in the fields of risk management and safety. This questionnaire seeks to evaluate the strategies and mechanisms of structures and processes put in place in healthcare institutions in terms of patient engagement, particularly regarding how patients are mobilized to improve the safety of care and services. The questionnaire is designed to help managers at every level of governance (clinical, tactical, and strategical) in healthcare organizations institutionalize or have a comprehensive vision of their patient engagement initiatives in patient safety. Patient Engagement (PE) is an approach in which patients can be solicited at different levels of the organization (Clinical (operational), organizational (tactical) and strategic) to achieve better risk management and safety outcomes in care and services. PE generally occurs in four different forms through which patients may: (1) be kept informed by the healthcare providerss; (2) be consulted to provide their opinion and input; (3) cooperate so that their needs remain considered; (4) co-develop interventions in partnership with stakeholders.



INFORMATION

CONSULTATION



COLLABORATION / COOPERATION

CO-CONSTRUCTION/ CO-DEVELOPMENT

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[45] The term "patient" includes patients, users and relatives (including family members)

[46] Patient-as-partner: a relationship between the patient, his or her family and health and social service professionals (clinicians, managers or others) that is part of a dynamic process of interaction and learning that promotes the patient's self-determination and attainment of optimal health outcomes. To achieve this, the patient commits himself/herself through his/her participation, collaboration, or through a co-development to a care, program, service or health policy (Université de Montréal, 2017).

Instructions

- The questionnaire is to be completed by those responsible for the development of patient engagement in healthcare and social health services, and by those in charge of safety/risk management. Therefore, **the questionnaire can be filled out by more than one person. The Patient Engagement Officer (or person in charge of engagement/partnership in care and service, or even chairs of patient group) should be able to answer questions from pages 3 to 11 of the questionnaire; while the Risk Management Officer (in collaboration with the Professional/Nurse/Multidisciplinary Services Branch) should be able to answer questions on pages 3 and from pages 12 to 23 of the questionnaire.**
- The questionnaire is made up of statements for which a level of agreement or disagreement is sought.
- For some statements, additional comments or clarifications are required.
- Additional documents are to be attached to the questionnaires (see page 23).
- Information provided is confidential.
- The purpose of the use of the masculine genre is to lighten the text.
- The approximate time required to complete the questionnaire of **72 questions,** is 45 minutes to 1 hour. Questions **from pages 3 to 11 of the questionnaire will take approximatively 20-30 minutes** per person; and questions **from pages 12 to 23 of the questionnaire, will take approximatively 25-35 minutes** per person**.**
- Healthcare leaders could also decide to adapt certain themes to what they are used to, and therefore change the questionnaire and choose certain types of questions over others to meet their needs.

Thank you very much for your participation!

3. Name of the Organization:

____

4. Identification of the persons in charge of completing the questionnaire:
(complete the section below. If more than two persons are answering the questionnaire, please copy and paste this section on another page.)

Person no 1

Job Title:

Time spent in this position:

The name of the directorate/department where you are working:

How long have you been working in the health network? __________________________

Over the last month, how much time, on average, have you spent on “patient engagement”?

○ Less than 50% of your working time ○ More than 50% of your working time

Over the last month, how much time, on average, have you spent on safety/ risk management?

○ Less than 50% of your working time ○ More than 50% of your working time

Person no 2

Job Title:

Time spent in this position:

The name of the directorate/department where you are working:

How long have you been working in the health network? __________________________

Over the last month, how much time, on average, have you spent on “patient engagement”?

○ Less than 50% of your working time ○ More than 50% of your working time

Over the last month, how much time, on average, have you spent on safety/ risk management?

○ Less than 50% of your working time ○ More than 50% of your working time

Section 1: General Questions

Introduction

15. Does the healthcare institution refer to patient engagement?
    a. In its strategic plan? ○ Yes ○ No
    b. Other documents (operational plans, program plans, board meeting's agenda, performance planning and reporting (e.g. scorecard))?

○ Yes ○ No

Please specify: ______________________

16. If so, in what way? ____

____

____

____

Description of the healthcare institution in patient engagement

17. What department (s) is/are responsible for supporting the implementation of patient engagement in care and services? Please check the relevant boxes:
    - ○ Department of Quality, Evaluation, Performance and Ethics / patient safety/ quality improvement/ risk management
    - ○ Professional Services Department
    - ○ Multi-disciplinary Services Department
    - ○ Public Health Department
    - ○ Patient engagement/ experience Department
    - ○ Others (Specify): ____

18. Which departments have programs, initiatives, activities related to patient engagement, and how many programs, initiatives, activities are carried out in each of these services? (Please complete the table below)

Name of the department **(Please list the appropriate name of each department accordingly)**	**Specify the programs in which these projects are located**	**Number of projects carried out**
m.		
n.		
o.		
p.		

* Possibility to add more lines if needed.

19. Identification of individuals within the directorate/department who contribute to the implementation of patient engagement? (Please complete the table below)

#	**Initial Training** **(nurse/social worker/others)**	**Patient Engagement Training**	**Job Title**	**% of time spent on patient engagement**	**Date of hiring in this function** **dd/mm/yy**
1.	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			
2.	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			
3.	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			
4.	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			
5.*	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			

* Possibility to add more lines if needed.

Description of the patient experience evaluation structure

20. Which department(s) is/are in charge of coordinating the evaluation of the patient experience (if different from the department in charge of patient engagement)?

   o Department of Quality, Evaluation, Performance and Ethics / patient safety/ quality improvement/ risk management
   o Professional Services Department

- Multi-disciplinary Services Department
- Public Health Department
- Patient engagement/ experience Department
- Others (Specify): ____

21. Which service (s) uses the patient experience tool (s) / questionnaire (s) & What tool (s) / questionnaire (s) is (are) used to evaluate patient experience?

Service Name	**Questionnaire made by the institution internally or by an external body**	**Name of the questionnaire/tool**	**Frequency at which the questionnaire/tool is used**	**Used for accreditation?**
6.	○ Internal ○ External		○ Continuously ○ More than once a year ○ Once per year ○ Less than once a year	○ Yes ○ No
7.	○ Internal ○ External		○ Continuously ○ More than once a year ○ Once per year ○ Less than once a year	○ Yes ○ No
8.	○ Internal ○ External		○ Continuously ○ More than once a year ○ Once per year ○ Less than once a year	○ Yes ○ No
9.	○ Internal ○ External		○ Continuously ○ More than once a year ○ Once per year ○ Less than once a year	○ Yes ○ No
10.	○ Internal ○ External		○ Continuously ○ More than once a year ○ Once per year ○ Less than once a year	○ Yes ○ No

* Possibility to add more lines if needed.

22. Identification of persons leading the patient experience program, initiative or activities? (Please complete the table below or provide the resume of these persons.)

#	**Initial Training** **(Nurse/Social worker/others)**	**Patient Engagement Training**	**Job Title**	**% of time spent on patient engagement**	**Date of hiring in this function** **dd/mm/yy**
1.	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			
2.	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			
3.	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			
4.	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			
5.*	○ Nurse ○ Social worker ○ Other (specify): ____________________	○ Yes ○ No			

* Possibility to add more lines if needed.

Description of the safety/risk management structure

23. Which department(s) coordinate(s) risk management?

- o Department of Quality, Evaluation, Performance and Ethics / patient safety/ quality improvement/ risk management
- o Professional Services Department
- o Multi-disciplinary Services Department
- o Public Health Department
- o Patient engagement/ experience Department
- o Others (Specify): ____

24. Do departments collaborate to improve patient engagement for the betterment of safety/risk management?

    ○ Yes ○ No

25. If so, what common mechanisms or work are being put in place to facilitate this collaboration (participation in joint committees, projects carried out together, etc.)?

    ____

    ____

    ____

26. If there are no collaborative mechanisms, why?

    ____

    ____

    ____

27. Are there any coordination mechanisms (bodies, procedures, situation analysis, etc.) between the patient-as-partner, risk management and the user committee?

    ○ Yes ○ No

28. If so, which ones?

    ____

    ____

Section 2. Questions related to patient engagement (in general)

Activities carried out with regard to patient engagement **- in general**	**Never/ No**	**Sometimes**	**Always / Yes**	**In progress**
15. Does your institution have a **strategy or policy on patient engagement**?	○	○	○	○
16. Is there a **database of Patient-as-Partners** [47] at the institutional level? Other type of **database?** Please specify: ____ ____	○	○	○	○
17. Is there **Is there at least one standard form to be filled by the different departments to solicit a Patient-as-Partner**? Which one (s)? ____ ____	○	○	○	○
18. Is **there a patient-as-partner database per department**? In which department(s)? ____ ____	○	○	○	○
19. Is **training on patient engagement** available to **health professionals?** ____ ____	○	○	○	○

---

[47] Patient-as-Partner is a former patient who has completed rehabilitation/treatment, etc. and who now wants to help other patients recover their full autonomy/health as well. The Patient-as-Partner is a full-fledged partner of the care team. It ensures that the team listens to the needs of patients and helps, for example, to fully understand the treatment plans that are proposed (CHUM, 2017).

Activities carried out with regard to patient engagement **- in general**	**Never/ No**	**Sometimes**	**Always / Yes**	**In progress**
20. Are **promotional materials on patient engagement** available to **health professionals**? ____________________ ____________________ ____________________	○	○	○	○
21. Are there any **promotional materials on patient engagement** available **to patients**? (If yes, please provide the documents) ______________	○	○	○	○
22. Have patients participated in the development of the organization's strategic plan? **Specify the type of patients (please circle the correct answer):** 4- Patients-as-partners 5- Patients 6- Other? (e.g. representative of the user's committee) ____________	○	○	○	○
23. Are **patients invited** to testify **on the Board of Directors**? **Specify the type of patient (please circle the correct answer):** 1- Patients-as-partners 2- Patients 3- Other (e.g. representative of the user's committee) ________	○	○	○	○

If sometimes, what % of the time?

0- 25 %   25-49 %   50 %   51-75 %   75 -99%

(Please circle the correct answer)

Activities carried out with regard to patient engagement **- in general**	**Never/ No**	**Sometimes**	**Always / Yes**	**In progress**
Specify the type of testimony (e.g. patient videos followed by a facilitated dialogue, etc.) ______________________________				
24. Are **patients integrated into the strategic steering room (where simulation initiatives related to strategic activities take place) in** the healthcare organization? **Specify the type of patient (please circle the correct answer):** 1- Patients-as-partners 2- Patients 3- Other (e.g. representative of the user's committee) _____________ ***If sometimes,*** what % of the meetings? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer) **How are patients integrated in these activities?** ____	○	○	○	○

Activities carried out with regard to patient engagement- in general	**Never/ No**	**Sometimes**	**Always / Yes**	**In progress**
25. Are patients involved in the development of the main orientations of the institution? ***If sometimes,*** on what occasions? ____ ____	○	○	○	○
26. Are patients present during the onboarding of **new employees?** **Specify the type of patient (please circle the correct answer):** 1- Patients-as-partners 2- Patients	○	○	○	○

Activities carried out with regard to patient engagement- in general	Never/ No	Sometimes	Always / Yes	In progress
3- Other (e.g. representative of the user's committee) ____________				
If sometimes, what % of the time? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
27. Does the **CEO meet with patients** to **learn about their experience of care and services**?	○	○	○	○
***If sometimes,* please indicate the** number of times per year that he/she meets with patients: ______________________________				
28. Does the **Assistant General Manager meet with patients** to **learn about their experience of care and services**?	○	○	○	○
***If sometimes,* please indicate the** number of times per year that he/she meets with patients: ______________________________				

Section 3. Questions related to safety / risk management

Activities carried out with regard to patient engagement in safety / risk management	Never/ No	Sometimes	Always/ Yes	In progress
29. Does the **director in charge of quality and patient safety/ risk management meet with patients to learn about their experience of care and services**?	○	○	○	○
If sometimes, please indicate the number of times per year that he/she meets with patients: ______________________________				

Activities carried out with regard to patient engagement in safety / risk management	**Never/ No**	**Sometimes**	**Always/ Yes**	**In progress**
30. Do **Program Managers meet with patients to learn about their experience of care and services?**	○	○	○	○
If sometimes, please indicate the number of times per year that he/she meets with patients: ____________________				
31. Does the **institution promote patient engagement in the implementation of their individualized treatment plan**?	○	○	○	○
If sometimes, in which % of departments? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
32. Are there **any individualized treatment plans made in presence of patients?**	○	○	○	○
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
33. Are there **any patients-as-partners or patient advisors at the clinical level who intervene to accompany, if necessary, patients during their consultation**?	○	○	○	○
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
34. Are there **Patients-as-Partners** at the clinical level who intervene to accompany patient**s in the development of an individualized treatment plan**?	○	○	○	○
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
35. Is there a **procedure for preparing** the patient's **discharge?**	○	○	○	○

Activities carried out with regard to patient engagement in safety / risk management	**Never/ No**	**Sometimes**	**Always/ Yes**	**In progress**
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
36. Do **health professionals use a checklist to allow discharge**?	○	○	○	○
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
37. Is this **checklist routinely given** to all patients **being discharged** to **promote continuity of care and services, and to limit risks**?	○	○	○	○
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				

Activities carried out with regard to patient engagement in safety / risk management	**Never/ No**	**Sometimes**	**Always/ Yes**	**In progress**
38. Does the **institution promote feedback on the experiences lived within the context of healthcare acquired infections**? **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
39. Does **the institution promote feedback on experiences related to medication errors?** **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
40. Does the **institution use simulation to prevent potentially unsafe situations**? **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○

Activities carried out with regard to patient engagement in safety / risk management	Never/ No	Sometimes	Always/ Yes	In progress
Policies				
41. Is there a mechanism, or procedure or process **to encourage patients to discuss the risks of interventions they will receive with health professionals** (e.g., asking questions about treatment)?	○	○	○	○
If yes, which ones: ____				
If sometimes, in which % of the programs? 0- 25 %　25-49 %　50 %　51-75 %　75 -99% (Circle the Answer)				
42. Is there a mechanism, or a procedure or process **to encourage patients to ask questions** when feeling **part of an unsafe situation** (e.g., ask the professionals to wash their hands)?	○	○	○	○
If yes or sometimes, what mechanisms have been put in place? Name of the documents and mechanisms in place: ____ ____ ____				
43. Is there a mechanism, a procedure, or a process **to encourage patients to adopt behaviours that promote safety of care and services?** (e.g.: flag changes in medication)?				
If yes, what tools are used (leaflet, etc.) / what type of behaviors are used (have you seen anything or observed anything unusual, etc.): ____ ____ ____	○	○	○	○

44. Is there a mechanism, a procedure, or a process **to encourage patients to report incidents or accidents** (e.g., report to the administration of incidents or accidents)?

If yes, what tools are used (leaflet, etc.):

○ ○ ○ ○

____

____

45. Is there a mechanism, a procedure, or a process **to encourage patients to participate in the analysis of incidents and accidents**?

If yes, which ones:

____

○ ○ ○ ○

If sometimes, in which % of the programs?

0- 25 % 25-49 % 50 % 51-75 % 75 -99%

(Circle the Answer)

46. Is there a mechanism, a procedure, or a process **to encourage patients to participate in the disclosure of an incident or accident that happened to another person**?

If yes, which ones:

____

____

○ ○ ○ ○

If sometimes, in which % of the programs?

0- 25 % 25-49 % 50 % 51-75 % 75 -99%

(Circle the Answer)

47. Is there a mechanism, a procedure, or a process to encourage patients **to find solutions to prevent the recurrence of incidents or accidents**?

If yes, which ones:

____ ○ ○ ○ ○

If sometimes, in which % of the programs?

0- 25 % 25-49 % 50 % 51-75 % 75 -99%

(Circle the Answer)

48. Is there a mechanism, procedure, or process **to make patients aware of the actions that have been put in place to prevent incidents or accidents from happening again?**

If yes, how: ○ ○ ○ ○

____

____

49. Is there a mechanism, a procedure, or a process **to encourage patients to participate in the choices of *support measures* for those who have suffered an accident**?

If yes, which ones: ○ ○ ○ ○

____

50. Is there a mechanism, a procedure, or a process **to encourage a fair culture or discourage a culture of blame** in the healthcare institution**?**

If yes, which ones: ○ ○ ○ ○

____

Activities carried out with regard to patient engagement in safety / risk management	**Never/ No**	**Sometimes**	**Always/ Yes**	**In progress**
Training				
51. Is **training on patient engagement available to health care providers**? ____ ____ **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
52. Is **training available to patients on "*patient engagement*"**? ____ ____ **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
53. Is **patient engagement training available** to patient safety/risk management personnel to reduce risk? **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○

Activities carried out with regard to patient engagement in safety / risk management	**Never/ No**	**Sometimes**	**Always/ Yes**	**In progress**
Training (cont'd)				
54. Is **training available** for patients on how to be engaged in safety / risk management alongside **health care providers?** **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
55. Are **health professionals** trained **in methods of communication to address the reformulation of information by patients**? **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
56. Are health professionals trained in **tandem (patient -as-partner / health professionals)** to **reduce incidents and accidents**? **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
57. Are **interns** who work in the health institution **trained in risk management**? **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
58. Are **interns** who work in the health institution **trained in patient engagement?** **If sometimes,** in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○

Activities carried out with regard to patient engagement in safety / risk management	**Never/ No**	**Sometimes**	**Always/ Yes**	**In progress**
Organization and committees				
59. Do **patients participate in the Risk Management Committee?** **Specify the type of patients (please circle the correct answer):** 1- Patients-as-partners 2- Patients 3- Other (e.g. representative of the user's committee) _____________ **If sometimes**, in what% of the meetings are they present? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
60. Do **patients participate in the Disease Control and Infection Control Committee?** **Specify the type of patients (please circle the correct answer):** 1- Patients-as-partners 2- Patients 3- Other (e.g. representative of the user's committee) _____________ **If sometimes**, in what% of the meetings are they present? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)	○	○	○	○
61. Do **patients participate in other committees that have an impact on patient safety or risk management**? **Specify the type of patients (please circle the correct answer):** 1- Patients-as-partners 2- Patients 3- Other (e.g. representative of the user's committee) _____________	○	○	○	○

If yes, which committees?

____

____

Activities carried out with regard to patient engagement in safety / risk management	**Never/ No**	**Sometimes**	**Always/ Yes**	**In progress**
Organization and committees (cont'd)				
62. Are there **patients in working groups on care and service safety?** **Specify the type of patients (please circle the correct answer):** 1- Patients-as-partners 2- Patients 3- Other (e.g. representative of the user's committee) __________	○	○	○	○
If yes, which working groups? ____ ____				
63. Are there **Patients-as-partners** on **continuous quality improvement committees** (e.g., preparation for accreditation)**?**	○	○	○	○
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
64. Are there **security rounds made by senior management to detect and prevent risk** situations in different departments?	○	○	○	○
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% Please circle the correct answer)				

In the care given in Family Medicine Groups (FMG)				
65. Are **incidents and accidents reported in FMGs?**	○	○	○	○
If sometimes, In which% of the facilities? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
66. Are there any committees that carry out multi-professional Morbidity-Mortality Reviews (MMR) in FMGs**?**	○	○	○	○
If sometimes, In which% of the facilities? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				

Activities carried out with regard to patient engagement in safety / risk management	**Never/ No**	**Sometimes**	**Always/ Yes**	**In progress**
Indicators				
67. Does the institution **develop indicators which monitor patient engagement** (please provide examples or a list of indicators in attachment)? ____ ____	○	○	○	○
68. Has the institution **developed follow-up indicators** related to **patient engagement and their impact on safety in health care and social services**? (Please provide examples or the list of indicators in attachment)? ____ ____	○	○	○	○
If sometimes, in which % of the programs? 0- 25 % 25-49 % 50 % 51-75 % 75 -99% (Please circle the correct answer)				
69. Does **the institution develop ad hoc surveys to measure the degree of implementation** of patient engagement (please give examples)? ____ ____	○	○	○	○

Section 3: General Information to be completed by the risk manager

70. Do you participate, or have you participated in structures or committees of safety / risk management in your health institution?

a. Vigilance and Quality Committee	○ Yes ○ No
b. Risk Management Committee	○ Yes ○ No
c. Integrated Risk Management Committee	○ Yes ○ No
d. Committee on Infection Prevention and control	○ Yes ○ No
e. Committee dealing with the fight against pain	○ Yes ○ No
f. Committee on the proper use of medication	○ Yes ○ No
g. Medical Devices Committee	○ Yes ○ No
h. Other (Specify):	

71. Do you participate, or have you participated in structures related to patient engagement in your health institution?

○ Yes ○ No

72. Overall, what is your assessment of the safety of care and services in your institution?

○ Excellent ○ Very good ○ Acceptable ○ Low ○ Failing

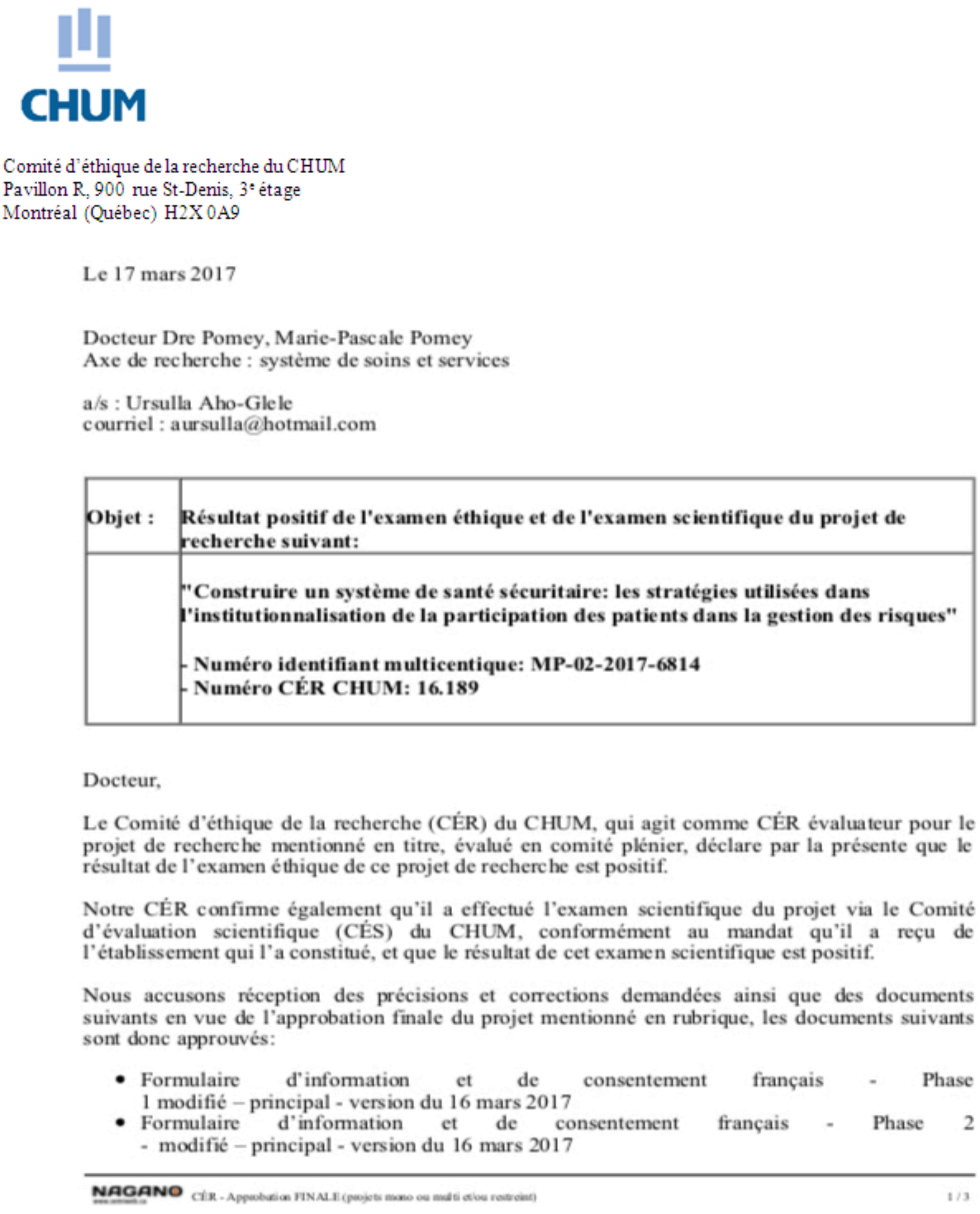
List of documents to be attached, if possible

Patient engagement policy
Definition of patient engagement
Grid projects partnership/engagement in patient engagement
List of indicators used to monitor patient engagement in care and services
List of indicators used to monitor the impact of patient engagement in care and services for safety
Last report of incidents/accidents

Comments?

Thank you for taking the time to fill out the questionnaire on patient engagement in safety / risk management.

APPENDIX D - CRCHU research protocol approval letter - MP-02-2017-6814 -- CÉR CHUM Number: 16.189



CHUM

Comité d'éthique de la recherche du CHUM
Pavillon R, 900 rue St-Denis, 3e étage
Montréal (Québec) H2X 0A9

Le 17 mars 2017

Docteur Dre Pomey, Marie-Pascale Pomey
Axe de recherche : système de soins et services

a/s : Ursulla Aho-Glele
courriel : aursulla@hotmail.com

Objet :	**Résultat positif de l'examen éthique et de l'examen scientifique du projet de recherche suivant:**
	"Construire un système de santé sécuritaire: les stratégies utilisées dans l'institutionnalisation de la participation des patients dans la gestion des risques" **- Numéro identifiant multicentique: MP-02-2017-6814** **- Numéro CÉR CHUM: 16.189**

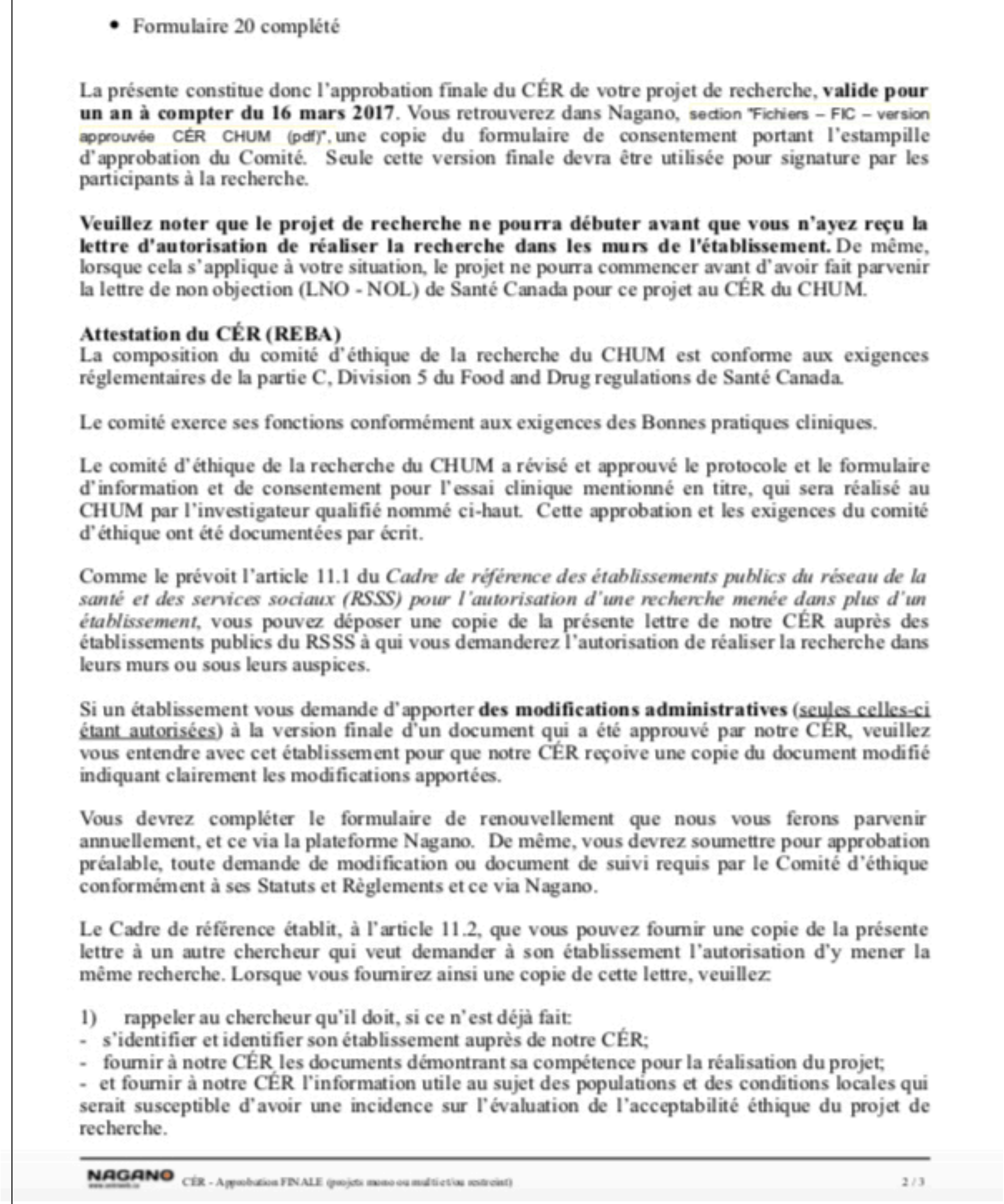
Docteur,

Le Comité d'éthique de la recherche (CÉR) du CHUM, qui agit comme CÉR évaluateur pour le projet de recherche mentionné en titre, évalué en comité plénier, déclare par la présente que le résultat de l'examen éthique de ce projet de recherche est positif.

Notre CÉR confirme également qu'il a effectué l'examen scientifique du projet via le Comité d'évaluation scientifique (CÉS) du CHUM, conformément au mandat qu'il a reçu de l'établissement qui l'a constitué, et que le résultat de cet examen scientifique est positif.

Nous accusons réception des précisions et corrections demandées ainsi que des documents suivants en vue de l'approbation finale du projet mentionné en rubrique, les documents suivants sont donc approuvés:

- Formulaire d'information et de consentement français - Phase 1 modifié – principal - version du 16 mars 2017
- Formulaire d'information et de consentement français - Phase 2 - modifié – principal - version du 16 mars 2017



- Formulaire 20 complété

La présente constitue donc l'approbation finale du CÉR de votre projet de recherche, **valide pour un an à compter du 16 mars 2017**. Vous retrouverez dans Nagano, section "Fichiers – FIC – version approuvée CÉR CHUM (pdf)", une copie du formulaire de consentement portant l'estampille d'approbation du Comité. Seule cette version finale devra être utilisée pour signature par les participants à la recherche.

Veuillez noter que le projet de recherche ne pourra débuter avant que vous n'ayez reçu la lettre d'autorisation de réaliser la recherche dans les murs de l'établissement. De même, lorsque cela s'applique à votre situation, le projet ne pourra commencer avant d'avoir fait parvenir la lettre de non objection (LNO - NOL) de Santé Canada pour ce projet au CÉR du CHUM.

Attestation du CÉR (REBA)
La composition du comité d'éthique de la recherche du CHUM est conforme aux exigences réglementaires de la partie C, Division 5 du Food and Drug regulations de Santé Canada.

Le comité exerce ses fonctions conformément aux exigences des Bonnes pratiques cliniques.

Le comité d'éthique de la recherche du CHUM a révisé et approuvé le protocole et le formulaire d'information et de consentement pour l'essai clinique mentionné en titre, qui sera réalisé au CHUM par l'investigateur qualifié nommé ci-haut. Cette approbation et les exigences du comité d'éthique ont été documentées par écrit.

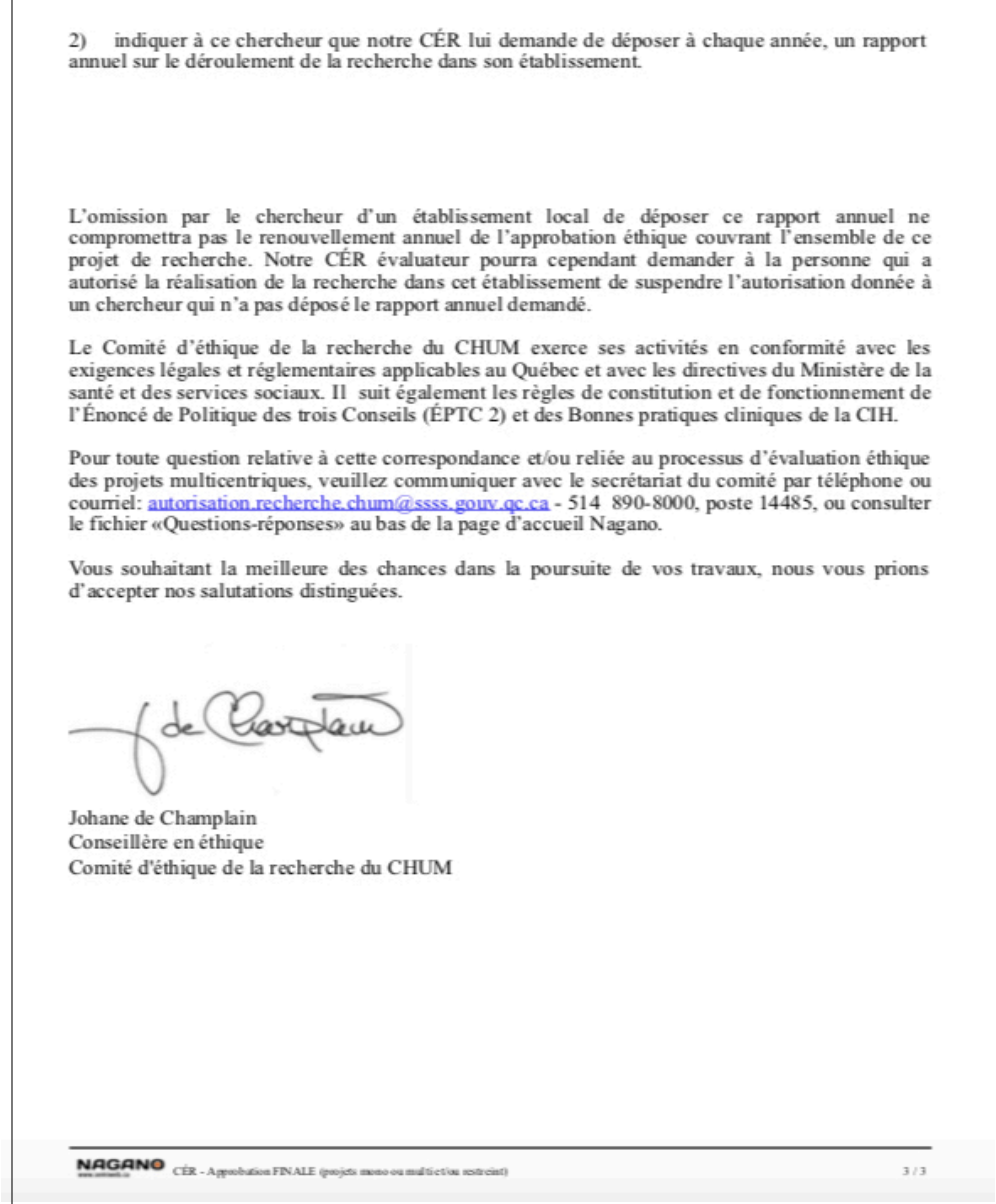
Comme le prévoit l'article 11.1 du *Cadre de référence des établissements publics du réseau de la santé et des services sociaux (RSSS) pour l'autorisation d'une recherche menée dans plus d'un établissement*, vous pouvez déposer une copie de la présente lettre de notre CÉR auprès des établissements publics du RSSS à qui vous demanderez l'autorisation de réaliser la recherche dans leurs murs ou sous leurs auspices.

Si un établissement vous demande d'apporter **des modifications administratives** (seules celles-ci étant autorisées) à la version finale d'un document qui a été approuvé par notre CÉR, veuillez vous entendre avec cet établissement pour que notre CÉR reçoive une copie du document modifié indiquant clairement les modifications apportées.

Vous devrez compléter le formulaire de renouvellement que nous vous ferons parvenir annuellement, et ce via la plateforme Nagano. De même, vous devrez soumettre pour approbation préalable, toute demande de modification ou document de suivi requis par le Comité d'éthique conformément à ses Statuts et Règlements et ce via Nagano.

Le Cadre de référence établit, à l'article 11.2, que vous pouvez fournir une copie de la présente lettre à un autre chercheur qui veut demander à son établissement l'autorisation d'y mener la même recherche. Lorsque vous fournirez ainsi une copie de cette lettre, veuillez:

1) rappeler au chercheur qu'il doit, si ce n'est déjà fait:
- s'identifier et identifier son établissement auprès de notre CÉR;
- fournir à notre CÉR les documents démontrant sa compétence pour la réalisation du projet;
- et fournir à notre CÉR l'information utile au sujet des populations et des conditions locales qui serait susceptible d'avoir une incidence sur l'évaluation de l'acceptabilité éthique du projet de recherche.



2) indiquer à ce chercheur que notre CÉR lui demande de déposer à chaque année, un rapport annuel sur le déroulement de la recherche dans son établissement.

L'omission par le chercheur d'un établissement local de déposer ce rapport annuel ne compromettra pas le renouvellement annuel de l'approbation éthique couvrant l'ensemble de ce projet de recherche. Notre CÉR évaluateur pourra cependant demander à la personne qui a autorisé la réalisation de la recherche dans cet établissement de suspendre l'autorisation donnée à un chercheur qui n'a pas déposé le rapport annuel demandé.

Le Comité d'éthique de la recherche du CHUM exerce ses activités en conformité avec les exigences légales et réglementaires applicables au Québec et avec les directives du Ministère de la santé et des services sociaux. Il suit également les règles de constitution et de fonctionnement de l'Énoncé de Politique des trois Conseils (ÉPTC 2) et des Bonnes pratiques cliniques de la CIH.

Pour toute question relative à cette correspondance et/ou reliée au processus d'évaluation éthique des projets multicentriques, veuillez communiquer avec le secrétariat du comité par téléphone ou courriel: autorisation.recherche.chum@ssss.gouv.qc.ca - 514 890-8000, poste 14485, ou consulter le fichier «Questions-réponses» au bas de la page d'accueil Nagano.

Vous souhaitant la meilleure des chances dans la poursuite de vos travaux, nous vous prions d'accepter nos salutations distinguées.

J de Champlain

Johane de Champlain
Conseillère en éthique
Comité d'éthique de la recherche du CHUM

APPENDIX E - Consent letter Part 2 – research project PE for PS

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

Phase 2

Titre du projet:	Construire un système de santé sécuritaire: les stratégies utilisées dans l'institutionnalisation de la participation des patients dans la gestion des risques.
Chercheuse responsable au CHUM et direction de recherche:	Marie-Pascale Pomey, MD, Msc, PhD Professeure titulaire, Département d'administration de la santé École de santé publique, Université de Montréal
Étudiante-chercheuse:	Ursulla Aho-Glele Candidate au doctorat Département d'administration de la santé École de santé publique, Université de Montréal
Identifiant multicentrique:	MP-02-2017-6814 (MP)
No de projet au CHUM:	16.189

PRÉAMBULE

Nous sollicitons votre participation à un projet de recherche parce que vous travaillez au sein du Centre intégré universitaire de santé et des services sociaux (CIUSSS) de la Mauricie et centre-du-Québec ou au sein du Centre intégré de santé et des services sociaux (CISSS) de la Montérégie-Est ou encore, au sein du Centre intégré universitaire de santé et des services sociaux (CIUSSS) du Centre-ouest-de-l ‘île-de-Montréal en tant que gestionnaire en gestion des risques, gestionnaire en partenariat-usager, gestionnaire en expérience-usager, gestionnaire en qualité, gestionnaire responsable de l’accréditation, gestionnaire clinico-administratifs, membre du conseil d’administration, gestionnaire - commissaire aux plaintes et de la qualité, membre du comité de gestion des risques, membre du comité de vigilance, membre du comité usagers, ou en tant que membre d’un groupe de travail en lien avec la gestion des risques / sécurité des soins et services de santé et services sociaux. Dans le cas échéant, vous êtes un professionnel de la santé un patient, un usager ou un proche de la famille.

Cependant, avant d’accepter de participer à ce projet et de signer ce formulaire d’information et de consentement, veuillez prendre le temps de lire, de comprendre et de considérer attentivement les renseignements qui suivent.

Ce formulaire peut contenir des mots que vous ne comprenez pas. Nous vous invitons à poser toutes les questions que vous jugerez utiles à la chercheuse responsable du projet, à l’étudiant(e)-chercheuse, ou aux autres membres du personnel affecté au projet de recherche et à leur demander de vous expliquer tout mot ou renseignement qui n’est pas clair.

NATURE ET OBJECTIFS DU PROJET

L’engagement des patients et de leurs familles au sein de l’organisation de soins de santé et des services sociaux reconnaît le patient comme faisant partie intégrante de l’équipe de soin et des services sociaux. Le patient est donc reconnu comme un expert qui possède des connaissances uniques. Cette étude a pour but de contribuer à l’avancement des connaissances dans le domaine de l’engagement des patients en gestion des risques pour la sécurité des patients. Les résultats contribueront à identifier les mécanismes et stratégies de l’organisation que les gestionnaires mettent en place dans l’institution de santé afin de permettre l’engagement des patients.

Actuellement, il existe peu d’études publiées qui évaluent l’engagement des patients et de leurs familles sur la gestion des risques dans l’ensemble de l’institution de santé. La présente étude sera la première à le faire.

Plus spécifiquement, les objectifs principaux sont de :

- Décrire les différentes stratégies d’engagement des patients et de leurs familles mises en place par l’établissement de santé; et expliquer si les stratégies mises en œuvre dans les établissements de soins de santé et services sociaux sont axées davantage sur la gestion des risques à des niveaux cliniques, organisationnels ou stratégiques.
- Identifier les facteurs qui favorisent ou inhibent l’’engagement des patients et de leurs familles en ce qui concerne la sécurité des patients;
- Analyser les indicateurs mis en place par les établissements pour évaluer l'impact de l’engagement des patients et de leurs familles conçues pour l'amélioration de la sécurité des patients.

Cette étape de l'étude (phase 2) - consistera en une analyse longitudinale de trois cas du CIUSSS de la Mauricie et centre-du-Québec, du CISSS de la Montérégie-Est, et du CIUSSS du Centre-ouest-de-l 'île-de-Montréal. Trois niveaux d'analyses avec des entrevues semi-dirigées seront privilégiés (clinique, organisationnel et stratégique) afin de comprendre les mécanismes et stratégies mis en place par l'établissement pour engager les patients et leurs familles dans la sécurité des soins et services de santé. La première étape de l'étude consistait en une étude descriptive des stratégies en engagement des patients en gestion des risques à travers les CISSS et CIUSSS du Québec afin de décrire un portrait de la situation avant et après deux ans.

NOMBRE DE PARTICIPANT(E)S ET DURÉE DE LA PARTICIPATION

Environ 30 personnes participeront à cette phase 2 du projet de recherche, et ce, à deux temps différents soit en 2017 et en 2018 en utilisant le même guide d'entrevue. Des entrevues face-à-face et des entrevues de groupes de types semi-dirigées seront mises de l'avant. La durée de votre participation sera de 60 minutes pour les entrevues face-à-face et les entrevues de groupes.

NATURE DE LA PARTICIPATION DEMANDÉE ET DÉROULEMENT DU PROJET

Si vous acceptez de participer à ce projet de recherche et après avoir signé le présent formulaire, votre participation consistera à :

- assister à un groupe de discussion animé par l'étudiante-chercheuse d'une durée approximative de 60 minutes et portant sur :
    - Les différentes stratégies d'engagement des patients et de leurs familles mises en place par l'établissement de santé en gestion des risques.
    - L'identification des facteurs qui favorisent ou inhibent l'engagement des patients et de leurs familles en ce qui concerne la sécurité des patients.
    - Et l'analyse des indicateurs mis en place par les établissements pour évaluer l'impact de l'engagement des patients et de leurs familles conçues pour l'amélioration de la sécurité des patients.
- rencontrer l'étudiante-chercheuse pour une entrevue individuelle d'une durée approximative de 60 minutes, portant sur les stratégies, les facteurs et l'analyse des indicateurs d'impacts en engagement des patients et de leurs familles sur la sécurité des soins et services.

Pour faciliter la collecte et l'analyse des données, la discussion de groupe et l'entrevue en profondeur seront enregistrées sur support audionumérique.

L'étudiante-chercheuse communiquera avec vous pour vous inviter à participer à l'une des modalités suivantes de collecte de données.

☐ Entretien en personne (enregistrement sonore; durée approximative de 60 minutes)

☐ Groupe de discussion (durée approximative de 60 à 90 minutes)

Sur acceptation préliminaire de votre participation, les entrevues individuelles et les groupes de discussion seront réalisés en personne à un moment qui sera convenu en fonction de vos disponibilités. Si au cours de l'entretien une question s'avère plus difficile, vous n'êtes pas obligé d'y répondre. Il n'y a pas de bonnes, ni de mauvaises réponses.

Lorsque l'activité se tiendra, l'étudiante-chercheuse vous demandera si vous avez des questions sur le formulaire d'information et de consentement auxquelles elle répondra, en s'assurant de votre compréhension. Vous serez ensuite invité à signer le formulaire d'information et de consentement que le membre de l'équipe de recherche signera également. Une copie signée vous sera remise et l'activité débutera.

La participation à ce projet de recherche est **confidentielle.**

RISQUES ET INCONVÉNIENTS

À notre connaissance, la participation à cette étude comporte peu de risque. Le temps requis pour remplir le questionnaire, peut représenter un inconvénient pour certain(e)s participant(e)s. Vous pourrez décider de cesser l'entrevue en tout temps et sans aucun préjudice. Toutefois, certaines questions peuvent entrainer certains inconvénients pour des participant(e)s et susciter un questionnement ou un stress. Vous pourrez décider de cesser l'activité en tout temps et sans aucun préjudice. Le personnel de recherche vous offrira de poursuivre à un autre moment, si vous le désirez.

Risque lié au bris de confidentialité :

Puisque parmi les participants nous retrouvons des directeurs, conseillers et / ou professionnels de la santé, il serait possible que vous soyez identifiable indirectement lors des publications en raison de la fonction unique que vous occupez. Toutefois, tous les efforts seront déployés pour protéger votre identité et assurer la confidentialité de nos échanges afin d'éviter une telle identification.

AVANTAGES

Il se peut que vous retiriez un bénéfice personnel de votre participation à ce projet de recherche, mais on ne peut vous l'assurer. À tout le moins, les résultats obtenus contribueront à l'avancement des connaissances dans ce domaine.

CONFIDENTIALITÉ

Durant votre participation à ce projet de recherche, la chercheuse responsable de ce projet ainsi que l'étudiante-chercheuse recueilleront, dans un dossier de recherche, les renseignements vous concernant et nécessaires pour répondre aux objectifs scientifiques de ce projet de recherche.

Ces renseignements peuvent comprendre le nom de votre établissement et le titre de votre fonction.

Tous les renseignements recueillis demeureront confidentiels dans les limites prévues par la loi. Vous ne serez identifié(e) que par un numéro de code. La clé du code reliant votre nom à votre dossier de recherche sera conservée par la chercheuse responsable de ce projet de recherche.

Ces données (transcriptions et questionnaires remplis) de recherche seront conservées pendant 7 ans sous clé, après la fin de l'étude par Mme Marie-Pascale Pomey dans un classeur de son département universitaire à l'Université de Montréal et sous son unique responsabilité. Après ce délai, les données seront totalement détruites.

Dans le cas des groupes de discussion, la confidentialité des échanges dépend de l'engagement réciproque des participants à ne pas divulguer l'identité des autres participants et de la nature des échanges avec des personnes n'ayant pas participé à la rencontre.

Les données de recherche pourront être publiées ou faire l'objet de discussions scientifiques, mais il ne sera pas possible de vous identifier.

À des fins de surveillance, de contrôle, de protection et de sécurité, votre dossier de recherche pourra être consulté par des représentants de l'établissement et du comité d'éthique de la recherche. Toutes ces personnes et ces organismes adhèrent à une politique de confidentialité.

Vous avez le droit de consulter votre dossier de recherche pour vérifier les renseignements recueillis et les faire modifier au besoin.

COMMUNICATION DES RÉSULTATS GÉNÉRAUX

Vous pourrez connaître les résultats généraux de cette étude si vous en faites la demande à la chercheuse responsable à la fin de l'étude.

COMPENSATION

Vous ne recevrez aucune compensation financière pour votre participation à ce projet de recherche.

EN CAS DE PRÉJUDICE

En acceptant de participer à ce projet de recherche, vous ne renoncez à aucun de vos droits et vous ne libérez pas la chercheuse responsable de ce projet de recherche et l'établissement de leur responsabilité civile et professionnelle.

PARTICIPATION VOLONTAIRE ET DROIT DE RETRAIT

Votre participation à ce projet de recherche est volontaire. Vous êtes donc libre de refuser d'y participer. Vous pouvez également vous retirer de ce projet à n'importe quel moment, sans avoir à donner de raisons, en informant la personne-ressource de l'équipe de recherche et ce, par simple avis verbal.

Si vous vous retirez du projet ou êtes retiré(e) du projet, l'information et le matériel déjà recueillis dans le cadre de ce projet seront néanmoins conservés, analysés ou utilisés pour assurer l'intégrité du projet.

Si vous êtes un patient, un usager ou un proche de la famille, votre décision de ne pas participer à ce projet de recherche ou de vous en retirer n'aura aucune conséquence sur la qualité des soins et des services auxquels vous avez droit ou sur votre relation avec les équipes qui les dispensent.

Si vous êtes un gestionnaire, ou un professionnel de la santé, votre décision de ne pas participer à ce projet de recherche ou de vous en retirer n'aura aucune conséquence sur votre emploi.

Toute nouvelle connaissance acquise durant le déroulement du projet qui pourrait avoir un impact sur votre décision de continuer à participer à ce projet vous sera communiquée rapidement.

IDENTIFICATION DES PERSONNES-RESSOURCES

Si vous avez des questions ou éprouvez des problèmes en lien avec le projet de recherche, ou si vous souhaitez vous en retirer, vous pouvez communiquer avec la chercheuse responsable, Madame Marie-Pascale Pomey, professeure titulaire au département d'administration de la santé (Université de Montréal) au numéro suivant :

- Madame Marie-Pascale Pomey : 514-xxx-xxxx poste xxxx (du lundi au vendredi de 8h00 à 16h00) ou par courriel : marie-pascale.pomey@umontreal.ca.

Vous pourriez aussi contacter l'étudiante-chercheuse au :

- Madame Ursulla Aho-Glele, étudiante-chercheuse : 514-xxx-xxxx (du lundi au vendredi de 8h00 à 17h00) ou par courriel : ursulla.aho-glele@umontréal.ca.

Pour toute question concernant vos droits en tant que participant(e) à ce projet de recherche ou si vous avez des plaintes ou des commentaires à formuler, vous pouvez communiquer avec le commissaire local aux plaintes et à la qualité des services de l'Hôpital Notre-Dame du CHUM, au 514-890-8000, poste 26047.

SIGNATURE

J'ai pris connaissance du formulaire d'information et de consentement. On m'a expliqué le projet de recherche et le présent formulaire d'information et de consentement. On a répondu à mes questions et on m'a laissé le temps voulu pour prendre une décision. Après réflexion, je consens à participer à ce projet de recherche aux conditions qui y sont énoncées.

____

Nom (en lettres moulées)   Signature du/de la participant(e)   Date

SIGNATURE DE LA PERSONNE QUI OBTIENT LE CONSENTEMENT

J'ai expliqué au/à la participant(e) le projet de recherche et le présent formulaire d'information et de consentement et j'ai répondu aux questions qu'il/elle m'a posées.

Nom (en lettres moulées) Signature de la personne qui obtient le consentement Date

ENGAGEMENT DE LA CHERCHEUSE RESPONSABLE AU CHUM

Je certifie qu'on a expliqué au/à la participant(e) le présent formulaire d'information et de consentement, que l'on a répondu aux questions que le sujet de recherche avait.

Je m'engage, avec l'équipe de recherche, à respecter ce qui a été convenu au formulaire d'information et de consentement et à en remettre une copie signée et datée au/à la participant(e).

Nom (en lettres moulées) Signature de la chercheuse responsable Date

APPROBATION PAR LE COMITÉ D'ÉTHIQUE DE LA RECHERCHE

Le comité d'éthique de la recherche du CHUM a approuvé le projet et assurera le suivi du projet pour les établissements du réseau de la santé et des services sociaux du Québec participants.

APPENDIX F: Description of the Heath Institutions

	Variables	
	Solicited organizations (n = 24)	**Description**
1	(CIUSSS de l'Ouest de l'Île-de-Montréal) - the Montréal West Island Integrated University Health and Social Services Centre (Montréal West Island IUHSSC)	Emerged from the grouping of 7 health and social services institutions: Douglas Mental Health University Institute; West Montreal Readaptation Centre; St. Mary's Hospital Center; Grace Dart Extended Care Centre; Batshaw Youth and Family Centres; Ste. Anne's Hospital (since April 1, 2016). The Montréal West Island IUHSSC is the largest of the 5 IUHSSCS on the island of Montréal.
2	CIUSSS Centre –Sud-de-l'Île-de-Montréal (CCSMTL)	The IUHSSC of the Centre-Sud-de-l'Île-de-Montréal is located in the south-central part of the island of Montréal. And comprises of 5 types of health insititutions:- Youth centres; The Institut universitaire de gériatrie de Montréal (for the elderly); Addiction rehabilitation centres (drugs and other dependencies); Physical disability rehabilitation centres; Intellectual disability and autism spectrum disorder (ID-ASD) rehabilitation centres.
3	CHUM	The CHUM is one of the largest hospital centres in North America. It is being built in three phases: the Research Centre (2013), the hospital (2017) and complementary buildings (2021): Montreal Heart Institute; Institut Philippe-Pinel-de-Montréal.
4	CIUSSS du Centre-Ouest-de-l'Île-de-Montréal	Total population: 345,275 in the 2016 census*. 17.8% of the total population of the Montréal area Recoups: 4 hospitals, one Geriatric Hospital Centre, one Long-Term Care Centre, 3 residential centres, one birth centre, one rehabilitation centre, 7 clinics (CLSC).
5	CISSS des Laurentides	595,000 population to be served in a territory of 21,500 km2. Recoups: 6 hospitals; 12 clscs; 15 chsld pulics, including 1 english-speaking; 2 private CHSLDs (CHSLDs) under contract; 1 private

		CHSLD with service agreement; 18 FMGS; 3 Family Medicine Units (FMU); 24 surgery rooms and 11 endoscopy rooms; 107 functional stretchers in emergencies; 877 short-term beds.
6	CIUSSS de l'Est-de-l'Île-de-Montréal	The second largest employer in East Montreal. Recoups : - 2 hospitals - 1 insititution - 15 CHSLD - 8 CLSC
7	CIUSSS CHUS (CIUSSS de l'Estrie – Centre hospitalier universitaire de Sherbrooke (CHUS))	The facility serves over 500,000 people. The IUHSSC Estrie - CHUS is made up of more than 101 points of service divided into various types of services: - Hospital centres (CH and CHU), CLSCs and CHSLDs - Centre de protection de l'enfance et de la jeunesse (CPEJ) (Child and Youth Protection Centre) - Rehabilitation Centres (RCs): physical disability, intellectual disability, autism spectrum disorder, addictions, youth and mothers with adjustment problems. The service area of the IUHSSC Estrie - CHUS, covers nearly 13,000 km2.
8	CIUSSS Saguenay Lac-st-Jean	The Saguenay-Lac-Saint-Jean IUHSSC has 62 facilities spread over a territory of 95,762 km^2. The Saguenay-Lac-Saint-Jean IUHSSC, created on April 1, 2015, is the result of the merger of the following nine public health and social services institutions: - Centre de santé et de services sociaux Cléophas-Claveau - Chicoutimi Health and Social Services Centre - Jonquière Health and Social Services Centre - Lac-Saint-Jean-Est Health and Social Services Centre - Domaine-du-Roy Health and Social Services Centre - Maria-Chapdelaine Health and Social Services Centre - Saguenay-Lac-Saint-Jean Youth Centre - Centre de réadaptation en déficience intellectuelle et en troubles envahissants du développement du Saguenay-Lac-Saint-Jean (Saguenay-Lac-Saint-Jean Centre for Rehabilitation of Intellectual Disabilities and Pervasive Developmental Disorders)

		- Agence de la santé et des services sociaux du Saguenay-Lac-Saint-Jean
9	CIUSSS du Nord-de-l'île-de-Montréal	The territory of the IUHSSC in the North End of the Island of Montreal covers 88 km2 and is located in the northern part of the Island of Montreal. It also provides specialized and super-specialized services to 1.8 million Quebecers in various regions. I. The persons accommodated The ICSU of the North Island of Montreal is responsible for: - 1,756 accommodation beds - 72 geriatric acute care beds and 56 geriatric short-term care beds - 716 places in non-institutional resources - 18 places in family-type resources On the territory of the IUHSSC in the Nord-de-l'Île-de-Montréal region, you will find: - 60 medical clinics - 16 Family Medicine Groups (FMGs) including: - 2 FMG family medicine units (FMU) providing clinical training - 6 Family Medicine Network Groups (FMG-R)
10	CISSS du Bas-Saint-Laurent	I. The IHSSC of the Lower St. Lawrence in brief - 471 short-term beds (hospital centre mission) - 13 residential and long-term care centres (CHSLDs) - 1 birth center - 9 emergencies, 8 of which are on duty 24 hours a day, 7 days a week - 42 installations - 51 medical clinics - 12 Family Medicine Groups (FMGs) - University Medical Teaching Mission - 2 University Family Medicine Groups (GMF-U) - 124 community organizations - 141 private seniors' residences (RPPs)

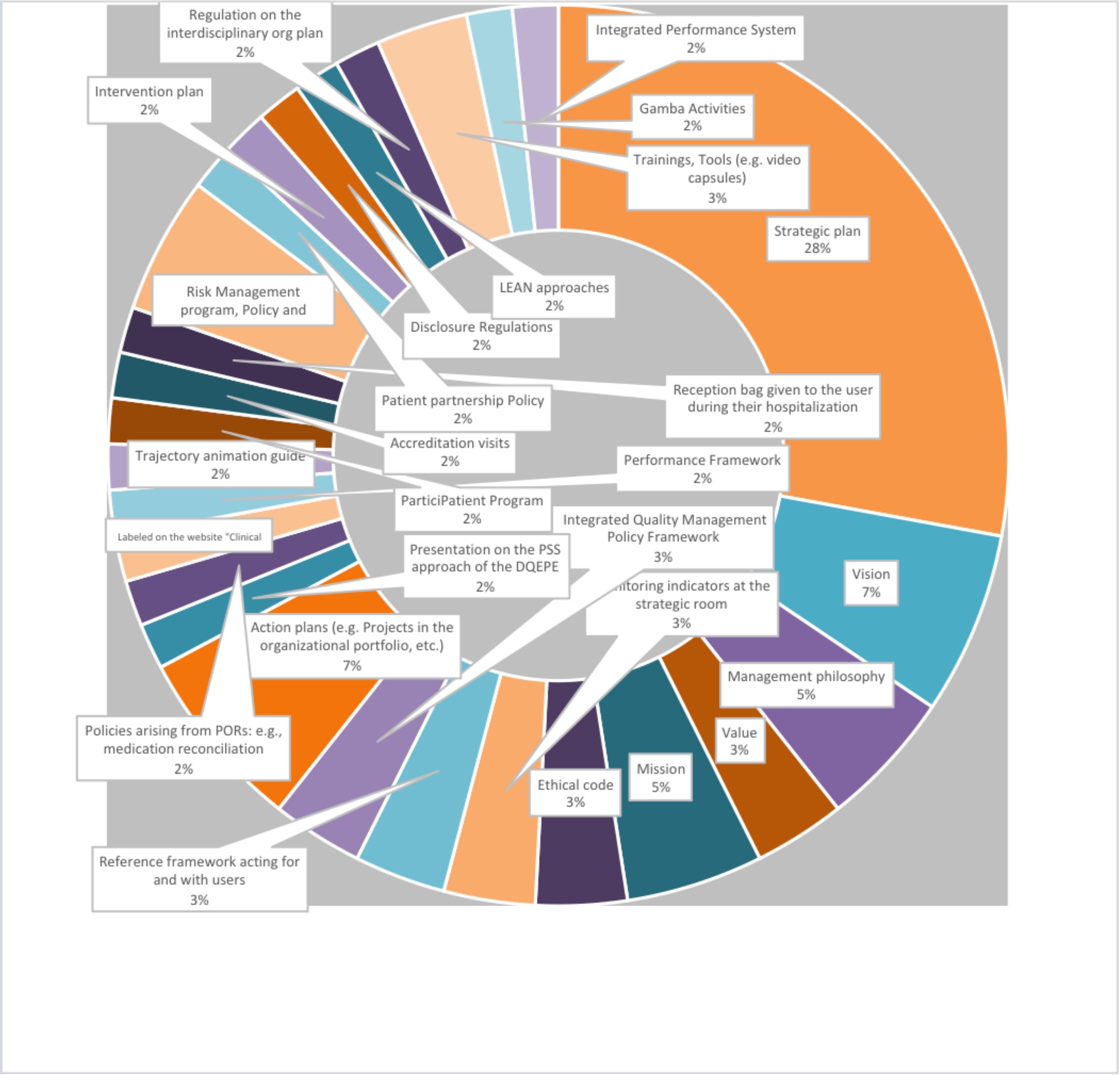
11	CIUSSS Abitibi Timiskaming	The Centre intégré de santé et de services sociaux (CISSS) de l'Abitibi-Témiscamingue was created on April 1, 2015 with namely the five health and social services centres, the Centre de réadaptation en déficience intellectuelle - Clair Foyer, the Centre de réadaptation La Maison, the Centre Normand and the Centre Jeunesse. The CISSS is distinguished by the size of its territory, 58,000 km2, and by the front-line and community-based care and services it provides in its 67 facilities spread throughout Abitibi-Témiscamingue.
12	CISSS Montérégie Ouest	The Centre intégré de santé et de services sociaux (CISSS) de la Montérégie has 128 facilities. Montérégie-Ouest territory: 460,000 inhabitants Territory of Montérégie: 1 500 000 inhabitants Offering general services, routine primary care and long-term residential care, the facility is also dedicated to specialized hospital and rehabilitation services. As such, the Montérégie-Ouest CISSS has regional responsibility for physical rehabilitation, intellectual disability, autism spectrum disorder and addiction. Since April 1, 2015, the Montérégie-Ouest CISSS is a public institution that is the result of the merger of the health and social services centres of Jardins-Roussillon, Suroît, Haut-Saint-Laurent and Vaudreuil-Soulanges, the CRDITED de la Montérégie-Est and the SRSOR, the Centre montérégien de réadaptation, as well as the two addiction rehabilitation centres Le Virage and Foster.
13	CIUSSS MCQ	The ICSUSS MCQ, created on April 1, 2015, is the result of the 12 public health and social services institutions of this socio-sanitary region. It is responsible for organizing services and ensuring their complementarity within the framework of its various missions (CH, CLSC, CHSLD, child and youth protection centre, rehabilitation centres, public health), and this, according to the needs of its population and its territorial realities.
14	CUSM	Recoups: Montreal Children's Hospital; Montreal General Hospital; Royal Victoria Hospital; Cedars Cancer Centre; Montreal Neurological Hospital and Montreal Neurological Institute; Shriners Hospitals for Children;Montreal Chest Institute
15	CISSS DE L'OUTAOUAIS	Created on April 1, 2015, the CISSS (*Centre intégré de santé et services sociaux*, or integrated health and social services centre) de l'Outaouais integrates the following institutions:

		• 5 health and social service centres, namely Gatineau, Pontiac, des Collines, Vallée-de-la-Gatineau and Papineau • a physical disability rehabilitation centre (the Centre régional de réadaptation La RessourSe) • an intellectual disability and pervasive developmental disorder centre (Pavillon du Parc) • an addiction rehabilitation centre (CRDO) • Outaouais youth centres (*centres jeunesse de l'Outaouais*) • and the Outaouais health and social services agency (*Agence de la santé et des services sociaux de l'Outaouais*).
16	CISSS de Laval	10,357 employees
17	CISSS de la Côte-Nord	The CISSS covers a territory that goes from Tadoussac to Blanc-Sablon (almost 1300 km of shoreline) and includes Anticosti Island and the northern towns of Fermont and Schefferville. 8 installations: - Haute-Côte-Nord - Manicouagan - Port-Cartier - Sept-Îles - Minganie - Lower North Shore - Caniapiscau Other establishment - Naskapi CLSC
18	CISSS Chaudière- Appalaches	The Chaudière-Appalaches CISSS is responsible for maintaining and improving the health and well-being of the population of region 12, which includes nearly 100 facilities in 136 municipalities. The Chaudiere-Appalaches CISSS is : - 4 hospitals; - 29 long-term care centres (CHSLDs) and 5 private CHSLDs under contract; - 23 CLSCS; - 1 birthing centre; - 2 university family medicine groups (GMF-U);

		- Nearly 50 facilities adapted to specific needs: specialized services for youth, intellectual disability and autism spectrum disorders, physical disability, dependence and services for seniors.
19	CIUSSS de la Capitale -Nationale	The ICSUSS of the Capitale-Nationale serves rural and urban areas in the Charlevoix, Quebec City and Portneuf regions It responds to the needs of more than 750,000 citizens living on a territory of 18,643 km2. - It includes 4 research centres and 4 university institutes. - It collaborates with 12 foundations. - It is responsible for more than 200 facilities.
20	CISSS Lanaudière	Recoups: • CHSLD - Residential Centres (14) • CLSC (23) • Intellectual disability and autism spectrum disorder rehabilitation centres (9) • Physical Rehabilitation Centres for the Physically Impaired (6) • Addiction rehabilitation centres (3) • Child and Youth Protection Centres/Rehabilitation Centres for Youth with Adjustment Difficulties (6) • Outpatient Mental Health Service Centres (5) • Academic Family Medicine Groups (2) • Hospitals (2) • Midwifery service (1)
21	CISSS Montérégie Est	The Centre intégré de santé et de services sociaux (CISSS) de la Montérégie-Est is a public institution that resulted, as of April 1, 2015, from the merger of the Pierre-Boucher, Pierre-De Saurel and Richelieu-Yamaska health and social services centres, as well as the Centre jeunesse de la Montérégie. The territory covers an area of 3,485 km2. It also encompasses the entire Montérégie health region in terms of child and youth protection and rehabilitation services for young people with adjustment problems.
22	CISSS Montérégie Centre	The Montérégie-Centre CISSS is the result of the merger of the Centres de santé et de services sociaux (CSSS) Champlain-Charles-Le Moyne and Haut-Richelieu-Rouville, the Institut Nazareth et Louis-Braille and the former Agence de santé et de services sociaux de la Montérégie.

		It has more than 11,000 staff members and 866 physicians working in some 40 facilities, including Hôpital Charles-Le Moyne, designated as an affiliated university centre, Hôpital du Haut-Richelieu, research centres, as well as several CHSLDs and CLSCs. It serves a population of 408,715 citizens.
23	CISSS des îles	The CISSS des Îles has a large mission and four legal missions: CLSC, CHSGS, CHSLD and CRDITED.
24	CISSS de la Gaspésie CISSS des Îles	The Gaspésie CISSS is at the heart of a vast territorial service network (RTS) that includes forty-nine facilities. It assumes populational responsibility for the health and well-being of all Gaspesians. Born from the merger of the health and social services centres as well as the rehabilitation centres and youth centre in its region, it is responsible for ensuring accessibility to quality care and services to meet the needs of its populations.

APPENDIX G: **Type of documents mentioning PE** _ Does the institution make reference to patient engagement? If yes, how? In which documents or programs?



APPENDIX H: Description of participating institutions and individual participants

	T1	T2
GENERAL DATA ABOUT THE QUESTIONNAIRE		
Collection dates	From Mai 2017 until December 2017	From March 2018 until December 2018
Frequency	22	22
%	100%	100%
Total questionnaires answered	22	22
DESCRIPTION OF THE PARTICIPATING INSTITUTIONS* (PLEASE REFER TO APPENDIX F FOR A DESCRIPTION OF THE INSTITUTIONS)		
Number of solicited organizations	24	24
Number of participating organizations	22	22
# participating CIUSSS	9	9
# participating CISSS	11	11
Others: (major teaching healthcare networks institutions affiliated to a French-speaking university or an English-speaking university)	2	2
Does the institution make reference to user engagement? (see APPENDIX G for detail information on the type of documents mentioning PE)	**N (%)**	**N (%)**
In strategic plan + other documents	13 (45.5%)	19 (86.4%)
In other documents (including strategic plans)	16 (73%)	15 (68.2%)
In other documents only	6 (27.3%)	2 (9.1%)
No mention of PE at all	3 (13.6%)	1 (4.5%)
DESCRIPTION OF THE INDIVIDUAL PARTICIPANTS		
# of individual participants in total	49	38
Average of participants per institutions	2	2
Minimum	1	1
Maximum	4	4
Median	2	2
Number of patient's resources participating in the research project	1	**0**
Job title of the participants (see APPENDIX H - Description of participating institutions and individual participants, for more details on the job titles of the participants	49 answered	38 answered
Upper management	15	15
Upper and middle Management	11	8
Healthcare Professional: APPR or executive advisor in quality and safety	18	13
Others = (patient safety officer, ethical advisor, program evaluator, patient partner)	5	3
Departments in which participants work	49 answered	38 answered
DQEPE	44	34
DSM	4	2

Direction of multidisciplinary services, quality, evaluation, performance and ethic	1	1
DSP	0	1
Date the participants were hired	37 answered	33 answered
2011-2014	6 (16%)	5 (15%)
2015	17 (46%)	15 (45.5%)
2016	8 (21.6%)	8 (24.2%)
2017	6 (16.2%)	2 (6.1%)
2018	0	3 (9.1%)
In the past month, how much time, on average, did you spend on patient engagement?	49 answered	38 answered
More than 50% of your time	16 (32.6%)	12 (31.6%)
Less than 50% of your time	33 (67.3%)	26 (68.4%)
In the past month, how much time, on average, have you spent on risk management?	49 answered	38 answered
More than 50% of your time	24 (49%)	21 (55.3%)
Less than 50% of your time	25 (51%)	17 (44.7%)
How long have you been working in the health care system?	35 answered	28 answered
Less than 5 years	6 (17.1%)	4 (14.3%)
Less than 10 years	4 (11.4%)	5 (18%)
Less than 20 years	8 (23%)	4 (14.2%)
Between 20-30 years	12 (34.2%)	9 (32%)
Between 31-35 years	4 (11.4%)	5 (18%)
More than 35 years	1 (3%)	1 (3.6%)
SECTION 4- OTHER GENERAL QUESTIONS ABOUT THE INSTITUTION'S PARTICIPATION IN PE AND IN RISK MANAGEMENT STRUCTURES		
Participation of institutions in structures related to user engagement?		
For T1 and T2 alike, 85% of the participants have participated in structures related to patient engagement. 15% have not.		
Committees related to risk management in which the institution has participated in (* T1 and T2 responses are combined for this question because the answers are alike.)		
100% of the institutions participated in "Risk management Committees" and in Vigilance and quality committees"		
68% of the institutions participate in Infection Prevention and Control Committee		
58% of the institutions participate in Committee on the Appropriate Use of Drugs		
28% of the institutions participate in Committee on Medical Devices		
16% of the institutions participate in Control measures and prevention of falls		
9% of the institutions participate in Prevention and suicides as well as Restraint committees		
7% of the institutions participate in Continuous improvement committee and Information Security Committee		

4.6% of the institutions participate in Audit Committee, Preventive Withdrawal Program, obstetrics' Team, Abuse 4.6%, White Code[48], Committee (Behavioural Emergencies)
2% of the institutions participate in Committee on Pain Control; Committee for safety in continuing assistance resources, Run away committee, Regional food committee, Code blue (cardiac arrest), Evaluation committee of the board of directors (by invitation), Health and safety
To note that, only 40% of the institutions have Integrated Risk Management Committees. And 60% have the conventional Risk Management Committee dealing with healthcare risks.
Overall, how would you rate the safety of care and services in your facility?
For T1 and T2 alike, 70% of the participants score their appreciation of safety in their institutions "very good"; 20% rated it "acceptable"; and 5% rated it "excellent" or "weak".

APPENDIX I: Governing structure of Patient engagement/Patient experience/Risk management

HEALTHCARE INSTITUTIONS STRATEGIES AND MECHANISMS ON PE BEFORE IMPLEMENTATION
Creation of a strategic committee on PE by the CEO or a leader (3 directors, 1 DGA, 1 member of the CMDP (doctor), partner patient + executive counsellor).
Create a strategic plan and an action plan
Identify best practices to create Strategies for patient partnership deployment with an action plan (based on e.g.: MSSS reference framework on PE; MSSS's prevention policy (on population health) in risk management to integrate best practices. E.g. the Presence of peer support workers in MH comes from the MSSS's MH reference framework; Safety reference framework and the Integrated Risk Management Framework to guide our practices in PS and try to integrate PE
Created a procedure for PE implementation
Create or adapt tools, documents, etc. with the help of patient-resource
PE strategy integration: in the mission (exceptional patient-experience), bill of rights, values, code of ethics (patient-experience), strategic planning, action plans, A3, etc.
Deployment of policies: e.g.: PE policy, Deployment of Family presence policy with the Patient committee, etc.
Integration of PRs in pilot projects. E.g. PRs are present in the working group and working on policy; service provision; operating rules; the people who make up the bureau; strategic plans (e.g. A3; A3 on deployment).
Monitoring indicators in the strategic room or control room (e.g. We integrate ROPs, in the practices (which are about patient and family input).
COLLABORATION AND COORDINATION MECHANISMS BETWEEN PATIENTS, PATIENTS' GROUP AND RISK MANAGEMENT DIRECTORATE
Collaboration with patients in co-decision making/co-management, etc.
Tactical Committee of the Centre of Excellence in Citizen Partnership A permanent member of the patients committee and/or a Resource Patient on the RG committee. A member of the patients' committee on the quality vigilance and safe delivery of care and services committees The health promotion team and the patient committee have forged ties. To better separate our roles. We have collaborations ad oc. (e.g., our CEO wanted us to look at universal access, tours were made). Since 2002 we have been in co-management with the PP. (he is on the Risk Management Committee, and Drugs). They conduct interviews together with managers to recruit new PPs. They are paired. Patient partners sit on the Patient Safety Committee and on the coordinating committee for projects related to risk safety (approach adapted to the elderly, control of nosocomial infections). Members of the Patients' Committee sit on the Quality and Risk Committee of the Board of Directors The risk management subcommittees (n =7) set up in each of the clinical divisions to include a "patient partner" member representing the clientele as well as a representative of a patient committee. Creation of a partnership committee in collaboration with the DQEPE
Collaboration and coordination between different instances

Partnership with the executive advisers, the PP office, volunteers, and the CU

Partnership with PP and CU and patient groups: Speak up campaign, bill of right, respect campaign. Requests for 2 years from the CU to be part of the PP.

Partnership with volunteers: Hope and cope: Special volunteer program in oncology: They've lived with cancer. Are in waiting rooms. Sitting with people. Play the piano. For the peruques, makeup. We have a place called the wellness center.

The Deputy Assistant Director is responsible for this coordination since she is on the Risk Management Committee and cu.

The Deputy assistant Director of the DQEPE participates in the regional and local patient, risk management, vigilance and quality committees and is responsible for implementing the patient partner approach. I am present at each of the patients' committee meetings. They bring me back information. And I bring them back dashboards, etc. 3 meetings per year. There is no link between the clinical committee and the patient committee.

The DQEPE collaborates with the CU, we have presented our service offer, what we do, we present our risk management indicators, there is a member of the CU who is a member of the risk management committee (only one representative of the CU).

Recognition mechanisms

Compensation: parking, recognition (annual volunteer party); accommodation (meetings are more like the evenings of 4-6).

Creating tools and analyzing patient experience

The CU analyzes the degree of patient experience in collaboration with the DQEPE. Two DQEPE liaison officers who work with the CUCI to report concerns raised by patients.

Patients are involved in the elaboration of the surveys and experiences. And within the framework of the accreditation.

The DQEPE works together with the partnership office (BEEP), which provides a close link with the patient committee.

Supporting teams and other departments

We are going to set up multi-disciplinary teams to support the clinical departments: one person in RM, evaluation, ethics (it is the ethics counsellor who works with the CU), and all the people who formulate statistics and the management system (to make a more integrated approach)" = multi-disciplinary team. The aim is to support the clinical directorates in the aspects that deal with quality.

A group of 6 patient and family partners has just been created to support the activities of the patient safety program in general. Patient partners sit on the quality committees of a majority of the programs. Guidelines requiring teams to consult with patients when creating or revising policies, procedures or protocols are being developed.

STRATEGIES AND MECHANISMS ON RISK MANAGEMENT

34. Are there resource-patients at the clinical level who intervene to accompany, if necessary, patients during their consultation?

In oncology, chronic disease, surgeries (orthopaedics, etc.) …
In psychiatry and in mental health.
You have to consider the confidentiality aspect when you do that. We have interpreters (there's a whole process that everything that is said must not be disclosed)"

"Jerome +" was a bank of interpreters made by the MSSS agency.
We have IPs who accompany patients in psychiatry.
At the time of hospitalization but not at the time of consultation

35. Are there resource patients at the clinical level who intervene to accompany patients in the development of an intervention plan?

Family, Peer Helpers, Volunteers (for appointments and travel, but not for IP development)
It's done in surgery. We discuss the surgery and the risks.
During orientation or reception, or admission (e.g. in a CHSLD, family reunion)
We insist on professionals by giving presentations and training to management (e.g. in MS approach). It is the DSM that takes care of this.
In youth and rehabilitation: 100% of plans with patients In hospitals and long-term care facilities: improvement needed
It is an obligation (MSSS response plan). If the patient is not present in his plan, then there is no plan.
Hospital mission is very low 0-25%; community mission is 75-99%; accommodation 51-75%.
In hospitals, messages circulate on closed-circuit cameras, video messages. And in the code of ethics

36. Is there a procedure for preparing the discharge of patients?

We have checklists. Each unit is very different. We have long-term care, we have rehabilitation, it's a care plan, and it's signed. (It's varied. Not an ICSU policy. Made by each department. Others get calls afterwards.
From DSM and/or DSP: procedure on admission management and bed management.
There are pivot nurses, they do a follow-up (Hospital care. In physical impairment (process))
Early planning by the patient to advise of his or her stay.

37. Do health professionals use a checklist to authorize the leave of absence

(discharge checklist) ?

40% return questionnaires to find out what people think about the leave. For the patient experience. And the teams get the results quarterly. There's the standard planning leave. (so they worked on their starter kit, the interveners worked on their kit with resource patients in medicine, surgery (orthopedics, etc.), oncology, rehabilitation. It is not standardised; it would be difficult because it is not the same services. Probably there are services that don't have a checklist.
This year, we just said to review the discharge and admission processes. Make a quality chart, etc.
VA ROPs
More in Home Care
There's a preparation for the holiday.
Depends on the pathology. We give him documentation for his pathology.
When the file is closed

39. Does the facility promote feedback on experiences with healthcare-acquired infections?

Accidents with consequences, or in prospective analysis (e.g., when an environment is going to solicit us, with concerns (falls or medication errors, safe travel to avoid injuries), we will identify the risks). Often, it is when we realize that there are several minor accidents.
We have a questionnaire and we go visit them (we did them this year). We took a %age of people, a sample in 6 months, who had a diagnosis. If they understood the risks, etc., on courtesy and understanding.
By survey of experience, meeting with family
We're doing a systematic follow-up. We are accountable to MS. We monitor hospital-acquired infections a lot. With staff and family to explain safety procedures.
For example, at the moment, we have increased the frequency of cleaning during nosocomial infections.
Counsellors meet with patients. In cases of nosocomial infections.
Because of the notion of disclosure, are not in direct contact with patients.

40. Does the facility promote feedback on experiences related to medication errors?

When there are consequences on the person (accident, serious cases systematically and in all programs), yes. There is an obligation to put in place supports through the disclosure process. But not systematically.
Only sentinel events. We've started the process and we're following up with the teams. In serious cases, but no return afterwards with the patient.
Disclosure regulations. When there's an accident. Medication errors. Not when there is an incident (patient not affected).
The process has been initiated and is being followed up with the teams. In serious cases. We do capture that wasn't done before. It is not in the law. In addition to disclosing and declaring, we ask them how they lived the experience. And what are the possible solutions. Then we follow up with them to let them know what is going on. This happens not only in serious cases, but in other cases as well. We do this in an accident and incident. Since last year.
It is in the overall questionnaire, it is not done systematically.
There are ad hoc committees to prevent recurrence. But it is not done with a resource patient.

At the Risk Management Committee level is a project this year. And the falls and declarations in the forms

41. Does the institution apply the principle of "never on the patient the first time" for the learning of technical acts and invasive gestures by trainers?

Confusing question. Residents come from the university after training. Yes, we have residents, but they're supervised. Very supervised.
But before we ask this question, is it the right patient (for the training of new employees, we have a double identification procedure).
We have a lab with a mannequin. There are practices that are in laboratories.
Plus the nurses who do it
We have labs for the Infectious Diseases Branch, but for intravenous drugs, we don't do it again, because it's already done in universities.

42. Does the facility use simulation to avoid potentially risky situations?

When code blue
During prospective analysis within the framework of Code Orange simulation (massive reception of disaster victims). Each institution has a risk prioritization list
We have a nice simulation lab. We did a simulation this year of a mom who had to have a quick emergency delivery. She was bleeding, etc.) and we simulated that (sentinel event - on the emergencies of at-risk mothers). They reviewed the checklists. And right after that they received a similar case. So we're thinking of doing these kinds of simulations to work on communication, and other sentinel events for people to practice. We're going to do one or two more. We formalize the simulation committee and it begins November 23, 2018. (We ask ourselves the question: do we put a patient resource at all times, or according to the event?).
This is done on situations that are more at risk (e.g. intravenous and adding medication, etc.). Much related to medication, which is more at risk.
In nursing care. We talk a little bit about infection prevention: it's the inappropriate use of gloves, etc.
Emergency response plan (e.g. evacuation); Stroke (CPR)

STRATEGIES AND MECHANISMS ON POLITICS

43. Is there a policy or procedure or process in place to encourage patients to discuss the risks of interventions (e.g., asking questions about treatment)?

Procedure and mechanism on reporting for patients and accidents at work. And any person can testify, a volunteer, an employee, etc.
In front of a surgery, yes.
Promotion made during Patient Safety Week
Use of documents created by the Canadian Patient Safety Institute; document available on ICSU's web page

44. Is there a mechanism, procedure or process in place to encourage patients to ask questions when they feel they are at risk (e.g., asking professionals to wash their hands)?

By the complainants, posters
There are Accreditation Canada's standards booklets - this is done regularly. Especially in team meetings, attached to a nurse. In some missions it's more frequent.
Promotion done during Patient Safety Week; Use of documents created by the Canadian Patient Safety Institute; document available on the ICSU web page.
Meeting with the liaison nurse or physician (exchange of information and for the patient, exchange of concerns).
The sign is called "Let's be safe".
Informal. To get their point of view. Nothing formalized to my knowledge, more depending on the individuals and variable from one mission to another (CH, CHSLD, CR, CJ...)
A campaign on the element of handwashing. Handwashing posted, there are initiatives, but not systematic. E.g. posters for infection prevention and control: hand washing. In procedures too.
Risk management policy.
Website and promotion patients' committee: We should talk http://www.thechildren.com/patients-families/we-should-talk
In the better program itself. Procedure at the interprofessional practice level that empowers and informs the patient
A dedicated web page on the CISSS website is under development.
Code of Ethics, McGill conceptual model (frame of reference, and to consider professionals, and patients)

45. Is there a mechanism, procedure, or process in place to encourage patients to engage in behaviours that promote safe care and services? (e.g., pointing out that a medication is not the right one)?

Leaflet that is given to the patient. And during the meeting discussion with the patient.
Promotion made during Patient Safety Week; Use of documents created by the Canadian Patient Safety Institute; document available on the ICSU webpage
The bill of rights for their rights and responsibilities that come with it. The patient committee did that. It's a poster and a banner.
Posters. E.g. Awareness campaign for hand hygiene; Harmonized pamphlet for the prevention of falls for patients.
Brochure, and the welcome guide, code of ethics, etc.; and the guide for patients. At the CHSLD, it is given in a welcome kit.
Application of the 5 elements, verification, transition point
there is a procedure for dual identification and fall prevention available to patients.
There are documents made on drug safety.
Hand washing. The new made-to-measure control (family responsibility)
Risk Management Policy. We are trying more and more to have a patient section...but it is not yet very well done.
There is in the SAPA Accommodation Patient Guide to report any event to the staff - the right to complain. And there are signs with "file a complaint" on them.

in the code of ethics, have their request to report any complaints to the patient committee. We have a speak up campaign_(made with a resource patient) it's a sign posted next to the respect and bill of right campaign but we don't give the training anymore. So since 2015 we don't do it anymore. We started the planetree training. But the posters are still there.
We encourage people to complain if they are dissatisfied. There is an opportunity to talk to the chief beforehand, or a family member can do so. And has an opportunity to make a complaint.
The volunteers were saying. In their training as volunteers.
The procedure: complaints; the general survey or patients can leave a comment (present in the majority of service points and available on the website) .
We will mention it if they are dissatisfied with the services, to the complaints commissioner. But not in a systematic way. And depends on the sectors.
There is a process of patient participation (comment and suggestion boxes; a Gemba (managers go to meet the patients - in the participation model; services can make questionnaires; and the patient can file complaints, which is a known improvement process); We also encourage the presence of a caregiver; he can talk about it with his caregiver _______________________ They are informed (on posters; articles published in local newspapers; on the website; in our participation model it is distributed to the managers. There is a change in the culture of patient involvement. But we don't make a diagnosis to know how many patients know it).
In our procedures to declare any event that we think has had a consequence. Disclosure policy. We have them sign the risk sheet.
We have posters on RBM, specifying the responsibility of an employee, a volunteer, or a doctor to report any accident; and to others, if they see something to report. Volunteers receive training in RM (one-day orientation plan; hand washing; confidentiality; RM; etc.).
Reporting policy, which provides for patients to report. Presentation to the patient committee, pamphlets in the waiting rooms. And welcoming of a new patient.
Not formal. Through the patient committee, is very active with patients. Patients tell us (the patient committee) and they are afraid to tell Quality, so the patient committee takes the pulse and they are partners. Via the risk management committee. We have two members of the patients' committee in risk management.
We have a declaration procedure for healthcare providerss.

47. Is there a mechanism, procedure, or process to encourage patients to participate in the analysis of incidents and accidents?

Procedure for the analysis of incidents and accidents. Patients are consulted depending on the event.
Just at the level of risk management where he has a patient resource. In the quality improvement teams too, and in the trajectory teams
The patient participates in the disclosure. A questionnaire is being developed to ask them how they experienced it and how the process can be improved. We are going to get their perception of what can be improved. This questionnaire will be given to them during an incident or accident.
It's going to happen during discovery. Is there ever a conversation if there's something left out or done? E.g., there have been cases that have been done at home.
The patient will be asked for suggestions during disclosure. In reflection so that the patient is included in the analysis.
Patients committee, they are assured of the comments, of the evaluation of the satisfaction by the patients. The procedure of the sentinel event. Disclosure. The patient committees, just present the statistics, and present what is being put in place to prevent the event from happening again.
Sentinel event procedure.
During meetings and calls to patients or families. We ask them what we could have done better. Serious accidents and accidents that could have had serious consequences. _

Ad hoc committee, for the search for a solution. __excellent experience. - (e.g. directive procedure for products at risk in residential and long-term care centres. To have 100 ml containers).

Within the risk management committee, the most serious situations, sentinel situations, are analyzed. So that each one gives us her perspective. E.g., we have had cases of suicide. And there is the patient who says, "is our suicide rate higher than the rate in QC" and we redo the analysis. Ex 2: the pharmacist came to tell us how to do things....These are things where the patient's perspective seems important to us.

48. Is there a mechanism, procedure, or process to encourage patients to participate in the reporting of an incident or accident that has happened to another person?

When making a complaint

These are initiatives. Ex. Volunteers.

Informal. Patients tell the nurse and the nurse says.

Confidentiality issues

the patient can come accompanied

Resource patients will be on the risk management committee: it's going to be two- or three-year terms. We meet about five times a year. We choose him based on his experience.

We have posters and pamphlets on risk management, we specify the responsibility of an employee, a volunteer, or a doctor to report any accident that he or she sees, and to others, if they see something that needs to be reported. Volunteers receive training in risk management (one-day orientation plan; hand washing; confidentiality; etc.).

Disclosure procedure (e.g. baby in intensive care, ... dad volunteered to validate our procedure)

We have a declaration policy, but the means have yet to be developed.

49. Is there a mechanism, procedure, or process to encourage patients to find solutions to avoid the recurrence of incidents or accidents?

Procedure for the analysis of incidents and accidents. Patients are consulted depending on the event. When they are consulted, their recommendations are integrated into the recommendations of the event analysis team.

In risk management, in trajectory teams, or management teams and committees

Questionnaire to be developed to get the perception of patients who have experienced an accident.

When a disclosure is made, the leaflet. When a disclosure is made, the patient is encouraged to provide us with possible solutions. In the leaflet we talk about being a partner. In the section on falls prevention and dysphagia.

At the meetings of the patient committee, but it's more of a presentation. But we don't ask them what they can do.

During meetings and calls to patients or families. We ask them what we could have done better. Serious accidents and accidents that could have had serious consequences.

Patient partners participate in quality committees that review incident/accident + data on the Patient Safety Committee.

In the event of an incident it's related to disclosure. There is a document on Accreditation Canada, to provide information on incident analysis. The new framework (Incident Analysis Workbook) released by Canadian Insight on Patient Safety.
When making a disclosure in risk management, cpss, capture, disclose
The patient partner is questioned for risky products. More at the level of recruitment.
In the event of a disclosure. In the Forces project. But no due process.
The risk management committee. They exist in PPI, nursing home, and rehabilitation. When he's had a fall, for example.
Patients' committee are solicited.

Q50. Is there a policy, procedure, or process to inform patients of the actions that have been put in place to prevent incidents or accidents from happening again?

According to the ROPs, a quarterly security plan report is submitted to the ICSU Board of Directors (available to the public). Actions are then implemented in the sectors concerned. A quarterly report on patient security is submitted to the Board of Directors. There are 6 GR committees. And patients who are not part of the patient committees. Ditsadp, di, df, youth program, SAPA, SM. In the risk management committee. During disclosure processes (but not broadly. But the statistics with the accidents is something public every year), _
Patient Committee, Resource Patients, posters, disclosure policy
Checklist for staff and managers
Quarterly reports are reported or a representative of the patient committee (e.g. on the risk management committee, a patient resource person also sits on the committee. And also on the vigilance and quality committee. A way to be transparent).
At the time of disclosure; any incident that has a certain consequence. Support measures: consultation with specialist; parking;
Disclosure regulation, for the patient who has experienced a sentinel event. 1 disclosure. 2- we say it. and then we call him back to tell him what has been put in place. IF we disclose, we follow up with the patient and the family.
If disclosure is made, follow up with the patient and the family.
Participation in the patients' committee. Report created
1- Complaints management process; 2- Disclosure process (to the DQEPE). There, people are made aware)

If so, which ones: 51. Is there a mechanism, procedure, or process to encourage patients to participate in the choice of supports for patients who have had an accident?

The law (When making a disclosure, as part of the disclosure of an accident. This should include care for support measures proposed by the patient to counteract or mitigate the consequences suffered) says that support measures must be offered: we assess what the need is (this is a consultation, we assess with them what the need is)
Support Measures Regulations
There is no formal process. The Risks and Ethics Department is in discussion with the unit heads to encourage them to consult patients. taxi tickets, On the other hand, in terms of disclosure, support measures must be discussed with the chief, the patient's need must be collected. Psychological, financial support

Included in the disclosure procedure. Supports are offered according to the availability of the organization's resources

Procedure, - support measure guide (on intranet). Transparency is more successful than supports. But it doesn't happen often. They don't know that they have the right to make a request for support choices for patients. can and should be made known. Sites, articles, when you are not confronted you are less interested. What is more important, however, is to inform them about the situation and let them know what they are entitled to. That's transparency too. People don't know that when something happens in a health facility, it's analyzed, reported, disclosed, supported. The procedure must be made known to the public. If you don't face that, you don't care as much

The PRRAs do the risk management analysis. It's a discussion between the PRPA, the head of the unit, and the patient. We discuss support measures. Ex: fall of a lady from a treadmill. Support measure: physiotherapy treatment. We try to use the resources we have here to promote support measures. We can use any of the services in our centres for supports. But if the waiting list is long, we go outpatient

Victims: what supports they need are tailor-made. Logistics, psychologists, etc.

Disclosure procedure. The need is validated upon disclosure. Identify through procedure in risk management in the committee. We work with the patients in the committee. E.g. loss of effects, patients on the committee are consulted to see how they see the new procedure.

52. Is there a mechanism, procedure, or process to encourage a just culture or discourage a culture of blame in the institution?

It's part of the risk management policy and procedure: non-punitive mechanism. __: team awareness; department heads raise team awareness. Something that is experienced on a daily basis. We offer information and awareness sessions (during a team meeting) on the culture of non-blame, (4 to 5 times).

We have partnered with the pharmacy, we have partnerships. We encourage reporting to understand why it happened? The institution has a policy and procedures for reporting incidents and accidents, in an effort to cultivate a culture of no blame. - Awareness is also raised with clinical management by the risk management team. - The subject is also addressed when welcoming new employees. - Awareness is raised during National Patient Safety Week in late October/early November. A different theme is proposed each year (e.g., safety with medications).

Development of a just culture in progress. Development of training courses. Ongoing training.

The culture of no blame (declaration document) is given at orientation, training (employee safety fare, and the Resource Patients are there, the declaration, fall prevention, indicators,) during this meeting, we move from table to table and we have a visit to each site review site. All the teams that need training are trained or at a sentinel event. The managers contact us to make the presentation. Etc. we look at the causal factors, so that it doesn't happen again.

In all of our documents, we remind people of the right culture. We no longer talk about blame culture. Policy or procedure: sentinel event analysis (we don't try to blame anyone, in our training (on the declaration) available online. The objective is to find a corrective measure.

double identification, safety culture, declaration, disclosure, we analyze the process in a professional way and the right to make mistakes. If we review the process and its related to the person, we give additional training. This program is well used by the recipient's attendants.

we have a safe delivery framework. At the entrance each employee receives a common core of training on risk and quality management or indicates that it is mandatory. We have a scenario where the different causes are explained. It is explained that the aim is for training and not punitive and it is to improve. The only downside is that there is zero tolerance for negligence and abuse. For the managers, summary analyses are made. If necessary, they ask us for help with the analysis if it is not a sentinel analysis. They ask for help from HR if disciplinary measures are taken.

We meet at the reception days. We talk to them about a culture of fairness, not blame. Our management and with the Informant Directorate. And we meet for an hour. Risk management and risk prevention. AH-223, Accreditation Survey, Sentinel Event Reporting Procedure and Ad Hoc Event Analysis Committees

Articles for the quality approach newsletter. And some articles deal with safety culture____.

Security plan. We want to validate our disclosure process with resource patients. In addition, with the awareness component (ethics rating, the patient's right to safe care, etc.).
We have a policy on adverse events, the safety plan, and the sole objective of this is to discourage the blame culture.
Reporting measures are not used as a means of differentiating between employees.
It's different by facility. But we do provide training. Awareness of reporting events. Focus on processes. Event: analysis tools and method and we have risk management subcommittees and we put them in touch with what happened in their department.
Yes, when we did the Accreditation Canada questionnaire on safety culture and results, what was in red was the culture of blame. We asked each of the branches to give us solutions. And they proposed action plans that we submitted to Accreditation Canada. The element of declaration was in the verse. But the blame culture, we had to have fairer actions. The behaviour expected from the manager is the right to make mistakes, but we said we had to improve. We have the behaviour expected of managers as an indicator = right to make mistakes.
Promotion of safety week, employee training, tour of the branches, welcoming new employees and support for advisors.
Patient safety training for all staff (orientation, ongoing)
Policy on the code of conduct as well as the institution's code of conduct. This is discussed at each jurisdiction. You don't identify the intervener; you identify the problem. (are there accompaniments and supports from the establishment?).
Integral to the regulation of the risk management program. I am responsible for monitoring incident and accident reports. When a manager wants to make a report, he is asked for documents, his facts, etc. And then once a year, we give a risk management training course; and a specific one for managers; reminder capsules; we accompany managers a lot in a process analysis.
Risk management frame of reference; co-source ; disclosure process and patient involvement in the solution, client satisfaction survey, negative experience ; the patient is reminded and asked to go through the process again to find out if it has improved, etc. The commissioner is contacted for safety and quality complaints and the process is reviewed. - And during our committees, I tell her I'm working on this.
We meet during the welcome days. We talk to them about a just culture and not blame. Our management and with the nursing management. And we meet for an hour. Risk management and risk prevention. No policies. But we have a safety delivery regulation in which we integrate a just culture. We involve the employees, we advertise, we congratulate people, it's in our DNA.
Reporting policy, action plan put in place with statements A (may occur) and B (and followed up at the CEO's strategy room). Prevention measure.
_Presentation at the job integration day. Regulation on the safe delivery of care and services under development 1- we have employee integration days___2- the delivery of care and services in which a culture of non-blame is defined. 3- Safety week. We promote a just culture. We do analyses on the units. This is the approach that the risk management consultants have with the healthcare providerss, in our surveys, it is a question of attitude.
Procedure for reporting incidents and accidents. We write that we promote the right culture. People need to disclose and report. The procedure is diffuse, managers know that they must encourage reporting. There is also training given at the time of hiring on a very regular basis.
Promotional activities on disclosure of accidents and incidents. More than 400 people have been reached through training and awareness raising. At the managers' meeting. At least once a year and mention is made of the transparency of accidents and incidents, confidentiality of the disclosure of these accidents. We also raise awareness about confidentiality and we communicate.
Code of ethics and morbidity and mortality review and risk management. Supports: for the patient - informational, psycho. For the employee: ethics counsellor or risk manager who facilitates a debriefing session.

TRAINING OFFERED _ TOOLS AND DOCUMENTS to create : Documents of PE in safety is missing as well as training of patient engagement in safety for both patients and healthcare providers and managers. Training is available only on PE but both are rarely integrated.

Informational tools to create

During family sessions
Right of patients and their families
Information on PE for patients and healthcare providers
Leaflet, advice, welcome
During the reception of patients or residents, volunteers, information is given.

Resources tools to create

Canada's TPP Accreditation on Safety and PE, PE Brochure, Safety Capsules, Website (Intranet Toolbox), there is a patient resource section. They can go. The paper welcome guide or there is an explanation, the integration guide, posters in their waiting room, articles in the internal newspaper.
Video capsule presenting the programme available on the Intranet, role description for patient partners
Guide for the patient who is going to join a team.
They are trained (patient resources) on the patient experience (with documentation from CPSI and the Barrel Institute, AC).
DCEPP
Training on Home Care and PE
HCP supports and accompanies teams and/or patients
Tandem patient-resource-professional
Awareness video "Acting for and with patients" for trainees; A 4-hour course. To be given twice a year. On quality, ethical risks and patients' experiences. In general risk
Tandem of managers and resource patients at the reception of employees
Documents on the patient's contribution to the prevention of falls, medication errors, information on the use of restraints, suicide prevention, etc.
We have a working committee with the Volunteer Service in order to facilitate the link between their service and the Quality Service, including the sharing of a communication plan for the promotion of resource patients (addressed to ICSUSS personnel and patients/friends).

Via the internet, YouTube; occasional presence on social media. For patients who become patient resources. And the upcoming code of conduct available to everyone in the rooms.
For the Patient resources, we have a guide, so that he understands his role. We talk about the approach; his roles and responsibilities; logbook; role and responsibility of a little everyone; we compensate (travel expenses; meals).
There are documents from the patient committee.
We are in the process of developing a welcome guide for new partner patients. In addition, the CISSS website will soon include a web application form for those interested in becoming a patient partner.
We should affiliate with the volunteer service to create the documents. We will then partner with the communications department.
We have a working committee with the Volunteer Service to facilitate the link between their service and the Quality Service, including the sharing of a communication plan for the promotion of resource patients (addressed to ICSUSS staff and patients/neighbours).
We work a lot by word of mouth. Presentations have been made to managers to promote it. Sometimes messages were posted on the intranet. Factors: there is a constraint that we can't post on the walls so as not to damage).
We have a 360 journal, where we talk about good practices, testimonials from patients, resources and physicians.
We have a lot of them______: in the ICSUSS journal, there is always an article; a promotional video in which patients testify (on the intranet there is a patient resources section in which the tools are available and on YouTube); a pamphlet; and we are preparing for the dynamic screens for patients; and we meet more than 300-400 people and professionals and workers in pseudo psychiatry.
Guide de recrutement de patient partenaire (UdeM), référentiel des compétences (UdeM), Référentiel des pratiques collaboratives et partenariat patients (UdeM)

Training materials to create

Management training with a patient
Training in communication for healthcare professionals and patients when they join a team
Official training giving to patient-resource on PE
Official training to HCP on PE
7hrs training for managers on safety
Modular training according to the time allowed. Between 15mins and 1 hour. (Definition, procedures, roles, skills; why it comes to this, delivery and evaluation, the trajectory of patient integration. And advice to facilitate the integration.) we do a follow-up with the patient and the intervener after the first meeting. And after that it is annual)
A preparatory workshop (20 and 30 min) in person. The basics of the Resource Patient, the organizational vision of the Resource Patient, how to integrate patients into committees and working groups, pre- and post-meeting coaching that must be done and redone.
Training on interdisciplinarity we train all the teams - Managers were trained with the DCPP, 7-8 moments, training 1hr30 on PP. 125 managers trained on 3oo and some_

Training for managers. For healthcare providerss, to come.
Training is given and done by the team where there are PDs: SAPA, onco; dialysis. But the criteria are not the same.
In action: support by the patient experience department + tools available on the intranet + workshops.
Intranet Toolbox
Awareness yes, 1 hour presentation
In pilot project
There is a one-day training course for risk management. The training is in two parts. 1- basic concepts + risk management. And then testimony. In the afternoon, the patient experience and commitment and the link with service quality. The training is offered to managers. And we talk about interdisciplinarity. 400 interveners have also been trained (we have 200 managers trained and is done in tandem with a resource patient).
Short workshop on partnership at the organizational level given to teams working with patient partners.
Currently, a TPP for outreach on the care and service partnership has been developed but has not yet been used with healthcare providerss. However, we are working on a project entitled Meilleurs Ensemble, where training is offered to staff on the contribution of the involvement of family and friends during hospitalization and how to promote this involvement by acting in partnership with the patient and his or her family and friends. In addition, the model of interprofessional collaboration that was chosen in our CISSS is adapted from the UdeM's care and services partnership model. Training will be offered to caregivers in this regard starting this fall.
Mandatory training for all managers is currently provided and several training sessions are given to care providers as needed.
Training adapted to certain speakers " How the organization uses the 3 axes to respond to the partnership " between 1 hour and 2 hours of training.
We're trained in the collaborative approach. How we work with patients. (Many healthcare providerss have had it). Training given by DSM management. On our intranet, management presents training and people register. And after the sequence, it's once a year.
A training session of one and a half hours that we give - plus an awareness session. We also organize training for the intervener and the patient (2x half a day).

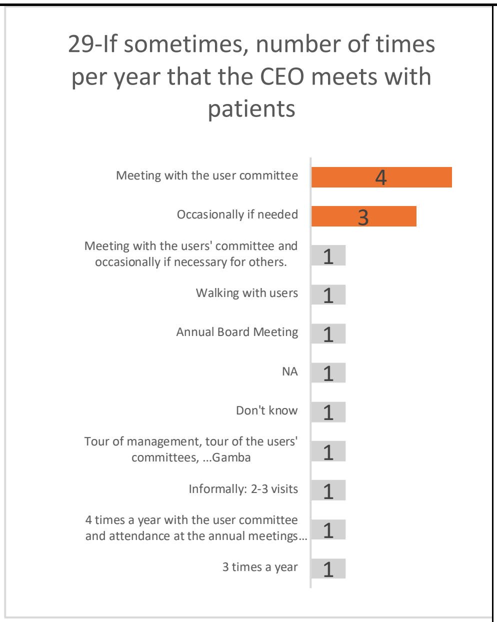
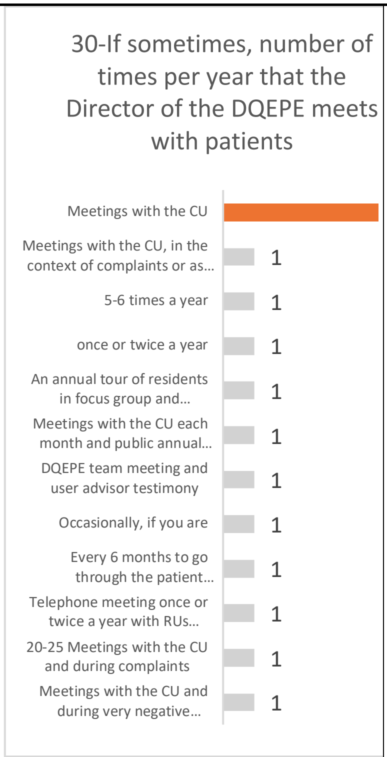
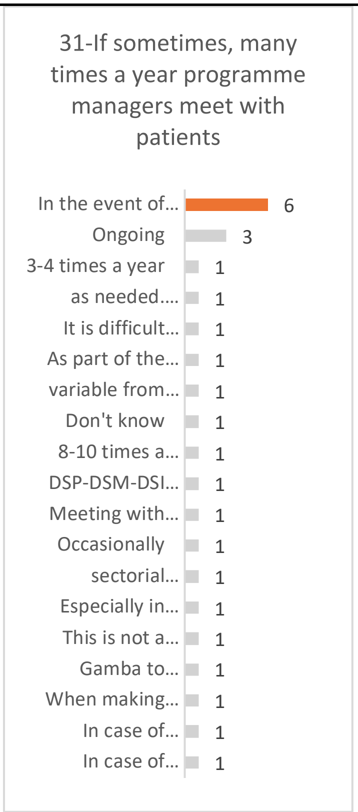
TYPES OF PATIENT BANKS AND OW THE REQUESTS ARE MADE?
Types of resource patient banks
Per department or direction (e.g. SAPA; SM; DSP; ONCO; dialysis, etc.)
Centralized at the DQEPE (with the different departments and type of patients and their contacts and training received, and projects integrated in) but with access to the directions (which are trained on it and accompanied). We become the intermediary
Volunteer data base, which give them access to compensation: access to parking; meal allowance ($6.50 per day); ID cards that identify them to open certain doors to move around the organization).
We are trying to decentralize the bank: to empower the teams.
Resource or advisor patient’s database
Patient bank and family partners

Peer-help database
The patient bank is coordinated by the patient resource office. But we have patients in this bank for all directions
Central Bank, but we're identifying the department they came from
Bank formed through the patient committee

How are requests made?
We've got tools for recruiting. The sector approaches us, they make the request; word of mouth; the teams send them to you. They become official volunteers.
On the intranet there is a way to make a request.
Manager-request (needs and objective)
They can go to the healthcare providerss or the DQEPE
Every department has its own form. They created it themselves.
Short questionnaire on Survey Guizmo to detail the request, sent to the coordinator
We have a pamphlet to promote PD (passed by ex-member patients; and by professionals). We have it on the website; we do a lot of reminders (phone calls, etc.).
When departments wish to involve partner patients in a project, they fill out an application form in which they specify the nature of the involvement, the duration, their expectations of the partner patient, the care or service profile, etc. The application form is sent to all the departments involved.
Access counter
It is the project manager who asks the Director of DQEPE, a resource patient.

How to gather feedback from patients and / or patients and their families

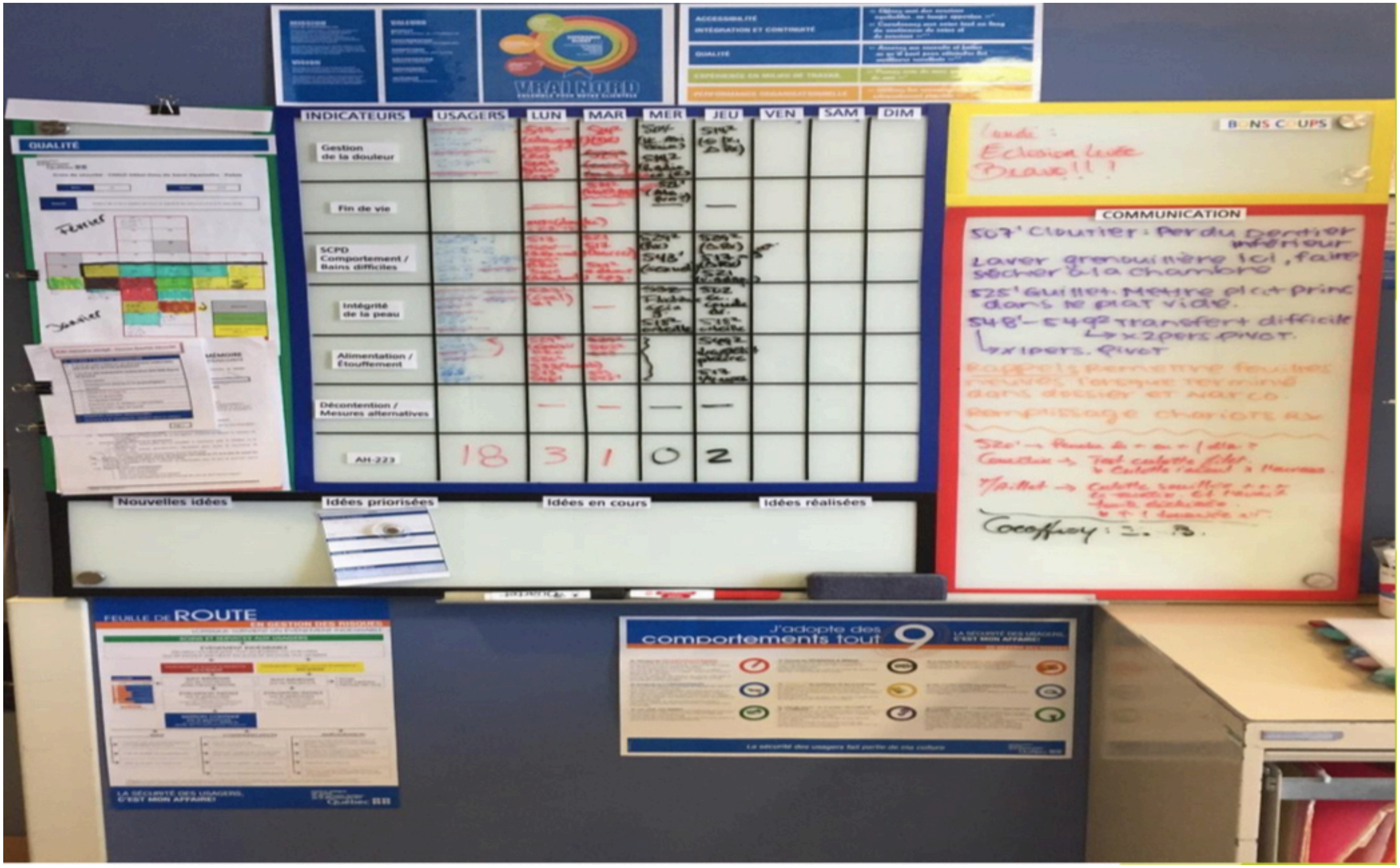
Mechanisms to collect feedback	**Types of feedback**	
Surveys	Internal surveys (commentary boxes, formal surveys, etc.); External surveys AC, PORs	
Consultation	With patients ‘committee, patients, patient-resource	
Focus group	With patients, CU, PP, volunteers Peers	
Complaints	Complaints comments from the complaints department	
Patients presence on committees	The board of directors	Analysis of accidents and incidents in the risk management committee
Population Forum	With citizens, patients	

Gamba tours: the emotional experience visits. (CEOs tour health organizations to gather patient feedback)				

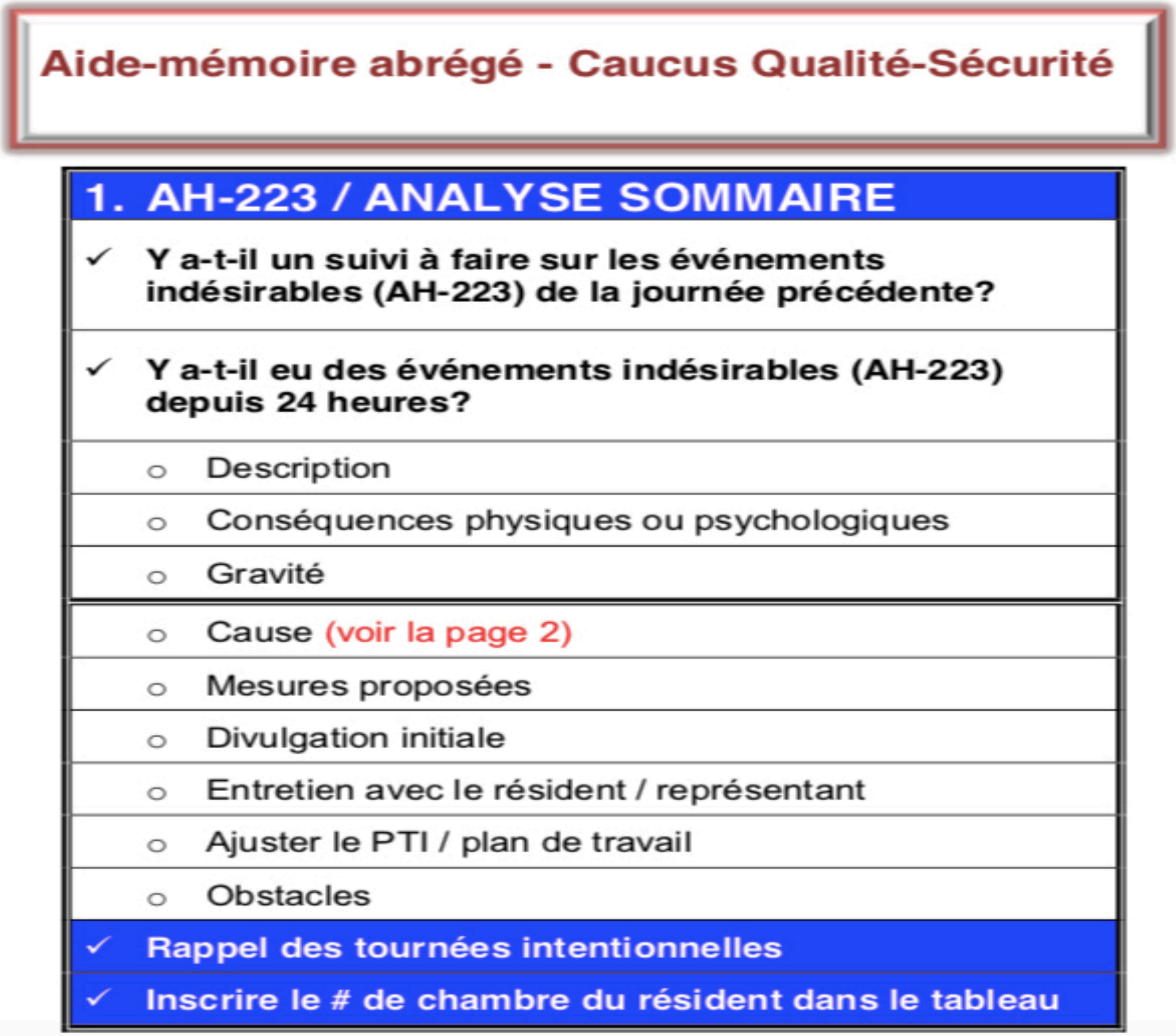
PE ENGAGEMENT IN DIFFERENT INITIATIVES
26. Were patients involved in the development of the institution's major orientations and decisions?
Code of Ethics
Kaizens and Kaikaku, Gamba
Redeployment projects (CU)
CU to the Board
the Help Dying Act, we've consulted a P.U.
Survey on values
24. Are patients invited to the steering committee or control room (or directory committee)?
Testimonials
Ad hoc invitation e.g. invitation from the patient committee’s president
On the Vigilance Committee

APPENDIX J - Visual board and all the elements which it comprises are presented below (all of the resources listed below are taken from document sand presentations received from the CISSS Montérégie - Est [136].

1- Visual board:



Element 1: Safety caucus on Adverse Events:

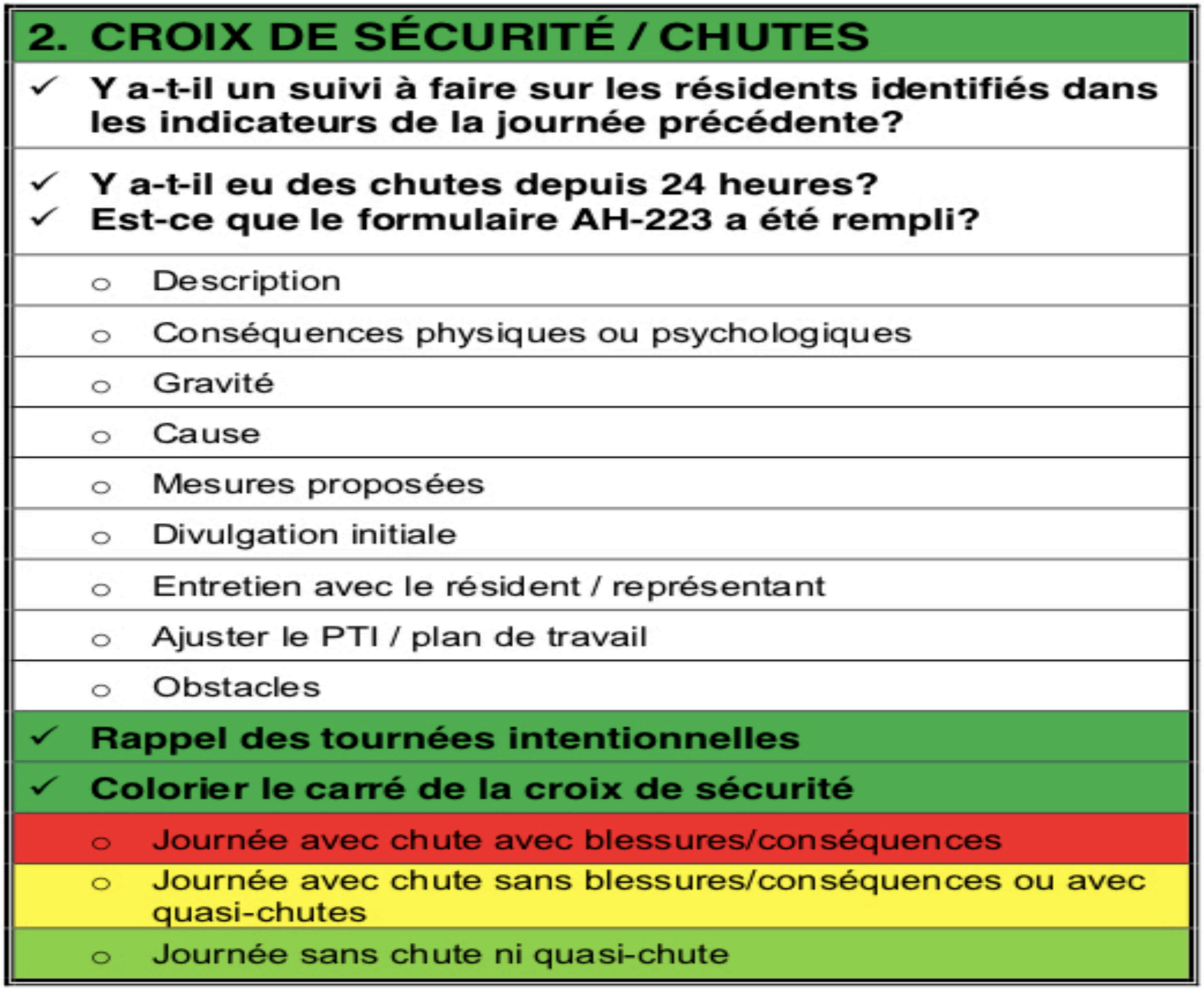


Aide-mémoire abrégé - Caucus Qualité-Sécurité

1. AH-223 / ANALYSE SOMMAIRE

- ✓ **Y a-t-il un suivi à faire sur les événements indésirables (AH-223) de la journée précédente?**
- ✓ **Y a-t-il eu des événements indésirables (AH-223) depuis 24 heures?**
  - ○ Description
  - ○ Conséquences physiques ou psychologiques
  - ○ Gravité
  - ○ Cause (voir la page 2)
  - ○ Mesures proposées
  - ○ Divulgation initiale
  - ○ Entretien avec le résident / représentant
  - ○ Ajuster le PTI / plan de travail
  - ○ Obstacles
- ✓ **Rappel des tournées intentionnelles**
- ✓ **Inscrire le # de chambre du résident dans le tableau**

Element 2 – Safety cross:



2. CROIX DE SÉCURITÉ / CHUTES

✓ **Y a-t-il un suivi à faire sur les résidents identifiés dans les indicateurs de la journée précédente?**

✓ **Y a-t-il eu des chutes depuis 24 heures?**
✓ **Est-ce que le formulaire AH-223 a été rempli?**

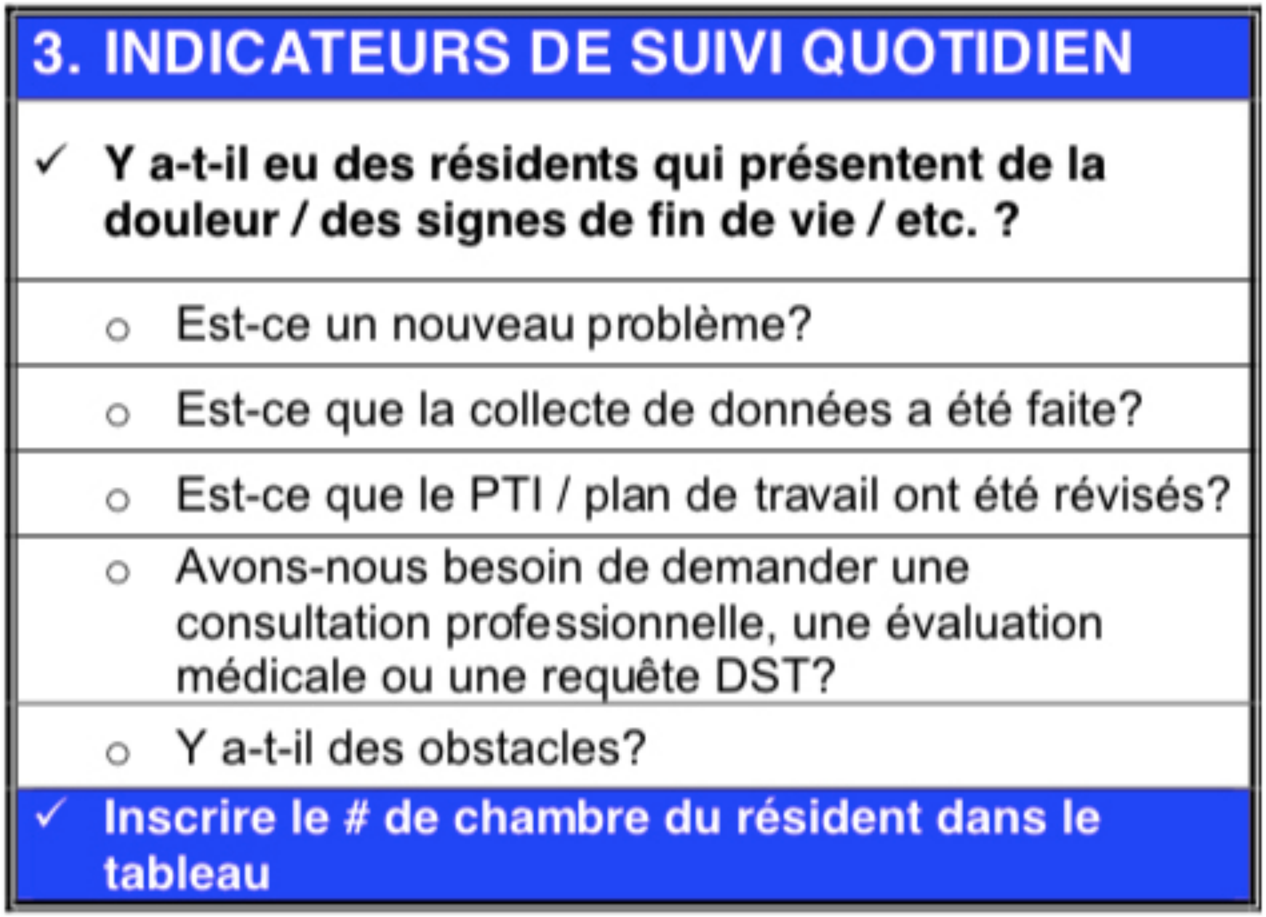
- ○ Description
- ○ Conséquences physiques ou psychologiques
- ○ Gravité
- ○ Cause
- ○ Mesures proposées
- ○ Divulgation initiale
- ○ Entretien avec le résident / représentant
- ○ Ajuster le PTI / plan de travail
- ○ Obstacles

✓ **Rappel des tournées intentionnelles**

✓ **Colorier le carré de la croix de sécurité**

- ○ Journée avec chute avec blessures/conséquences
- ○ Journée avec chute sans blessures/conséquences ou avec quasi-chutes
- ○ Journée sans chute ni quasi-chute

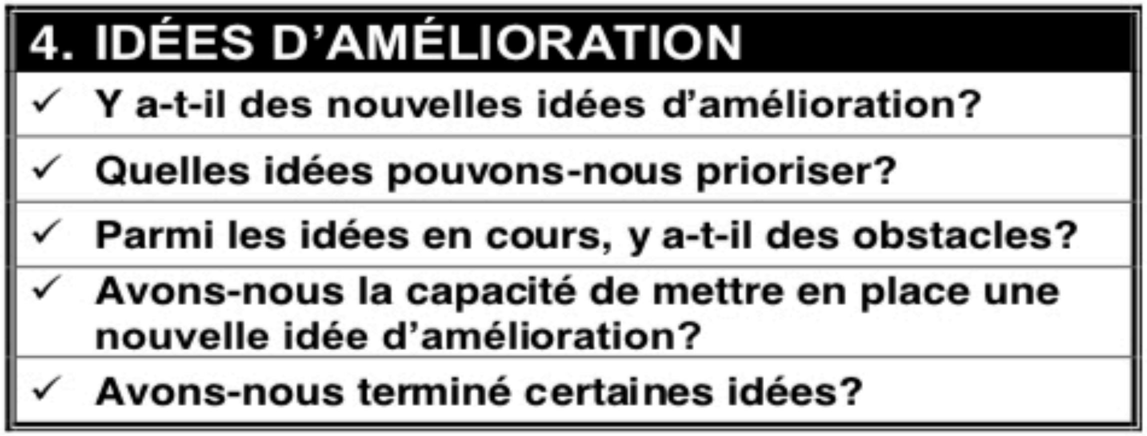
Element 3 – Daily follow-up indicators:



3. INDICATEURS DE SUIVI QUOTIDIEN

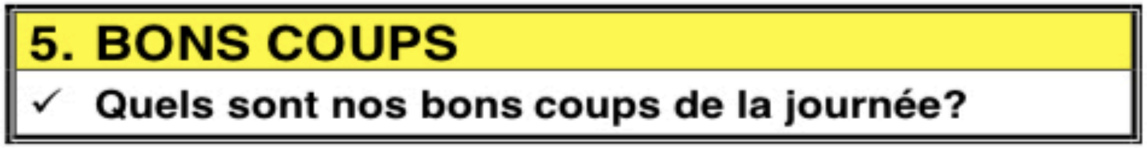
- ✓ **Y a-t-il eu des résidents qui présentent de la douleur / des signes de fin de vie / etc. ?**
  - Est-ce un nouveau problème?
  - Est-ce que la collecte de données a été faite?
  - Est-ce que le PTI / plan de travail ont été révisés?
  - Avons-nous besoin de demander une consultation professionnelle, une évaluation médicale ou une requête DST?
  - Y a-t-il des obstacles?
- ✓ **Inscrire le # de chambre du résident dans le tableau**

Elements 4: Other elements of institutional values, best practices, improvement ideas, and communication:



4. IDÉES D'AMÉLIORATION

- ✓ Y a-t-il des nouvelles idées d'amélioration?
- ✓ Quelles idées pouvons-nous prioriser?
- ✓ Parmi les idées en cours, y a-t-il des obstacles?
- ✓ Avons-nous la capacité de mettre en place une nouvelle idée d'amélioration?
- ✓ Avons-nous terminé certaines idées?



5. BONS COUPS

- ✓ Quels sont nos bons coups de la journée?

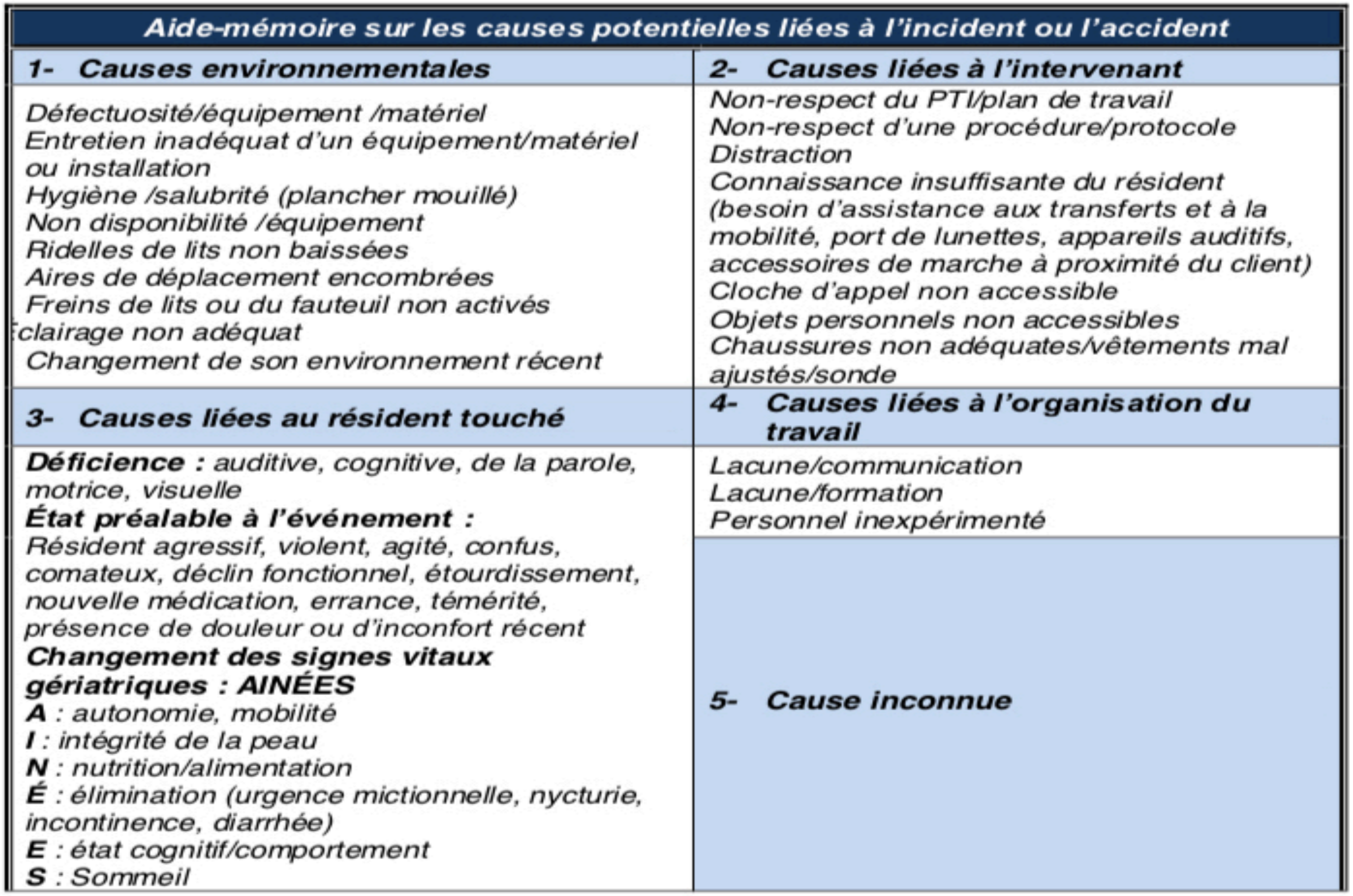
6. COMMUNICATION

- ✓ Quels sont les messages de la journée?

7. VRAI NORD, MISSION, VISION ET VALEURS

- ✓ En tout temps, un rappel peut être fait pour ne pas perdre ces concepts de vue!

Element 5: Memory-aid on the causes related to an accident:



Aide-mémoire sur les causes potentielles liées à l'incident ou l'accident	
1- Causes environnementales	**2- Causes liées à l'intervenant**
Défectuosité/équipement /matériel Entretien inadéquat d'un équipement/matériel ou installation Hygiène /salubrité (plancher mouillé) Non disponibilité /équipement Ridelles de lits non baissées Aires de déplacement encombrées Freins de lits ou du fauteuil non activés Éclairage non adéquat Changement de son environnement récent	Non-respect du PTI/plan de travail Non-respect d'une procédure/protocole Distraction Connaissance insuffisante du résident (besoin d'assistance aux transferts et à la mobilité, port de lunettes, appareils auditifs, accessoires de marche à proximité du client) Cloche d'appel non accessible Objets personnels non accessibles Chaussures non adéquates/vêtements mal ajustés/sonde
3- Causes liées au résident touché	**4- Causes liées à l'organisation du travail**
Déficience : auditive, cognitive, de la parole, motrice, visuelle **État préalable à l'événement :** Résident agressif, violent, agité, confus, comateux, déclin fonctionnel, étourdissement, nouvelle médication, errance, témérité, présence de douleur ou d'inconfort récent **Changement des signes vitaux gériatriques : AINÉES** **A** : autonomie, mobilité **I** : intégrité de la peau **N** : nutrition/alimentation **É** : élimination (urgence mictionnelle, nycturie, incontinence, diarrhée) **E** : état cognitif/comportement **S** : Sommeil	Lacune/communication Lacune/formation Personnel inexpérimenté **5- Cause inconnue**

APPENDIX K – Intentional rounds

« Intentional rounds are a recognized practice for improving care and service quality. The goal is to ensure the safety of residents through four questions that any valid person can ask, verbally or by observation, after a care, service or visit:

1. *Does the user have pain?*
2. *Does the patient appear comfortable?*
3. *Does the patient need to go to the bathroom?*
4. *Does the user have his/her bell and personal belongings handy? »* [136]

APPENDIX L – Interview guide – Part 2 research study PE for PS

Guide d'entrevue - Stratégique

Temps 1 et 2

Remerciements

Nous vous remercions d'avoir accepté de répondre aux questions dans le cadre de notre étude « ***sur l'EP pour la sécurité des soins et services de santé et services sociaux »***

Objectifs de l'entretien

Faire un bilan de ce qui s'est passé en matière de participation des patients/usagers dans votre établissement, depuis 2015.

Notre étude porte sur **l'implantation et l'impact de l'engagement des patients et usagers aux niveaux de la qualité et de la sécurité des soins et des services**. Les questions qui suivent vont donc porter à la fois sur la participation des patients dans la sécurité/gestion des risques. Pour chaque question, nous aimerions vous entendre sur ces deux volets.

Durée de l'entretien

- 1h00

Règles de l'entretien

- **Tout ce qui sera dit durant l'entrevue restera confidentiel. Votre nom n'apparaîtra nulle part et vous demeurerez entièrement anonyme.**
- À tout moment de l'entrevue, laissez-nous savoir si vous avez des questions ou si vous préférez ne pas répondre à une question en particulier.
- Aussi, vous pouvez décider d'arrêter l'entretien à n'importe quel moment.
- Rappelez-vous que nous voulons savoir ce que vous pensez et ce que vous percevez. Il n'y a donc pas de bonne ou de mauvaise réponse.

Formulaire d'information et de consentement - FIC

- Avez-vous bien lu et bien compris le FIC?
- Est-ce que vous avez des questions en lien avec le FIC?
- Nous vous invitons à signer les deux copies du FIC, veuillez nous remettre une copie et en garder une dans vos dossiers.
- Acceptez-vous que l'entretien soit enregistré? L'enregistrement sert à des fins d'analyse des données et votre anonymat est garanti.

[Début de l'enregistrement]

1- **Comment êtes-vous impliqué dans toutes les questions stratégiques qui touchent la qualité des soins et services et la gestion des risques au sein de votre établissement ?**

- Dans quel cadre êtes-vous impliqué (comité de direction, conseil d'administration, comité de vigilance, autres)?

2- **Pouvez-vous nous décrire le modèle de participation des patients/usagers qui a été implanté dans votre établissement ?**
    - Selon vous, quels sont les points forts et points faibles de ce modèle?
    - Quelles sont les principales réalisations dont vous êtes le plus fier par rapport à la participation des patients dans votre établissement?

3- **Quelles sont les principales raisons qui vous ont poussé à initier/implanter ce modèle?**
    - Considérez-vous que la participation des patients est un levier important de l'amélioration de la qualité? Et pour l'amélioration de la sécurité/gestion des risques?

4- **Est-ce que la participation des patients est une priorité organisationnelle?**
    - Si oui, de quelle manière se manifeste-t-elle (planification stratégique, code éthique, RH, ordre du jour des comités et du conseil d'administration, autres exemples)?

5- **Au niveau stratégique, suite à la restructuration (loi 10), comment a été prise la décision d'attribuer le mandat (participation patient) à la direction qui est maintenant en charge?**

6- **Depuis les nouvelles orientations du MSSS en lien avec la participation des patients/usagers, comment votre fonction/rôle a évolué?**

7- **Comment vous assurez-vous que le modèle de participation patients soit intégré dans toute l'organisation?** Est-ce une préoccupation pour vous?

8- **Pouvez-vous nous dire dans quel cadre vous recevez de l'information sur la démarche de participation implantée dans votre établissement?** A quelle fréquence ?

9- **Avez-vous des indicateurs ou outils qui vous permettent de mesurer l'impact du modèle de participation patients ?**
    - A quel niveau (**stratégique**, tactique, clinique) ces mesures sont-elles utilisées?
    - Quel(s) type(s) d'impacts sont mesurés (outcome/résultats santé; processus organisationnels)?

10- **Quels sont les facteurs qui selon vous ont facilité ou nuit à la participation des patients dans votre établissement (culture, leadership/gouvernance, ressources, outils/méthodes/procédures) ?**

11- **Est-ce que vous constatez des effets de la participation des patients à ces différents niveaux :**
    - Patients, ex : *expérience de soins, satisfaction, observance thérapeutique, etc.*
    - Professionnels de santé, ex : *pratiques cliniques, relation patient/professionnel*;

- Réorganisation des soins et services, *ex : modification de l'offre de soins et services;*
- Établissement/culture d'établissement, *ex : culture centrée vers le patient, la participation des patients/usagers*

12- Quelle est votre vision, à moyen/long terme, de la participation des patients/usagers au niveau de la qualité et au niveau de la sécurité des soins?

- Comment pensez-vous élargir votre modèle de participation à d'autres opportunités d'amélioration?
- Comment pouvez-vous assurer de la pérennité de la participation des patients/usagers dans votre établissement ?

13- Avez-vous d'autres points ou informations à partager avec nous?

FIN DE L'ENTREVUE

MERCI BEAUCOUP POUR VOTRE COLLABORATION!

GROUPE DE DISCUSSION - Organisationnelle et clinique

Temps 1 et 2

Remerciements

Nous vous remercions d’avoir accepté de répondre aux questions dans le cadre de notre étude « ***sur l’EP pour la sécurité des soins et services de santé et services sociaux »***

Objectifs de l’entretien

Notre étude porte sur **l’implantation et l’impact de l’engagement des patients et usagers aux niveaux de la qualité et de la sécurité des soins et des services**. Les questions qui suivent vont donc porter à la fois sur la participation des patients dans la sécurité/gestion des risques. Pour chaque question, nous aimerions vous entendre sur ces deux volets.

Objectif de l’entretien

Le groupe de discussion a pour but de comprendre comment l’engagement des patients, que ce soit au niveau de comités, ou de l’équipe clinique, ou de groupes de travail , ou encore au niveau de leurs propres soins, contribue à améliorer la sécurité des soins et services.

Durée de l’entretien

- Environ 2h00- 2h30

Règles de l’entretien

- **Tout ce qui sera dit en entrevue restera confidentiel. Votre nom n’apparaîtra nulle part et vous demeurerez entièrement anonyme.**
- À tout moment durant notre conversation, laissez-nous savoir si vous avez des questions ou si vous préférez ne pas répondre à une question en particulier. Aussi, vous pouvez décider d’arrêter l’entretien à n’importe quel moment.
- Rappelez-vous que nous voulons savoir ce que vous pensez et ce que vous percevez. Il n’y a donc pas de bonne ou de mauvaise réponse.
- Pour le bon déroulement du groupe de discussion, nous vous demandons de répondre à tour de rôle, de répondre brièvement aux questions afin de laisser assez de temps aux autres participants pour s’exprimer.

Formulaire d'information et de consentement - FIC

- Est-ce que vous avez bien lu le FIC? Est-ce que vous avez des questions en lien avec le FIC?
- Nous vous invitons à signer les deux copies du FIC, nous remettre une copie et en garder une dans vos dossiers.
- Acceptez-vous que l’entretien soit enregistré? L’enregistrement sert à des fins d’analyse des données et votre anonymat est garanti.

[Début de l’enregistrement]

Le groupe de discussion sera divisé en deux temps :

- Intervenants ayant participé à un groupe de travail, comité incluant des patients (20 min)

- Participation des patients dans leurs propres soins (30 min)

Intervenants ayant participé à un groupe de travail, comité incluant des patients

Nous aimerions débuter par quelques questions sur **votre expérience** *comme intervenant impliqué* dans des activités, groupes de travail ou comité incluant des patients.

1- **Comment avez-vous été impliqué(e) comme intervenant dans des activités, groupes de travail ou comités incluant des patients**?
   - Avec qui avez-vous collaboré (gestionnaires, médecins, infirmières, patients)?
   - Depuis quand?
   - Est-ce que votre travail était en lien avec la qualité des soins et services ou avec la sécurité des soins/gestion des risques ?
   - Sur quoi vous avez travaillé dans le cadre de ce comité/groupe de travail (ex : réalisation de guides d'information, processus d'amélioration des soins et services, formations, autres projets cliniques ou organisationnels)?

2- **Comment avez-vous été sollicité pour faire partie de ce comité/groupe de travail ?** Si oui de quelle manière?

3- **Avez-vous participé au recrutement des patients inclus dans le comité/groupe de travail ?** Si oui de quelle manière?
   - Selon vous, quelles sont les expériences, qualités et les compétences recherchées chez les patients (ou proches de patients) pour les impliquer dans des activités/comités/groupes de travail ?

4- **Comment l'équipe ou vous-même reconnaissez le travail accompli par les patients dans les groupes de travail/comités**
   - Rémunération, compensation, félicitations, autres formes de reconnaissance

5- **Comment l'établissement vous a aidé ou accompagné afin de collaborer avec les patients ?** Type de formation reçue

6- **Comment avez-vous perçu l'intégration des patients au sein du groupe de travail/comité ?**

   - Quelle a été votre perception de l'accueil par l'équipe (respect, langage, équité, compréhension)?
   - Avez-vous senti que les patients étaient membres à part entière de l'équipe?
   - Les patients étaient-ils à l'aise de communiquer/ faire valoir leurs points de vue /leurs opinions?
   - À quel point avez-vous senti que leurs points de vue /leurs opinions étaient pris en compte par les membres de l'équipe ?

7- **Est-ce que l'établissement et/ou l'équipe fait un bilan de l'implication des patients dans les différentes activités/comités/groupes de travail ?** Si oui, comment ? Êtes-vous impliqué?

8- **Comment le groupe de travail/comité partage l'information sur le suivi du projet/activité avec les patients?** Si oui, comment ?

8bis comment les personnes qui ne sont pas sur le comité entendent parler de ce qui s'y passent et comment ils bénéficient des décisions qui y sont prises?

9- **Êtes-vous régulièrement informé sur les différents projets/activités réalisés en collaboration avec des patients ?** Si oui, comment ?

10- **Quels sont les facteurs qui ont favorisé ou nuit à l'implication des patients dans le groupe de travail/comité** ?
  - Quelles sont les qualités et compétences recherchées auprès des professionnels de la santé pour mieux impliquer les patients ?

11- **Avez-vous des suggestions pour améliorer l'implication des patients dans les différentes activités/comités/groupes de travail** ?
  - Quel type de soutien souhaiteriez-vous obtenir pour mieux impliquer les patients ?
  - Quel type de soutien les patients devraient-ils obtenir pour faciliter leur participation ?

12- **Avez-vous d'autres choses que vous aimeriez ajouter ? D'autres sujets que vous aimeriez aborder et que vous jugez important d'explorer ?**
  - Comment assurer la pérennité de la participation des patients ?

Participation des patients dans leurs propres soins

Pourriez-vous revenir sur la façon dont vous impliquez les patients dans toutes les décisions qui concernent leur problème de santé.

1. **Dans quelle équipe de soins travaillez-vous ?** Quelle est la composition de l'équipe?

2. **Comment les activités réalisées dans le comité ont un impact au niveau clinique : relation entre les patients et les professionnels et réalisation de PII et autres … et si pas eu ce comité est ce que cela aurait quand même eu lieu?**

3. **Est-ce que les plans d'intervention ou plan de traitements des patients sont réalisés en interdisciplinarité (avec l'équipe) ou avec un professionnel de la santé/médecin en particulier?**

4. **Comment impliquez-vous les patients lors de la réalisation de leur plan d'intervention ou plan de traitements?**
    - De quelle manière (information, consultation, collaboration, partenariat) ? Exemple de plan d'intervention co-construit vs avec collaboration du patient ?

5. **Est-ce que vous recevez des formations ou de l'information sur la façon de d'impliquer les patients dans leurs propres soins?**
    - Est-ce que vous utilisez des outils destinés à mieux impliquer les patients ?

6. **Êtes-vous à l'aise pour impliquer les patients dans les décisions qui les concernent ?**
    - Quelles sont les qualités et compétences recherchées auprès des professionnels de la santé pour mieux impliquer les patients ? (qualité vs. sécurité)

7. **Quels sont les facteurs qui ont favorisé ou nuit à l'implication des patients dans leurs propres soins** ?
    - Qualité et compétences recherchées auprès des patients ?

8. **Quels sont les facteurs qui ont favorisé ou nuit à votre capacité à impliquer les patients dans leurs propres soins** ?
    - Contrainte/charge de travail, Est-ce réalisable ?
    - Sensibilisation/information/formation

9. **Selon vous, qu'est-ce que signifie être un partenaire de ses soins/en partenariat les professionnels de santé?**
    - Dans quelles situations le partenariat est-il possible ou pertinent?
    - Avez-vous des exemples à nous donner à partir de votre pratique ? Par rapport à la sécurité des soins ?

10. **Quel est le message le plus important que vous aimeriez voir ressortir de l'entretien?** Avez-vous d'autres choses que vous aimeriez ajouter ?

FIN DE L'ENTREVUE

MERCI BEAUCOUP POUR VOTRE COLLABORATIO

APPENDIX M – Analysis of the data collected

5.2.4.2. Analysis of the data collected

5.2.4.2.1. Analysis of the results from Table 7: Description of participating institutions and individual participants

Table 7 provides a detailed look into the questionnaire's results which reflect the current patient engagement (PE) structures and implemented strategies in Quebec's 22 Integrated Health Centers (CISSS, CIUSSS), the CHUM and the MUHC. Results are presented according to the structure of the questionnaire.

There were two data collection periods: from May 2017 to December 2017 (T1), and March 2018 to December 2018 (T2). T1 and T2 had a perfect response rate of 100 % (N=22). However, in T2's four CIUSSS's asked to use the same response made in T1 for T2 (since there were no changes or evolution in their PE strategies in risk management for safety).

Regarding the mention of PE in the different institutions' strategic plans, in T1, 13 institutions (45.5%) versus 19 institutions (86.4%) in T2 (an increase of 41% from T1), made reference to PE in their strategic planning including in other types of documents. However, 13.6% (N=3) in T1 / versus 4.5% (N=1) in T2, said their institution does not mention PE in the strategic planning nor in other type of documents.

In terms of number of individual respondents (responding on behalf of their respective organisations), there were 49 in T1 and 38 in T2, with a range of one to four respondents per organisation. Out of the combined total of respondents ((N=87)), The majority of the respondents were (N=30) from upper management (director-level and up) as well as Healthcare professionals and advisors (N=31). Mid-managers were (N=19), and we also had a category of “others” (patient partners, patient safety officer, etc. N= 8). As a study on patient engagement, it is also worth noting that one patient participated as respondent as part of a team (of management personnel and healthcare professional) in T1.

Most respondents (90 % and more) worked at the health center’s DQEPE, with a majority (more than 45 %) having joined the department in 2015, shortly after Quebec’s healthcare network reform under Bill 10. That said, more than 48 % of respondents have been working in the healthcare system for over 20 years.

Nearly more than two thirds of respondents in T1 and in T2 (67 % in T1, and 68% in T2) claimed to have spent less than 50 % of their time on patient engagement. A larger proportion of respondents (49 % in T1 and 55 % in T2) affirm that more than half of their time was spent on risk management.

In fact, all respondents claimed to participate or to have participated in “Risk management Committees” and “Vigilance and quality committees”, which were the only committees with 100 % participation rates in the questionnaire. “Infection Prevention and Control Committees” came second, with 68 %.

5.2.4.2.2. Analysis of the results from Table 8: Governing structures of PE, PExp, and risk management

Table 8 explains the PE, patient experience and risk management governing structures in participating healthcare institutions, as well as collaboration mechanisms between different departments.

It is also worth noting that two questions were eliminated from this study: (question 4) "Which departments have patient engagement projects and how many projects are being carried out in each of these services (specify the number of projects per department)?" and (question 7) "Which service(s) uses patient experience questionnaires?". For both questions, too many institutions were not in a position to answer due to a lack of an overall portrait of ongoing projects on PE in PS.

5.2.4.2.2.1. Governing Structure and Personnel Profile of the PE Department

In the case of PE, there appears to be more collaboration among departments, as only 50 % and 73 % of institutions (in T1 and T2 respectively) identified the DQEPE as sole responsible for supporting the implementation of PE. Another directorate responsible is the department of Multidisciplinary Services (*Direction des services multidisciplinaires* - DSM) with 9% in T1, and 4.5% in T2.

While the DQEPE remains involved, it collaborates (41% in T1, and 23% in T2) with other departments. The most common collaboration is between the DQEPE and (1) multiplying agents in each directorate, or (2) collaborating with clinical directorates (such as the Nursing service directorate, department of Multidisciplinary Services (*Direction des services multidisciplinaires* - DSM), or patients' offices / Patient's experience's office, or the Professional Directorate Services, or(3) collaborating with the Public health directorate, or (4) even with outside organisations such as the DCEPP (PE experts). Other structures include collaboration with the Department of Public Health (*Direction de Santé publique* - PH) and the Patient Partnership Office.

Notable structures include the Patient Experience Office in conjunction with the PP committee, as well as the PP office in collaboration with the DQEPE to create tools, etc.

While most surveyed PE structures (67% in T1, 76% in T2) reported up to three managerial staff members contributing to the deployment of patient engagement, it is worth mentioning that five structures in T1 and four structures in T2 reported more than four managerial staff members involved, including a case of 10 staff members or more via a collaboration between the DQEPE, Patient Experience Office, the PP committee and the Patient Committee.

At first, directors, deputy directors and health professionals working in these departments were the ones in charge of PE's issues. But with time, many healthcare institutions started creating specific job descriptions for PE (such as PE coordinator, etc.). At the same time, only few institutions (N=2) had formal PE offices with patients working under DQEPE leadership as PPs. Within those offices, the average number of workers is three.

When identifying managerial staff contributing to the deployment of PE in care and services, findings indicated 18 types of **diversified professional background** or formal training. However, over three quarters (79 %) of hired personnel had a **social work background** (e.g.: nursing or social worker, etc.). While the majority had received some type of formal and informal training in PE such as conferences, readings, and partnering with universities and DCEPP (T1 = 57% and T2 = 71%), still, this indicates that a significant portion did not (T1 = 41%, and T2 = 30%). Most people working in these PE structures were hired between 2015 and 2016, with 71 % within T1 and 61% in T2. In 2018, data suggests a hiring increase similar to the 2015-2016 period within those structures, with six new hires (21%) in the PE Department in T2 (compared to zero hires in T1, in 2018).

Regarding time spent on patient engagement, in T1, only 10-11 % of respondents claimed to spend 100 % of their time on it. In T1, the majority of respondent (55%) spent less than 50 % of their time on PE, with 30% spending less than 10% of their time on PE. In T2, we can see that 62 % spent less than 50% of their time on PE. However, most respondents in T2 (55%) increased their time spent on PE, by spending 20-49% of their time on PE. Compared to T1 (25%).

5.2.4.2.2.2. Governing Structure and Personnel Profile of the Patient's Experience Department

For most healthcare institutions (82% in T1, and in T2), the DQEPE is the only department responsible for supporting the implementation of the Patient's Experience Department. However, in the remaining cases (14% in T1 and in T2), it collaborates with other departments, such as the DSM, the Patients Committee, the Pexp office, or the Population and Partnership Department.

The official title of 45.5 % of professionals working in the PExp department is "Program evaluation professionnal or HCPs", while 18 % are "Executive advisors", 16 % are "Quality deputy director" or "quality advisor manager", 7 % "Chief of quality", 4.5 % "Patient Partnership

Program coordinator", and 2 % are "CEO". The others titles (7%) comprised: intern, risk manager, patient committee, deputy assistant to the director. Most people working in these Patient Experience structures were hired between 2015 and 2016, with an average proportion of 59.5 % within T1 and T2. In 2018, data suggests a hiring increase similar to the 2015-2016 period within those structures, with four new hires in T2 (compared to zero in T1).

In terms of managerial staff contributing to the deployment of Patient Experience in care and services, among the 18 types of professional background or formal training identified, over three quarters (79 %) of hired personnel also had a social work background (e.g.: nursing or social worker, etc.).

Five types of structures in charge of patient experience were reported in Quebec healthcare institutions and, on average, two to three people handle this issue. While most surveyed PExp structures (23% in T1, 36% in T2) reported two to three staff members contributing to PExp, it is worth mentioning that one structure in T1 and two structures in T2 reported more than four or more staff members involved. In addition, seven institutions (32% in T1) compared to six institutions (27% in T2) reported they have one staff for their PExp projects. Many institutions did not respond to that question (nine institutions in T1, compared to six institutions in T2).

Looking at time spent on patient engagement in the Patient Experience Department, in T1, only 5 % of respondents claimed spending 100 % of their time on PExp (N=1), wheareas in T2, this number jumped to 20 % (N=4). While slightly over a quarter (26%) spent more than half of their time, the vast majority (74%) says to have spent less than 50 % of their time on patient engagement in T1. In T2, however, there are as many respondents on both sides (a 50 % split).

Lastly, when engaging patients regarding their experience, 85 % of surveyed institutions produce their questionnaires internally (th eother 15% is produced by an external organization such as an accreditation organization), and the pocess was underway in 71 % of insitutions. Only 18 % of them use the questionnaire more than once a year.

5.2.4.2.2.3. Governing structure and Personnel Profile of the Risk Management department

The structure of risk management (RM) departments is consistent across healthcare institutions in Quebec. Quite markedly, based on questionnaire results, the DQEPE is the sole department responsible for supporting the implementation of risk management (in 100 % of institutions, N=22).

While most RM departments (73% in T1, 77% in T2) collaborate with other departments to improve patient engagement and enhance risk management, instances when this does not happen are reportedly due to the massive restructuring which took place since Bill 10, which led to the transfers of many managers (N=2), or to the PE approach not being developed yet (N=1).

Moreover, most institutions (82% in T1, 91% in T2) have coordination mechanisms in place with several committees. Notable moments of collaboration with patient engagement/patients' groups are the National Security Week, or within other safety committees such as RM committees, in which sits a patients committee member, and occasionally a resource-patient.

As far as organisation and collaboration is concerned, surveyed institutions describe good cooperation between the different departments, often with departments responsible for quality and safety of care, often merged with departments overseeing patient rights and relations, clinical departments and department in charge of multiple services. Security remains a powerful vector for collaboration between departments, whether facing issues of quality or dealing with other departments (professionals, clinical, public health, etc.). That said, the way to operationalize these collaborations is yet to be figured out [92, 14].

5.2.4.2.3. Analysis of the results from Table 9 and Table 10: Identified Emerging themes

In total, 14 themes were identified from the results of the questionnaire (Tables 9 and 10) and described in the following sections:

5.2.4.2.3.1. Patient Engagement Policy/Strategy

As far as having an official PE policy or strategy (question 15), in T1, more than half of surveyed institutions claimed to have either one in place or in the works (68 %), which reached nearly three quarters of institutions in T2 (73 %). In T1 and T2, respectively, those with a policy or strategy already in place represent almost half of surveyed institutions with 47 % and 49 %. Notably, around a quarter of institutions still do not have policies or strategies (T1=27%, T2=23%).

5.2.4.2.3.2. Recruitment tools

In terms of recruitment tools for PE (such as data bases of PPs, recruitment forms, etc.), while more than half of surveyed institutions in T1 (54.5 %) and more than three-quarters in T2 (77 %) affirmed not having a readily available bank of resource patients/patients per department, around three-quarters of them at least have one bank for the entire institution (77% in T1, 72% in T2), of which more than half to three-quarters are already available for use (65% in T1, 75% in T2). When asked about the existence of program-specific forms to solicit participation from PPs, slightly less than half of surveyed institutions answered positively in T1 (45.5 %), but a significant increase to more than half (54.5 %) was observed in T2, with an additional 14 % still in the works.

5.2.4.2.3.3. Tools to Raise Awareness

With regards to raising PE awareness amongst healthcare providers and patients, around a quarter of surveyed institutions claimed to have PE promotional documents “always” (23%) or “sometimes” (23%) available for healthcare providers in T1, with an increase to 36 % and 27 % respectively in T2. Conversely, institutions that did not have any documents available dropped by half between T1 and T2, from 32 to 14 %. While in T1, a little more than half (55 %) “always” or “sometimes” offered patient engagement training to healthcare providers, that proportion grew to 63 % in T2. Interestingly, among institutions that offered training, 58 % did so “sometimes” in T1. However, in T2, a growing majority appears to be doing it “always”, as the %age reached 57 per cent, while the “sometimes” respondents decreased to 43 %. When asked about the availability of promotional materials geared towards patients, most notable results in T1 were as follows: “never” 27 %; “sometimes” 32 %; “always” 9 %; and “in progress” 27 %. In T2, while "sometimes" and "in progress" responses remained stable at 32 and 27 % respectively, "never" dropped significantly to 9 %, most likely in favor of "always" which tripled to 27 %.

5.2.4.2.3.4. Patient involvement in strategic planning and decision-making

When it comes to involving patients in the institutions' strategic orientations and decisions, while the majority of surveyed institutions claim "sometimes" (55% in T1, 54.5% in T2), only 9 % claim "always" consistently in T1 and T2, and over a quarter (27% in T1 and T2) say "never". Around a quarter of institutions consistently involve patients when developing their strategic plans (32% in T1, 23% in T2), whereas nearly half have yet to do so (41% in T1, 50% in T2). Furthermore, eight out of 10 institutions have yet to integrate patients in their steering rooms (82% in T1, 85% in T2 – only one institution achieved this in T2), and around three-quarters have yet to invite patients to their Steering Committees (73% in T1, 77% in T2). Those that have responded positively to the latter specified "sometimes" (23% in T1, 18% in T2). That said, the area in which patients seem the most allowed to participate is when sharing testimonials in front of the board of directors. Indeed, in T1, institutions that "sometimes" or "always" invited patients to the board represented a combined 59 % of respondents, among which more than half (54 %) would do so "always". In T2, while the combined total of "always" and "sometimes" responses grew to 77 %, now a larger proportion do so "sometimes" (65%) rather than "always" (35%).

5.2.4.2.3.5. Senior Leadership Involvement

One of the best practices in PE is the senior leadership involvement. In that regard, a slight increase was observed from T1 to T2. In T1, while half of surveyed institutions (N=11) affirmed that the CEO "sometimes" meet with patients and patients to learn about their care and service experiences, very few do so "always". In fact, only two institutions "always" do so for their patients, and one institution for its patients. In T2, the actual numbers in CEO involvement increased. Now 12 institutions claim that their CEO "sometimes" meets with patients to learn about their care and service experiences; 13 do so with their patients; three "always" meet with patients; and two with patients. Considering overall numbers (the combination of "sometimes" and "always" responses), the number institutions where CEOs meet with patients increased slightly from 13 to 15, and with patients from 12 to 15, which represent a 15 and 25 % increase respectively.

Similar observations apply to the Director of the DQEPE and Program Managers with regards to meeting with patients. Half of institutions claim that the Director meets patients "sometimes" (50% in T1 and T2), while the 9 % of institutions in which this happens always grew to 14 % in T2. That said, more institutions (64% in T1, 68% in T2) indicated that Program managers met patients compared to both CEOs and DQEPE Directors.

5.2.4.2.3.6. The Type of Patients involved

In patient engagement, there are several types of patients that could be engaged: Resources-patients (or expert patients), members or representatives of Patient Committees, and general patients. When asked about the type of patients involved in institutional activities such as onboarding new employees, sitting on the Steering Committee, participating in strategic planning, most of these questions were skipped by respondents. In T1, the "skip" response rate ranged from

41 to 100 % and 27 to 95.5 % in T2, which suggests that most respondents probably did not know the specific answer to those questions. Despite the high skip rate, the questions with the lowest ones concerned patients invited to testify in front of the board of directors (question 23) and patients who participate in developing the institution’s major orientations and decisions (question 26).

5.2.4.2.3.7. Patient Involvement in Risk Management Intervention Plans

When surveyed institutions were asked if they promoted patient involvement in the implementation of intervention plans, 77 % responded positively (“sometimes” 41%, “always” 36%) in T1, even more so in T2 with 81 % of positive responses, including more than half claiming “always” (67%). In an almost perfect 95 % case of positive responses, whether in T1 or T2, institutions expressed that intervention plans are carried out in presence of patients (“sometimes” 77%, “always” 18%).

However, results also indicate that patients are most likely to be involved during implementation phases rather than development phases. During the development phase, compared to 36.5 % of surveyed institutions in T1 claiming that PPs either “always” (4.5%) or “sometimes” (32%) intervene at a clinical level to accompany other patients, half of institutions said “never”. In T2, the latter %age further grew to 59 %, while “always” (9%) and “sometimes” (18%) contracted to a combined 27 %. A contraction was also observed with regards to PPs intervening to accompany other patients during consultation periods. What was first said to occur in 59 % of surveyed institutions in T1 (“always” 23%, “sometimes” 36%), patient involvement during intervention plan consultations dropped to 32 % of institutions in T2 (“always” 4.5%, “sometimes” 27%). In fact, over a quarter of institutions in T1 said the resource-patients “never” intervened during consultation phases (27%), which doubled to 54.5 % in T2.

5.2.4.2.3.8. Patient Involvement in patient discharge

Eight out of 10 surveyed institutions indicated the existence of a procedure to prepare patient discharge (86% in T1, 86.5% in T2), although only 31 % in T1 and 47 % in T2 specified “always”. As part of that process, staff members use a checklist to authorize discharge in 73 % of institutions, among which 81 % of respondents in T1 and 88 % in T2 believe this happens “sometimes”. In fact, when asked if the checklist was handed out to all patients at discharge, the only positive responses from institutions were “sometimes” at 41 % in T1 and 36 % in T2, which are inferior to the 45 % that responded “never” both in T1 and T2.

Encouraging feedback from patients following adverse events can play an important role when promoting care and service continuity in risk management and limiting future risks. However, in T1, less than two out of ten institutions claim to “always” promote feedback on experiences related to nosocomial infections (18%) and even fewer regarding medical errors (4.5%). In T2, those %ages drop even further to 4.5 % and zero % respectively. While close to a quarter of institutions (23% in T1 and T2) admit to “never” promoting feedback on experience related to medical errors, surprisingly more than half (54.5%) “never” did so for nosocomial infections in T1, which decreased in T2, but still remained at 36 %. Nevertheless, the largest proportion of institutions at least claims to promote feedback “sometimes” concerning medical errors (64% in T1, 68% in T2), and the small 18 % of institutions that did it “sometimes” for nosocomial infections in T1 tripled to 54.5 % in T2.

5.2.4.2.3.9. Risk management in technical and invasive procedures

To avoid potentially risk situates related to procedures, simulations can be performed before conducting them on actual patients. While a convincing majority of institutions responded positively, for the most part, the selected response was “sometimes” at 82 % in T1 and 86 % in T2. Only a tiny 4.5 % responded “always” in T1, which was reduced to zero % in T2. As for applying the “never on the patient the first time” principle when learning technical and invasive procedures, 32 % of surveyed institutions claimed to do it “sometimes” in T1 and T2; 13 % and 9 % claimed “always” in T1 and T2 respectively. Of note, the “skipped” response was unusually high for this particular question: 27 % in T1 (second largest response group) and 41 % in T2, the largest response group. This begs a question about people’s actual awareness of the “never on the patient the first time” principle.

5.2.4.2.3.10. Patient Safety Policies and Mechanisms

This section will examine the presence of mechanisms, procedures or processes meant to encourage patient engagement or participation in risk management. Even if surveyed institutions do not “always” have those mechanisms, procedures or processes in place, the fact that they have them “sometimes” is already encouraging. On the other hand, those still presenting high %ages of “never” responses illustrate ongoing challenges to their implementation. For instance, 68 % of surveyed institutions do not have a mechanism, procedure or process to encourage patients to participate in reporting incidents or accidents that happened to another person in T1 and, despite slightly decreasing in T2, still concerned more than half of institutions (54.5%). Also, while 36 %

of institutions didn’t have a mechanism to encourage patients to participate in the analysis of incidents and accidents in T1, the %age increased to 59 % in T2.

Processes “always” or “sometimes” present in a larger number of institutions were those: encouraging a just or no-blame culture (91% in T1 and T2, the only one with no “never” responses); informing patients of measures that have been taken to prevent the recurrence of incidents and accidents (74% in T1, 91% in T2); encourage patients to engage in behaviour that promote self-care (55% in T1, 73% in T2); encourage patients to ask questions when they feel at risk (45% in T1, 68% in T2).

Overall, mechanisms meant to engage patients in technical activities, such as analysis, seem to be the toughest ones to find in institutions, whereas the ones designed to engage patients in desired behaviours are more likely to be found.

5.2.4.2.3.11. Patient Engagement in Training Programs

Around half of surveyed institutions provide patient engagement training to health care providers (54% in T1, 45% in T2) and patients (45% in T1, 55% in T2), but a majority of institutions don’t offer it to staff (64% in T1, 77% in T2). Another type of training that appears tougher to provide is one given by health care providers to patients on how to be engaged in risk management. 65 % of organizations “never” provided that training in T1, and that %age grew to 73 % in T2. Moreover, while 73 % of institutions did not provide healthcare providers training on the roles of patients in limiting incidents and accidents in T1, the %age in T2 reached 82 %.

5.2.4.2.3.12. Patient Engagement in organizational committees

In T1 (50%), half of the senior management had never practiced safety rounds (question 66) to detect and prevent risky situations, vs 13.6% in T2. In T2, more than half had “sometimes” practiced it (55% in T2, vs, 23% in T1). And, 13.6% are always practicing it (T1 and T2 alike).

PE in risk management committee (question 61): 100% in T2, of patients attend the risk management committee vs, 86% in T1. An increase of 14% from T1 to T2. On occasion, patients (PP, volunteers, etc.) were asked to share their experiences or their voice (T1 = 14%, T2 = 0%).

Only 18% in T1 and in T2 alike, had answered “sometimes or always” to the fact that patients attend the infection prevention and control committee (IPCC) (Question 62). In both cases (T1, and T2), the institutions (64%) said that they “never” engaged patients in that committee.

Question 63: 77% of patients in T2, vs 68% in T1 had sometimes (41% in T1, vs 36% in T2) or always (27% in T1, vs 41% in T2) attended other committees that have an impact on Risk management. 18% (T1 and T2 alike) of institutions had never engaged patients in these types of committees.

Question 64: PE in working groups on the safety of the care and services had decrease from T1 (59%) to T2 (54%). 32% in T1, vs 41% in T2 had mentioned that they “never” engaged patients in these types of committees.

There seemed to be an evolution between T1 and T2 when it comes to (Question 65) PE in continuous quality improvement committees. 45.5% in T1, vs 55% in T2 had mentioned that they sometimes engage patients. 14% (T1 and T2 alike) had mentioned that they always engage patients. And 22.7 in T1, vs 18% in T2 had never engaged patients.

5.2.4.2.3.13. Patient Engagement in Family Medicine Groups (FMG)

Questions 67-73 have been deleted from this section because there was a repetition of questions 43-47, and 49-50. That been said, there are committees that conduct multi-professional morbidity and mortality reviews (MMRs) in FMGs? 27% in T2, vs 13.6% in T1 answered "always" to the fact that there are committees that conduct multi-professional morbidity and mortality reviews (MMRs) in FMGs (question 75). However, 45.5% institutions in T1, vs 27% in T2 answered that there were "never" a committee that conduct multi-professional morbidity and mortality reviews (MMRs) in FMGs. Only 4.5% in T1 answered "sometimes".

68% of institutions in T1 and T2 alike said that incidents and accidents are reported in FMGs (question 74). 13.6% in T1, 9% in T2, said that they "never" reported incidents and accidents in FMGs.

Question 46: Out of the 11 FMGs which answered that question, 45.5% of GMF's (N= 5) said that there is a mechanism, procedure, or process in place to encourage patients to report incidents or accidents (e.g., reporting incidents or accidents to the administration).

Question 47: Out of the 12 FMGs which answered that question, 31% (N=4) said that there is a mechanism, procedure, or process to encourage patients to participate in the analysis of incidents and accidents.

Question 49: Out of the 10 FMGs which answered that question, 30% (N=3) said that there is a mechanism, procedure or process to encourage patients to find solutions to avoid the recurrence of incidents or accidents

Question 50: Out of the 12 FMGs which answered that question, 50% (N=6) said that there is a policy, procedure, or process for informing patients of the actions that have been taken to prevent the recurrence of incidents or accidents.

5.2.4.2.3.14. Patient Engagement's Indicators

About 36% in T1, vs 41% in T2 of surveyed institutions had developed some type of PE indicator as a general performance measure (Question 76). There are still 27.3% in T1, vs 22.7% in T2, that are in progress of doing so, or 27.3% in T1 and in T2, that are not yet there. About 3/5 of the institutions have not yet developed indicators (Question 77) related to PE in safety (64% in T1, 55% in T2). 18.2% in T1, vs 27.3% in T2 of the institutions mentioned that "sometimes" they have developed such indicators (see **box 1** for more information). The rest of the institutions are in progress of doing so (9% in T1, vs 13.6% in T2), or have skipped that question (9% in T1, vs 4.5% in T2). More than half of the institutions 59% in T1 and in T2, had not yet developed any ad hoc survey to measure the degree of PE implementation (question 78). Only 23% in T1, vs 27% in T2 have done some type of ad hoc survey.

5.2.4.2.4. Analysis of the results from Table 11 (indicators)

Table 11 shows the different indicators identified through the research project. Three specific indicators related to PE for PS have being identified: 1- Number of PP engaged in the evaluation of sentinel events/incidents/accidents, 2- Double Identification of patients with a bracelet, 3- Number of security committees or teams that have a PP. Other type of indicators are more general to PE and include, the number of PP existing in the institution, the presence of a PP bank, number of PP integrated in teams, etc. (see table 11 for more information).

5.2.4.2.4. Analysis of the results from Table 11 (Factors)

Table 11 describes the types of factors influencing PE for PS. Seven types of factors which are found influencing PE in risk management for safety were identified: Environmental factors, Leadership, organizational culture, organizational structure, internal politics, personal, and resources.

5.2.5.1.3.2. Identified themes and emerging strategies / mechanisms of PE for PS

<u>Identified themes</u>

From the 14 identified themes in the results section, these themes were grouped into six major themes emerged from the data analysis: (1) best practices in strategic, organizational and clinical leadership involvement, (2) resource bank and recruitment tools, (3) training and tools to raise awareness, (4) best practices in patient involvement in risk management for safety, (5) PE for PS indicators, and (6) Policies/strategies, as well as procedures/mechanisms/processes/ practices

Knowledge acquisition	Strategic level

1. BEST PRACTICES IN STRATEGIC, ORGANIZATIONAL AND CLINICAL LEADERSHIP INVOLVEMENT

- CEOs, and other organizational and clinical leaders practice safety rounds to detect and prevent risky situations
- CEO, and other organizational and clinical leaders meet frequently (5-6 times a year) with patients to learn about their experience of care and services. Through
    - Patient committees
    - Annual board meetings
    - Gemba tours
    - Patient partners testimonies
    - Population forums, etc.
- The CEO integrates PE in the strategic planning of the institution, at each level of governance (clinical, organizational and strategic)
- The CEO creates a working group or task force involving PPs/patients/family members, etc. to participate in developing and reviewing the institution's major orientations, vision and mission
- The CEO enables patient [49]involvement in strategic planning and decision-making
- Organizational and clinical management involve patients into the action planning of their directorate, departments, or sectors
- Clinical Leaders with the help of strategic and organizational priorities **identify pilot projects** to involve patients according to the institutional priority sectors of improvement and work on them for the year to come

Knowledge acquisition	**Organizational level**

2. RESOURCE BANK OF PPs AND RECRUITMENT TOOLS

- The institution creates a resource bank of PP at an organizational level / directorate, etc.
- The institution / directorates have a process or methodology how to **recruit and accompanied** patients with the right training and support in their bank
    - Few examples on Patient recruitment:
        - At the point of service: applications are made available at reception /websites, etc.
        - Doctors/HCP meetings and they refer patients which they judge fit to become a PP
        - From the patient committees /volunteer's office/other patient's group
- The institution creates and develop recruitment tools for PE and specifically for PE in PS: promotional videos, pamphlets, application forms (also made available on the institution's website and user committee's department and websites), support videos and trainings on how to become a PP, etc.

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[49] Institutions must be careful which type of patients to involve [121].

Knowledge acquisition	**Organizational / clinical**

3. TRAINING AND TOOLS TO RAISE AWARENESS

- PE in PS promotional documents are available for patients, healthcare providers and leaders (through per example: pamphlets, videos, modules, PPT presentations, reference documents, guidelines, etc.)
- **Pe in PS Training is available** for patients (especially, in the role of patients in limiting incidents, accidents and other types of risks), healthcare providers and leaders through "in house" made modules, PPT presentations, university courses, etc.
- Training is available for patients **/ HCPs and teams (involving PPs) on how to be engaged with each other in risk management for safety**

Knowledge sharing and development	**Strategic level**

4.BEST PRACTICES IN PATIENT INVOLVEMENT IN RISK MANAGEMENT FOR SAFETY

Patient involvement in strategic planning and decision-making

- Patients are involved in the strategic/tactical and clinical planning and decision-making of the institution's orientation (revision of the strategic plan, mission, ethic, vision, action plan, etc.)
    - Through: working groups, board meetings, etc.
- Patients are always involved in duos, or more (not only to support each other, but in case one person is absent during a meeting, the other one can continue the task at hand)

Patient Involvement in Risk Management Intervention Plans

- Patients are involved in the implementation of their PI
- Patients are accompanied in the development of their PI by a PP[50]
- Patients are accompanied by PP[51] during consultation periods

Patient Involvement in patient discharge

- PP are involved in handing in checklist for patients at discharge

Feedback from patients following adverse events

- Patients give their feedback on experiences related to adverse events

Patient involvement in simulations

- Patients are involved in simulations activities

Patient involvement in organizational committees

- Patients and / or PPs are involved in risk management committees / safety sub-committees/ or other working groups on safety or committees having an impact of risk management
- Patients and / or PPs are involved in the infection prevention and control committee (IPCC)
- Patients and / or PPs are involved in continuous quality improvement committees

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[50] Make sure confidentiality issues are taking care of

[51] Make sure confidentiality issues are taking care of

Patient involvement in Family Medicine Groups (FMGs)

- Patients and / or PPs are involved in committees that conduct multi-professional morbidity and mortality reviews (MMRs) in FMGs

Patient involvement in incident / accidents analysis

- Patients are engaged in the analysis of incidents and accidents

Patients involvement in reporting incidents or accidents

- Patients are engaged in reporting incidents or accidents

Patients involvement in finding solutions of measures that have been taken to prevent the recurrence of incidents and accidents

- Patients are engaged in finding solutions of measures that have been taken to prevent the recurrence of incidents and accidents

Patient involvement to engage in behaviour that promote self-care

- Patients are engaged in behaviour that promote self-care (PI, etc.)

Patient involvement to ask questions when they feel at risk

- Patients ask questions when they feel at risk

Knowledge sharing and development	**Organizational / strategic**

1. BEST PRACTICES IN PE FOR PS INDICATORS/ EVALUATION

- **Institution integrates PE in PS indicators into performance measurement:**
    - # of project / pilot projects involving patients
    - Active patients in resource bank
    - # of PP integrated (and supported) into safety teams per year / per department
    - # of request for a PP per year
    - # of PP per direction or for the whole institution
    - Level of satisfaction of patients with their care and services
        - # of Improvement plans and follow up results
    - Level of satisfaction of PP involvement in projects, organizational projects, with their teams, etc.
    - # of PP involved in revision / tool creation/ committees, / etc.
        - # of Improvement plans and follow up results
    - Assessment of leaders /team's satisfaction of PE in PS
    - Assessment of management/ Healthcare providers / patient's knowledge of PE in PS
    - # Number of PP engaged in the evaluation of sentinel events/incidents/accidents
    - # of patients involved in their PI
    - # of disclosure coming from patients / PP
    - Etc.

Knowledge preservation	**Strategic/organizational/clinical**

2. POLICIS / STRATEGIES

- The institution has a **PE policy or strategy based** on evidenced reference framework/national or international guidelines, etc.
- The institution has an **integrated risk management** plan/policy (which integrated all aspects and directorates of the institution: e.g. technical services, cleaning services, etc.)
- The institution has a well-defined strategy of **a "no-blame culture"** in which "no-blame managerial / Healthcare providers practices and behaviors are described and enumerated:
    - Patients are consulted and involved in the analysis of an incident or accident
    - A system approach is used to find the problem
    - Improvement plans are created and continuous training for staff and management is given / revision of procedures and guidelines are made
    - Patients are made aware of the ongoing plans and results
- The institution has clear **transparency and communication policies integrating** PE for PS
- The institution **integrates quantitative indicators, as well as qualitative indicators into the performance** measures of the organization (see Box1 for more detailed information on the type of indicators available)
- The institution has a guide in place for PPs recruitment and competence profile
- The institution has a guide in place for HCPs' competence profile
- The institution has a mechanism, procedure, or process to **encourage interdisciplinary collaboration, as well as external collaboration** (with other national or international institutions)
- Strategies focussing **on prevention**
    - The institution creates **innovation spaces** and steering rooms to develop ideas and work on plans
    - The institution has a **well-being strategy** in place for the staff and for PP, and patients
    - **The institution encourages Leaders safety rounds / as well as PPs and patient's reporting of safety rounds or an event which may be a potential risk**

PROCEDURES / MECHANISMS / PROCESSES / PRACTICES

- The institution promotes the involvement of patients in the implementation of their intervention plan (PI)
- The institution has a mechanism, procedure, or process to encourage patients in the choice of support measures for users
- The institution has a mechanism to **inform patients of measures that have been taken to prevent the recurrence of incidents and accidents**
- Procedures and mechanisms exist for preparing the patient's **discharge:** checklist handed to all patients at discharge
- The institution **promotes feedback on experiences related to adverse events** / nosocomial infections/ etc.
- The institution has procedures and mechanisms in place to conduct **simulations** and involve Patients / PP in them
- The institution has procedures and mechanisms in place for **applying the "never on the patient the first time" principle when learning technical and invasive procedures**
- The institution has procedures and mechanisms in place to **train healthcare providers in communication methods** based on patient's rephrasing of information given by HCP
- The institution has a procedure or process to encourage patients to participate in **reporting incidents or accidents**
- The institution has a mechanism to encourage patients to p**articipate in the analysis of incidents and accidents**
- The institution has a mechanism/process or policy in place **to train patients and healthcare providers on PE in PS**

- The institution has a mechanism/process or policy to **encourage patients to engage in behaviour that promote self-care**
- The institution has a mechanism/process or policy to **encourage patients to ask questions when they feel at risk**
- The institution has a mechanism/process or policy to **encourage patients to discuss the risks of interventions**
- The institution has a mechanism/process or policy to **encourage patients to report incidents or accidents in FMGs**
- The institution has a mechanism/process or policy to **encourage patients to participate in the analysis of incidents and accidents in FMGs**
- The institution has a mechanism/process or policy to **encourage patients to find solutions to avoid the recurrence of incidents or accidents in FMGs**
- The institution has a mechanism/process or policy **for informing patients of the actions that have been taken to prevent the recurrence of incidents or accidents in FMGs**
- The institution train new employees, volunteers, interns on PE in Risk management for safety
- **The institution uses quantitative and qualitative** (satisfaction surveys, complaints data, data collected from patient's consultation, citizen's forums, focus groups, CEO's Gemba tours or safety rounds, and patient's groups/ patient committees 'voice) data to analyse and evaluate risks for **continuous improvement plan**
- The institution identifies **pilot projects of PE in PS to** invest its time and energy
- **The institution has a mechanism, procedure or process in place to compensate the involvement of PPs in the organization's committees, projects, etc.**
- The institution has **a mechanism, procedure or process in place to support PE structures in their implementation of PE approach (e.g. Instances of PPs involved with universities which have elaborated university courses and programs to accompany healthcare institutions in the implementation of PE strategies)**
- The Institution has **a Human Resource mechanism, procedure or process in place to review and integrate PE competencies in job descriptions of patients, PPs, healthcare providers, and leaders**
- The institution has **a mechanism, procedure or process in place to engage and identify multiplying agent in all directorate to help deploy PE in safety**

Emerging Health Organization Strategies in Patient Engagement for Safety (HOSPES)

Based on the identified themes, 43 identified emerging strategies are presented and recommended in the section below following the conceptual model (figure 4) of the institutionalization theory: the creation of knowledge, its development and sharing, and, finally, its preservation (PE for PS being the knowledge created, shared and preserved).

Knowledge acquisition (preparation phase)

At the **strategic level**, for a more structured approach to PE, decision-makers should ensure that institutions formally adopt (1) reference frameworks or guidelines, per example, the PE Reference Framework from the Quebec Ministry of Health and Social Services (MSSS) [79], as well as PE policy recommendation and abide by Required Organizational Practices from of accreditation bodies (i.e. Accreditation Canada, Quebec Accreditation council, ISQUA, and other national or international accreditation bodies) [66, 92]. Then, those references should be used by institutional leaders to (2) create an official PE action plan which formally describe the PE and Patient Experience structures. The action plan should include regulations and strategies to ensure the inclusion of expert patients in work/task groups, particularly those responsible for reviewing/developing internal policies on safety, care pathways, training tools and documents. In addition, (3) training and awareness campaigns about the PE action plan should be conducted internally so that patients, HCPs and managers become familiar.

At the **organizational level,** leaders/healthcare providers in risk management/ PE / and PExp, should be (4) identified and hired to oversee and coordinate PE projects in the organization on a full-time basis, preferably with a (5) PE team. This team would help implement the type of (6) PE and Patient Experience structure, in addition to (7) developing and managing PE for safety resources, tools and material for patients and staff (HCPs, Senior Managers, Managers), and (8) creation of a PE pool bank to recruit patients (development of recruitment form, database for PPs, etc.).

Finally, at the **clinical level**, based on the PE action plan, and with support of the DQEPE, (9) create task groups (involving patients and professionals) to review clinical practices and pathways to clearly define the scope and moments of patient engagement, as well as (10) develop strategies and tools to identify and recruit potential PPs based on co-developed criteria and co-defined competencies [121].

Knowledge sharing (implementation phase)

At the **strategic level,** upper management overseeing PE should implement and promote (in collaboration with the communications department for increased visibility and awareness, and with patients) (11) PE policies (i.e. integrated risk management with patients involved) and culture (no-blame, transparency and empowerment regarding adverse events, complaints, etc.). In addition, (12) a task group (involving PPs) should be created to review the mission, vision, ethical governance of the institution as well as (13) identify at least, one sector where a pilot project be conducted in the organizational as a whole (clinical, organizational and strategic).

At the **organisational level,** middle/program managers implement (14) collaboration strategies with Patients Committees, complaint departments, risk management, volunteer departments, public health departments, clinical departments, multiplying agents at different departments of the institution, community organizations, universities, and other patient groups, etc. Moreover, they should (15) develop continuous training (PE for PS training adapted to managers, patients, HCP and other staff), and assessment programs for PE in risk management for safety. As they report back to senior management, they will also (16) implement an approach or methodology for the data collection and evaluation plan in order to collect data for decision making.

Other elements include:

- (17) Implementation in collaboration with the Human Resources of a clear and detailed description of staff, patients, patients, volunteers, and other patient group job descriptions
- (18) Development of a continuous training program for PE in risk management for safety
- (19) A No-blame culture procedure and methodology in management and HCP's practices to capture experiences and practices
- (20) hiring patients for the PPs database from different sources such as patients, associations, volunteers and citizens:

> *« In our approach for and with patients, we have four recruiting pools: (1) volunteers, (2) patient associations, (3) clinical patients, (4) citizens. We noticed that when we work in duos or trios, the degree of success increases. We believe it demonstrates diversity in experiences, it's less intimidating, and it will improve continuity because when a patient is not there, the others can take over»*

Other respondents spoke about developing and (21) reviewing existing and creating patient experience surveys to continuously assess the PE situation throughout the year via evidence and cooperation with the complaints department, other clinical departments, patient groups and committees as well as collaboration with universities, and community of practices. Such surveys use should be determined by the different departments and at the strategic level of the institution.

Lastly, at the **clinical level,** the PE team should (22) implement pilot projects in PE while capturing patient and family experiences and satisfaction with decision-support tool, as well as outcomes of shared decision making via, for example, the use of a direct feedback loop (surveys, committees, patient groups and complaint departments, comments and analysis). (23)

Mechanisms should also be in place to empower and enable patients and families to report, analyse adverse safety and quality events (rapid response teams, etc.), health risks and incidents/accidents related to their health in collaboration with the clinical team. As well as, be involved in the choice of support measures for patients after an incident or accident, come up with solutions and be informed of measures taken by the organization to reduce or eliminate the risk.

In terms of training, patients should be (24) integrated in clinical teams to educate and develop patient and family engagement sections in the training curriculum of HCPs (i.e. role learning), as well as (25) help HCPs develop standardized patient and family engagement competencies. Both patients and families should be (26) invited to coach/train other patients in disease management and risks identification, and (27) patients should be involved in different safety, risk management and other local safety committees, and task group (e.g. Fall prevention, suicide, etc.), as one respondent stated:

> *"10 patients participated in the risk management committee, care and service quality committee; Two patients in the coordination committee, and two patients per subcommittee for falls, control measures, suicide and transition point information".*

Knowledge preservation (sustainability)

As for knowledge preservation, at the **strategic level**, (28) Human Resource departments should include PE competencies in job descriptions of HCP and staff, as well for PPs [121], while (29) senior management incorporates performance indicators into organizational practices (quantitative and qualitative data (e.g. complaints data, patient committee, patient's groups, etc.), while (30) setting up communication methods and technology to coordinate activities in-between departments as well as (31) produce quarterly reports on PE in risk management / ongoing activities, etc. They should also (32) encourage and structurally empower patients and families to officially and regularly attend board meetings, patient committees, and take part in shared decision-making through organizational communications (videos, pamphlet, Patients Committees, etc.). Furthermore, (33) develop organizational policies that specify families as full members of the healthcare team. To (34) encourage patients to participate and professionals to welcome them, senior management should design and provide recognition and reward programs for care that fully incorporates patient and family engagement. Empowerment also goes by (35) developing policies that define access and transparency regarding information related to risks, benefits, costs of care, treatment options, medical records in the annual report. Moreover, the institution should (36) develop strategies and policies for the well-being of staff and patients [92], as well as strategy and mechanisms for interdisciplinary collaboration (which include the patient), collaboration with universities (such as the university of Montreal-department of DCEPP, which supports institutions in the implementation of their PE approach), but also collaboration with national and international organizations (through conferences, communities of practices, etc.) [92].

At the **organization level**, (37) the creation of a plan for continuously developing a curriculum and training programs in PE in risk management which explain roles, organizational structure, quality and risk management improvement processes to key stakeholders (patients, HCPs, etc.), as well as (38) develop a sustainable methodology or system to capture and assess Patient experience in risk management for safety at an institutional level (reviewing surveys and creating or adapting new ones, collaborating with other departments (complaint department, Patient committee, PPs, clinical departments, citizen’s forum, CEO/upper management or other HCPs or PP’s safety rounds, and other data collected through consultations, and focus groups, etc.). In addition to capture PExp data, it is also important to capture PE initiatives in the institution, and measure PE degree of integration in different sectors of the institution. (39) should there be a sub-structure to the PExp office, to be the assessment / evaluation of projects in PE/ PExp bureau?

Finally, at the **clinical level,** (40) there should be documents available to elicit structured care processes to support patient and family involvement in care planning and self-management. For example, dedicated full-time staff and the creation of departments to oversee work with patient and family advisors; as well as safety and quality improvement committees co-led with patients, etc.). To support HCPs in PE, (42) mechanisms should be in place which help clinicians elicit, understand, and respect patient perspectives and concerns (active listening, patient coach, etc.). (43) In terms of recruitment, not only should clinician tasks and job descriptions be updated to account for PE-related tasks, but also recruitment tools and tactics should enable the ongoing identification and selection of effective patient and family advisors for an interdepartmental PE databank (institution-wide).