



Université de Montréal

**The Implementation of an Organizational Committee for  
Patient Engagement in the Context of Mental Health:  
A Case Study**

par Anna-Paulina Ewalds

Département de gestion, d'évaluation, et de politique de santé  
École de santé publique

Mémoire présenté  
en vue de l'obtention du grade de maîtrise  
en administration des services de santé  
option analyse des organisations et systèmes de santé

Décembre 2016

© Anna-Paulina Ewalds, 2016

## Résumé

**Objectif :** Il existe un besoin de structuration de l'engagement des patients dans des organisations de santé mentale. Toutefois, peu est connu concernant l'implantation de structures de ce type, et encore moins à un niveau stratégique. L'objectif est d'étudier l'implantation d'un comité organisationnel stratégique pour l'engagement des patients à travers son processus d'initiation et d'opérationnalisation, les facteurs qui facilitent et limitent l'implantation, et les conséquences perçues dans l'organisation.

**Méthode :** Une approche qualitative a été utilisée, plus spécifiquement une étude de cas unique. Les différentes sources de données étaient des entrevues semi-structurées, des groupes de discussion, et des documents organisationnels. Les participants étaient différents acteurs (usagers des services, gestionnaires de différents niveaux, chercheurs, clinicien, membres de la direction générale et du comité d'usagers) en lien avec l'engagement des patients.

**Résultats :** Le processus d'initiation incluait un besoin de formalisation et l'introduction d'une vision de la pleine citoyenneté. Le processus d'opérationnalisation incluait la composition et le rôle du comité, l'élaboration d'un encadrement pour la participation et son application continue incluant l'évaluation. Plusieurs facteurs facilitants ont été identifiés, incluant le soutien de la direction générale, du leadership et une vision pour la participation. Les facteurs limitants concernaient la résistance contre la participation et l'existence de la stigmatisation. Les conséquences étaient une augmentation et un meilleur engagement des patients, et une réduction de la stigmatisation dans l'organisation.

**Conclusion :** Cette étude illustre le processus d'implantation d'un comité organisationnel stratégique pour l'engagement des patients en incluant des nombreux éléments, d'acteurs et de facteurs. L'importance d'un leadership provenant de plusieurs acteurs, ainsi qu'une vision pour la participation afin d'encadrer efficacement l'engagement des patients sont mises en évidence.

**Mots-clés :** Engagement des patients, patient partenaire, santé mentale, implantation, comité, structure

## **Abstract**

**Objective:** There is a need for structure for patient engagement to function within mental healthcare organizations. Despite this, little is known about how to implement these kinds of structures, and even less on a strategic level. The aim is to study the implementation of a strategic organizational committee for patient engagement through its initiation and operationalization process, the factors that are facilitating or limiting the implementation, and the perceived consequences within the organization.

**Method:** A qualitative approach has been used in this study. A single case study has been carried out with semi-structured interviews, focus groups and organizational documents as data sources. The participants were different actors (service users, managers on different levels, researchers, clinician, members of top management and user's committee) taking part in the patient engagement.

**Results:** The initiation process included a need for formalization, and the introduction of a vision of full citizenship, while the operationalization process contained the composition and role of the committee, the elaboration of a frame for the participation, and its ongoing application including evaluation. Several facilitating factors were identified, including top management support, leadership, and a vision behind the participation. The limiting ones mainly concerned resistance towards the participation and the existence of stigma. The consequences included increased and improved patient engagement, and reduced stigma within the organization.

**Conclusion:** This study illustrates the process of implementation of a strategic organizational committee for patient engagement including multiple elements, actors, and influencing factors. It highlights the importance of leadership by many actors and a vision behind the participation, to successfully frame the patient engagement.

**Keywords:** Patient engagement, patient partner, mental health, implementation, committee, structure

# Table of Contents

Résumé.....	i
Abstract.....	ii
Table of Contents.....	iii
List of Tables.....	v
List of Figures.....	vi
Acronyms.....	vii
Thank You.....	viii
1. Introduction.....	1
2. Literature Review.....	5
2.1 What Does Patient Engagement Imply?.....	5
2.2 Patient Engagement Within Mental Health.....	8
2.2.1 Particularities of mental health.....	8
2.2.1.1 Citizenship.....	9
2.2.1.2 Recovery.....	10
2.2.2 The different expressions of patient engagement.....	10
2.2.3 The components of patient engagement.....	11
2.2.3.1 Facilitators.....	11
2.2.3.2 Barriers.....	12
2.3 The Implementation of a Structure for Patient Engagement.....	14
2.3.1 Influential factors.....	16
2.3.2 Consequences.....	17
2.4 The Implementation of Change and Innovation in Organizations.....	18
2.4.1 Implementation in the healthcare field.....	20
2.4.2 Factors that can facilitate or limit implementation.....	21
3. Conceptual Framework.....	24
4. Methodology.....	28
4.1 Research Strategy.....	28
4.2 Research Design.....	28
4.2.1 The case in the study.....	29

4.2.1.1 Delimitations.....	30
4.3 Data Collection .....	30
4.3.1 Recruitment of study participants .....	31
4.3.2 Interviews.....	33
4.3.3 Focus groups .....	33
4.3.4 Document analysis.....	34
4.4. Data Analysis .....	34
4.5 Validity .....	36
4.6 Ethical Considerations .....	37
5. Article: A voice for the Patients: Patient Engagement in Mental Health Through the Implementation of a Strategic Organizational Committee .....	39
6. Discussion.....	72
6.1 Summary of Results.....	72
6.2 Comparison with Literature .....	73
6.2.1 Participation in the implementation process .....	73
6.2.2 Support for implementation .....	74
6.2.3 Reform in the healthcare system.....	75
6.3 Comparison with Theory .....	76
6.3.1 Initiation process.....	77
6.3.2 Operationalization process.....	77
6.4 Strengths and Limits .....	78
7. Conclusion .....	81
8. References.....	82
Appendix 1. List of analyzed documents.....	i
Appendix 2. Interview Guide.....	ii
Appendix 3. Focus Group Guide – Patient Partners .....	vi
Appendix 4. Focus Group Guide – Key Actors.....	viii

## List of Tables

Table 1: Study participants.....	32
Table 2: Data collection and study participants.....	32
Table 3 (in article): Examples of participation activities.....	55
Table 4 (in article): Facilitating and limiting factors.....	58
Table 5 (in article): The implementation process of the committee and the influencing factors .....	71

## List of Figures

Figure 1. Conceptual framework to study the implementation of a strategic organizational committee for patient engagement in mental health.....	26
---	----

## **Acronyms**

MHAP: Mental Health Action Plan

MSSS: Ministère de la Santé et des Services sociaux (Ministry of Health and Social Services)

## **Thank You**

First, a warm thank you to Marie-Pascale Pomey, my supervisor, for your enthusiasm, presence, and valuable advice during the work with my master's thesis. A big thank you to Jean-François Pelletier, my co-supervisor, for your support and for introducing me to the field of mental health and its specificities.

Further, thank you to Francine Desbiens, coordinator of the research project, for much appreciated presence and collaboration. Thank you to Julie Bordeleau, for kind assistance, and availability during the entire study. Also, thank you to Nathalie Clavel for multiple interesting discussions and for being there throughout my studies.

Finally, I would like to thank all participants in the mental healthcare organization for making this study possible.

# 1. Introduction

The society is in constant development, on a technological, economic as well as a social level. Consequently, there are changes concerning the way the citizens act and relate to the society. A growing subject within public health is the changing role of the patients within the healthcare system. Traditionally, this role is characterized by being taken care of (Coulter, 2002). This traditional and paternalistic conceptualization has been challenged to make room for a new vision where the patients have more power and possibilities to act (Charles & DeMaio, 1993; Coulter, 2002). The new vision is targeting increased quality of care and services within the healthcare system, and is realized through the participation of patients in decision-making in various ways (Carman et al., 2013). This approach of patient engagement can be localized in aspects of the patients' care, but also in larger contexts of the health care system, that is, on an organizational level, as well as the system itself (Carman et al., 2013). Patient engagement can additionally take place in the context of research projects as well as in the field of education of healthcare professionals (Pomey et al., 2015). It is therefore an extensive approach. The scope of patient engagement is also shown by the diversity when it comes to the terminology present in the literature treating this subject (Gallivan, Kovacs Burns, Bellows, & Eigenseher, 2012).

One area where the changes within the society are clearly present is the one of mental health, where is it question of a new “paradigm” that is being put in place (Nelson, Kloos & Ornelas, 2014). This domain is traditionally characterized by a separation between the patients and the rest of the society by, among others, institutionalization implying physical separation, and by the patients not having power to affect things concerning themselves or on any larger scale (Lord, Nelson, & Ochocka, 2001). Mental health is also characterized by stigmatization, equally creating a barrier between these two traditionally separated worlds of the patients and the rest of the society (Lord et al., 2001). In Quebec, the detachment from these aspects started around the years 1970-1980 in connection with the realization of the necessity to re-integrate people with a mental illness in the society (Clément, 2011). However, engagement of mental healthcare users within the healthcare system of Quebec can in reality only be discussed closer to the new millennium (Clément, 2011). The Mental Health Action Plan (MHAP) of Quebec of 2005-2010 includes the engagement of patients within the healthcare system (Ministère de la Santé et des

Services sociaux [MSSS], 2005). The need for further development in order for this approach to fully become a routine has been brought forward despite it being concretely introduced in the MHAP of 2005-2010 (Clément, Lourdes, Gagné, Levesque, & Vallée, 2012). Currently, the most recent MHAP of Quebec of 2015-2020 articulates the essentiality of each person being able to be a citizen like others with all that it implies, including the importance of the patients as well as their close ones to participate in decision-making within the healthcare system (MSSS, 2015).

The literature on patient engagement specific to mental health extends to frequently include democratic and social aspects, implying an overlap with other approaches, such as citizenship (Barnes, 1999; Hickey & Kipping, 1998; Pilgrim & Waldron, 1998; Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2003) and recovery (Storm & Edwards, 2013; Tambuyzer, Pieters, & Van Audenhove, 2014). Citizenship treats the integration of mental health patients in the society in order for them to have the possibilities to function as other citizens (Barnes, 1999; Rowe et al., 2012). Recovery, on the other hand, touches aspects closer to the individual, implying that despite the presence of a mental illness, there is a path towards a life that is considered adequate by the person (Anthony, 1993). These two approaches can therefore be connected to the above-mentioned development within the mental health domain, through a diminished gap between the patients and the rest of the society (Pelletier, Corbière, et al., 2015). Patient engagement has been mentioned as integral of these two approaches (Pelletier, Davidson, & Roelandt, 2009), indicating the importance of further developing this subject.

In connection to this wider perspective on patient engagement within mental health, additional advantages are mentioned in the literature, both on the level of the well-being of the individual, and on a larger scale, concerning the inclusion of patients in the society (Truman & Raine, 2002). It is important that all advantages of this approach are brought forward and sought for (Rutter, Manley, Weaver, Crawford, & Fulop, 2004), although patient engagement principally seeks for increased quality of the care and services being offered (Carman et al., 2013). Nevertheless, the engagement of patients in mental health takes place in a context where there is a difference regarding the power held by the patients and the one held by the healthcare professionals, which is in disfavour to the patients (Rise et al., 2013). This incongruence motivates the attempt to level the relationship between patients and other actors of the healthcare

system (de Freitas & Martin, 2015). A knowledge gap has been expressed concerning how positive effects of the engagement of patients are produced within a healthcare organization, pointing to a need to unravel regarding its functioning - especially regarding activities on a larger scale than the individual treatment (Baker, 2014). In line with this, specific to the mental health field, more emphasis on patient engagement has been suggested, as well as a need to further explore its implementation, that is, how to practically carry it out on different levels including the organizational one (Storm, Knudsen, Davidson, Hausken, & Johannessen, 2011). This need for clarification has equally been identified in the general patient engagement literature (Groene & Sunol, 2015).

A functioning engagement of patients can be considered the contrary of the question of “tokenism”, often brought up in the literature on patient engagement as a challenge to be defeated since it implies a kind of symbolic presence of patients absent of their input being effective (Fitzgerald, Kirk, & Bristow, 2011; Millar, Chambers, & Giles, 2016; Omeni, Barnes, MacDonald, Crawford, & Rose, 2014; Rose, Fleischmann, & Schofield, 2010). This brings us to the question of how to go about in obtaining a functioning patient engagement - a knowledge gap brought forward in the literature (Munro, Killoran Ross, & Reid, 2006; Rutter et al., 2004; Storm, Knudsen, et al., 2011), expressed in the need to go from “rhetoric to reality” (Robert, Hardacre, Locock, Bate, & Glasby, 2003, p. 62). The literature is consensual regarding the need of a structure for the patient engagement allowing for it to take place in a mental health context, involving a variety of its constituting elements to be considered (Lammers & Happell, 2003; Munro et al., 2006; Simpson & House, 2003; Truman & Raine, 2002). The importance to proceed in patient engagement within healthcare organizations on a larger level than the individual participation initiative for it to be functioning has been brought forward (Bowl, 1996; Storm & Edwards, 2013; Tritter & McCallum, 2006). However, the establishment of a structure aiming to ameliorate the patient engagement on an organization-covering and therefore strategic level has not been thoroughly treated in the literature - something also pointed out by others authors (Rise, Solbjør, & Steinsbekk, 2014).

Patient engagement is an important approach implying comprehensive changes to the above discussed traditional aspects of this domain (Borg, Karlsson, & Kim, 2009). In order for these aspects to be altered, and the services to be improved, there is room, as well as a necessity for

innovation that includes increased attention on patients and their role within mental health organizations (Brooks, Pilgrim, & Rogers, 2011). Despite its importance, how to go about in implementing innovations specifically in the field of mental health has been mentioned as needing further development (Brooks et al., 2011).

According to the above-presented introduction, there are specific concerns traditionally linked to the domain of mental health that have been raised in the literature. Furthermore, the introduction shows that there is also room for further knowledge on patient engagement on an organizational level (i.e., in aspects beyond the patients' individual care) regarding structures for this approach on a strategic level (i.e., organization-wide, covering the whole organization) in healthcare organizations, as well as when it comes to the implementation of innovations within the mental health domain. An initiative to structure the patient engagement on an organization-wide level in a mental healthcare organization in the province of Quebec has been carried out, in the form of a strategic committee - constituting an opportunity to advance the research within this subject and in this particular context. This master's thesis aims to study the approach of patient engagement within mental health through the implementation of a strategic organizational committee taking into consideration the process of implementation, the factors that are facilitating or limiting the implementation, and the perceived consequences within the organization. The results are presented in the article in *chapter 5*.

This master's thesis is part of a larger research project on patient partnership within different health contexts (both mental health and oncology) (Pomey et al., 2014-2017). Within this larger research project, specific research questions regarding the implementation of the strategic committee for patient engagement have been developed by the master's student. The master's student has done the literature review and developed the conceptual framework of this master's thesis with a focus on the mental health domain. In addition to the focus on mental health, the conceptual framework specifies the implementation process based on the steps by Rogers (2003). Consequently, a narrower analytical angle has been used in this master's thesis in order to analyze the data stemming from the data collection made within the larger research project (see *chapter 4* for further details regarding data collection and analysis).

## **2. Literature Review**

This chapter of the master's thesis treats the literature on patient engagement and implementation of change and innovations in order to present what is already known concerning the subject. Firstly, what is meant by patient engagement is discussed. Secondly, the approach in the context of mental health is reviewed. Thirdly, how to implement a structure for patient engagement is treated. And finally, the implementation of organizational change and innovation is presented. What stems from this literature review constitutes the base for the conceptual framework in *chapter 3* and the analysis realized in the article in *chapter 5*.

### **2.1 What Does Patient Engagement Imply?**

The existing lack of a common definition of patient engagement has repeatedly been brought forward (Barello, Graffigna, & Vegni, 2012; Carman et al., 2013; Gallivan et al., 2012), leading to fuzziness regarding the approach as it is disguised under several terms in the literature (Gallivan et al., 2012). Examples of other appellations are involvement, participation (Gallivan et al., 2012), as well as partnership (Pomey et al., 2015). Furthermore, the word patient is not always used in the reviewed literature. User, as well as citizen (Gallivan et al., 2012) or consumer (Lammers & Happell, 2003), are also used. In addition, terms used for patients that participate in contexts outside their own care are, among others, user representatives (Rise et al., 2014), patient advisors (Kemper, Blackburn, Doyle, & Hyman, 2013; Pomey et al., 2016), or patient partners (Pelletier, Lesage, et al., 2015). Patient engagement has theoretically been mentioned as poor, caused by the variation when it comes to the definitions of it, and the approaches used to examine it (Barello et al., 2012). It has even been mentioned that this confusion can create problems concerning the advancement of the research in this subject since the diverse terms that are employed are discussed either as having the same or different meaning, and this in a sporadic manner (Fumagalli, Radaelli, Lettieri, Bertele', & Masella, 2015). Furthermore, the unclarity surrounding the implications of this approach has also been argued as preventing it from being carried out within organizations (Elstad & Eide, 2009; Rise et al., 2013). Repetitive calls for clarity have been made in the literature during the last decades concerning this dispersed usage of terms (Gallivan et al., 2012; Hickey & Kipping, 1998), as

well as for a standardization of the conceptualization of the engagement of patients, which includes a plurality of aspects to consider (Barello et al., 2012; Charles & DeMaio, 1993).<sup>1</sup> Patient engagement will be further developed in the following paragraph.

In an effort to bring clarity to the approach, Carman et al. (2013) have created an outline for patient engagement. Carman et al. use the definition “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system - direct care, organizational design and governance, and policy making - to improve health and health care” (p. 224). Patients can therefore be engaged in activities on behalf of themselves in their individual care, or on behalf of a larger group of patients within an organization or the society (Carman et al., 2013). Carman et al. further indicate that the engagement can be of different intensity, at its weakest constituting the consulting of patients, while at its strongest involving a partnership with them. The word partnership is of significance in the definition of patient engagement by Carman et al., but is at the same time mentioned as a form of patient engagement by these authors. This can be seen as an example of the mix of terms prevalent regarding this approach, and indicates that there is still a need for conceptual clarification. More integrative is the “Montreal Model” for partnership with the patients presented by Pomey et al. (2015). These authors include further domains where patient engagement can take place, namely in the context of research projects, as well as in the field of the education of healthcare staff. Although the emphasis by Pomey et al. is on the patient being a partner in activities of these various domains, these authors also classify engagement in its weaker intensity as the patient either receiving information, being consulted, or collaborating with other stakeholders. Pomey et al. situate partnership in the context of patient engagement, and these two are therefore not considered as synonyms. The models of Carman et al. and Pomey et al. are both illustrating several dimensions of patient engagement; its localization within the healthcare system, its intensity, the activity of engagement, and elements that affect this engagement. Further aspects characterizing this approach will be explored in the following paragraphs.

---

<sup>1</sup> In this master’s thesis, for clarity purposes, user will be used interchangeably with patient, and the concept of patient engagement is also considered equal to the involvement or participation of patients.

The dynamic character of patient engagement has been brought forward by several authors (Tambuyzer et al., 2014; Tritter & McCallum, 2006). The conceptualization of patient engagement as increasing in intensity which is present in the literature, has been criticized by Tritter and McCallum (2006), who express that this multidimensional concept is being treated with a lack of consideration for all its facets, and indicate a need to discover additional aspects. They mean that this impedes from viewing the reality of involving patients on a deeper level. Tritter and McCallum underline the complexity of this approach and apply their criticism specifically on the model developed by Arnstein (1969) which is based on the participation of the citizens of the society in different aspects of governance, not specific to the healthcare domain. In the model of Arnstein, the different forms of participation are piled according to their intensity in power for the citizen. This model is often constituting the starting point for models of engaging patients with similar outlines (Tambuyzer et al., 2014). For example, Carman et al. (2013) are explicitly basing their above-presented conceptualization on Arnstein, although adding additional dimensions. Tritter and McCallum (2006) also propose a conceptualization of the participation of patients in an integrative manner including all its specificities in order to move away from the simple way of approaching the subject. Although their description is not easy for the reader to visualize and follow, they present patient engagement as being universal and heterogenic within the healthcare system. These authors mean that the participation of patients is therefore diffused in a multiplicity of aspects, even in its own elaboration at first, and its evaluation at last. Other authors have also pointed to the necessity of considering and exploring patient engagement out of all its constituting parts (Barello et al., 2012).

Like in other domains of the healthcare system, as seen in the general models presented earlier (Carman et al., 2013; Pomey et al., 2015), patients in the field of mental health can be involved in a variety of aspects on several different levels (Tambuyzer et al., 2014). An illustration by Tambuyzer et al. (2014) including the connections between these different localizations of the patient engagement within the healthcare system specific to mental health, can be connected to the expressed need by Tritter and McCallum (2006) of an engagement diffused in an integrative way within this system, as discussed above. Another model specific to the field of mental health is the one of Hickey and Kipping (1998), also presenting the participation according to its

intensity. Interestingly, these authors place the control held by the patients as the most intensive form of engagement, thereby passing to the other side of a partnership. These authors also add one additional aspect by further categorizing the engagement implying that only democratic forms of participation constitute a possibility for the patient to influence decisions being made. Hickey and Kipping bring attention to and promote an explicit value and ideology based view of patient engagement within the field of mental health. In connection to democracy, although not specific to mental health, Abelson (2001) applies a conceptualization that brings forward the context-sensitiveness of this approach when it comes to engagement of the public at the level of the healthcare system. While concentrating on the surroundings of the participation initiative, Abelson also includes additional elements of participation, such as measuring its quantity.

The explicative models of patient engagement presented in this section show that there is a variety in the literature when it comes to the understanding of what this approach implies. As presented above, patient engagement is viewed differently according to different authors. Furthermore, it is important to note that besides the patients themselves, this approach also embraces other actors, for example family members and diverse persons linked to the healthcare system, such as citizens in general (Carman et al., 2013). These aspects indicate the scope of the approach of patient engagement.

## **2.2 Patient Engagement Within Mental Health**

The domain of mental health is very present in the reviewed literature on patient engagement. Since this approach is context-dependant (Barello et al., 2012; Tritter & McCallum, 2006), this part of the literature is important to discuss. It covers other dimensions of patient engagement than those in the section above.

### **2.2.1 Particularities of mental health**

When it comes to the particularities within the field of mental health, the literature reveals points such as stigmatization (Bee, Brooks, Fraser, & Lovell, 2015; Munro et al., 2006), disproportion in the power distribution (Rise et al., 2013), and the questioning whether patients within this domain even can participate (Munro et al., 2006; Solbjør, Rise, Westerlund, & Steinsbekk, 2013). As previously mentioned, there is also a large ideology aspect of the approach within this

specific domain (Hickey & Kipping, 1998) expressed by the emphasis on a necessary culture change in order for patient engagement to be realized within mental health organizations (Borg et al., 2009; Linhorst, Eckert, & Hamilton, 2005; Tambuyzer & Van Audenhove, 2013). Furthermore, the extent this approach takes within mental health can be connected to the prevailing community anchorage of organizations within this sector, following the aimed for deinstitutionalization of services (Lord et al., 2001; Pilgrim & Waldron, 1998). Finally, the literature directs attention towards the history of this healthcare domain in the sense that the engagement of patients in various aspects concerns the modification of their traditionally unequal relation to others within the healthcare system (Borg et al., 2009; Lammers & Happell, 2003).

The domain of mental health has a long history with traditions that it is trying to move away from, and there is a necessity for users of mental health services to participate in these changes (Lord et al., 2001). Patient engagement therefore takes place in a larger context than the healthcare organization itself (Truman & Raine, 2002). As mentioned in the introduction, the notions of citizenship and recovery are closely connected to this approach (Pelletier et al., 2009) and will consequently be presented in the following paragraphs.

### **2.2.1.1 Citizenship**

In connection to the larger context of mental health services, the notion of citizenship refers to the functioning of the individual within the boundaries of the society including rights and responsibility based elements, but also elements of leading a life that is equal to that of other citizens in an all-comprising way (Barnes, 1999; Rowe et al., 2012). These different aspects need to be present and actualized in order for citizenship to prevail (Rowe & Pelletier, 2012). This also includes for the patients to take on their role as citizens (Mezzina et al., 2006). In the field of mental health, this approach has been discussed through participation in groups where users come together with the aim to improve the situation for themselves as well as others within the society (Barnes, 1999; Barnes & Sharlow, 1997; Pilgrim & Waldron, 1998). It has also been expressed and carried out in France through “citizen psychiatry”, implying an active social inclusion of users of mental health services on the community level including actions to be made in this direction by a variety of different actors (Pelletier et al., 2009).

### **2.2.1.2 Recovery**

The notion of recovery is closely associated to the one of citizenship described above (Pelletier, Corbière, et al., 2015). Concerning recovery, it is however question of an approach close to the person and stemming from his or her initiatives, although supported by various other actors of the society (Anthony, 1993). This concept has been defined by Anthony (1993) “as a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness” (p. 15). This is a concept comprising many facets, and has been discussed in various ways in the literature (Davidson & Roe, 2007; Pelletier et al., 2009). The meaning of the word recovery in the case of mental health takes a large perspective regarding what it implies, meaning that recovery can take place regardless of ongoing illness and therefore removing the focus from diminishing it (Anthony, 1993; Davidson & Roe, 2007). This can be explained as a kind of regaining of the aspects of one’s life that were lost because of mental illness and its associated stigmatization, for example a job, various activities in life etc. (Anthony, 1993; Davidson & Roe, 2007). Recovery adds to the understanding of the importance of the inclusion of individuals in the society, and of an elimination of stigmatization (Mezzina et al., 2006).

### **2.2.2 The different expressions of patient engagement**

The reviewed literature specific to mental health shows that patient engagement can take various expressions in this field. The literature concerning patient engagement on the organizational level frequently treats participation in the planning, development, design, delivery, and evaluation of services, as well as the training and teaching of healthcare professionals, by a variety of different means (Barnes & Wistow, 1994; Bowl, 1996; Crawford et al., 2003; Omeni et al., 2014; Peck, Gulliver, & Towel, 2002; Robert et al., 2003; Rutter et al., 2004; Simpson & House, 2003; Storm, Hausken, & Knudsen, 2011). This literature indicates that the participation can be realized through, for example, meetings, different organizational committees or councils, surveys, groups organized by patients and active within or in interaction with the organization, and even through patients being employees. Patients being employees can take place through so called peer mentors or workers supporting other patients in their contact with mental health services (Jewell, Davidson, & Rowe, 2006). Patients can also be involved in research within

mental health by adding their perspective in a variety of different ways (Pelletier, Bordeleau, Dumais, Renaud, & Rowe, 2013).

Innovative ways to engage patients in mental health are present in the literature, for example the use of an actual board game played by patients that is aimed at seeking their input on changes to be carried out on a care department level, pointing to the importance of being able to counter challenges such as merely symbolic participation (Fitzgerald et al., 2011). The need for creativity regarding how to involve patients has also been brought forward by other authors (Munro et al., 2006; Rutter et al., 2004).

### **2.2.3 The components of patient engagement**

Knowing that patient engagement can take these above-mentioned expressions, it now convenes to look further into what this engagement is constituted of. Many of the components of patient engagement in mental health mentioned in the reviewed literature that will be presented in the two sections hereafter, that are considered either facilitators or barriers, point to its structuration.

#### **2.2.3.1 Facilitators**

The necessity of training for the different parties in the patient engagement is prominent in the literature, in informing of its importance and preparing them to work together, as well as in helping the patients to function within new contexts (Bowl, 1996; Crawford et al., 2003; McDaid, 2009; Robert et al., 2003; Simpson & House, 2003; Tambuyzer & Van Audenhove, 2013). Further, the availability of different kinds of resources is mentioned as important (Bowl, 1996). Among these are the financial ones allowing the elaboration of a functioning patient engagement (Bowl, 1996; Crawford et al., 2003; Simpson & House, 2003). This element includes pay attributed to the patients for their participation, although debated, considered important in equalizing their role (Lester, Tait, England, & Tritter, 2006; McDaid, 2009; Rutter et al., 2004). In connection to this is the provision of different kinds of support from the organization for the involved parties, in the form of necessary information regarding the activity of patient engagement, or staff that is available specifically for this purpose, but also support among patients themselves (Bowl, 1996; McDaid, 2009; Restall & Strutt, 2008; Robert et al.,

2003). The importance of the support from the management of the organization has also been brought forward (Crawford et al., 2003).

Another condition facilitating patient engagement concerns whether it has been formalized or not within the organization, through for example inclusion of it in various organizational documents to assure its continuity (Tambuyzer et al., 2014). On the same line, several authors have mentioned the existence of processes and procedures for the patient engagement that have been made explicit to the involved actors, although without specifying what these consist of (Lammers & Happell, 2003; Tambuyzer & Van Audenhove, 2013), pointing to the need for clarification regarding the realization of patient engagement. Facilitators such as the above-mentioned are also mentioned as imperative in the more general literature on patient engagement (Kovacs Burns, Bellows, Eigenseher, & Gallivan, 2014; Pomey et al., 2016).

Other less concrete facilitators also brought up in the literature are in line with the value-based approach of patient engagement in mental health. One facilitator of this kind is a functioning interaction based on the different parties' attitudes, leading to the patients also having an impact on the decisions being made (Rise et al., 2013). It is therefore important to explicit what each of them are supposed to do in the collaboration in order for favourable conditions to prevail (Bowl, 1996; Broer, Nieboer, & Bal, 2014; Elstad & Eide, 2009; Rise et al., 2013). On the same line is the necessity of clarity regarding the aim of patient engagement (Crawford et al., 2003; Simpson & House, 2003). Finally, the importance of the weight given to the input of the patients stemming from their knowledge based on their experience from the mental healthcare system is frequently mentioned in the literature (Borg et al., 2009; McDaid, 2009). This kind of knowledge plays an important role in the integration of their perspective in healthcare services (Pomey et al., 2015). This indicates the need of arranging for patients to be included.

### **2.2.3.2 Barriers**

The more intangible elements bring us to the barriers for patient engagement in mental health. There are a multitude of different barriers to patient engagement that are brought up in the literature, but within mental health these also concern aspects linked to the history and traditions of this domain (Munro et al., 2006). The above-mentioned facilitators are often reversed in the literature and mentioned as for example the absence of training (e.g., Crawford et al., 2003).

Therefore, only additional barriers than those constituting the opposite of the above-mentioned facilitators will be brought up in this section.

Firstly, the question whether patients in mental health that represent others in different participation activities are representative is an element present in the literature (Crawford et al., 2003; Omeni et al., 2014; Rutter et al., 2004). Clarifications regarding this element have been made, meaning that it is not automatic that those who are participating are very distinctive in comparison to others, even if they are doing it by choice (Crawford & Rutter, 2004). Omeni et al. (2014) bring forward the paradox in this aspect since the patients that are representing others in decision-making within organizations are not always properly included unless they are considered capable by other types of stakeholders. The capability of every single patient to participate has been questioned (Bee, Price, Baker, & Lovell, 2015), but could be improved by the previously mentioned necessary preparation (Simpson & House, 2003). This further shows that the barriers and facilitators of patient engagement are closely interconnected.

Secondly, and connectable to the previously mentioned aspect, are hesitance and attitudes towards the engagement among healthcare professionals and other personnel, which are mentioned as determinant and to be altered through explicit action since these actors are the ones working close with the patients (Bee, Price, et al., 2015; Crawford et al., 2003; Gordon, 2005; Lammers & Happell, 2003; Rise et al., 2013). This barrier is part of the prevailing culture within an organization, also mentioned as playing a role when it comes to the engagement of patients (Hickey & Kipping, 1998; Omeni et al., 2014), and can be expressed in resistance towards the engagement (Crawford et al., 2003).

Thirdly, existing organizational structures can be seen as a barrier towards patient engagement in the sense that they need adaptation in order for patients to be able to function on equal levels as other actors (Bowl, 1996), and that they contain the power differences prevalent within mental health (Stickley, 2006). Nevertheless, Tritter and McCallum (2006) argue that the power-question must be understood in a flexible matter, as being held by various actors and with attention given to the differing and complementary contributions they can make, and not as stemming from one predetermined bank of power. On the same line are Broer et al. (2014) who emphasize on less focus on this aspect since it can lead to divergence from the concrete development of a functioning participation of patients. However, paying attention to the

decision-making power is essential specifically regarding mental healthcare, where any power held by the patients traditionally is marginal (Borg et al., 2009).

Finally, stigma surrounding the mental illness is a barrier towards patient engagement brought up in the literature (Bee, Brooks, et al., 2015; Munro et al., 2006).

## **2.3 The Implementation of a Structure for Patient Engagement**

Having presented patient engagement in a mental health context and its constituting components brought up in the literature, it now pertains to clarify regarding its implementation. How to concretely proceed in dealing with these above-discussed aspects in the context of mental health needs clarification (Munro et al., 2006). Considering the particularities surrounding this approach in mental health and the extent it takes treated in the paragraphs above, it is pertinent to review how to proceed for patient engagement to be successfully implemented and more specifically how a structure for it can be realized. However, this specific aspect is difficult to identify in the literature.

Case studies zooming in on the different expressions that patient engagement can take in mental health by exploring the subject with an organizational and even regional perspective emphasize on a disseminated participation taking place in many aspects within the organization of services (Omeni et al., 2014; Rutter et al., 2004). Despite of their width, these studies zoom in on the participation itself, leaving the structuration of the approach on a wider organizational level less explored. Similarly, studies often treat patient engagement in mental health organizations with a focus on how different stakeholders comprehend and experience the participation itself (Elstad & Eide, 2009; Rise et al., 2013; Storm, Hausken, et al., 2011; Tambuyzer & Van Audenhove, 2013), and are therefore leaving the questions of whether there is a structure for it and how it is implemented unanswered. Simpson and House (2003) take a larger perspective on the implementation of patient engagement in mental health, and present its realization as a sequence constituted of planning including the awareness of the purpose of the patient engagement activity, follow-up during the participation, as well as evaluation at the end. Simpson and House also bring forward the importance of ameliorating one's practice of patient engagement through previous experiences, highlighting the need for a clear and structured proceeding in this approach.

Among the structures for patient engagement identified in the literature is the methodology developed at the University of Montreal, the “Montreal Model”, allowing the participation of patients in the amelioration of the healthcare quality, also being carried out in mental health (Flora et al., 2015). Although this methodology applied in mental health described by Flora et al. (2015) remains on a clinical level of the organization, it illustrates the implementation of a structure for patient engagement in an explicit way. Additional studies that treat local structures with certain organizational missions also exist that allow for patient engagement to take place within mental health, such as different committees and councils where patients participate (Linhorst et al., 2005; McDaid, 2009; Perreault et al., 2010). These types of committees also exist on larger scales than the individual organization (Serapioni & Duxbury, 2014). These studies bring forward several of the components of patient engagement presented in section 2.2.3 and discuss its functioning, therefore bringing clarity to elements important to consider, and showing the essentiality of an established ground for the approach within mental healthcare organizations. However, these studies treat the kinds of organizational structures that make up local participation instances, and are therefore keeping a narrow perspective. Studies exploring the subject with a wider lens although focusing on inferior organizational levels close to the provision of care have also been identified (Brooks, Sanders, Lovell, Fraser, & Rogers, 2015; Storm, Knudsen, et al., 2011). However, since this master’s thesis treats the implementation of the approach covering the entire organization, namely a structure on a strategic level aiming to ameliorate the patient engagement, the literature connected to this larger perspective will be reviewed in the following paragraph.

A few studies presenting a strategic, organization-covering approach have been identified in the reviewed literature, although only one specifically in mental health (Rise et al., 2014), and the rest in other domains (Brooks, 2008; Kendell, Urquhart, Petrella, MacDonald, & McCallum, 2014; Pomey et al., 2016). These studies show the variety of expressions structures for patient engagement on a more strategic level can take. In the field of mental health, Rise et al. (2014) present the topic through an explicit strategy consisting of a plan for the execution of patient engagement involving a multitude of actions to be performed. In this study by Rise et al., the complexity of the approach is expressed through the difficulties regarding the entire organization being covered. These authors do not explicit the concrete proceeding of the

implementation of the strategy. Nevertheless, they do bring forward aspects to be considered in these types of large-scale initiatives, such as the necessity of clarity regarding the aim of the implementation, namely patient engagement, as well as assuring that it is truly fulfilled. Surprisingly, the perspective of the patients was not included in the study by Rise et al., as also recognized by the authors themselves. More detailed is a study by Pomey et al. (2016), who present an initiative of a structure for patient engagement including participation activities covering an entire organization, ranging from the clinical to the higher governance levels. Pomey et al. present the organizational process used for the engagement of patients and how this was implemented. These authors highlight the necessary integration within the organization regarding the culture, but also its wider structure, in order for this kind of patient engagement structure to function. In accordance with the integration of the approach presented by Pomey et al. is the approach described by Kendell et al. (2014), who have studied the implementation of an advisory committee including patients and other representatives as a means for patient engagement on a larger scale. Kendell et al. present this structure as an instance contributing to ameliorate and carry out the approach of patient engagement within the healthcare system in one locality, therefore extending beyond the organization. Although focusing on the committee itself, Kendell et al. point out the holistic aspect of this way to proceed, since the patients participated in shaping the patient engagement in different aspects. These authors bring forward the challenges of such a comprising initiative, while pointing to the importance of the permanence this kind of structure implies. Finally, Brooks (2008), focuses on the particularities of the evolving dynamics between healthcare professional and patient in the implementation of a council constituted of a majority of patient representatives, aiming increased engagement of patients within the organization. Brooks, however, leaves other aspects of the implementation process to be further clarified. Common for all these studies that are taking a strategic perspective treated in this paragraph is the participation of patients in the implementation process.

### **2.3.1 Influential factors**

While many of the factors that are brought up in the literature as influencing the implementation of different kinds of structures for patient engagement are included in the previously presented facilitators and barriers of patient engagement itself, the factors that are present in the literature

specifically taking a larger organizational perspective will be mentioned hereafter. Among the frequently present factors influencing the implementation of patient engagement on a wider level are management support, the organizational culture, various forms of leadership (Brooks et al., 2015; Pomey et al., 2016; Rise et al., 2014), support from external parties, as well as different resources for the implementation (Kendell et al., 2014; Pomey et al., 2016).

### **2.3.2 Consequences**

The reviewed literature is sparse regarding the impact of the engagement of patients within healthcare organizations, although it is widely mentioned as aiming towards reaching quality of the care (Crawford et al., 2002; Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012). In the mental health field, the possible benefits of engaging patients range between personal aspects and the wider society, touching the patients, the services, the professionals, and finally aspects outside the organization, such as the prevailing stigmatization (Millar et al., 2016). A need to bring clarity to the knowledge regarding the impacts of engaging patients in various aspects of healthcare beyond the patients' own care has been expressed (Crawford et al., 2002; Mockford et al., 2012). The literature has explored the impact of patient engagement in mental health, approaching the subject in different ways (Omeni et al., 2014; Rose et al., 2010; Storm, Knudsen, et al., 2011). Benefits close to the patient, such as concerning the notion of recovery, but also regarding the services, have been reported (Omeni et al., 2014). Furthermore, Rose et al. (2010) have viewed the matter out of the patients' appreciations of what their engagement in different ways can lead to. Rose et al. mention favourable influences on the provision of services, but they also emphasize the need for more research on the outcomes in mental health, especially according to perspectives of further types of actors.

It is difficult to identify the consequences of a strategic structure aiming to ameliorate patient engagement in the reviewed literature. The knowledge gap regarding the impact of these types of strategic initiatives concerning the patient engagement has been emphasized (Rise & Steinsbekk, 2015, 2016), although the promotional effect it can have among the healthcare professionals has been carefully expressed (Rise & Steinsbekk, 2016). This effect has also been mentioned by Storm, Knudsen, et al. (2011), who further indicate the effect of more participation

of patients, although with a focus on lower organizational levels closer to the care provision, instead of within the entire organization.

The above-presented section 2.3 of the literature review shows that it is challenging to identify studies explicitly treating the process of implementation of a structure on a strategic level aiming to ameliorate patient engagement within healthcare organizations. The identified literature explicitly treating this subject (Brooks, 2008; Kendell et al., 2014; Pomey et al., 2016; Rise et al., 2014) does not systematically present its theoretical base. Studying implementation within organizations can be done with organizational change theory as a base (Champagne, Brousselle, Hartz, Contandriopoulos, & Denis, 2011). Therefore, in order to study the implementation of an organizational strategic committee for patient engagement, the literature on the implementation of organizational change and innovation will be briefly reviewed in the following section. The application of such organizational theories is also relevant considering the transformation the domain of mental health is going through, demanding changes to equally occur at the level of organizations and their activities (Lord et al., 2001). It has been mentioned as essential that these changes in mental health organizations involve the engagement of patients (Brooks et al., 2011; Lord, Ochocka, Czarny, & MacGillivray, 1998; Rose et al., 2003).

## **2.4 The Implementation of Change and Innovation in Organizations**

The literature on organizational change is wide, in volume as well as in range regarding the various concepts being used (Demers, 1999). An example of the latter is that the notion of change often is treated simultaneously with innovation, as these concepts are closely connected (Poole & Van de Ven, 2004). An overlap therefore exists among the two parts of the literature (Greenhalgh, Robert, MacFarlane, Paul, & Kyriakidou, 2004), and these concepts can be treated in a uniform way regarding the aspect of implementation (Champagne, 2002). Consequently, change and innovation are presented in a synchronized manner in this part of the literature review, treating the literature on implementation in organizations including both concepts.

As explained by Van de Ven and Poole (1995), change can be defined as “an empirical observation of difference in form, quality, or state over time in an organizational entity” (p.

512), and innovation is one element leading to a change. The latter can be described as the addition of some kind of novelty within for example an organization, aiming positive impacts to occur on various levels, including on the societal one (West & Farr, 1990). As previously mentioned, patient engagement is an approach within healthcare organizations that is aiming quality care (Carman et al., 2013), but also aiming positive effects on a larger scale, such as increased social inclusion (Truman & Raine, 2002). Patient engagement can therefore be considered an innovation in mental health organizations that implies changes on different levels.

The aspect of implementation is reflected in processes, which are manifested in how the organizational change is developing (Bullock & Batten, 1985; Grol, Bosch, Hulscher, Eccles, & Wensing, 2007). May (2013) explains that “an implementation process involves agents in the intentional modification of the social systems that occupy a field, or fields, of action” (p.12). It therefore depends on explicit actions by a variety of different actors (May, 2013). Several authors illustrate organizational change as being spread over a number of phases including activities that are being carried out, in order to accomplish its implementation (Bullock & Batten, 1985; Kotter, 1995). These phases are generally divided into an introduction where preparation is done, the concrete activities to carry out the change, and its sustained activity. One widely cited phase-model is the one by Rogers (2003), detailing the diffusion process of innovations, and can often be found in the literature regarding implementation of healthcare interventions (Greenhalgh et al., 2004; Meyers, Durlak, & Wandersman, 2012; Nilsen, 2015). Rogers (2003) focuses on the diffusion process including several large phases, one of them being implementation. However, Rogers also takes a narrower perspective on the process concerning the implementation of innovations on the organizational level in a linear manner, consisting of five different stages ranging from the existence of a need to carry out an innovation, to finally its integration in the organization. What is interesting in the process by Rogers is that it is constituted of two major parts, with its initiation not necessarily being followed by the carrying out of the implementation of the innovation, depending on the decision that is made based on previous events. An active decision therefore plays a crucial role in the process depicted by this author. While theories, such as the one by Rogers, bring forward the mechanisms of the innovation being implemented, there are other types of frameworks consisting of steps that include more concrete actions, although aiming to instruct implementers (Nilsen, 2015). One

example is the one by Meyers et al. (2012), including as many as fourteen concrete steps. The steps by Meyers et al. are elaborated from a mix of several other frameworks, whereof many within the healthcare sector. Interestingly, the larger categorization of the implementation steps by Meyers et al. do not significantly differ from the above-mentioned narrower stages by Rogers, since both these frameworks include the need for and the adequateness of the innovation, as well as the importance of a structure that is adapted in order to for it to be functional within the organization. To conclude, although Rogers makes a distinction between the initiation of the innovation, as well as its implementation, his model remains comparable to the one of Meyers et al. treating the subject matter uniquely in terms of implementation.

### **2.4.1 Implementation in the healthcare field**

It has been argued that the various stages of carrying out changes with the aim of reaching better healthcare quality need thorough consideration (Garside, 1998). The existence of these stages has been mentioned as varying among different frameworks for implementation (Moullin, Sabater-Hernández, Fernandez-Llimos, & Benrimoj, 2015). On the same line, the use of existing change-theory as a base when studying such interventions has been suggested by Grol et al. (2007), in order to clarify the implementation process specific to the healthcare field. This is of significance due to the domination of empirical studies and deficient improvement initiatives (Grol et al., 2007). The change-theories that can be used are not necessarily of organizational kind, but can be connected to a variety of other domains, such as behavioural sciences (Grol et al., 2007). The variety and importance of theoretical grounding has been discussed in an exhaustive literature review on the diffusion of innovations by Greenhalgh et al. (2004), also specific to healthcare. Greenhalgh et al. put emphasis on the knowledge gap concerning the process of implementation of innovations in this domain. The same knowledge gap has equally been established specifically concerning the mental healthcare sector (Brooks et al., 2011). There is therefore a need for clarification to be done concerning the implementation of innovations within healthcare, and specifically mental health. Much of the literature that can be connected to the implementation process is focused on the clinical level within healthcare organizations, treating so called evidence-based interventions on the level of services (e.g., Aarons, Hurlburt, & Horwitz, 2011; Proctor et al., 2009), and many of the existing frameworks treat this type of interventions (Nilsen, 2015). The process of implementation within healthcare

is non-linear, which is expressed by possible repetition of its preceding phases and illustrating its dynamism (Fixsen, Blase, Naoom, & Wallace, 2009; Meyers et al., 2012; Moullin et al., 2015). Non-linearity is central to complex interventions, which are prominent within healthcare organizations and has been discussed within the healthcare domain (Begun, Zimmerman & Dooley, 2003). Furthermore, connections between various levels within a “system” (comprising both the organization and its surroundings) in which a complex intervention is implemented, is another aspect characterizing these types of interventions (Begun et al., 2003). Many frameworks illustrating implementation as a process concerning different interventions on a variety of levels (organizational, treatment etc.) exist in the literature, including specific ones to healthcare and even a few in mental health (Meyers et al., 2012).

The literature on implementation includes a participatory element involving different actors, such as those within the organization (Fernandez & Rainey, 2006), and also lay persons (Durlak & DuPre, 2008), mentioned as important specific to change efforts in mental health (Lord et al., 1998). This can be connected to the question of power when it comes to decision-making within an organization (Scheirer, 1981), and is therefore in line with the core of this master’s thesis - patient engagement, in which the power-question is central (Stickley, 2006). A review regarding the participation of patients in changes specifically within the field of mental health has been carried out by Rose et al. (2003), who conclude that it is imperative that patients in mental health take an integral part in the organizational change process, from the start to the end, as actors among the others.

The literature on implementation reviewed in the section above also includes discussions about contextual factors that affect this process in a positive or a negative way, as well as the need to take these factors into account (Greenhalgh et al., 2004; Grol et al., 2007; Moullin et al., 2015). These types of factors will be reviewed in the following section.

#### **2.4.2 Factors that can facilitate or limit implementation**

Scheirer (1981) describes contextual elements that play a role in implementation as stemming from different levels of the organization, and this at various moments in the process. These factors can be in interaction and exist even outside the organization itself (Damschroder et al., 2009). The implementation literature specific to the healthcare field often separates factors

belonging to the organization in which the novelty is introduced from those situated on the outside (Aarons et al., 2011; Damschroder et al., 2009; Greenhalgh et al., 2004; Pomey, Forest, Sanmartin, De Coster, & Drew, 2010). In the following paragraphs, factors pertaining to both of these areas that can be found in the literature will be presented. Although factors that can influence the implementation process also can be situated on the level of the innovation, or even on the level of the individuals (Moullin et al., 2015), only the contextual ones within and outside the organization will be treated in this literature review.

These factors are categorized differently according to different authors. Some mean that the same types of factors exist both inside and outside the organization (Pomey et al., 2010), while others identify distinguishing factors (Aarons et al., 2011). Furthermore, the attribution of specific influential factors per distinct phase has also been suggested in an attempt to further entangle the process (Aarons et al., 2011), although the above-mentioned non-linearity of the implementation process in healthcare makes the application of this kind of division complicated to visualize. These factors can be categorized in a detailed manner as shown in a literature review by Durlak and DuPre (2008), who are presenting sub-categories for each of them. Other authors have applied a larger perspective, for example Pomey et al. (2010) who are dividing these factors as pertaining to the four domains of the organizational culture, the governance, the tools and the resources within the organization.

A myriad of different factors, both of intangible and tangible kind, situated inside the organization can be found in the reviewed literature, although a few mentioned below are particularly recurring. These are cultural aspects, the leadership being exercised, the decision-making in connection to the innovation, the support from higher governance instances, the infrastructure and possibilities for communication, the organizational structure (e.g., how long it has been operating, how comprising its activity is etc.), as well as different types of resources attributed for the process (Aarons et al., 2011; Damschroder et al., 2009; Durlak & DuPre, 2008; Greenhalgh et al., 2004).

The above-mentioned literature of more general kind that discuss the influential factors also include contextual factors situated outside of the organization. However, a need to take into account the specific context of implementation has been expressed (Aarons et al., 2011; Durlak & DuPre, 2008), and this especially when it comes to innovation in the mental health sector

(Brooks et al., 2011). Two frameworks treating the subject in this field that are highlighting contextual factors on the organizations' outside are those by Brooks et al. (2011) and Mendel, Meredith, Schoenbaum, Sherbourne, and Wells (2008). These two frameworks consider the contextual factors as permeating the organizational ones. While similar organizational factors as the above-mentioned from the more general literature are brought up in the literature specific to mental health, such as adequate resources and leadership (Brooks et al., 2011; Fairweather, Sanders, & Tornatzky, 1974; Lord et al., 2001; Mendel et al., 2008), the contextual ones in this field mainly concern the specific culture on a larger scale than solely regarding the organization, the effective policy (Brooks et al., 2011; Mendel et al., 2008), as well as other actors in the network of the organization (Mendel et al., 2008). The two last-mentioned factors are also present in the literature regarding other community-anchored health domains (Aarons et al., 2011; Durlak & DuPre, 2008), as well as in the more general implementation literature (Damschroder et al., 2009; Greenhalgh et al., 2004).

With the reviewed literature as a base, the next chapter presents the conceptual framework in this master's thesis.

### 3. Conceptual Framework

In order to meet the objectives of this master's thesis, that is, to study the approach of patient engagement within mental health through the implementation of a strategic organizational committee, considering the process of implementation, the factors that are facilitating or limiting the implementation, and the perceived consequences, a conceptual framework will be presented in this section. In light of the absence of conceptual frameworks illustrating the process of implementation of patient engagement within mental health, the following conceptual framework is hereby proposed that is based on the previously discussed frameworks of Rogers (2003), Pomey et al. (2010), Brooks et al. (2011) and Mendel et al. (2008). First, the different elements will be defined, and thereafter the conceptual framework will be presented.

The **process** of implementation is drawn from the framework for innovation within an organization by Rogers (2003) presented in this paragraph. In the framework by Rogers, the different stages are embraced by one "sub-process" involving preparatory action for the innovation representing its initiation, and another illustrating its concrete implementation. The stage of *agenda-setting* includes the recognition of the existence of a need to carry out an innovation, meaning that something requires to be changed within the organization, as well as the detection of an innovation that could respond to this need for change. The next stage, *matching*, involves actions in order to make sure that the chosen innovation is appropriate. This implies an assessment of whether it is adequate to be implemented in the specific organization and to fulfil the need for innovation, including planning concerning how the innovation should be shaped. The initiation of the innovation is represented by these above-defined stages that include a decision of whether to go ahead and implement, leading to an entry to the second sub-process where actions made by various actors and different key events are taking place in the following stages. The stage of *redefining/restructuring* refers to actions involving adjustments of, or the establishment of a structure within the organization that allows for the innovation to function. In its turn, the innovation also needs to be adapted to the organization in this stage. The *clarifying* stage involves increased practice of the innovation by actors within the organization, and actions leading to it having a more fixed character than earlier, implying further permanence and a continuous structure. This stage also involves that the different actors

within the organization are getting more familiar with the innovation. Finally, *routinizing* is the stage where the innovation is entirely implemented, meaning that it is no longer considered a novelty, but instead an everyday part of the organization.

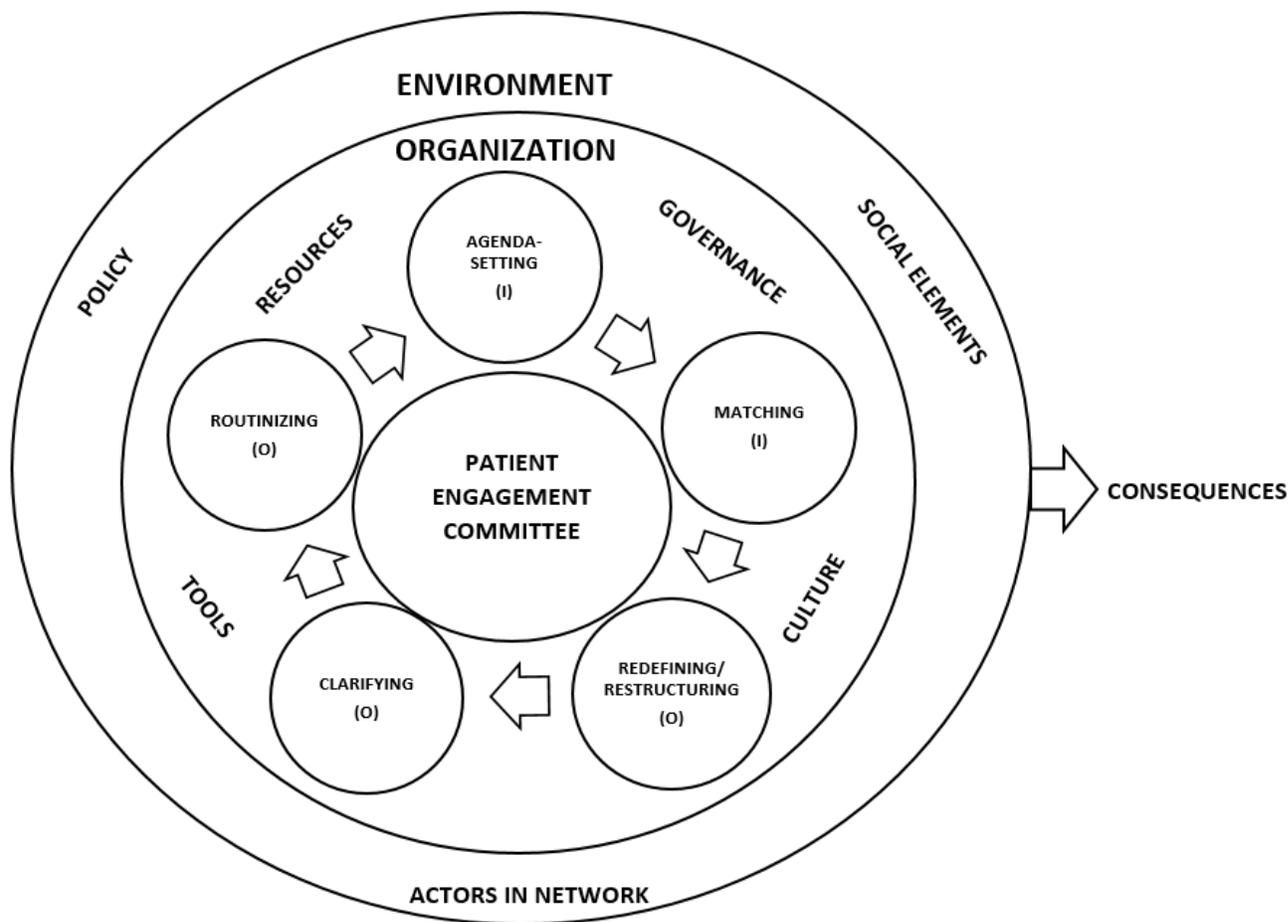
In the conceptual framework of this study, the above-described process by Rogers (2003) has been adapted to the previously mentioned non-linearity of innovation implementation in healthcare (Moullin et al., 2015). Since there is a gap in the literature concerning the process of implementation of innovations specific to mental health (Brooks et al., 2011), the process by Rogers seems appropriate to apply since it is not specific to one type of organization, and allows for flexibility regarding the content proper to each stage.

The **organizational** factors are drawn from the above-mentioned model of Pomey et al. (2010) indicating the *culture*, the *governance*, the *tools* and the *resources* within a healthcare organization as having an impact on the implementation process. Pomey et al. define culture in their model using the definition of Shortell, Levin, O'Brien, and Hughes (1995, p. 5): “underlying beliefs, values, norms and behaviours”. These kinds of elements together represent the culture when they have become common for the organization and its actors with time (Schein, 1985). It is transformable and can exist at various levels, covering the entire organization, or only smaller groups of people within it (Schein, 1985). Governance in the model of Pomey et al. is defined as per (Hatchuel, 2000, p. 31): “the conduct of collective action from a position of authority”. To this definition of governance can be added that the authority implies decision-making (Mintzberg, 1989). Furthermore, the collective aspect also extends to the notion of leadership implying that different leaders in the organization can influence the implementation process, both those in an explicit position of authority as well as others (Denis, Langley, & Rouleau, 2010). Finally, tools refer to different “instruments or procedures” within the organization that can have an influence on the process, while resources involve a range of different kinds that are available for the implementation, for example financial, human and those concerning information within the organization (Pomey et al., 2010, p. 71).

The factors of the **environment** of the organization are sought from two frameworks for innovation implementation within the field of mental health (Brooks et al., 2011; Mendel et al., 2008). These factors concern *social elements*, *policy*, and *actors in the network* of the organization that influence the implementation. Social elements refer to culturally inherent

aspects, such as different actors' attitudes regarding the illness itself and the introduction of a novelty, prevalent norms (Mendel et al., 2008), the stigma of mental illness, as well as social exclusion present in the field of mental health (Brooks et al., 2011). Policy refers to the existing mental health policy affecting the activity of organizations (Brooks et al., 2011; Mendel et al., 2008). Finally, actors in network refer to different actors in the organization's network, possibly having an impact on the implementation process (Mendel et al., 2008). Since not all factors can be considered in one study (Mendel et al., 2008), only those that are mentioned specific to the environment of mental health have been included.

**Figure 1. Conceptual framework to study the implementation of a strategic organizational committee for patient engagement in mental health.** Adapted from Rogers (2003), Pomey et al. (2010), Brooks et al. (2011) and Mendel et al. (2008).



The conceptual framework in this study in Figure 1. above illustrates the implementation of a strategic organizational committee for patient engagement within a mental healthcare organization. The process of implementation of the committee is situated in the middle of the conceptual framework inside the organization in a non-linear manner, manifested in the process being shaped as a circle. The stages of *agenda setting*, and *matching* constitute the initiation-process (I) of the committee, while the stages of *redefining/restructuring*, *clarifying*, and *routinizing* make up its operationalization<sup>2</sup>-process (O). The inner sphere surrounding the implementation process refers to the mental healthcare organization itself. This sphere includes the *culture*, the *governance*, different *tools* and *resources* within the organization that can either facilitate or limit the implementation of the committee. The outer sphere refers to its environment which is also including these types of influential factors being the *policy*, different *social elements*, and *actors in network*. Finally, the *consequences* of the implementation of the committee perceived by various actors are placed to the right. This conceptual framework allows for the implementation process of the committee to be studied, and influential factors from the environment and the organization itself, as well as the perceived consequences of its implementation to be identified.

With the literature review and the above-presented conceptual framework as a base, this master's thesis aims to study the approach of patient engagement within mental health through the implementation of an organizational strategic committee. More specifically, it aims to:

- Study the process of implementation of an organizational strategic committee for patient engagement through the distinct sub-processes of initiation and operationalization.
- Identify the organizational and environmental factors that can facilitate or limit the implementation of this committee.
- Identify the perceived consequences of its implementation within the organization regarding the patient engagement.

---

<sup>2</sup> The term operationalization is used in this study instead of “implementation” as in the framework by Rogers (2003). This adaption has been done in order to illustrate that the implementation process consists of both initiation and operationalization.

## **4. Methodology**

This master's thesis is part of a larger multi-site research project on patient-partnership in different contexts that is funded by the Canadian Institutes of Health Research (Pomey et al., 2014-2017), however concentrating on one case in one of the studied sites. The results are presented in the form of an article in *chapter 5*. on page 39.

### **4.1 Research Strategy**

The study has a synthetic research strategy, which allows for several aspects of a phenomenon to be examined at the same time, in a non-linear manner (Contandriopoulos, Champagne, Potvin, Denis, & Boyle, 2005), and is therefore suitable in the case of studying patient engagement in a mental healthcare organization using the conceptual framework presented in the previous chapter.

A qualitative approach has been applied. This approach allows for multidimensional information to be obtained concerning an intervention in order to understand how it has developed, and this specifically out of the perspectives of the individuals taking part in it (Patton, 2002). It therefore seems to be appropriate when exploring the implementation process of an organizational strategic committee for patient engagement in the specific context of mental health taking into consideration factors on the organizational and the environmental level. When studying processes where careful attention is directed to how it develops and at the same time to influential factors around it, this type of approach can be applied (Champagne et al., 2011).

### **4.2 Research Design**

The research design chosen for this study is a case study. This research design is suitable when seeking to study the proceeding of something, as well as when examining actual circumstances within for example an organization (Yin, 2009), which has been done in this study when focusing on the implementation of an organizational strategic committee for patient engagement. More specifically, a single case study has been carried out including the creation of the committee as its unit of analysis (Yin, 2009). This research design allows for in-depth

study illustrating one specific case including its context (Yin, 2009), permitting for clarifications to be done regarding patient engagement in the specific context of mental health.

#### **4.2.1 The case in the study**

The case to examine in this single case study is the creation of a strategic organizational committee for patient engagement within a public mental healthcare organization in the province of Quebec. The organization has a long history and provides both inpatient (short term hospitalization) and outpatient services in a variety of areas within mental health, covering a large territory in Montreal, therefore in a metropolitan area. The organization is built of administrative and clinical departments placed under the top management (e.g., teaching, clinical services, research, human resources etc.). The healthcare is organized according to specific clinical programmes in psychiatry, as well as certain general healthcare services for the clientele. The organization also conducts activities of research and teaching. It is a large organization with approximately 2000 employees (healthcare professionals, researchers, teachers, and administrative staff). The committee that has been implemented works to frame the patient engagement within the mental health organization, more specifically, the participation of patient partners in different activities organized by employees (e.g., clinical programming committees, conferences, research projects etc.). The committee includes representatives from several of the different administrative and clinical departments within the organization, as well as user representatives. The actions to put the committee in place occurred between 2008 and 2015, and therefore imply that this study is of retrospective kind. This case has been chosen since it allows for the study of how a structure for patient engagement, in the form of a strategic organizational committee, is implemented within the context of mental health. Therefore, the sampling of the case in this study is “purposeful” in order to be able to thoroughly examine the chosen subject (Patton, 2002). This case is unique and a successful example (Yin, 2009) of the implementation of this approach in the context of mental health. It highlights an integrated approach of patient engagement in a mental health organization by the implementation of a strategic committee.

#### **4.2.1.1 Delimitations**

Although other elements of patient engagement exist within the mental healthcare organization of the case in this study, for example the participation of peer mentors<sup>3</sup>, the subject of this master's thesis is however limited to examine the approach of patient engagement that has been carried out through the implementation of an organizational strategic committee.

### **4.3 Data Collection**

In order to study the process of implementation of an organizational strategic committee through the sub-processes of initiation and operationalization, the organizational and environmental factors that can facilitate or limit the implementation, and its perceived consequences within the organization, the data collection has included the following main elements: interviews, focus groups, and analysis of documents.

Different means of data collection and sources of data have been used to respond to the research objectives, since this “triangulation” increases the likelihood for a more complete and accurate picture of what is being studied (Patton, 2002). In December 2015, the first interviews were carried out, and from February to August 2016, further interviews as well as focus groups have been done. Throughout the data collection period (December 2015 - August 2016) analysis of organizational documents has been conducted (see *Appendix 1*) for information to be obtained regarding the committee, the patient engagement, as well as the mental health organization itself. Notes were taken during the entire data collection period in order to document observations regarding the data and the data collection.

The interviews and focus groups were carried out by the research coordinator together with the master's student, except for one interview and one focus group led by the main researcher. Interview guides regarding the sought for aspects were developed for both the interviews, and for the focus groups excluding a first exploratory one (see *Appendix 2, 3, and 4*). These instruments were developed in collaboration with the research coordinator, and discussed with other members of the research team in order to assure their appropriateness. The guide for the

---

<sup>3</sup> Peer mentors (see page 10 for definition) in the studied organization differ from the patient partners, which are patients participating in various activities within the organization.

interviews was modified after the first half of the interviews that were carried out in December 2015 for it to better correspond to the research objectives (Miles & Huberman, 1994). Since this master's thesis is part of a larger research project, it is not concerned by certain aspects of the instruments used for data collection.

### **4.3.1 Recruitment of study participants**

Recruitment of study participants was done by the research coordinator and the master's student. The participants of the study have been recruited with the assistance of the main contacts of the research project within the organization, who helped to organize the data collection. At first, a start list of participants (n=9) was established with their help during introductory meetings by phone. Also the sampling regarding the participants was of purposeful kind, and additional participants were identified while the data collection proceeded, hence recruited according to the "snowball" technique through previous interviews (Patton, 2002). In order to invite the participants for the interviews, the main contacts at the organization first informed them of the study. Thereafter, contact was made by telephone to schedule a time for the interview according to their availability. Finally, they received a confirmation e-mail specifying the date and exact location of the interview, including a copy of the information and consent form. Regarding the focus groups, the participants for the last one were invited and contacted by e-mail including the necessary documentation and information, while those of the first two ones were invited through contacts at the organization.

Five participants took part in two different data collection instances (e.g., one interview and one focus group). A total of 27 different individuals that had been part of the patient engagement within the organization participated in the interviews and focus groups, whereof seven members of the committee. See Table 1. for details regarding the study participants, and Table 2. for details regarding the data collection and the participants.

**Table 1. Study participants<sup>4</sup>**

<b>Participant type</b>	<b>#</b>
Patient partner	7
User's committee	1
Peer mentor	3
Top management	2
Researcher	2
Clinician	1
Senior manager	5
Middle manager	6
Clinical administrative manager	3

**Table 2. Data collection and study participants**

<b>Data collection</b>	<b>#</b>	<b>Participant type (#)</b>
<b>Interviews</b>	10	<ul style="list-style-type: none"> <li>• Patient partner (2)</li> <li>• Member of the user's committee (1)</li> <li>• Clinician (1)</li> <li>• Researcher (2)</li> <li>• Senior manager clinical department (3)</li> <li>• Senior manager administrative department (1)</li> <li>• Member of top management (2)</li> </ul>
<b>Focus groups</b>	3	N=9 <ul style="list-style-type: none"> <li>• Peer mentor (2)</li> <li>• Clinical administrative manager clinical programme (2)</li> <li>• Middle manager clinical department (2)</li> <li>• Middle manager administrative department (1)</li> <li>• Senior manager clinical department (1)</li> <li>• Researcher (1)</li> </ul>
		N=4 <ul style="list-style-type: none"> <li>• Patient partner (4)</li> </ul>
		N=9 <ul style="list-style-type: none"> <li>• Peer mentor (2)</li> <li>• Patient partner (2)</li> <li>• Clinical administrative manager clinical programme (1)</li> <li>• Middle manager clinical department (2)</li> <li>• Middle manager administrative department (1)</li> <li>• Senior manager clinical department (1)</li> </ul>

<sup>4</sup> Several study participants pertained to more than one participant type.

### **4.3.2 Interviews**

Carrying out interviews within a case study has been mentioned as imperative (Yin, 2009). Ten semi-structured interviews of approximately 60 minutes each have been carried out with different actors involved in the patient engagement within the organization (see Table 2. for details), of which several were or had been members of the organizational strategic committee for patient engagement. These types of interviews allow for flexibility regarding the topics being treated, and leave room for additional angles to be discovered (Kvale, 2007). Two of the interviews included two participants at the same time, for logistical reasons. The interviews were imperative in order to explore all the objectives of the study, since they allowed for information to be obtained concerning both the initiation and the operationalization of the committee, as well as concerning its organizational and environmental context. These interviews also treated the perceived consequences within the organization of the implementation of the committee.

### **4.3.3 Focus groups**

Focus groups as data collection bring forward the experiences of people in a wider perspective, and allow for several viewpoints to come together (Kitzinger, 2006). Three focus groups of approximately 120 minutes each have been carried out (see Table 2. for details regarding the participants). Firstly, one with different types of actors (n=9), including a few peer mentors but mostly managers on different levels, that had been involved in the patient engagement in various ways within the organization. This focus group was exploratory and also aimed to narrow down the scope of the research project. Secondly, one exclusively with patient partners (n=4) that had been participating in different activities within the organization in connection to the committee. Information concerning their involvement and their experience was collected. Finally, a focus group (n=9) was carried out that included patient partners and managers, but also peer mentors, whereof most of the participants had been involved directly in connection to the implementation of the committee. Since this focus group included a variety of participants that had been part of the implementation at different points in time, it allowed for the chronology of events, as well as important pieces of the implementation process to be highlighted. Different types of participants took part in the focus group in order for all important actors' perspectives to be

included and contribute to the discussion. Furthermore, the variety of actors permitted for information to be obtained regarding the connections between the participation of patient partners as well as peer mentors within the organization, although outside the scope of this master's thesis (see section *4.2.1.1 Delimitations*). This last focus group aimed the validation of the understanding of the previously collected data, and allowed for connections to be made between various elements of the implementation process of the committee.

#### **4.3.4 Document analysis**

The analysis of documents facilitates the comprehension of, and can provide information regarding the studied events as well as their context (Marshall & Rossman, 2011). Therefore, different types of documents specific to the committee and the patient engagement, but also wider regarding the mental healthcare organization have been analyzed (see *Appendix 1* for list of analyzed documents). Analyzed documents specific to the committee were: Annual reports, meeting minutes, an evaluation report regarding the participation of patient partners within the organization, presentations, publications and different working documents. The analyzed wider organizational documents were: Organizational reports (annual and population), organization charts, and newsletters.

#### **4.4. Data Analysis**

Software (QDA Miner) to assist throughout the data analysis process has been used in this study. This has facilitated and helped to structure the treatment of the data (Miles & Huberman, 1994). All interviews and focus groups have been recorded and were thereafter sent to a professional for transcription to be done. All notes have been clearly written down and structured after each interview/focus group. Furthermore, the different data sources have been categorized according to their type (i.e., interview, focus group, type of document, notes taken during data collection). This kind of organizing prepares for the rest of the analysis work and eases the orientation through the collected data (Contandriopoulos et al., 2005). The data (transcribed interviews/focus groups, documents, and notes) has thereafter been entered into the analysis software. The data analysis took place throughout the data collection period and one month after (January - September 2016).

Qualitative analysis according to Miles and Huberman (1994, pp. 10-11) is a repetitive process involving the identification of important content and the contextualization of the text segments (“data reduction”), the organization of the data showing its interrelations (“data display”), and the determination of how to understand it (“conclusion drawing/verification”). Following the three-component method of Miles and Huberman (1994), the analysis was carried out as described hereafter. First, when it comes to the component of “data reduction”, codification of the collected data was done in the software by the initial development of codes, and the attribution of these codes that concerned the stages of the implementation of the committee for patient engagement, the different organizational and environmental factors that can facilitate or limit the implementation, as well as the consequences. The data also revealed additional aspects of the implementation of the committee to be analyzed that were not counted for in these original codes. A few additional codes were therefore included, for example more specific ones concerning certain factors. In contrary, codes were also deleted and modified when considered appropriate. Codes were developed and modifications were done in connection to discussions during meetings of the research project that this master’s thesis is part of. Specific codes were developed by the master’s student according to the elements of the conceptual framework of the master’s thesis. Two interviews as well as one focus group were coded by both the master’s student and other members of the research team (research coordinator or another team member), to make sure that the codes were well placed according to their signification. Additionally, as part of reducing the data, a report as well as a chronology summarizing the sought for aspects were written and modified throughout the data collection. Secondly, concerning the component of “data display”, codes regarding the influential organizational and environmental factors and the stages of the process of implementation of the committee were combined with the help of the software. Consequences of the implementation of the committee occurring at different moments in the process were also highlighted this way. These combinations, showing which factors played a role at certain points in the implementation process of the committee, indicating the content of each stage in this process, and the consequences, allowed for the third and last component “conclusion drawing/verification” of the collected data to be done. A table (Table 5. on page 71) illustrating the process of implementation of the committee and the influencing factors can be found in the appendix of the article in *chapter 5*.

## 4.5 Validity

The validity of the study can be discussed through the four elements of “credibility”, “transferability”, “dependability”, and “confirmability” for rigor in qualitative studies (Lincoln & Guba, 1985 cited in Devers, 1999, p. 1165). These elements will be applied to this study in the following paragraphs.

For “credibility” of the study to be obtained, triangulation including different types of data and means to collect it has been done (Devers, 1999), through the individual interviews, the focus groups, and the analysis of documents concerning the patient engagement within the organization as described in section 4.3 *Data collection*. The triangulation also concerns the individuals that perform data collection (Devers, 1999; Guba, 1981), implying that the data being collected by several persons in collaboration has contributed to augment the credibility of the study by helping to assure that all pertinent topics were included during the interviews and focus groups. Likewise, discussions during the meetings of the research team allowed for further perspectives on the data collection to be taken into account. Furthermore, the various means of data collection have been carried out during several months, which can increase the credibility of the study by making participants comfortable with and used to the researcher, and by helping to avoid the potential bias that can be caused by the researcher merely being present (Guba, 1981). Participation in organizational events took place during the data collection period. This also contributed to the above-mentioned, however, the fine line that exists between being distanced and being too close (Guba, 1981) has been taken into consideration. Additionally, parts of the information obtained through the data collection were validated with key actors involved in the patient engagement within the organization and the implementation of the strategic committee. Verification was done in the last focus group at the end of data collection, aiming to validate the previous understanding of the proceedings within the organization. Finally, a presentation of the results of the study (Ewalds, Desbiens & Pomey, 2016) during the annual meeting for all sites included in the larger research project also permitted for verification of the content by comments from key actors of the studied events. This is a method to make sure that the credibility is augmented (Guba, 1981; Devers, 1999).

The “transferability” of the study can be augmented by the provision of information regarding the conditions and environment of the study, constituting its context (Devers, 1999). This kind of information has been obtained, as mentioned above in section 4.3.4. *Document analysis*, through the analysis of different documents regarding the committee and the mental healthcare organization. This information was also explicitly sought for through one of the objectives of the study being the identification of organizational and environmental factors influencing the implementation of the committee. Further, the sampling method for the participants of this study, where individuals taking part in the implementation process of the committee in one way or another (either directly in the process, or in its context) were sought to be included, can have contributed to the transferability of the results in the sense that pertinent and much data was obtained (Guba, 1981).

The “dependability” of the study can be increased by using proper procedures around the data collection and analysis (Devers, 1999), as included in this study and described in detail in the two previous sections of this chapter (4.3 *Data collection* and 4.4. *Data analysis*). For example, the interview guide was modified during the data collection process to better assure that it contained the sought for elements in order to study patient engagement in mental health through the implementation of a strategic organizational committee. These modifications concerned further details under each theme, and a clearer structure regarding both the implementation process of the committee as well as its context (within the organization and outside it).

Finally, the “confirmability” of the study can also be augmented through triangulation (Devers, 1999), as addressed in detail concerning the credibility criteria above. A field note diary has also been kept, helping to handle and to be aware of the subjectivity that can occur on behalf of the researcher regarding different aspects of the studied events, constituting a tool to stay the most objective in one’s research approach (Devers, 1999).

## **4.6 Ethical Considerations**

Ethical approbation has been obtained from the University of Montreal Health Sciences Research Ethics Committee (14-127-CÉRES-D), as well as the ethics committee of the Centre hospitalier de l’Université de Montréal (MP-02-2015-5710 - CE.14.232) handling the multi-site certificate for the research project. A detailed information and consent form regarding the

research project on patient engagement has been provided to the participants in order for them to get to know the project and for them to sign. This form contained information about the project, and informed the participants of the confidentiality of the study, as well as the opportunity for them to stop their participation at any time during the project. The participants have been given time to consider their participation before the data collection. All the collected data is kept confidential and is treated anonymously, therefore the participants have all been assigned a number occurring on the collected data instead of their name. The data is also kept secure, with solely the members of the research team having access to it, under password in computers and in a locked drawer in the research coordinators office.

# **5. Article: A voice for the Patients: Patient Engagement in Mental Health Through the Implementation of a Strategic Organizational Committee**

## **Authors:**

Anna-Paulina Ewalds <sup>a</sup>, Marie-Pascale Pomey <sup>b</sup>, Jean-François Pelletier <sup>c</sup>, Julie Bordeleau <sup>d</sup>, Francine Desbiens <sup>e</sup>

## **Author affiliations:**

<sup>a</sup> Master's student in Health Services Administration, School of Public Health, University of Montreal

<sup>b</sup> Professor, Department of Health Management, Evaluation and Policy, School of Public Health, University of Montreal

<sup>c</sup> Assistant Professor, Department of Psychiatry, University of Montreal, Centre de recherche de l'Institut universitaire en santé mentale de Montréal. Assistant Clinical Professor, Department of Psychiatry, Yale University

<sup>d</sup> Co-Director, Association of Recovery Mentors, Centre de recherche de l'Institut universitaire en santé mentale de Montréal

<sup>e</sup> Research Coordinator, Institut de recherche en santé publique de l'Université de Montréal

## **Author contributions:**

Anna-Paulina Ewalds conceptualized, did data collection and analysis, and wrote the paper.

Marie-Pascale Pomey conceptualized, participated in data collection and analysis, and reviewed the paper.

Jean-François Pelletier conceptualized and reviewed the paper.

Julie Bordeleau reviewed the paper.

Francine Desbiens conducted data collection, participated in analysis, and reviewed the paper.

The research project this paper is part of is funded by the Canadian Institutes of Health Research (CIHR, subvention number 201311PHE-318871-PHE-CFCA-119899).

## **Aimed for journal:**

Journal of Public Mental Health, Patient Experience Journal or Health Expectations

## **Corresponding author:**

Anna-Paulina Ewalds

anna-paulina.ewalds@umontreal.ca

## **Abstract**

**Objective:** There is a need for structure for a functional patient engagement within mental healthcare organizations to be reached. How to proceed on a strategic level needs clarification. In this paper, patient engagement is studied through the implementation of a strategic organizational committee for this purpose in a mental health context. The research questions concern why and how the committee is implemented, the organizational and environmental factors that can facilitate and limit this process, and the perceived consequences of its implementation.

**Method:** A qualitative approach has been used in this study. A single case study has been carried out with ten semi-structured interviews, three focus groups, and organizational documents as data sources.

**Results:** The strategic committee for patient engagement was implemented following a need for formalization and the introduction of a vision of full citizenship. How it was implemented concerned its composition and role, the elaboration of a frame for the participation of patient partners, and finally the ongoing application of the previously elaborated including evaluation. Several facilitating factors were identified, including top management support, leadership, and a vision behind the participation. The limiting ones mainly concerned resistance towards the participation and the existence of stigma. The consequences included increased and improved patient engagement, as well as reduced stigma within the organization.

**Conclusion:** This study shows that the implementation of a strategic organizational committee for patient engagement is comprehensive. It further shows the importance of a vision and an articulate leadership involving several actors. Further research is needed regarding consequences of this type of strategic structure on a clinical level.

## **Introduction**

In recent years, the approach of patient engagement has been frequently studied within various areas of the healthcare system. The literature is consensual on the importance of engaging patients in different aspects within the healthcare system, whether the motive is better quality of care, or other aspects that can be positively affected on both individual and organizational levels (Carman et al., 2013; Simpson & House, 2003). The motive for involving patients in decision-making brings attention to the importance of going much beyond a merely symbolic participation without an actual role for the patients - an issue frequently brought forward (Omeni, Barnes, MacDonald, Crawford, & Rose, 2014; Rose, Fleischmann, & Schofield, 2010), pointing to the importance of further clarification regarding patient engagement. This is a context-sensitive approach, containing several interconnected parts (Barello, Graffigna, & Vegni, 2012; Tritter & McCallum, 2006).

### **The approach within mental health**

When it comes to the literature on patient engagement within mental health, additional angles are added. Patient engagement is often discussed including challenges linked to the traditional perceptions of mental illness and the limitations that this implies for the patients, for example in terms of inequality within power-relations (Borg, Karlsson, & Kim, 2009), and stigmatization (Bee, Brooks, Fraser, & Lovell, 2015). Aspects like these are brought forward through an integration of patient engagement as a fundamental part of notions such as recovery and citizenship (Pelletier, Davidson, & Roelandt, 2009), two approaches aiming to promote full community inclusion and participation despite or beyond enduring negative implications of mental illness (Pelletier et al., 2015). Recovery treats the retrieval of aspects close to an individual's everyday life lost through mental illness but parallel to its continuing existence (Anthony, 1993), while citizenship takes a larger perspective, implying for these individuals to function as other citizens within the society (Barnes, 1999; Rowe et al., 2012). In line with this is the approach of "citizen psychiatry" developed in France, implying an active social inclusion of mental health service users (Pelletier et al., 2009). Furthermore, in the context of Quebec, the most recent Mental Health Action Plan (MHAP) integrates patient engagement in the aim for all to be considered citizens (Ministère de la Santé et des Services sociaux [MSSS], 2015). These

particularities point to the necessity of patient engagement in the context of mental health. While the importance of the approach is clear, the question of how to concretely proceed remains to be further clarified (Munro, Killoran Ross, & Reid, 2006; Rutter, Manley, Weaver, Crawford, & Fulop, 2004; Storm, Knudsen, Davidson, Hausken, & Johannessen, 2011). In mental health organizations, several different models or ways to involve patients exist, both in individual and in larger aspects (Storm & Edwards, 2013; Tambuyzer, Pieters, & Van Audenhove, 2014). This paper focuses on the last-mentioned.

## **How to proceed**

The literature expresses a necessary framing or structure for the patient engagement for it to work well within mental health organizations, demanding explicit actions to be taken in this direction (Lammers & Happell, 2003; Munro et al., 2006; Simpson & House, 2003; Truman & Raine, 2002). Ingredients of a successful participation of patients are frequently brought forward comprising, among others, preparation of actors, support mechanisms, and allocation of resources (Pomey et al., 2016; Tambuyzer et al., 2014). This indicates a need to figure out how to successfully add these positive ingredients and at the same time overcome the negative influences brought up in the literature as prevailing both within the organization and in the society at large (Truman & Raine, 2002). The literature contains various patient engagement initiatives within mental health where local structures enabling participation within organizations are created, such as different councils and committees including patients (Linhorst, Eckert, & Hamilton, 2005; McDaid, 2009; Perreault et al., 2010). These initiatives point to the importance of the establishment of a ground for the patient engagement within organizations. However, it has been mentioned necessary to zoom out from the individual participation initiative and apply a larger perspective in order to visualize a functioning patient engagement (Tritter & McCallum, 2006). Despite this, there is less evidence in the literature on the establishment of structures like the above-mentioned on a strategic level aiming to ameliorate patient engagement, which is important since it covers the complete organization. This knowledge gap has also been identified by Rise, Solbjør, and Steinsbekk (2014) who examine the implementation of an organization-wide strategy for patient engagement in the form of a plan for its execution. A few studies taking a wider organizational perspective have been identified, focusing on the establishment of a structure for the benefit of patient

engagement (Brooks, 2008; Kendell, Urquhart, Petrella, MacDonald, & McCallum, 2014; Pomey et al., 2016; Rise et al., 2014). These studies however, are not explicit regarding the theory that they lean on. Since having a theoretical basis is considered important when studying the implementation of interventions within healthcare organizations (Grol, Bosch, Hulscher, Eccles, & Wensing, 2007), the implementation of a structure for patient engagement touching the entire organization is to be further examined.

An initiative to structure the engagement of patients within one mental healthcare organization in the province of Quebec has been carried out by the creation of an organizational committee on a strategic level, constituting an opportunity to advance the research in this subject. Therefore, the aim of this paper is to respond to the following research questions:

- Why and how is a strategic organizational committee for patient engagement implemented within a mental healthcare organization?
- What organizational and environmental factors facilitate or limit its implementation?
- What are the perceived consequences of its implementation within the organization?

## **Theoretical Framework**

Despite the existence of a range of frameworks illustrating different aspects of implementation of innovation and change within healthcare (Moullin, Sabater-Hernández, Fernandez-Llimos, & Benrimoj, 2015), the knowledge specific to the process of implementation within mental healthcare organizations has been identified as needing further development (Brooks, Pilgrim, & Rogers, 2011). Due to this, the model by Rogers (2003) depicting the innovation process in a general way leaving the content of each stage to be discovered, seems appropriate to apply. Rogers describes this process as composed of two parts, one where the reasoning for the innovation takes place before deciding to carry it out, and another where it is concretely being implemented. *Agenda-setting* and *matching* belong to the first part of his model, involving the need to innovate to be brought forward, and the planning of how to form the innovation in accordance with this need, followed by the decision whether to continue with the subsequent stages or not. The second part of Rogers' model consists of the stages of *redefining/restructuring*, *clarifying*, and *routinizing*, and involves the adjustment of the innovation according to the particular organization and vice-versa, its further structure, and

finally its integration in the organization. It is to note that the process of implementation in healthcare is non-linear (Fixsen, Blase, Naoom, & Wallace, 2009; Moullin et al., 2015).

Factors that can influence the implementation process are prevalent both within the organization, and in the context outside of it (Aarons, Hurlburt, & Horwitz, 2011; Damschroder et al., 2009; Durlak & DuPre, 2008; Greenhalgh, Robert, MacFarlane, Paul, & Kyriakidou, 2004; Pomey, Forest, Sanmartin, De Coster, & Drew, 2010). There is a multitude of different organizational factors brought up in the literature. Pomey et al. (2010) categorize these factors as pertaining to the organizational *culture*, its *governance*, different *tools*, as well as *resources* that are made available. It is important to consider the specific context of this field and to look beyond the organization when studying the implementation of innovations within mental health (Brooks et al., 2011; Mendel, Meredith, Schoenbaum, Sherbourne, & Wells, 2008). Elements such as mental health policy, different social aspects of mental health in the society (e.g., norms, attitudes, stigmatization, social exclusion) (Brooks et al., 2011; Mendel et al., 2008), and various actors operating in connection with an organization (Mendel et al., 2008), are highlighted as environmental influences of the process of implementation.

## **Methodology**

### **Study context**

This paper zooms in on the context of mental health by focusing on events taking place in a large public mental healthcare organization in a metropolitan area in Montreal in the province of Quebec, providing both inpatient and outpatient services. The organization comprises different administrative and clinical departments. The healthcare is provided through specific clinical programmes in psychiatry, as well as certain general healthcare services. The organization also conducts activities of research and teaching. A formal structure in the form of a strategic committee for patient engagement has been established, in order to frame the participation of patient partners in different activities within the organization. The committee includes representatives from several of the administrative and clinical departments, as well as user representatives. A single case study has been carried out (Yin, 2009), allowing for the proceedings within the organization regarding the implementation of the strategic committee to

be explored by various means of data collection (Baker, 2011). The study is of retrospective kind, studying events taking place between 2008 and 2015, and has been carried out with a qualitative approach to obtain several perspectives on the implementation process (Patton, 2002). Other elements of patient engagement exist within the studied organization, such as peer mentors, however outside the scope of this paper.

## **Data collection**

The data has been collected through interviews, focus groups and analysis of organizational documents. The data collection took place between December 2015 and August 2016. A total of 27 individuals participated in the study. The types of participants<sup>5</sup> were: patient partners (n=7), members of user's committee (n=1), peer mentors (n=3), members of top management (n=2), researchers (n=2), clinicians (n=1), senior managers in departments (n=5), middle managers in departments (n=6), and clinical administrative managers in clinical programmes (n=3). Ten semi-structured interviews (Kvale, 2007) of approximately 60 minutes were carried out with participants that had been involved in the events around the implementation of the committee (members of top management, middle and senior managers, patient partners, researchers, clinician, member of user's committee), whereof several of its members. Two of the interviews involved two participants at the same time for logistical reasons. Three focus groups of 120 minutes each were also carried out. One with nine actors, (mainly managers, but also peer mentors) taking part in patient engagement in different ways within the organization, another with four patient partners, and finally one with nine different actors (patient partners, managers, and peer mentors) involved in the patient engagement, and the majority directly in the implementation of the committee. The first focus group also intended to narrow down the scope of the research project, while the last one aimed the validation of the understanding of the research team of the previously collected data. Guides for the interviews and focus groups were developed, and validated during meetings of the research team. The interview guide was created containing the sought for themes regarding the implementation process, and modified when considered appropriate after the first interviews carried out in December 2015 (Miles &

---

<sup>5</sup> Several participants pertained to more than one participant type.

Huberman, 1994). Finally, analysis of pertinent organizational documents was carried out (annual reports of organization, organization charts, newsletters, different publications, annual reports of committee, evaluation report concerning the patient participation, meeting minutes, presentations, and working documents). This diversified data collection allowed for triangulation to be done (Patton, 2002; Yin, 2009).

### **Recruitment of participants**

The recruitment of participants was done with the help of main contacts of the research project at the organization. A start list of participants that could provide information about the studied events was elaborated at first, and further participants were recruited through the “snowball” method implying that these participants were identified as important to include as the data collection proceeded (Patton, 2002). The participants were contacted by telephone or by e-mail by a member of the research team, except for two of the focus groups where the participants were invited by contacts at the organization.

### **Data analysis**

The interviews and focus groups were recorded and transcribed, and all data was analyzed following the repetitive process of Miles and Huberman (1994) for qualitative studies: Software (QDA Miner) for data analysis was used. The codification was developed based on the sought for aspects regarding the implementation of the committee (process, organizational and environmental factors, and consequences) and was modified throughout the analysis in connection to meetings of the research team. The first author coded and compiled the data. Two of the interviews and one focus group were also coded by FD or another member of the team in order to validate the attribution of codes. All authors verified the results emerging from the analysis.

### **Ethical considerations**

Ethical approval has been obtained from the University of Montreal Health Sciences Research Ethics Committee (14-127-CÉRES-D), and from the ethics committee of the Centre hospitalier de l'Université de Montréal (MP-02-2015-5710 - CE.14.232) handling the multi-site certificate for the research project.

## Results

### Agenda-setting (2008-2011)

The first stage of implementation comprised the initiation of the participation of patient partners<sup>6</sup> within the organization including the identification of the need of a formal structure and an opportunity for it to be realized.

In this stage, the beginning of two overlapping chains of events can be identified. First, following the inclusion of the notion of *recovery* in the MHAP of Quebec of 2005-2010 (MSSS, 2005) including the participation of patients on an organizational level, an initiative was taken by the management of one clinical department to involve patients in the organization of services. A reflection regarding recovery and how to go about in involving patients was undertaken within this department, together with actors from the research department. This process was described as “action-research” as the reflection was combined with experiences of starting to involve patients. Many questions were raised:

*“...whom do I invite? Why do I invite them? Should they be paid? How will the others react? So we were stuck with all these questions, but we really did it sort of as ‘action-research’. We told ourselves: ‘Well, we’ll figure it out, we’ll start to integrate them.’”*  
(Interview 75, non-patient)

There was an interest for the participation of patient partners to work well and to capture their experience. The initiating department organized a training for personnel and patient partners, in collaboration with a provincial mental health association with knowledge in involving patients. Furthermore, a partly independent self-help group was also formed, to discuss recovery and to help to elaborate the participation of patient partners. This group constituted the pool of patient partners at this point.

The above-described development allowed for an informal structure for the participation to take shape, including the work to develop a policy and the patient partners being compensated for their time. However, a need of formalization for the participation to work well was identified.

---

<sup>6</sup> The term patient partner is used for patients participating in various activities within the organization.

*“There were already patients that were integrated in patient-partnership activities, in committees. They felt a need to formalize all of that...”* (Interview 73, patient partner)

Secondly, actions on a strategic level of the organization took place starting in 2010. The initiatives of key actors generated an opportunity to create a formal structure for the participation, making it an institutional priority. A member of the research department included in the above-mentioned reflection introduced a new angle to recovery by combining it with another approach, *citizen psychiatry*. This inspired a member of the top management (the deputy CEO, who became CEO later in the process) who had identified a need for changes to be done concerning the whole organization in moving away from a traditional functioning, towards becoming a university institute. This resulted in efforts to develop a concept for carrying out ameliorative changes in line with citizen psychiatry and recovery - based on the insight that the latter alone did not work in the context of Quebec.

*“Recovery, which is an American movement to which the francophone milieu did not at all adhere, zero...”* (Interview 72, non-patient)

In effect, there was a need to adapt the English-American concept of recovery for it to be eventually applied in a French-speaking area in Montreal, recovery being one of the main orientations of the MHAP of the Ministry of health and social services. This need was expressed as being based on the lack of support for recovery-oriented transformation even though there was openness for its underlying values and principles.

### **Matching (2010-2011)**

This stage contained exploration concerning recovery and citizen psychiatry, leading up to the creation of the strategic committee for patient engagement.

Several key actors from the previous events worked together to elaborate how to develop the notions of recovery and citizen psychiatry within the organization. This investigative work consisted of deliberation, observation and conceptualization.

These key actors organized a civic forum for reflection on recovery and citizen psychiatry. The forum consisted of presentations and discussions involving different participants: patients (some of them were also presenting), the top management and other employees, community instances,

patient organizations, and international actors. This forum led to an intensified exploration of the subject and an increased collaboration both inside and outside the organization.

After the forum, study visits were organized to observe examples of recovery and citizen psychiatry. To see how services can be scattered throughout the city instead of being offered in specialized settings, a trip to France with a wide range of participants took place. This trip was particularly prominent in the collected data. Patients (n=3), researchers (n=2), managers including top management (n=3), clinicians (n=2), administrators (n=3), and family members (n=2) studied the French realization of citizen psychiatry during one week. In contrary to the first stop of the trip where the approach remained within the organizational boundaries, the observation at the second stop was inspiring regarding the integration of patients in the community. However, a large significance of this trip lay in the experience of travelling together. The equal position of all participants was described as eye opening for how far from equal the everyday functioning of their own organization was concerning the relation between patients, health professionals, and other personnel. One participant expressed:

*“.. it changes completely..., we experienced during one week together [...] During one week we ate all our meals together, we slept at the same place, we spent our days together, we waited for the train together. It really changes the relation with... even with the professionals, the physicians.”* (Interview 71, non-patient)

Following this experience, the conceptualization of an approach adapted to their organization was elaborated by previously mentioned key actors. A new clinical vision centered on full citizenship (Fortin, Fortier, Pelletier, & Saulnier, 2012, October) was formally embedded in the Strategic Plan to promote full community inclusion and participation, including the decision-making and planning processes of the institution and collaboration with the surrounding community and other partners through civic forums. This was a vision aiming for full citizenship for all, comprising the participation of patients at different levels as a corner stone:

*“Recovery concentrated on the individual, and then the more public citizen approach, it is that we can support individuals in having an influence on social determinants and public action. That is how we cross them.”* (Interview 70, non-patient)

With the introduction of this vision, there was an augmentation of initiatives in various places within the organization to involve patient partners in different activities. A mandate from the top management, including a financial subvention, to realize the participation of patients within

the new vision of full citizenship was assigned to the member of the research department involved in the previous events.

At this point, the two previously described chains of events converged, i.e., the identified need for a formal structure for the participation of patient partners within the organization, and the opportunity to create this. The mandate concerning the realization of patient engagement came to be actualized through the creation of an organizational committee to frame the participation in line with the new vision (see following stages of implementation). This was done as an extension of the previous elaboration of the participation, where a need of a formal structure had been identified.

*“We involved patients, but at the same time... we had many questions for which we did not have the answers, at one point leading to that there was a need for a space to reflect in a good way, and since it had worked well in the beginning, we told ourselves: ‘But if we want it to last, we need to create an official committee’. To have a budget, for it to not go in all kinds of directions, for people to feel well when participating and that we did not have patient partners only because it is good for the façade of the institute.”*  
(Interview 75, non-patient)

### **Redefining/Restructuring (2011-2015)**

This stage contained the establishment of the strategic committee for patient engagement and the determination of its role.

The committee was described as developed “in action”. The collaboration between key actors of the previous stages continued (from the previous reflection within the initiating department, and from the research department), holding the leadership roles as presidents of the committee in the beginning. Other representatives were gradually invited as the composition of the committee evolved, to finally comprise eight members. The representativeness was discussed, and there was a concern to have a wide perspective within the organization in order to diffuse the participation of patient partners. This was expressed through the inclusion of members, mainly managers, from several different departments (research, support for social integration, teaching, clinical services), the user’s committee of the organization, and the assignment of the role of coordinator to a patient partner. Eventually, another patient partner who also was a member of the previously created self-help group was included.

*“We had decided that ideally we should have two patient partners on the committee, so that people do not feel intimidated, to feel that there is a peer that can understand us.”* (Interview 73, patient partner)

A few members changed with time and the above-mentioned wide perspective was also strengthened by the change of president.

*“This committee changed president every two years to assure that there was a penetration of the concept in all the directions.”* (Interview 81, non-patient)

The committee was connected to and responded to the top management.

*“We considered inside the committee that it was necessary to have a direct link to the top management. For the committee to be transversal inside the institute, not depending on one particular programme.”* (Interview 73, patient partner)

The first meeting of the committee took place in the fall of 2011. Meetings were held in average six times per year. In the beginning, they worked to elaborate their mandate. The aims of the committee were to promote, to document and evaluate, and to establish a policy for participation of patient partners. This included an advisory role towards the top management. The role of the committee was wide and described as both supervisory and consultative, functioning as a “guard dog”, but also as a “guide”, aiming to frame the participation of patient partners within the organization in order for it to take place in a good way. Modifications to the role were carried out as the work of the committee advanced.

A budget for the compensation of patients participating within the organization was provided by the top management each year (ranging between 5000\$ in 2011/2012 and 15000\$ in 2014/2015), upon request from the committee. Additionally, the hospital’s foundation provided finances covering fees above the actual participation of patient partners, for example for transport to activities taking place outside the organization.

### **Clarifying (2011-2015)**

With the previous informal structure for the participation of patient partners as a base, the committee pursued the elaboration of how it should be framed - in the light of full citizenship. The content of this stage can be summarized in two themes: the creation of functioning conditions for the participation of patient partners, and communication and promotion.

The committee elaborated a centralized system for the participation activities through the establishment of: 1) A formal policy including procedures for the concrete functioning of the participation that were illustrated through a cartography (document detailing the different steps and roles of the involved actors). The policy had already been elaborated before the formalization of the committee, but was revised and adjusted at this point. 2) Standard forms for requesting the participation of a patient partner and for compensation. These were made available through the intranet to be used by different actors within the organization wishing to involve a patient partner in an activity. 3) A document working as a tracking mechanism for the participation activities and the compensation was created as part of budget management, allowing for closer monitoring.

The work of the committee was characterized by continuing reflection and discussion. Clarifications were carried out along the way, for example, regarding aspects of the procedures, the terminology used (patient instead of user, indemnity instead of payment), and the budget (compensation amounts, attribution guidelines and fiscal aspects). The committee also sought to understand the function of the participation of patient partners, through the conduction of internal research, and the collaboration with research projects within the organization. There was a concern for the participation to function well, and for patients not to be participating in activities only for the sake of it.

*“In order for us to approve patient-partnership activities, it had to favour the full citizenship of the users involved [...] and that their experiential knowledge is taken into account.”* (Interview 73, patient partner)

*“It is good to follow accreditation, but putting a patient on a committee doesn’t mean anything. [...] There has always been a preoccupation, a follow-up that we did, with the patients, and with the manager or clinician initiating the committee...”* (Focus group, non-patient)

Different challenges emerged along the way, leading to the committee reflecting on ethics...

*“And what we saw is that at times when people took the parole, users, in public, it stressed them as there are people that are nervous. Sometimes to the point that quite evidently we conclude that she is disorganized, it is no longer logic. Here, we asked ourselves in the committee: ‘What do we do in these types of situations? Do we remove the microphone, something we would not do with a psychiatrist [...]?’, the committee reflected upon these challenges.”* (Interview 70, non-patient)

...and more functional aspects, for example concerning the representativeness of the patients that participate in different activities when the same patients were frequently assigned. This was a concern raised by several interviewees.

*“We need to change patient partners because otherwise we will always come back to the same vision [...]. That’s what worried me a little more since it is as with the professionals, we have our vision, if it’s always this user on the committees, well, it’s his experience, but it’s not representative...”* (Interview 74, non-patient)

In line with the full citizenship vision, there was a concern to make the role of the patients more equal to the roles of other actors within the organization. The committee brought attention to structures concerning physical places and activities where patients were not allowed. This concerned for example access to the documentation centre, noticed by a patient partner on the committee. It was mentioned as discriminating but also paradoxical since the patients that participated in various activities also needed certain resources. This highlighted the important role of the patients.

*“Because we don’t see it anymore. It takes patients to denounce it or to bring attention to things like this.”* (Interview 70, non-patient)

The committee communicated their role to the rest of the organization to inform about policy and procedures. Annual reports were produced to summarize their activities and accomplishments, as well as the diverse participation activities taking place within the organization. They also promoted both their own work, and the participation of patient partners, through, for example, presentations at conferences, and during the introduction day for new employees, and the creation of an advertising banner regarding the participation. These types of activities also aimed to “destigmatize” the mental illness. Promotion took place both inside the organization and gradually more on the outside, even internationally sustaining the exchange with international actors. Patient partners, both those who were members of the strategic committee, as well as others, were involved in all these above-mentioned activities.

### **Routinizing (2011-2015)**

This stage concerns the ongoing application of the procedures for the participation of patient partners within the organization, the creation of an evaluation mechanism, and the increased participation.

The different participation activities within the organization passed through the committee and the procedures they had established. At this point, the procedures for participation that had been developed and gradually improved through the work of the committee, were described as well functioning.

*“It was integrated in the whole system. Whether it was a public conference, a management committee on the organization of services, the welcoming of employees, in many aspects. It was logic, it was natural to say that a patient partner was integrated [...] ‘did you pass by the patient partner kiosk?’”* (Focus group, non-patient)

The centralized system for the participation activities constituted the frame for the ongoing administrative work taken care of by a few members of the committee including the coordinator. This work consisted of the handling of the procedures for participation. 1) When a health professional or manager within the organization wished to involve a patient in an activity, the request form was filled out on the intranet and automatically transferred to the committee. 2) This request was treated (approval or refusal) and 3) a patient partner was thereafter assigned, either chosen by the committee or identified by the person making the request. Many patient partners came from the self-help group, but health professionals and managers also referred patients to participate. 4) The preparation was done by the person requesting the participation (e.g., provision of documents to read), although the committee was there as support. 5) After the participation, the committee received satisfaction surveys filled out by both patient partner and health professional or manager, for follow-up to be done. The pay-out of the compensation, and the distribution and reception of satisfaction surveys were handled by the top management in the beginning, but were eventually taken over by the coordinator of the committee who also was a certified peer mentor.

Through these procedures that included satisfaction surveys, an evaluation mechanism was created. The committee formed a sub-committee that was responsible for evaluating the satisfaction of the health professionals, managers and patient partners involved in the participation activity. In addition to the satisfaction surveys, focus groups were carried out. This allowed for feedback to be obtained regarding different aspects of the procedures and the participation itself. For example, a need for better preparation prior to the participation activity was identified. The patient partners from the committee were members of the sub-committee.

Although policy and procedures had been developed, certain aspects were brought forward as remaining informal, for example, the criteria regarding the recruitment of patient partners.

The participation activities taking place both inside and outside the organization, passing through the above-described procedures, touched a variety of different areas; organization of services, research, teaching, evaluation and other activities (see Table 3.).

**Table 3. Examples of participation activities**

<b>Area of participation</b>	<b>Examples of activities</b>
<b>Organization of services</b>	<ul style="list-style-type: none"> <li>• Testimonies on specific topics</li> <li>• Clinical programming committees</li> <li>• Other committees (suicide prevention, legal psychiatry etc.)</li> <li>• Writing of guides (practical, welcome)</li> <li>• Workshops</li> </ul>
<b>Research, teaching, evaluation</b>	<ul style="list-style-type: none"> <li>• Research projects</li> <li>• Validation of research instruments and surveys for satisfaction of services</li> <li>• Class for medical students</li> </ul>
<b>Other activities</b>	<ul style="list-style-type: none"> <li>• Conferences and presentations</li> <li>• Civic forums</li> <li>• Study trips</li> <li>• Video capsules aiming to reduce stigmatization</li> <li>• “Living libraries” where patient partners tell their stories</li> <li>• Theatre pieces</li> </ul>

The participation within the organization passing through the procedures doubled between the years of 2011 and 2014. The increase concerned both the number of activities and the number of patient partners (27 activities and 30 patient partners in 2011/2012 versus 60 activities and 67 patient partners in 2013/2014). The different activities often involved several patient partners at the same time, and could be punctual or take place at several occasions. More and more actors within the organization requested patients to participate and less resistance towards it was expressed by several interviewees. However, patient partners also expressed a wish for more participation.

This positive trend stopped with the arrival of a reform in the healthcare system of Quebec in 2015 (National Assembly of Quebec, 2015) affecting the structure of the organization by it being

merged with others, and a decrease in the number of participation activities was noted. A reflection begun on how to assure the continuing activity of the committee, and how to spread this strategic patient engagement practice on a larger scale within the new organizational structure.

## **Facilitating and limiting factors**

Several organizational and environmental facilitating and limiting factors were identified as described below (see Table 4.).

### **Organizational factors**

Starting with the *facilitating organizational factors* there was a continual support from the top management throughout the primary elaboration of the participation of patient partners, the elaboration of the full citizenship vision, and the establishment of the committee. This support was realized and efficient through the committee's connection to the top management and the attribution of a budget for their activity. The support from the management within the initiating department was also determinant for the start of the participation of patient partners.

*“... we were supported by the top management, by our managers [...] also by the CEO at the time. You cannot sustain something that complex with resistance if it is not supported by the top management.”* (Focus group, non-patient)

*“The whole board of directors of the hospital was impregnated by these new ways of doing things.”* (Interview 71, non-patient)

Strong leadership and dedication from the key actors from the top management and the research department was essential in the elaboration of the vision of full citizenship. There was also a shared leadership and understanding (“common philosophy”) among the first members of the committee through their collaboration management-research which facilitated its creation.

*“... So we joint forces to be able to create this unity to sustain the process.”* (Focus group, non-patient)

Furthermore, the vision of full citizenship enabled a culture change within the organization which helped the establishment and the work of the committee.

*“.. what is important, is what made it work. We were supported by the top management, it was implemented in the organizational culture, we talked about full citizenship, there was a clinical vision accompanying these activities...”* (Focus group, non-patient)

Also individuals becoming “bearers” of the vision of full citizenship within the organization (many of them participating in the eye-opening trip to France), for example psychiatrists referring patients to be patient partners, as well as key actors within the committee, facilitated its work. Finally, financial resources allowed for the start of the committee and for its continuing function each year.

The *limiting organizational factors* included resistance from actors within the organization, mainly health professionals, particularly in the beginning of the participation of patient partners.

*“There was also a little bit of insecurity to integrate the patients because certain people, not in unanimity, but certain thought that we were there to slow down their work.”* (Focus group, patient partner)

The last factor concerned difficulty in sharing the full citizenship vision that had been conceptualized by a few key actors with the rest of the organization.

*“...the less you communicate, the people on the field will say: ‘It’s a way of management’. The more frequent the communication, the clearer it is, it will help. And to explain what full citizenship is because we did not understand it in the beginning. ‘What does it mean?’”* (Interview 74, non-patient)

### **Environmental factors**

When it comes to the *facilitating environmental factors* the provincial mental health policy, MHAP of 2005-2010 instigated the process of involving patient partners within the organization. There was also an influence from international actors in recovery and citizen psychiatry, both regarding the full citizenship vision, and the way to involve patient partners.

*“We came back home impregnated of all these values and since a long time we had invited patients to take place in our committees [...] where the experiential knowledge is important because the patients were sometimes bored when it did not concern them, I think.”* (Interview 71, non-patient)

The self-help group constituted an important collaborator and provided support throughout the implementation of the committee, starting at the first elaboration of the participation of patient partners. Similarly, the committee being one element in a supportive network for patient

participation both inside and outside the organization where different instances collaborated, contributed to its work (e.g., participatory research group, self-help group, community organization where patient partners were active). Furthermore, the aim to become a university institute involved an obligation to evolve towards a structure of research and innovative practices, which had an influence on the process.

The *limiting environmental factors* mainly regarded the existence of stigma within the organization, which was expressed through resistance towards the participation of patient partners and the existence of discriminating organizational structures. Finally, the arrival of the reform in the healthcare system of Quebec in 2015 influenced the activity of the committee.

**Table 4. Facilitating and limiting factors**

<b>Factors</b>	<b>Facilitating</b>	<b>Limiting</b>
<b>Organizational</b>	<ul style="list-style-type: none"> <li>• Top management support</li> <li>• Management support in initiating department</li> <li>• Leadership key actors from top management/research department</li> <li>• Shared leadership management-research</li> <li>• Full citizenship vision</li> <li>• “Bearers” of vision</li> <li>• Financial resources</li> </ul>	<ul style="list-style-type: none"> <li>• Resistance within organization</li> <li>• Difficulty in sharing the vision</li> </ul>
<b>Environmental</b>	<ul style="list-style-type: none"> <li>• Mental health policy (MHAP of 2005-2010)</li> <li>• Collaboration with self-help group</li> <li>• International influence</li> <li>• Supportive network for participation</li> <li>• Obligation to evolve in research and innovative practices</li> </ul>	<ul style="list-style-type: none"> <li>• Stigmatization</li> <li>• Reform in healthcare system</li> </ul>

### **The consequences of the implementation of the strategic committee**

The implementation of the committee for patient engagement was mentioned as allowing for the participation of patient partners to be continuing, through the formal structure for it within the organization including, among others, a budget for participation and the production of annual reports. Further, the evaluation mechanism constituted a possibility to obtain feedback and ameliorate the procedures for participation.

The work of the committee implied better quality regarding the procedures around the participation, for example improved support for the actors involved in the participation activity, and also regarding the participation itself.

There was an increased participation of patient partners that was not only due to the full citizenship vision, but also to the creation of the committee that promoted and framed the participation in a systematic way. This allowed for a culture change within the organization to emerge resulting in reduced resistance towards the participation. The committee also contributed to a wider participation within the organization, through its work, and the inclusion of a variety of different departments as members.

*“The involvement of [...], research, also the teaching department in order to spread out the practice has allowed for it [patient engagement] to be sustained.”* (Focus group, non-patient)

Several discriminating structures within the organization were removed through the observations and actions taken by the committee. Through the work of the committee and the increased participation, the patients were given a formal and larger presence within the organization, which contributed to destigmatize the mental illness.

*“... when it comes to stigmatization, what works is direct contact. Of course we try to frame it with conferences, information pamphlets [...] But for the moment researchers arrive at the conclusion that what works, is direct contact.”* (Focus group, non-patient)

## **Discussion**

### **Limits of the study**

The data collection being carried out retrospectively implied that no observational data of the implementation process was included in this paper, which is an important part of case studies (Yin, 2009). The retrospective data collection, and the arrival of the reform in the healthcare system in Quebec in 2015<sup>7</sup> involving structural organizational changes, implied that not all concerned informants were included in the study. The retrospective data collection also meant

---

<sup>7</sup> Reform involving fusions of organizations into larger entities, leading to a reorganization and removal of various managers' positions (National Assembly of Quebec, 2015).

that many years had passed since several of the studied events. Additionally, the embeddedness and parallelism of different events in the implementation process of the committee led to difficulties in knowing when an aspect was depending on the committee itself or on the full citizenship vision. There is therefore an absence of clear-cut causality that would allow for the impact of the implementation of the committee on different levels of the organization to be established. Finally, the perspective of the health professionals could further have been included in this study.

## **Main findings**

The results show how a structure for patient engagement can be put in place, in the form of an organizational committee on a strategic level. The reasons for the implementation of the committee were based on the need of formalization of already existing participation of patient partners, and the introduction of a new vision of full citizenship that implied changes within the organization. How the committee was implemented concerned its structuration, the work to elaborate a frame for the participation of patient partners within the organization, and finally the ongoing application of the previously elaborated including evaluation. A majority of facilitating factors were identified, among others, top management support, strong leadership, international influence, and a vision behind the participation. Limiting ones were mainly resistance towards participation and the existence of stigma. The implementation of the committee lead to increased and improved participation of patient partners through the framing and promotion of the participation. Finally, reduced stigma within the organization followed the implementation of the committee since their work allowed for a formal and larger presence of patients. The results of this study show a multidimensional process and bring forward several angles of the implementation of a strategic committee for patient engagement. A few of these are discussed below.

## **The committee as a model to ameliorate patient engagement**

Despite the lack of literature regarding the subject, both specifically in mental health and other healthcare domains, the importance of being able to spread the practice of patient engagement through the implementation of a strategy focusing on the entire organization has been

emphasized (Pomey et al., 2016; Rise et al., 2014; Rise & Steinsbekk, 2016). In the present study, this kind of spread was illustrated and effective through the purposeful inclusion of various departments on the strategic committee. This implies that the committee could be a model for others interested in implementing a similar structure. What also was observed was the active and conscious direction that was taken in ameliorating patient engagement mentioned in the literature as necessary, including promotion of the approach and support for its realization, both regarding practical, and more ideological aspects concerning the values of the involved parties (Lammers & Happell, 2003; Restall & Strutt, 2008). This points to the need of the explicit creation of both a practical and democratic structure for patient engagement, as also expressed by others (McDaid, 2009). In accordance with other studies discussing efforts in considering the patients' experiential knowledge (Elstad & Eide, 2009; Lammers & Happell, 2003; McDaid, 2009), and the reduction of visible discriminatory elements (Borg et al., 2009), the present study highlights these aspects. However, this demands for a culture change to occur (Borg et al., 2009), discussed further down. The visible and comprising role of coordinator of the strategic committee held by a patient partner can be considered as an actualization of this above-mentioned democratization and inclusion of experiential knowledge. It can also be seen as an expression of recovery and greater participation within the healthcare system and the society – as promoted in the context of Quebec through mental health policy since many years (MSSS, 2005, 2015). Thus, it illustrates the different facets of individuals, ranging from patients to citizens (Pelletier, 2015).

Based on the literature, two limits of the model for patient engagement presented in the results of this study can be identified. Firstly, the non-inclusion of healthcare professionals on the strategic committee. In a literature review by Rose, Fleischmann, Tonkiss, Campbell, and Wykes (2003) on patient engagement in change management, the lack of focus on healthcare professionals as leaders of the approach is brought forward. Secondly, the non-centralization of the preparation for participation. The importance of training to work together, and take part in new contexts, on a larger scale than regarding the individual participation activity has been expressed (Bowl, 1996).

## **A vision behind the patient engagement and an articulate leadership**

Calls for conceptual clarification regarding patient engagement can be linked to the vision of full citizenship in this study (Hickey & Kipping, 1998), constituting a conceptual meaning behind the participation of patient partners (Pelletier et al., 2013). It has been argued that it is necessary to have a vision constituting a concept carrying a change, but also a concretion of this mental content by actors within the organization, for the message to be passed (Kotter, 1995). Thus, solely having a vision supporting the participation is non-sufficient. This was expressed by the initial lack of comprehension of it lower down in the studied organization, although the vision further contributed to an organizational culture change in the present study. This indicates the importance of leaders who can develop the substance inherent of a vision of an innovation, and who can put it in action, especially within organizations such as those in the field of mental health (Valiant Cook, 1995). Hence, leadership constitutes an important aspect when it concerns organizational culture change (Schein, 1985). Building on this, patient engagement should be given a veritable place within the holistic organizational culture of mental health organizations in order to function (Rose et al., 2003), something the present study also indicates.

## **Characteristics of the implementation process**

The results also confirm the non-linearity of the implementation process in healthcare (Moullin et al., 2015) as well as the patient engagement (Tritter & McCallum, 2006), illustrated by for example the changing composition of the committee, or modifications to the elaborated procedures of participation, taking place at several occasions. The non-linearity was further expressed by the content of each of the last three stages of implementation of the committee, overlapping and occurring in parallel. Findings like these confirm the non-ending process that implementation within healthcare is, continuing all through the innovation's existence (Meyers, Durlak, & Wandersman, 2012). Furthermore, the process of implementation of the committee was characterized by collective action involving a variety of different actors, something mentioned pertinent in tackling different complex subjects occurring along the way (Jewell, Davidson, & Rowe, 2006). Patients were participating at each stage of implementation of the committee, which is a central aspect when it comes to changes in mental healthcare organizations (Lord, Ochocka, Czarny, & MacGillivray, 1998; Rose et al., 2003). This

challenges the expressed potential incapacity of patients in mental health to participate in decision-making within organizations (Munro et al., 2006). Finally, this study supports and illustrates the importance of constant management support, as brought up in both the implementation literature (Durlak & DuPre, 2008), and when it comes to patient engagement (Pomey et al., 2016).

The use of a theoretical framework has allowed for several aspects of the implementation process of a structure for patient engagement in a mental health context to be brought forward. The theoretical framework of this study, including the implementation process based on Rogers (2003) as separated in an initiation part and another where concrete implementation takes place, has allowed for the preparatory actions of the implementation of the committee to be explored. The large role played by the vision of full citizenship in the present study, which was developed in the initial steps of implementation, supports the expressed importance of these first steps mentioned in the literature (Länsisalmi, Kivimäki, Aalto, & Rouranen, 2006). In order to further develop the theoretical framework on the basis of the results of the present study, the consequences of implementation can be categorized in quality, range, and volume of participation, as well as organizational culture.

### **Continuing implementation process**

As the results indicate, the routinizing step of the implementation process (Rogers, 2003) was affected by the reform within the healthcare system of Quebec where a reflection started regarding how to continue the committee's activity within the new larger organization. Top management support for the patient engagement within the larger organizational entity, as well as the continuing participation of key individuals from the prior implementation of the original structure, has been brought up as important aspects in a case described by Pomey et al. (in press) treating the successful spread of a similar structure for patient engagement following the reform in Quebec's healthcare system.

### **Conclusion**

This paper treats the implementation of a committee for patient engagement aiming an entire organization. It shows that reaching increased and ameliorated patient engagement through the

implementation of a strategic committee is depending on many factors and involves multiple dimensions to be considered. A vision combined with an articulate leadership assured by several actors in the implementation of this kind of structure is vital for the patient engagement to function and to take place in various places through democratic conditions within mental health organizations. Drawing on this, recommendations that can be made for decision-makers interested in implementing this type of structure are to include multiple actors in the process, to have a vision behind the change, to appoint leaders, and finally to attribute adequate resources so that all aspects of the patient engagement within the organization can be overseen.

The reform in the healthcare system of Quebec as from 2015 raises several questions. What do these types of changes involve for organizational structures for patient engagement like the committee treated in this paper? What are the conditions for diffusion of a structure for patient engagement in a larger organization? These are interesting topics for further research. Further research is also needed to explore the consequences on more clinical levels regarding the quality of the care and services of this kind of strategic organizational structure for patient engagement.

## References

- Aarons, G. A., Hurlburt, M., & Horwitz, S. M. (2011). Advancing a conceptual model of evidence-based practice implementation in public service sectors. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(1), 4-23. doi:10.1007/s10488-010-0327-7
- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11-23. doi:10.1037/h0095655
- Baker, G. R. (2011). The contribution of case study research to knowledge of how to improve quality of care. *BMJ Quality & Safety*, 20(Suppl 1), i30-i35. doi:10.1136/bmjqs.2010.046490
- Barello, S., Graffigna, G., & Vegni, E. (2012). Patient engagement as an emerging challenge for healthcare services: Mapping the literature. *Nursing Research and Practice*, 2012, 1-7. doi:10.1155/2012/905934
- Barnes, M. (1999). Users as citizens: Collective action and the local governance of welfare. *Social Policy & Administration*, 33(1), 73-90. doi:10.1111/1467-9515.00132
- Bee, P., Brooks, H., Fraser, C., & Lovell, K. (2015). Professional perspectives on service user and carer involvement in mental health care planning: A qualitative study. *International Journal of Nursing Studies*, 52(12), 1834-1845. <http://dx.doi.org/10.1016/j.ijnurstu.2015.07.008>
- Borg, M., Karlsson, B., & Kim, H. S. (2009). User involvement in community mental health services – principles and practices. *Journal of Psychiatric and Mental Health Nursing*, 16(3), 285-292. doi:10.1111/j.1365-2850.2008.01370.x
- Bowl, R. (1996). Involving service users in mental health services: Social Services Departments and the National Health Service and Community Care Act 1990. *Journal of Mental Health*, 5(3), 287-304.
- Brooks, F. (2008). Nursing and public participation in health: An ethnographic study of a patient council. *International Journal of Nursing Studies*, 45(1), 3-13. <http://dx.doi.org/10.1016/j.ijnurstu.2006.08.012>
- Brooks, H., Pilgrim, D., & Rogers, A. (2011). Innovation in mental health services: What are the key components of success? *Implementation Science*, 6(1), 120. doi:10.1186/1748-5908-6-120
- Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements

- and developing interventions and policies. *Health Affairs*, 32(2), 223-231. doi:10.1377/hlthaff.2012.1133
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, 4(1), 50. doi:10.1186/1748-5908-4-50
- Durlak, J. A., & DuPre, E. P. (2008). Implementation matters: A review of research on the influence of implementation on program outcomes and the factors affecting implementation. *American Journal of Community Psychology*, 41(3-4), 327-350. doi:10.1007/s10464-008-9165-0
- Elstad, T. A., & Eide, A. H. (2009). User participation in community mental health services: Exploring the experiences of users and professionals. *Scandinavian Journal of Caring Sciences*, 23(4), 674-681. doi:10.1111/j.1471-6712.2008.00660.x
- Fixsen, D. L., Blase, K. A., Naoom, S. F., & Wallace, F. (2009). Core implementation components. *Research on Social Work Practice*, 19(5), 531-540. doi:10.1177/1049731509335549
- Fortin, D., Fortier, L., Pelletier, J.-F., & Saulnier, B. (2012, October). *Une vision clinique centrée sur la pleine citoyenneté: axe de transformation d'un institut de santé mentale montréalais*. Paper presented at the XVIe Colloque de l'Association québécoise pour la réadaptation psychosociale - Rétablissement et pleine citoyenneté: du discours à l'action, Québec, Québec.
- Greenhalgh, T., Robert, G., MacFarlane, F., Paul, B., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: Systematic review and recommendations. *The Milbank Quarterly*, 82(4), 581-629. doi: 10.1111/j.0887-378X.2004.00325.x
- Grol, R. P. T. M., Bosch, M. C., Hulscher, M. E. J. L., Eccles, M. P., & Wensing, M. (2007). Planning and studying improvement in patient care: The use of theoretical perspectives. *The Milbank Quarterly*, 85(1), 93-138. doi:10.1111/j.1468-0009.2007.00478.x
- Hickey, G., & Kipping, C. (1998). Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing*, 7(1), 83-88. doi:10.1046/j.1365-2702.1998.00122.x
- Jewell, C., Davidson, L., & Rowe, M. (2006). The paradox of engagement: How political, organizational, and evaluative demands can hinder innovation in community mental health services. *Social Service Review*, 80(1), 3-26. doi:10.1086/498837
- Kendell, C., Urquhart, R., Petrella, J., MacDonald, S., & McCallum, M. (2014). Evaluation of an advisory committee as a model for patient engagement. *Patient Experience Journal*, 1(2), 62-70.

- Kotter, J. P. (1995). Leading change: Why transformation efforts fail. *Harvard Business Review*, 73(2), 59-67.
- Kvale, S. (2007). *Doing interviews*. London, England: Sage Publications.
- Lammers, J., & Happell, B. (2003). Consumer participation in mental health services: Looking from a consumer perspective. *Journal of Psychiatric and Mental Health Nursing*, 10(4), 385-392. doi:10.1046/j.1365-2850.2003.00598.x
- Linhorst, D. M., Eckert, A., & Hamilton, G. (2005). Promoting participation in organizational decision-making by clients with severe mental illness. *Social Work*, 50(1), 21-30. doi:10.1093/sw/50.1.21
- Länsisalmi, H., Kivimäki, M., Aalto, P., & Rouranen, R. (2006). Innovation in healthcare: A systematic review of recent research. *Nursing Science Quarterly*, 19(1), 66-72. doi:10.1177/0894318405284129
- Lord, J., Ochocka, J., Czarny, W., & MacGillivray, H. (1998). Analysis of change within a mental health organization: A participatory process. *Psychiatric Rehabilitation Journal*, 21(4), 327-329.
- McDaid, S. (2009). An equality of condition framework for user involvement in mental health policy and planning: Evidence from participatory action research. *Disability & Society*, 24(4), 461-474. doi:10.1080/09687590902879064
- Mendel, P., Meredith, L. S., Schoenbaum, M., Sherbourne, C. D., & Wells, K. B. (2008). Interventions in organizational and community context: A framework for building evidence on dissemination and implementation in health services research. *Administration and Policy in Mental Health and Mental Health Services Research*, 35(1), 21-37. doi:10.1007/s10488-007-0144-9
- Meyers, D. C., Durlak, J. A., & Wandersman, A. (2012). The quality implementation framework: A synthesis of critical steps in the implementation process. *American Journal of Community Psychology*, 50(3), 462-480. doi:10.1007/s10464-012-9522-x
- Miles, M. B., & Huberman, M. (1994). *Qualitative data analysis: An expanded sourcebook* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications Inc.
- Ministère de la Santé et des Services sociaux. (2005). *Plan d'action en santé mentale 2005-2010 – La force des liens* (Publication No. 05-914-01). Retrieved from <http://publications.msss.gouv.qc.ca/msss/fichiers/2005/05-914-01.pdf>
- Ministère de la Santé et des Services sociaux. (2015). *Plan d'action en santé mentale 2015-2020: faire ensemble et autrement* (Publication No. 15-914-04W). Retrieved from <http://publications.msss.gouv.qc.ca/msss/fichiers/2015/15-914-04W.pdf>

- Moullin, J. C., Sabater-Hernández, D., Fernandez-Llimos, F., & Benrimoj, S. I. (2015). A systematic review of implementation frameworks of innovations in healthcare and resulting generic implementation framework. *Health Research Policy and Systems*, *13*(1), 16. doi:10.1186/s12961-015-0005-z
- Munro, K., Killoran Ross, M., & Reid, M. (2006). User involvement in mental health: Time to face up to the challenges of meaningful involvement? *International Journal of Mental Health Promotion*, *8*(2), 37-44. doi:10.1080/14623730.2006.9721738
- National Assembly of Quebec. (2015). *Bill n°10: An Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies*. Retrieved from <http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=5&file=2015C1A.PDF>
- Omeni, E., Barnes, M., MacDonald, D., Crawford, M., & Rose, D. (2014). Service user involvement: Impact and participation: A survey of service user and staff perspectives. *BMC Health Services Research*, *14*(1), 491. doi:10.1186/s12913-014-0491-7
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Pelletier, J.-F. (2015). Présentation : que la révolution patient-usager-citoyen se poursuive. *Santé Mentale au Québec*, *40*(1), 11-17. doi: 10.7202/1032379ar
- Pelletier, J.-F., Corbière, M., Lecomte, T., Briand, C., Corrigan, P., Davidson, L., & Rowe, M. (2015). Citizenship and recovery: Two intertwined concepts for civic-recovery. *BMC Psychiatry*, *15*(37), 1-7. doi:10.1186/s12888-015-0420-2
- Pelletier, J.-F., Davidson, L., & Roelandt, J.-L. (2009). Citizenship and recovery for everyone: A global model of public mental health. *International Journal of Mental Health Promotion*, *11*(4), 45-53. doi:10.1080/14623730.2009.9721799
- Pelletier, J.-F., Fortin, D., Laporta, M., Pomey, M.-P., Roelandt, J.-L., Guézennec, P., . . . Rowe, M. (2013). The global model of public mental health through the WHO QualityRights project. *Journal of Public Mental Health*, *12*(4), 212-223. doi:10.1108/JPMH-06-2013-0048
- Perreault, M., Renaud, J., Bourassa, F., Beauchesne, L., Mpiana, A., Bernier, S., & Milton, D. (2010). Implementation of a panel of service users for the evaluation of mental health outpatient services. *Evaluation & the Health Professions*, *33*(4), 480-496. doi:10.1177/0163278710383561

- Pomey, M.-P., Forest, P.-G., Sanmartin, C., De Coster, C., & Drew, M. (2010). Wait time management strategies for scheduled care: What makes them succeed? *Healthcare Policy*, 5(3), 66-81.
- Pomey, M.-P., Morin, E., Neault, C., Biron, V., Houle, L., Lavigne, L., . . . Beaumont, M. (2016). Patient Advisors: How to implement a process for involvement at all levels of governance in a healthcare organization. *Patient Experience Journal*, 3(2), 99-112.
- Pomey, M.-P., Morin, E., Neault, C., Clavel, N., D'Amour, M., & Beaumont, M. (in press). Engager les patients à tous les niveaux de gouvernance d'un établissement de santé et de services sociaux: le cas du CIUSSS de la Mauricie-et-du-Centre-du-Québec. *Le Point en administration de la santé*.
- Restall, G., & Strutt, C. (2008). Participation in planning and evaluating mental health services: Building capacity. *Psychiatric Rehabilitation Journal*, 31(3), 234-238. doi:10.2975/31.3.2008.234.238
- Rise, M. B., Solbjør, M., & Steinsbekk, A. (2014). Experiences from the implementation of a comprehensive development plan for user involvement in a mental health hospital: A qualitative case study. *International Journal of Social Psychiatry*, 60(4), 387-395. doi:10.1177/0020764013491739
- Rise, M. B., & Steinsbekk, A. (2016). Long term effect on professionals' knowledge, practice and attitudes towards user involvement four years after implementing an organisational development plan: A controlled study. *PLoS ONE*, 11(3), 1-18. doi:10.1371/journal.pone.0150742
- Rogers, E. M. (2003). *Diffusion of Innovations* (5<sup>th</sup> ed.). New York, NY: The Free Press.
- Rose, D., Fleischmann, P., & Schofield, P. (2010). Perceptions of user involvement: A user-led study. *International Journal of Social Psychiatry*, 56(4), 389-401. doi:10.1177/0020764009106618
- Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P., & Wykes, T. (2003). *User and carer involvement in change management in a mental health context: Review of the literature. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D*. Retrieved from [http://www.nets.nihr.ac.uk/\\_\\_data/assets/pdf\\_file/0006/64338/FR-08-1201-017.pdf](http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0006/64338/FR-08-1201-017.pdf)
- Rowe, M., Clayton, A., Benedict, P., Bellamy, C., Antunes, K., Miller, R., . . . O'Connell, M. J. (2012). Going to the source: Creating a citizenship outcome measure by community-based participatory research methods. *Psychiatric Services*, 63(5), 445-450. doi:doi:10.1176/appi.ps.201100272
- Rutter, D., Manley, C., Weaver, T., Crawford, M. J., & Fulop, N. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health

services in London. *Social Science & Medicine*, 58(10), 1973-1984. doi:10.1016/S0277-9536(03)00401-5

Schein, E. H. (1985). *Organizational culture and leadership* (1<sup>st</sup> ed.). San Francisco, CA: Jossey-Bass Publishers.

Simpson, E. L., & House, A. O. (2003). User and carer involvement in mental health services: From rhetoric to science. *The British Journal of Psychiatry*, 183(2), 89-91. doi:10.1192/bjp.183.2.89

Storm, M., & Edwards, A. (2013). Models of user involvement in the mental health context: Intentions and implementation challenges. *Psychiatric Quarterly*, 84(3), 313-327. doi:10.1007/s11126-012-9247-x

Storm, M., Knudsen, K., Davidson, L., Hausken, K., & Johannessen, J. O. (2011). "Service user involvement in practice": The evaluation of an intervention program for service providers and inpatients in Norwegian Community Mental Health Centers. *Psychosis*, 3(1), 29-40. doi:10.1080/17522439.2010.501521

Tambuyzer, E., Pieters, G., & Van Audenhove, C. (2014). Patient involvement in mental health care: One size does not fit all. *Health Expectations*, 17(1), 138-150. doi:10.1111/j.1369-7625.2011.00743.x

Tritter, J. Q., & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76(2), 156-168. doi:10.1016/j.healthpol.2005.05.008

Truman, C., & Raine, P. (2002). Experience and meaning of user involvement: Some explorations from a community mental health project. *Health and Social Care in the Community*, 10(3), 136-143.

Valiant Cook, J. (1995). Innovation and leadership in a mental health facility. *The American Journal of Occupational Therapy*, 9(7), 596-606.

Yin, R. K. (2009). *Case study research: Design and methods* (4<sup>th</sup> ed.). Thousand Oaks, CA: Sage Inc.

**Appendix: Table 5. The implementation process of the committee and the influencing factors**

	<b>AGENDA-SETTING</b>	<b>MATCHING</b>	<b>REDEFINING/RESTRUCTURING</b>	<b>CLARIFYING</b>	<b>ROUTINIZING</b>
<b>Content of implementation process</b>	Elaboration of patient engagement within one department (policy, compensation etc.)	Organization of civic forum  Study visits to explore recovery and citizenship psychiatry (France inspiring)	Establishment of committee for patient engagement  Researcher and member of initiating department as first members (presidents)	Elaboration of centralized system: - Formal policy and procedures - Request form - Compensation form - Tracking mechanism	Ongoing application of procedures  Creation of evaluation mechanism  Increased participation (activities and patient partners)
	Training for participation	Conceptualization of full citizenship vision	Inclusion of several departments, the user committee, two patient partners (one as coordinator)	Reflection on functioning participation	
	Creation of self-help group	Mandate assigned for realization of patient engagement within the new vision	Change of president	Removal of discriminating organizational structures	
	Introduction of combination of citizen psychiatry (CP) and recovery (R)		Elaboration of mandate and role of committee  Budget from top management	Communication and promotion	
<b>Organizational and environmental factors (facilitating (+)/limiting (-))</b>	Top management support (+)				
	Collaboration with self-help group (+)				
	Resistance towards participation (especially in the beginning) and stigma (-)				
	Mental health policy (MHAP of 2005-2010) (+)	Full citizenship vision (+)			
		Obligation to evolve in research and innovative practices (+)	Financial resources (+)		
	Management support in initiating department (+)	Leadership key actors top management /research department (+)	“Bearers” of full citizenship vision (+)		
		Difficulty in sharing the vision (-)	Supportive network (+)		
International influence (+)		Shared leadership management/research (+)		Reform in healthcare system (-)	

## **6. Discussion**

The discussion of the results in this study included in the article in *chapter 5*. brings up several aspects of the implementation of the strategic committee for patient engagement. Additional topics of discussion will be explored in the following sections of the master's thesis and certain of the previously discussed will be further treated.

### **6.1 Summary of Results**

Based on the conceptual framework presented in *chapter 3*, the results of this study present the process of implementation of an organizational strategic committee for patient engagement including both its initiation and operationalization process. To the initiation process belonged the need to formalize already existing participation of patient partners, as well as the introduction of a new organization-wide vision for full citizenship implying changes and an opportunity for this formalization. To the operationalization process of the committee belonged the creation of the structure for the committee through its composition and their role, the work of the committee to frame the participation of patient partners (e.g., elaboration of functioning conditions by a centralized system including structured procedures and by the removal of discriminatory elements, promotion of the participation), as well as the ongoing application of the elaborated framing including an evaluation mechanism for the participation of patient partners.

When it comes to the influencing factors on both organizational and environmental levels, the majority of the factors had a facilitating influence. The organizational facilitating factors concerned constant top management support, management support in the beginning of the implementation, leadership from different actors, financial resources, the vision of full citizenship, as well as individuals carrying this vision within the organization. The limiting factors were most present in the initiation process and concerned resistance towards the participation of patient partners, and difficulty in sharing the full citizenship vision within the organization. The environmental factors that had a facilitating influence were mental health policy, an obligation to advance when it came to research and innovative practices, the influence from international actors in the elaboration of the full citizenship vision, the support from a self-

help group of patient partners throughout the implementation, and finally a supportive network within and outside the organization for the participation of patient partners. The limiting factors in the environment of the organization were the stigmatization of the mental illness, as well as the arrival of the reform in the healthcare system in Quebec in 2015. The consequences of the committee concerned an increased and improved participation of patient partners, as well as reduced stigmatization within the organization through the formal and larger presence given to patients. The results show a process of implementation including many different elements and actors, as well as organizational and environmental influences.

## **6.2 Comparison with Literature**

In this section, the results will be compared with those of studies treating the implementation of similar structures of patient engagement, as well as other literature that is connectable to the results. The participation in the implementation process will firstly be discussed. Then follows a discussion regarding the support for implementation within the organization, and finally a short discussion on the reform in the healthcare system of Quebec in connection to the implementation of strategic structures for patient engagement.

### **6.2.1 Participation in the implementation process**

This study illustrates the implementation of an organizational strategic committee for patient engagement in mental health. Although no equivalent model has been identified in the literature, comparisons to similar ones can be done. When comparing the present study to other studies treating the implementation of various organization-wide structures for ameliorated patient engagement, the topic of participation in the implementation process is of interest. Rise et al. (2014) bring forward the lack of spread of the patient engagement within the organization, depending on the polarization it implies when only one department is directing the implementation. This is in complete opposition to the results of the present study, where the committee was based on the inclusion of a variety of representatives, covering several departments as well as patient representatives, leading to an increase and a spread of the participation of patient partners. Shared responsibility is built on an experience of being included in a context. In the study by Rise et al., the patient engagement rested on a thin base

for participation in the implementation process itself, where various actors within the organization felt excluded. Interestingly, the aspect of inclusion is concentrated on the participation of patients in the implementation of patient engagement structures on larger scales in the literature (Brooks, 2008; Kendell et al., 2014; Pomey et al., 2016), and even the patients being in majority (Brooks, 2008). This supports the expressed need to take the patients out of the traditional patient role in order for the other actors to familiarize with this new way of working, when aiming for patient engagement in a holistic way in all places within an organization (Storm & Edwards, 2013). This new role can be connected to the present study through the coordinator of the strategic committee being a patient partner. In addition to this important role of a patient partner, the present study also shows the importance of the inclusion of actors in positions of responsibility from different departments within the organization in the implementation of these kinds of structures for patient engagement, in order for the engagement to be spread out. This indicates that the roles of the actors involved are important to consider.

### **6.2.2 Support for implementation**

Another topic to be discussed regarding the results of this study in comparison to the implementation of similar structures for patient engagement is the need of support. First, the support of higher governance instances within the organization is an aspect emphasized both in the present study, and in several of the studies treating structures on larger scales (Brooks et al., 2015; Pomey et al., 2016; Storm, Knudsen, et al., 2011). The importance of this support for financial resources to be obtained has also been brought forward (Pomey et al., 2016), which is one prominent facilitator when it comes to patient engagement (Bowl, 1996; Simpson & House, 2003), as also the present study indicates. Despite this, the importance of management support has been partly disregarded in a study on different organizational innovations within healthcare, where instead the support further down in the organization on a clinical level is emphasized in the form of “champions” (Øvretveit et al., 2012). These champions are individuals supporting and explicitly applying the innovation (Øvretveit et al., 2012). Champions for innovations holding different roles have been widely present in the literature on implementation within the healthcare quality domain (Kaplan et al., 2010; Kirchner et al., 2012), and is therefore also connectable to patient engagement treated in this study. Also, when it specifically comes to changes carried out in mental healthcare organizations concerning patient engagement, both

managers as well as more clinical personnel as champions are determinant (Rose et al., 2003). This can be connected to the individuals of various roles supporting the vision of full citizenship and therefore the work of the committee, constituting a facilitating factor in the present study. This also raises the question of legitimacy for the change, which is of essence in the healthcare field (Lockett, Currie, Waring, Finn, & Martin, 2012). In this aspect, the role of the committee in the present study as a formal structure for the patient engagement is distinguished from that of the above-mentioned champions, who support the implementation in an informal manner. Finally, another level of support was identified in the present study, namely the one external to the organization (e.g., other organizations, different actors etc.), which is brought forward in the mental health field due to its community anchorage (Mendel et al., 2008). This kind of support was a facilitating factor in the present study, involving a network in which the committee functioned, constituted of different instances within patient engagement both on the organization's inside and outside. Although this aspect is mentioned to a certain extent concerning concrete assistance in implementation in studies treating similar structures (Kendell et al., 2014; Pomey et al., 2016), relations of support with other instances or individuals in connection to, or inside the organization have been emphasized specifically regarding innovation in mental health (Brooks et al., 2011).

### **6.2.3 Reform in the healthcare system**

The reform that arrived in the healthcare system of Quebec in 2015 involving the creation of larger organizational structures through comprising mergers (National Assembly of Quebec, 2015) had an impact on the work of the committee in this study, leading to a reflection on how to spread the structure for patient engagement on a larger scale within the new organization. A similar structure for patient engagement is treated in the study by Pomey et al. (2016), where this reform involved the same type of questionings as in the case of the present study. In the case described by Pomey et al. (in press), a successful spread of the initial structure for patient engagement took place within the new larger organizational entity following the reform. This spread was facilitated by key individuals from the prior approach and the recognition by the new top management of the importance of the structure for patient engagement (Pomey et al., in press). As a healthcare reform can be the trigger for innovativeness within organizations

(Breton, Lamothe, & Denis, 2014), the development for the mental healthcare organization of the present study constitutes an interesting topic for further research.

### **6.3 Comparison with Theory**

The previously identified lack of use of explicit theory when studying the implementation of structures for patient engagement on organization-wide levels, indicates that the study presented in this master's thesis has taken a new approach in this subject. Moreover, when it comes to qualitative studies regarding implementation in mental health, the theory based approach is scarce (Palinkas, 2014). The use of a conceptual framework based on implementation literature has allowed for several elements of the process of implementation to be brought forward in this study, specifically when it comes to patient engagement in mental health. Additionally, the expressed lack of focus on the first stages of implementation where preparation takes place in implementation studies in healthcare (Länsisalmi, Kivimäki, Aalto, & Rouranen, 2006), implies that the present study can highlight this aspect by its conceptual framework explicitly containing separate initiation and operationalization processes. This has allowed for the preparatory actions of the implementation of the committee, as well as its establishment to be presented in a distinguished way. Additionally, the inclusion of the organizational and environmental factors influencing the implementation of the committee implies that the context was considered, as emphasized by the literature (Aarons et al., 2011; Durlak & DuPre, 2008; Mendel et al., 2008). Finally, due to the need for clarification of what organization-wide patient engagement structures aiming ameliorations of the engagement can lead to (Rise & Steinsbekk, 2015, 2016), the consequences of the implementation of the committee emerging from the results in the present study can contribute to filling this knowledge gap. The conceptual framework in this study can be ameliorated and made more specific by adding details regarding what consequences the implementation of a strategic committee for patient engagement can have concerning the patient engagement within an organization. According to the consequences brought forward in the present study, the categories of quality of participation, range of participation, volume of participation, and aspects of the organizational culture could be added in a future conceptual framework.

The model by Rogers (2003) that constituted the base for the analysis of the stages of the implementation process (separated in initiation and operationalization) of the strategic committee for patient engagement through the conceptual framework in the present study (see *chapter 3*), allowed for the content of each stage to be brought forward. It is now pertinent to compare this content to the theoretic literature of more specific kind.

### **6.3.1 Initiation process**

Looking at more specific content, the models by Kotter (1995) and Meyers et al. (2012) both contain preparatory stages that are partly coherent with the content of the initiation process of the strategic committee in this study. An intentional collective leadership and a vision for the change that is to be carried out (Kotter, 1995), are present in this study through the efforts and leadership of several key actors in the development of the full citizenship vision, and continuing in the operationalization of the committee. This supports the expressed need for collective leadership throughout implementation (Kotter, 1995). Building on this, the adaption that took place regarding the full citizenship vision to the context of the mental healthcare organization in this study is in coherence with the model by Meyers et al., bringing forward this type of adaption as crucial in the beginning of implementation. However, the aspect of having a plan prior to explicit implementation (Kotter, 1995; Meyers et al., 2012) was not the case in the results of the present study. Interestingly, the majority of the stages in the models by Kotter and by Meyers et al. point to preparatory actions being done, and can be connected to the above-mentioned importance of these stages (Länsisalmi et al., 2006). This importance can also be identified through the results of this study, in which the vision of full citizenship was developed in the initiation process, supporting and playing a major role for the work of the committee and the participation of patient partners within the organization.

### **6.3.2 Operationalization process**

Moving to the operationalization process of the committee, the actions to create conditions for the participation of patient partners within the vision of full citizenship are particularly compliant with the model by Kotter (1995), in which a vision is central and needs to be accommodated through different means within the organization. Kotter indicates that these

means involve “risk-taking” implying that the old ways of doing things, but also organizational structures, need to be altered. A parallel can here be made to the mental health domain, where the need for distance from traditionally inherent aspects is prominent (Brooks et al., 2011), something the results of the present study also point to. Furthermore, the need for a team or individuals putting the innovation into use has been expressed by both Kotter and by Meyers et al. (2012), and can also be connected to the present study through the members of the committee itself. Additionally, ongoing efforts when implementing an innovation or a change when it comes to the innovation itself, but also to the individuals carrying it out (Kotter, 1995; Meyers et al., 2012), are illustrated in the present study through for example the changing composition of the committee and their continuing efforts to ameliorate the participation of patient partners. One final parallel between the specific theory and the implementation of the committee in this study, is the establishment of means to overview the innovation and its effect (Kotter, 1995; Meyers et al., 2012). It is interesting to note that an adapted structure for the innovation or the change is situated in the preparatory stages of the models of both Kotter and by Meyers et al., but in the present study was established in the operationalization process of the committee, where it was formally constituted.

## **6.4 Strengths and Limits**

In this section, the strengths and the limits of the study will be discussed in parallel. First, two of the co-authors of the article presented in *chapter 5*. of this master’s thesis were part of the implementation process of the committee. This potentially implies that the presentation of the results is influenced and reflected by their viewpoints, although these authors did not participate in the data analysis. The triangulation of data with a variety of participants in the study, and the combination of interviews, focus groups, and organizational documents as part of the data collection has been done in order to include many perspectives on the implementation process of the committee, and can, as previously mentioned, increase the credibility of the results of the study (Guba, 1981). However, foremost this aspect constitutes a strength since these co-authors’ knowledge of the matter has allowed for guidance and a thorough understanding of the studied events.

Saturation, implying the exhaustion of the data collection indicating it being complete (Palinkas, 2014) can be discussed in this study. The non-inclusion of all pertinent participants due to the changes following the reform in the healthcare system of Quebec in 2015, and the study being of retrospective kind, constitutes a limit of the study, since it implies that further perspectives could have shed light on additional aspects of the implementation of the committee. However, at the end of the data collection, the same themes were reoccurring and confirmed the already collected data, indicating a certain level of saturation. In connection to data collection was the inclusion of two participants at the same time during two of the interviews, which might have led to certain information not being expressed due to the presence of the other person. At the same time, a complementary effect can also be considered possible as more of a discussion was taking place.

Furthermore, the transferability of the results deserves to be discussed under this topic. This aspect is depending on both the obtained and the presented information regarding the context of the studied events (Guba, 1981). When it comes to the transferability of the results in this study, contextual information of the process of implementation of the strategic committee has been provided on several levels. As the literature review in *chapter 2*. shows, the specific context of mental health places the engagement of patients in a specific position with particularities to be considered (Munro et al., 2006). Contextual elements have, in the present study, been provided through previous literature presented in the introduction and the literature review. The results also contain these kinds of elements, both those stemming from the content of the stages within the initiation and the operationalization of the committee, and also elements identified through the influential contextual factors on organizational and environmental levels. Contextual information is fundamental when it comes to case studies (Yin, 2009), and contributes to the necessary “holistic” way of treating the studied events in the mental health field (Palinkas, 2014). Qualitative studies do not seek to generalize the results, but rather to thoroughly describe and understand them (Palinkas, 2014). In order for this to be done, participants that could provide information regarding the implementation process of the committee or its contextual elements were included in the study through a purposeful sample (Guba, 1981), which is a sampling method often employed in qualitative studies in the mental health field (Palinkas, 2014). Based on the discussion regarding the aspect of transferability in the present study, the

results can be considered transferable to the extent that the specificities of both the implementation of the committee and its context are taken into consideration. When applying the results of the present case study in other contexts, the points mentioned below are important to consider. Firstly, patient engagement in mental health is consistently included in policy guiding the activity of mental health organizations (Bee, Brooks, et al., 2015; Lammers & Happell, 2003). The MHAP of Quebec of 2005-2010 (MSSS, 2005) played a large role at the starting point of the engagement of patients within the mental health organization in the present study. Public mental health policy is therefore a central aspect of the context of the case in this study, working as a favourable element for the implementation of the strategic committee for patient engagement. Secondly, a strong interest for – and space for leaders to promote and put in place – a structure for patient engagement, are characterizing the case of the present study. This points to the necessity of an organizational will and an open organizational culture allowing for a structure like the one of the present case study to be implemented. Finally, structural organizational aspects are central in the present study. The mental health organization consisting of several departments, many taking part in the strategic committee, played a role in the implementation by allowing for large parts of the organization to be covered by the patient engagement. To summarize, the case described in this study is characterized by it being affected by mental health policy, and by the existence of a cultural and structural space for the strategic committee for patient engagement to be implemented. These aspects can be considered important for other mental health organizations interested in implementing similar structures for patient engagement.

Finally, in connection to the contextual elements discussed above, there was at times difficulty in identifying when an influential factor belonged to the implementation process of the committee itself, or to the organization and environment outside of it. The complexity of this type of interaction has been brought forward, implying that description of the relation between the implementation process and the influential factors, and how this relation develops at different points in time becomes important (Øvretveit, 2011). This kind of description is included in the present study through detailed information being provided regarding the process of implementation of the committee as well as the facilitating or limiting factors of its various stages.

## **7. Conclusion**

This master's thesis treats the implementation of an organizational strategic committee for patient engagement within a mental healthcare organization. Based on a conceptual framework including the initiation and operationalization process of the strategic committee, the organizational and environmental influential factors, as well as the perceived consequences of its implementation, this study illustrates an implementation process that is involving a multitude of elements, many different actors, and that is influenced by a variety of factors. The results show that in order to successfully frame the patient engagement within an organization including both its practical and democratic conditions, leadership by a variety of actors and a vision giving meaning and content to the engagement, are crucial. The presence of support from all levels of the organization, as well as from its outside, is of importance throughout the entire implementation process. Through the identified absence of equivalent committees for patient engagement in the literature, this case study highlights an innovative approach for patient engagement, undertaken in a mental health context. This study can function as an example for others interested in implementing similar structures. Further research is needed for the impact of this kind of structure further down in healthcare organizations to be explored, regarding the quality of the care and the services.

## 8. References

- Aarons, G. A., Hurlburt, M., & Horwitz, S. M. (2011). Advancing a conceptual model of evidence-based practice implementation in public service sectors. *Administration and Policy in Mental Health and Mental Health Services Research*, 38(1), 4-23. doi:10.1007/s10488-010-0327-7
- Abelson, J. (2001). Understanding the role of contextual influences on local health-care decision making: Case study results from Ontario, Canada. *Social Science & Medicine*, 53(6), 777-793. [http://dx.doi.org/10.1016/S0277-9536\(00\)00386-5](http://dx.doi.org/10.1016/S0277-9536(00)00386-5)
- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11-23. doi:10.1037/h0095655
- Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35(4), 216-224. doi:10.1080/01944366908977225
- Baker, G. R. (2014). *Evidence boost: A review of research highlighting how patient engagement contributes to improved care*. Canadian Foundation for Healthcare Improvement. Retrieved from <http://www.cfhi-fcass.ca/sf-docs/default-source/reports/evidenceboost-rossbaker-peimprovedcare-e.pdf?sfvrsn=8>
- Barello, S., Graffigna, G., & Vegni, E. (2012). Patient engagement as an emerging challenge for healthcare services: Mapping the literature. *Nursing Research and Practice*, 2012, 1-7. doi:10.1155/2012/905934
- Barnes, M. (1999). Users as citizens: Collective action and the local governance of welfare. *Social Policy & Administration*, 33(1), 73-90. doi:10.1111/1467-9515.00132
- Barnes, M., & Sharlow, P. (1997). From passive recipient to active citizen: Participation in mental health user groups. *Journal of Mental Health*, 6(3), 289-300.
- Barnes, M., & Wistow, G. (1994). Learning to hear voices: Listening to users of mental health services. *Journal of Mental Health*, 3(4), 525-540.
- Bee, P., Brooks, H., Fraser, C., & Lovell, K. (2015). Professional perspectives on service user and carer involvement in mental health care planning: A qualitative study. *International Journal of Nursing Studies*, 52(12), 1834-1845. <http://dx.doi.org/10.1016/j.ijnurstu.2015.07.008>
- Bee, P., Price, O., Baker, J., & Lovell, K. (2015). Systematic synthesis of barriers and facilitators to service user-led care planning. *The British Journal of Psychiatry*, 207(2), 104-114. doi:10.1192/bjp.bp.114.152447

- Begun, J.W., Zimmerman, B., Dooley, K. (2003). Health care organizations as complex adaptive systems, in S. M. Mick, M. Wyttenback (Eds), *Advances in Health care Organization Theory* (pp.253-288). San Francisco: Jossey-Bass.
- Borg, M., Karlsson, B., & Kim, H. S. (2009). User involvement in community mental health services – principles and practices. *Journal of Psychiatric and Mental Health Nursing*, 16(3), 285-292. doi:10.1111/j.1365-2850.2008.01370.x
- Bowl, R. (1996). Involving service users in mental health services: Social Services Departments and the National Health Service and Community Care Act 1990. *Journal of Mental Health*, 5(3), 287-304.
- Breton, M., Lamothe, L., & Denis, J.-L. (2014). How healthcare organisations can act as institutional entrepreneurs in a context of change. *Journal of Health Organization and Management*, 28(1), 77-95. doi:10.1108/JHOM-07-2011-0072
- Broer, T., Nieboer, A. P., & Bal, R. (2014). Mutual powerlessness in client participation practices in mental health care. *Health Expectations*, 17(2), 208-219. doi:10.1111/j.1369-7625.2011.00748.x
- Brooks, F. (2008). Nursing and public participation in health: An ethnographic study of a patient council. *International Journal of Nursing Studies*, 45(1), 3-13. <http://dx.doi.org/10.1016/j.ijnurstu.2006.08.012>
- Brooks, H., Pilgrim, D., & Rogers, A. (2011). Innovation in mental health services: What are the key components of success? *Implementation Science*, 6(1), 120. doi:10.1186/1748-5908-6-120
- Brooks, H., Sanders, C., Lovell, K., Fraser, C., & Rogers, A. (2015). Re-inventing care planning in mental health: Stakeholder accounts of the imagined implementation of a user/carer involved intervention. *BMC Health Services Research*, 15, 490. doi:10.1186/s12913-015-1154-z
- Bullock, R. J., & Batten, D. (1985). It's just a phase we are going through: A review and synthesis of OD phase analysis. *Group & Organization Studies*, 10(4), 383-412.
- Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223-231. doi:10.1377/hlthaff.2012.1133
- Champagne, F. (2002). *La capacité de gérer le changement dans les organisations de santé*. (Étude no 39). Commission sur l'avenir des soins de santé. Retrieved from <http://www.publications.gc.ca/collections/Collection/CP32-79-39-2002F.pdf>

- Champagne, F., Brousselle, A., Hartz, Z., Contandriopoulos, A.-P., & Denis, J.-L. (2011). L'analyse de l'implantation. In A. Brousselle, F. Champagne, A.-P. Contandriopoulos, & Z. Hartz (Eds.), *L'évaluation: Concepts et méthodes* (2<sup>nd</sup> ed., pp. 237-273). Montreal, Quebec: Les Presses de l'Université de Montréal.
- Charles, C., & DeMaio, S. (1993). Lay participation in health care decision making: A conceptual framework. *Journal of Health Politics, Policy, and Law*, 18(4), 881-903.
- Clément, M. (2011). La participation, les temps de la parole et le mouvement des usagers des services de santé mentale au Québec. *Le partenaire*, 20(2), 4-13.
- Clément, M., Lourdes, R., Gagné, J., Levesque, A., & Vallée, C. (2012). *État de situation sur la participation des personnes utilisatrices suite au Plan d'action en santé mentale 2005-2010*. Santé mentale et citoyenneté. Retrieved from [http://www.aruci-smc.org/fileadmin/documents/documents\\_divers/ARUCI-SMC\\_rapport\\_Final-Web.pdf](http://www.aruci-smc.org/fileadmin/documents/documents_divers/ARUCI-SMC_rapport_Final-Web.pdf)
- Contandriopoulos, A.-P., Champagne, F., Potvin, L., Denis, J.-L., & Boyle, P. (2005). *Savoir préparer une recherche: la définir, la structurer, la financer*. Montreal, Quebec: Gaëtan morin éditeur ltée.
- Coulter, A. (2002). *The Autonomous Patient: Ending paternalism in medical care*: London: The Nuffield Trust/The Stationary Office.
- Crawford, M. J., Aldridge, T., Bhui, K., Rutter, D., Manley, C., Weaver, T., . . . Fulop, N. (2003). User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. *Acta Psychiatrica Scandinavica*, 107(6), 410-414. doi:10.1034/j.1600-0447.2003.00049.x
- Crawford, M. J., & Rutter, D. (2004). Are the views of members of mental health user groups representative of those of 'ordinary' patients? A cross-sectional survey of service users and providers. *Journal of Mental Health*, 13(6), 561-568.
- Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*, 325(7375), 1263. doi:10.1136/bmj.325.7375.1263
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, 4(1), 50. doi:10.1186/1748-5908-4-50
- Davidson, L., & Roe, D. (2007). Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery. *Journal of Mental Health*, 16(4), 459-470. doi:10.1080/09638230701482394

- de Freitas, C., & Martin, G. (2015). Inclusive public participation in health: Policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare. *Social Science & Medicine*, *135*, 31-39.  
<http://dx.doi.org/10.1016/j.socscimed.2015.04.019>
- Demers, C. (1999). De la gestion du changement à la capacité de changer. L'évolution de la recherche sur le changement organisationnel de 1945 à aujourd'hui. *Revue Gestion*, *24*(3), 131-139.
- Denis, J.-L., Langley, A., & Rouleau, L. (2010). The practice of leadership in the messy world of organizations. *Leadership*, *6*(1), 67-88. doi:10.1177/1742715009354233
- Devers, K. J. (1999). How will we know "good" qualitative research when we see it? Beginning the dialogue in health services research. *Health Services Research*, *34*(5), 1153-1188.
- Durlak, J. A., & DuPre, E. P. (2008). Implementation matters: A review of research on the influence of implementation on program outcomes and the factors affecting implementation. *American Journal of Community Psychology*, *41*(3-4), 327-350. doi:10.1007/s10464-008-9165-0
- Elstad, T. A., & Eide, A. H. (2009). User participation in community mental health services: Exploring the experiences of users and professionals. *Scandinavian Journal of Caring Sciences*, *23*(4), 674-681. doi:10.1111/j.1471-6712.2008.00660.x
- Ewalds, A.-P., Desbiens, F., Pomey, M.-P. (2016). *La démarche de pleine citoyenneté à [...]*. Unpublished document.
- Fairweather, G. W., Sanders, D. H., & Tornatzky, L. G. (1974). *Creating change in mental health organizations*. New York, NY: Pergamon Press Inc.
- Fernandez, S., & Rainey, H. G. (2006). Managing successful organizational change in the public sector. *Public Administration Review*, *66*(2), 168-176.
- Fitzgerald, M. M., Kirk, G. D., & Bristow, C. A. (2011). Description and evaluation of a serious game intervention to engage low secure service users with serious mental illness in the design and refurbishment of their environment. *Journal of Psychiatric and Mental Health Nursing*, *18*(4), 316-322. doi:10.1111/j.1365-2850.2010.01668.x
- Fixsen, D. L., Blase, K. A., Naoom, S. F., & Wallace, F. (2009). Core implementation components. *Research on Social Work Practice*, *19*(5), 531-540. doi:10.1177/1049731509335549
- Flora, L., Lebel, P., Dumez, V., Bell, C., Lamoureux, J., & Saint-Laurent, D. (2015). L'expérimentation du programme partenaires de soins en psychiatrie : le modèle de Montréal. *Santé mentale au Québec*, *40*(1), 101-107. doi: 10.7202/1032385ar

- Fumagalli, L. P., Radaelli, G., Lettieri, E., Bertele', P., & Masella, C. (2015). Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. *Health Policy*, *119*(3), 384-394.  
<http://dx.doi.org/10.1016/j.healthpol.2014.10.017>
- Gallivan, J., Kovacs Burns, K. A., Bellows, M., & Eigenseher, C. (2012). The Many Faces of Patient Engagement. *Journal of Participatory Medecine*, *4*, e32. Retrieved from <http://www.jopm.org/evidence/research/2012/12/26/the-many-faces-of-patient-engagement/>
- Garside, P. (1998). Organisational context for quality: Lessons from the fields of organisational development and change management. *Quality in health care*, *7*(Suppl), S8-S15.
- Gordon, S. (2005). The role of the consumer in the leadership and management of mental health services. *Australasian Psychiatry*, *13*(4), 362-365. doi:10.1080/j.1440-1665.2005.02215.x
- Greenhalgh, T., Robert, G., MacFarlane, F., Paul, B., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: Systematic review and recommendations. *The Milbank Quarterly*, *82*(4), 581-629. doi: 10.1111/j.0887-378X.2004.00325.x
- Groene, O., & Sunol, R. (2015). Patient involvement in quality management: Rationale and current status. *Journal of Health Organization and Management*, *29*(5), 556-569. doi:10.1108/JHOM-07-2014-0122
- Grol, R. P. T. M., Bosch, M. C., Hulscher, M. E. J. L., Eccles, M. P., & Wensing, M. (2007). Planning and studying improvement in patient care: The use of theoretical perspectives. *The Milbank Quarterly*, *85*(1), 93-138. doi:10.1111/j.1468-0009.2007.00478.x
- Guba, E. G. (1981). ERIC/ECTJ Annual Review Paper: Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology*, *29*(2), 75-91.
- Hatchuel, A. (2000). Prospective et gouvernance: quelle théorie de l'action collective ? . In E. Heurgon & J. Landrieu (Eds.), *Prospective pour une gouvernance démocratique* (pp. 29-42). La Tour d'Aigues, France: Éditions de l'Aube.
- Hickey, G., & Kipping, C. (1998). Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing*, *7*(1), 83-88. doi:10.1046/j.1365-2702.1998.00122.x
- Jewell, C., Davidson, L., & Rowe, M. (2006). The paradox of engagement: How political, organizational, and evaluative demands can hinder innovation in community mental health services. *Social Service Review*, *80*(1), 3-26. doi:10.1086/498837

- Kaplan, H. C., Brady, P. W., Dritz, M. C., Hooper, D. K., Linam, W. M., Froehle, C. M., & Margolis, P. (2010). The influence of context on quality improvement success in health care: A systematic review of the literature. *The Milbank Quarterly*, 88(4), 500-559. doi:10.1111/j.1468-0009.2010.00611.x
- Kemper, C., Blackburn, C., Doyle, J. A., & Hyman, D. (2013). Engaging patients and families in system-level improvement : A safety imperative. *Nursing Administration Quarterly*, 37(3), 203-215. doi:10.1097/NAQ.0b013e318295f61e
- Kendell, C., Urquhart, R., Petrella, J., MacDonald, S., & McCallum, M. (2014). Evaluation of an advisory committee as a model for patient engagement. *Patient Experience Journal*, 1(2), 62-70.
- Kirchner, J. E., Parker, L. E., Bonner, L. M., Fickel, J. J., Yano, E. M., & Ritchie, M. J. (2012). Roles of managers, frontline staff and local champions, in implementing quality improvement: Stakeholders' perspectives. *Journal of Evaluation in Clinical Practice*, 18(1), 63-69. doi:10.1111/j.1365-2753.2010.01518.x
- Kitzinger, J. (2006). Focus Groups. In C. Pope & N. Mays (Eds.), *Qualitative Research in Health Care* (3<sup>rd</sup> ed., pp. 21-31). Oxford, England: Blackwell Publishing Ltd.
- Kotter, J. P. (1995). Leading change: Why transformation efforts fail. *Harvard Business Review*, 73(2), 59-67.
- Kovacs Burns, K., Bellows, M., Eigenseher, C., & Gallivan, J. (2014). 'Practical' resources to support patient and family engagement in healthcare decisions: A scoping review. *BMC Health Services Research*, 14(1), 175. doi:10.1186/1472-6963-14-175
- Kvale, S. (2007). *Doing interviews*. London, England: Sage Publications.
- Lammers, J., & Happell, B. (2003). Consumer participation in mental health services: Looking from a consumer perspective. *Journal of Psychiatric and Mental Health Nursing*, 10(4), 385-392. doi:10.1046/j.1365-2850.2003.00598.x
- Länsisalmi, H., Kivimäki, M., Aalto, P., & Rouranen, R. (2006). Innovation in healthcare: A systematic review of recent research. *Nursing Science Quarterly*, 19(1), 66-72. doi:10.1177/0894318405284129
- Lester, H., Tait, L., England, E., & Tritter, J. (2006). Patient involvement in primary care mental health: A focus group study. *The British Journal of General Practice*, 56(527), 415-422.
- Linhorst, D. M., Eckert, A., & Hamilton, G. (2005). Promoting participation in organizational decision-making by clients with severe mental illness. *Social Work*, 50(1), 21-30. doi:10.1093/sw/50.1.21

- Lockett, A., Currie, G., Waring, J., Finn, R., & Martin, G. (2012). The role of institutional entrepreneurs in reforming healthcare. *Social Science & Medicine*, 74(3), 356-363. <http://dx.doi.org/10.1016/j.socscimed.2011.02.031>
- Lord, J., Nelson, G., & Ochocka, J. (2001). *Shifting the paradigm in community mental health: Towards empowerment and community*. Toronto, ON: University of Toronto Press.
- Lord, J., Ochocka, J., Czarny, W., & MacGillivray, H. (1998). Analysis of change within a mental health organization: A participatory process. *Psychiatric Rehabilitation Journal*, 21(4), 327-329.
- Marshall, C., & Rossman, G. B. (2011). *Designing qualitative research* (5 ed.). Thousand Oaks, CA: Sage Publications.
- May, C. (2013). Towards a general theory of implementation. *Implementation Science*, 8(1), 18. doi:10.1186/1748-5908-8-18
- McDaid, S. (2009). An equality of condition framework for user involvement in mental health policy and planning: Evidence from participatory action research. *Disability & Society*, 24(4), 461-474. doi:10.1080/09687590902879064
- Mendel, P., Meredith, L. S., Schoenbaum, M., Sherbourne, C. D., & Wells, K. B. (2008). Interventions in organizational and community context: A framework for building evidence on dissemination and implementation in health services research. *Administration and Policy in Mental Health and Mental Health Services Research*, 35(1), 21-37. doi:10.1007/s10488-007-0144-9
- Meyers, D. C., Durlak, J. A., & Wandersman, A. (2012). The quality implementation framework: A synthesis of critical steps in the implementation process. *American Journal of Community Psychology*, 50(3), 462-480. doi:10.1007/s10464-012-9522-x
- Mezzina, R., Borg, M., Marin, I., Sells, D., Topor, A., & Davidson, L. (2006). From participation to citizenship: How to regain a role, a status, and a life in the process of recovery. *American Journal of Psychiatric Rehabilitation*, 9(1), 39-61. doi:10.1080/15487760500339428
- Miles, M. B., & Huberman, M. (1994). *Qualitative data analysis: An expanded sourcebook* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications Inc.
- Millar, S. L., Chambers, M., & Giles, M. (2016). Service user involvement in mental health care: An evolutionary concept analysis. *Health Expectations*, 19(2), 209-221. doi:10.1111/hex.12353
- Ministère de la Santé et des Services sociaux. (2005). *Plan d'action en santé mentale 2005-2010 – La force des liens* (Publication No. 05-914-01). Retrieved from <http://publications.msss.gouv.qc.ca/msss/fichiers/2005/05-914-01.pdf>

- Ministère de la Santé et des Services sociaux. (2015). *Plan d'action en santé mentale 2015-2020: faire ensemble et autrement* (Publication No. 15-914-04W). Retrieved from <http://publications.msss.gouv.qc.ca/msss/fichiers/2015/15-914-04W.pdf>
- Mintzberg, H. (1989). *Mintzberg on management: Inside our strange world of organizations*. New York, NY: The Free Press.
- Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: A systematic review. *International Journal for Quality in Health Care*, 24(1), 28-38. doi:10.1093/intqhc/mzr066
- Moullin, J. C., Sabater-Hernández, D., Fernandez-Llimos, F., & Benrimoj, S. I. (2015). A systematic review of implementation frameworks of innovations in healthcare and resulting generic implementation framework. *Health Research Policy and Systems*, 13(1), 16. doi:10.1186/s12961-015-0005-z
- Munro, K., Killoran Ross, M., & Reid, M. (2006). User involvement in mental health: Time to face up to the challenges of meaningful involvement? *International Journal of Mental Health Promotion*, 8(2), 37-44. doi:10.1080/14623730.2006.9721738
- National Assembly of Quebec. (2015). *Bill n°10: An Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies*. Retrieved from <http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=5&file=2015C1A.PDF>
- Nelson, G., Kloos, B., & Ornelas, J. (2014). Transformative change in community mental health: A community psychology framework. In G. Nelson, B. Kloos, & J. Ornelas (Eds.), *Community Psychology and Community Mental Health: Towards transformative change*. doi:10.1093/acprof:oso/9780199362424.003.0001
- Nilsen, P. (2015). Making sense of implementation theories, models and frameworks. *Implementation Science*, 10(1), 53. doi:10.1186/s13012-015-0242-0
- Omeni, E., Barnes, M., MacDonald, D., Crawford, M., & Rose, D. (2014). Service user involvement: Impact and participation: A survey of service user and staff perspectives. *BMC Health Services Research*, 14(1), 491. doi:10.1186/s12913-014-0491-7
- Øvretveit, J. (2011). Understanding the conditions for improvement: Research to discover which context influences affect improvement success. *BMJ Quality & Safety*, 20(Suppl 1), i18-i23. doi:10.1136/bmjqs.2010.045955
- Øvretveit, J., Andreen-Sachs, M., Carlsson, J., Gustafsson, H., Hansson, J., Keller, C., . . . Brommels, M. (2012). Implementing organisation and management innovations in

- Swedish healthcare: Lessons from a comparison of 12 cases. *Journal of Health Organization and Management*, 26(2), 237-257. doi:10.1108/14777261211230790
- Palinkas, L. A. (2014). Qualitative and mixed methods in mental health services and implementation research. *Journal of Clinical Child & Adolescent Psychology*, 43(6), 851-861. doi:10.1080/15374416.2014.910791
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Peck, E., Gulliver, P., & Towel, D. (2002). Information, consultation or control: User involvement in mental health services in England at the turn of the century. *Journal of Mental Health*, 11(4), 441-451.
- Pelletier, J.-F., Bordeleau, J., Dumais, A., Renaud, P., & Rowe, M. (2013). Les pairs-assistants de recherche : pour favoriser l'évolution d'un statut de patients vers celui de citoyens à part entière. *Drogues, santé et société*, 12(1), 57-78. doi:10.7202/1021539ar
- Pelletier, J.-F., Corbière, M., Lecomte, T., Briand, C., Corrigan, P., Davidson, L., & Rowe, M. (2015). Citizenship and recovery: Two intertwined concepts for civic-recovery. *BMC Psychiatry*, 15(37), 1-7. doi:10.1186/s12888-015-0420-2
- Pelletier, J.-F., Davidson, L., & Roelandt, J.-L. (2009). Citizenship and recovery for everyone: A global model of public mental health. *International Journal of Mental Health Promotion*, 11(4), 45-53. doi:10.1080/14623730.2009.9721799
- Pelletier, J.-F., Lesage, A., Boisvert, C., Denis, F., Bonin, J.-P., & Kisely, S. (2015). Feasibility and acceptability of patient partnership to improve access to primary care for the physical health of patients with severe mental illnesses: an interactive guide. *International Journal for Equity in Health*, 14(1), 78. doi:10.1186/s12939-015-0200-0
- Perreault, M., Renaud, J., Bourassa, F., Beauchesne, L., Mpiana, A., Bernier, S., & Milton, D. (2010). Implementation of a panel of service users for the evaluation of mental health outpatient services. *Evaluation & the Health Professions*, 33(4), 480-496. doi:10.1177/0163278710383561
- Pilgrim, D., & Waldron, L. (1998). User involvement in mental health service development: How far can it go? *Journal of Mental Health*, 7(1), 95-104. <http://dx.doi.org/10.1080/09638239818373>
- Pomey, M.-P., Flora, L., Karazivan, P., Dumez, V., Lebel, P., Vanier, M.-C., . . . Jouet, É. (2015). Le « Montreal model » : enjeux du partenariat relationnel entre patients et professionnels de la santé. *Santé Publique, HS(S1)*, 41-50.

- Pomey, M.-P., Forest, P.-G., Sanmartin, C., De Coster, C., & Drew, M. (2010). Wait time management strategies for scheduled care: What makes them succeed? *Healthcare Policy*, 5(3), 66-81.
- Pomey, M.-P., Morin, E., Neault, C., Biron, V., Houle, L., Lavigueur, L., . . . Beaumont, M. (2016). Patient Advisors: How to implement a process for involvement at all levels of governance in a healthcare organization. *Patient Experience Journal*, 3(2), 99-112.
- Pomey, M.-P., Morin, E., Neault, C., Clavel, N., D'Amour, M., & Beaumont, M. (in press). Engager les patients à tous les niveaux de gouvernance d'un établissement de santé et de services sociaux: le cas du CIUSSS de la Mauricie-et-du-Centre-du-Québec. *Le Point en administration de la santé*.
- Pomey, M.-P., Pelletier, M., Denis, J.-L., Beaulieu, M.-D., Dubois, C.-A., Karazivan, P., . . . Pelletier, J.-F. (2014-2017). *Évaluation de l'impact du partenariat de soins sur l'amélioration de la qualité et de la sécurité des soins*. Projet de recherche, Partenariats pour l'amélioration des services de santé (PASS), IRSC.
- Poole, M. S., & Van de Ven, A. H. (2004). Introduction. In M. S. Poole & A. H. Van de Ven (Eds.), *Handbook of Organizational Change and Innovation* (pp. xi-xvi). New York, NY: Oxford University Press.
- Proctor, E. K., Landsverk, J., Aarons, G., Chambers, D., Glisson, C., & Mittman, B. (2009). Implementation research in mental health services: An emerging science with conceptual, methodological, and training challenges. *Administration and Policy in Mental Health and Mental Health Services Research*, 36(1), 24-34. doi:10.1007/s10488-008-0197-4
- Restall, G., & Strutt, C. (2008). Participation in planning and evaluating mental health services: Building capacity. *Psychiatric Rehabilitation Journal*, 31(3), 234-238. doi:10.2975/31.3.2008.234.238
- Rise, M. B., Solbjør, M., & Steinsbekk, A. (2014). Experiences from the implementation of a comprehensive development plan for user involvement in a mental health hospital: A qualitative case study. *International Journal of Social Psychiatry*, 60(4), 387-395. doi:10.1177/0020764013491739
- Rise, M. B., Solbjør, M., Lara, M. C., Westerlund, H., Grimstad, H., & Steinsbekk, A. (2013). Same description, different values. How service users and providers define patient and public involvement in health care. *Health Expectations*, 16(3), 266-276. doi:10.1111/j.1369-7625.2011.00713.x
- Rise, M. B., & Steinsbekk, A. (2015). Does implementing a development plan for user participation in a mental hospital change patients' experience? A non-randomized controlled study. *Health Expectations*, 18(5), 809-825. doi:10.1111/hex.12105

- Rise, M. B., & Steinsbekk, A. (2016). Long term effect on professionals' knowledge, practice and attitudes towards user involvement four years after implementing an organisational development plan: A controlled study. *PLoS ONE*, *11*(3),1-18. doi:10.1371/journal.pone.0150742
- Robert, G., Hardacre, J., Locock, L., Bate, P., & Glasby, J. (2003). Redesigning mental health services: Lessons on user involvement from the Mental Health Collaborative. *Health Expectations*, *6*(1), 60-71. doi:10.1046/j.1369-6513.2003.00209.x
- Rogers, E. M. (2003). *Diffusion of Innovations* (5<sup>th</sup> ed.). New York, NY: The Free Press.
- Rose, D., Fleischmann, P., & Schofield, P. (2010). Perceptions of user involvement: A user-led study. *International Journal of Social Psychiatry*, *56*(4), 389-401. doi:10.1177/0020764009106618
- Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P., & Wykes, T. (2003). *User and carer involvement in change management in a mental health context: Review of the literature. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D*. Retrieved from [http://www.nets.nihr.ac.uk/\\_\\_data/assets/pdf\\_file/0006/64338/FR-08-1201-017.pdf](http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0006/64338/FR-08-1201-017.pdf)
- Rowe, M., Clayton, A., Benedict, P., Bellamy, C., Antunes, K., Miller, R., . . . O'Connell, M. J. (2012). Going to the source: Creating a citizenship outcome measure by community-based participatory research methods. *Psychiatric Services*, *63*(5), 445-450. doi:doi:10.1176/appi.ps.201100272
- Rowe, M., & Pelletier, J.-F. (2012). Citizenship: A response to the marginalization of people with mental illnesses. *Journal of Forensic Psychology Practice*, *12*(4), 366-381. doi:10.1080/15228932.2012.697423
- Rutter, D., Manley, C., Weaver, T., Crawford, M. J., & Fulop, N. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science & Medicine*, *58*(10), 1973-1984. doi:10.1016/S0277-9536(03)00401-5
- Schein, E. H. (1985). *Organizational culture and leadership* (1<sup>st</sup> ed.). San Francisco, CA: Jossey-Bass Publishers.
- Scheirer, M. A. (1981). *Program Implementation: The organizational context*. Beverly Hills, CA: Sage Publications Inc.
- Serapioni, M., & Duxbury, N. (2014). Citizens' participation in the Italian health-care system: The experience of the Mixed Advisory Committees. *Health Expectations*, *17*(4), 488-499. doi:10.1111/j.1369-7625.2012.00775.x

- Shortell, S. M., Levin, J. L., O'Brien, J. L., & Hughes, E. F. (1995). Assessing the evidence of CQI: Is the glass half empty or half full? *Hospital & Health Services Administration*, 40(1), 4-24.
- Simpson, E. L., & House, A. O. (2003). User and carer involvement in mental health services: From rhetoric to science. *The British Journal of Psychiatry*, 183(2), 89-91. doi:10.1192/bjp.183.2.89
- Solbjør, M., Rise, M. B., Westerlund, H., & Steinsbekk, A. (2013). Patient participation in mental healthcare: When is it difficult? A qualitative study of users and providers in a mental health hospital in Norway. *International Journal of Social Psychiatry*, 59(2), 107-113. doi:10.1177/0020764011423464
- Stickley, T. (2006). Should service user involvement be consigned to history? A critical realist perspective. *Journal of Psychiatric and Mental Health Nursing*, 13(5), 570-577. doi:10.1111/j.1365-2850.2006.00982.x
- Storm, M., & Edwards, A. (2013). Models of user involvement in the mental health context: Intentions and implementation challenges. *Psychiatric Quarterly*, 84(3), 313-327. doi:10.1007/s11126-012-9247-x
- Storm, M., Hausken, K., & Knudsen, K. (2011). Inpatient service providers' perspectives on service user involvement in Norwegian community mental health centres. *International Journal of Social Psychiatry*, 57(6), 551-563. doi:10.1177/0020764010371270
- Storm, M., Knudsen, K., Davidson, L., Hausken, K., & Johannessen, J. O. (2011). "Service user involvement in practice": The evaluation of an intervention program for service providers and inpatients in Norwegian Community Mental Health Centers. *Psychosis*, 3(1), 29-40. doi:10.1080/17522439.2010.501521
- Tambuyzer, E., Pieters, G., & Van Audenhove, C. (2014). Patient involvement in mental health care: One size does not fit all. *Health Expectations*, 17(1), 138-150. doi:10.1111/j.1369-7625.2011.00743.x
- Tambuyzer, E., & Van Audenhove, C. (2013). Service user and family carer involvement in mental health care: Divergent views. *Community Mental Health Journal*, 49(6), 675-685. doi:10.1007/s10597-012-9574-2
- Tritter, J. Q., & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76(2), 156-168. doi:10.1016/j.healthpol.2005.05.008
- Truman, C., & Raine, P. (2002). Experience and meaning of user involvement: Some explorations from a community mental health project. *Health and Social Care in the Community*, 10(3), 136-143.

- Van de Ven, A. H., & Poole, M. S. (1995). Explaining development and change in organizations. *Academy of Management Review*, 20(3), 510-540.
- West, M. A., & Farr, J. L. (1990). Innovation at work. In M. A. West & J. L. Farr (Eds.), *Innovation and creativity at work: Psychological and organizational strategies* (pp. 3-13). Chichester, England: Wiley & Sons Ltd.
- Yin, R. K. (2009). *Case study research: Design and methods* (4<sup>th</sup> ed.). Thousand Oaks, CA: Sage Inc.

## Appendix 1. List of analyzed documents

Document	#
<b>Patient engagement and committee</b>	
Document describing the full citizenship vision	1
Pamphlet regarding full citizenship vision	1
Annual reports of committee for patient engagement (2012/2013-2014/2015)	3
Meeting minutes of committee (2011-2015)	22
Evaluation report of the participation of patient partners	1
Surveys used for evaluation report (patient partners and responsible for participation activity)	2
Presentations, conference papers: Patient participation within the organization (n=3) Patient participation and the committee (n=1) Citizen Forum and trip to France (n=2)	6
Committee's mandate	1
Committee's action plan	1
Policy for participation of patient partners	1
Excel document of participation activities	1
Cartography of procedures for participation of patient partners	1
Published articles regarding the patient participation	3
<b>Wider organizational documents</b>	
Organizational newsletters	10
Organization charts	2
Annual reports of organization (2007/2008-2014/2015)	7
Population portrait	1

## Appendix 2. Interview Guide



*Impact du partenariat de soins sur l'amélioration de la qualité et de la sécurité des soins (PASS)*

### Guide d'entrevue Acteurs-clés

---

#### PRÉAMBULE

##### Durée de l'entretien

- Remercier le participant d'avoir accepté de répondre à nos questions dans le cadre de notre étude.
- Préciser que l'entretien durera :
  - Environ 30 minutes (DG et Présidents de conseil d'administration)
  - Environ 45 minutes pour les autres catégories d'acteurs-clés

##### Règles de l'entretien

- Comme le précise le formulaire d'information et de consentement, tout ce qui sera dit restera **confidentiel**. Afin de protéger votre confidentialité, votre nom n'apparaîtra nulle part et vous demeurerez entièrement anonyme.
- À tout moment durant notre conversation, laissez-moi 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 ressentez**. Il n'y a donc pas de bonne ou de mauvaise réponse.

##### Formulaire d'information et de consentement

- Avez-vous **bien lu et bien compris** le Formulaire d'information et de consentement ?
- Est-ce que vous avez des **questions** en lien avec le formulaire d'information et de consentement ?
- L'interviewer signe les deux copies puis invite le participant à signer à son tour.
- Remettre ensuite au participant sa copie.
- S'assurer que le participant accepte que l'entrevue soit enregistrée.

##### [Débuter l'enregistrement]

## MISE EN CONTEXTE

*J'aimerais débiter par quelques questions sur votre **fonction** actuelle.*

### 1. Pouvez-vous me parler de votre expérience et de votre fonction actuelle ?

- Formation
- Parcours professionnel
- La santé mentale
- Qualité et sécurité des soins et services
- Rôles et responsabilités actuelles

## L'IMPLICATION DES PATIENTS ET DE LEURS FAMILLES

*Notre projet de recherche vise à « étudier différentes formes de partenariat de soins et services dans diverses conditions, afin de mieux comprendre les **facteurs qui le favorisent ou l'entravent** dans différents contextes, et voir comment il contribue à améliorer la qualité et la sécurité des soins et services ».*

*J'aimerais avoir **votre point de vue** sur l'implication des patients et de leurs familles dans le partenariat de soins et services...*

### 2. Quelle est l'expérience de votre [organisation / comité] dans le partenariat-patient ? (Implication des patients-familles dans les processus d'amélioration de la qualité et de la sécurité des patients)

- Stratégie (gouvernance)
- Priorité organisationnelle
- Démarche privilégiée
- Étendue dans l'organisation
- Etc.

### 3. Parlez-nous du modèle d'implication des patients qui a été développé dans votre établissement, comment ça s'est déployé. *Chronologie.*

- Initiation / Introduction de la démarche
  - Qui
  - Comment
  - Pourquoi
  - Quand
- Contexte
  - Organisation locale
  - Valeurs, philosophie
  - Commande régionale

- Demande politique
  - Programme particulier où la démarche a débuté ?
  - Porteur de dossier ?
- 4. Comment ont été engagés les patients dans le modèle *d'implication des patients* ?**
- Demande des patients ? (ex : comité d'amélioration continue)
  - Sélection et recrutement des patients-partenaires
  - Évènement-clés dans le temps
- 5. Quelles ont été les réactions, à l'interne, face à l'implantation de *d'implication des patients* ? **Acceptation / Résistance****
- Programmes
  - Questionnaires
  - Syndicats
  - Équipes
  - Professionnels
  - Médecins
- 6. Comment la mise en œuvre (implantation) de *l'implication des patients* a évolué dans le temps ?**
- Événements-clés
  - Loi 10
  - Etc.
- 7. Selon vous, qu'est-ce qui a contribué le plus à la mise en œuvre de *l'implication des patients* ?**
- Gouvernance et leadership ;
  - Culture ;
  - Ressources ;
  - Outils et méthodes
- Y a-t-il des éléments spécifiques au domaine de la **Santé mentale / Oncologie** qui ont eu une influence positive ?
- 8. Selon vous, quelles ont été les embûches (limites, contraintes, barrières) à la mise en œuvre (implantation) de *l'implication des patients* ?**
- Gouvernance et leadership ;
  - Culture ;
  - Ressources ;
  - Outils et méthodes

- Y a-t-il des éléments spécifiques au domaine de la **Santé mentale / Oncologie** qui ont eu une influence négative ?

**9. Quels sont les impacts de la Loi 10 (Temps 2) sur le partenariat-patient ?**

- Fusions.
- Restructuration du partenariat-patient (Où ? Qui ? Comment ?)
- Comité pour la participation des patients-partenaires ?
- Etc.

**10. A. Est-ce que vous constatez des effets de l'implication des patients sur la qualité et la sécurité de soins ?**

**B.** Sinon, quels sont les **effets attendus** de cette implication ?

- Les patients :
  - Efficacité
  - Efficience
  - Satisfaction
  - Expérience de soins
  - Qualité de vie
- Intervenants :
  - Sur les pratiques cliniques
  - Sur le travail d'équipe
  - L'interdisciplinarité
- Organisation des soins / établissement :
  - Changements observés dans l'offre, planification, évaluation de soins et services
- Dans la communauté (santé mentale)

**11. Selon vous, quel est l'avenir de l'implication des patients au sein de votre organisation ?**

- Vers quoi souhaitez-vous que cela aille à l'avenir ?
- Que faudrait-il faire pour en arriver à ce point ?
- Comment pérenniser l'implication des patients ?
- Que feriez-vous **différemment** ?

**FIN DE LA RENCONTRE**

**10.** Quel est le **message le plus important** que vous aimeriez voir ressortir de l'entretien ?

**11.** Avez-vous d'autre chose que vous aimeriez **ajouter** ? D'autres sujets que vous aimeriez aborder et que **vous jugez important d'explorer** ?

*Merci beaucoup de votre participation à cet entretien.*

# Appendix 3. Focus Group Guide – Patient Partners



*Impact du partenariat de soins sur l'amélioration de la qualité et de la sécurité des soins (PASS)*

## **PATIENTS-PARTENAIRES PLAN D'ANIMATION – GROUPE DE DISCUSSION**

### **Déploiement du Partenariat de soins et de services Le partenariat patient**

**Objet :** Participation des patients partenaires dans l'organisation et dans leurs soins et services

- **Participants :** 5 patients partenaires qui participent à des activités diverses

#### **MATÉRIELS REQUIS :**

- Formulaires d'information et de consentement pour les patients
- Enregistreur
- Formulaires d'indemnisation

#### **CONTEXTE ET OBJECTIFS DE LA RENCONTRE**

Ce groupe de discussion vise les objectifs suivants :

- Mettre en évidence la valeur ajoutée de travailler avec des patients
- Mieux comprendre les facteurs favorisant ou freinant leur intégration
- Les impacts et effets

#### **DÉROULEMENT DE L'ACTIVITÉ (Accueil, Questions et Mot de la fin)**

##### **ACCUEIL**

- Présentation des participants :
  - Commencer par les personnes-ressources : qui fait quoi ?
  - Faire un tour de table et demander aux participants de se présenter
- Présentation du contexte et des objectifs de la rencontre
- Explications sur le déroulement de la rencontre (étapes du plan d'animation)
- Répondre aux questions des participants, le cas échéant.

## QUESTIONS D'ANIMATION

1. **Comment avez-vous été impliqué comme patient partenaire (par qui, quand, pourquoi, etc.) ?**
2. **À quel type d'activités ?**
3. **Est-ce que vous vous sentez membre à part entière quand vous participez ?**
  - Prise de décision ?
  - Est-ce que vous avez l'impression d'être un partenaire dans les activités ? Par exemple :
    - Dans les comités, activités, conférences, etc. ?
    - Dans votre plan de traitement ou plan d'intervention ?
4. **Est-ce que vous avez participé à une formation ?**
  - Si oui, quoi, par qui, déroulement ?
5. **Pourquoi avez-vous participé comme patient-partenaire ?**
  - Quelles étaient vos attentes ? Vos attentes ont-elles été répondues ?
6. **Qu'est-ce qui a fait en sorte que l'expérience a été constructive pour vous et pour l'organisation ? Et vice-versa (négative)**
7. **Savez-vous si vos suggestions ont été prises en compte par le personnel ?**
  - Si oui quels changements ont été mis en œuvre ?
  - Comment en avez-vous eu connaissance ?
  - Amélioration qualité et sécurité des soins et services ?
8. **À quel point avez-vous senti que votre point de vue/opinions étaient pris en compte ?**
9. **Selon vous, qu'est-ce que vous avez apporté de différent ?**
10. **Quels bénéfices personnels avez-vous tiré de votre participation ?**
11. **Qu'est-ce que vous avez le plus apprécié de votre participation ?**
12. **Quels sont les plus grands enjeux / obstacles actuels à l'implication des patients dans leurs soins ou dans l'amélioration des services ?**

### MOT DE LA FIN

- Présentation des faits saillants de l'activité par l'animateur.
- Donner des informations complémentaires quant aux suites à donner à ce projet.
- L'animateur remercie les participants.

### FIN DE LA RENCONTRE

## Appendix 4. Focus Group Guide – Key Actors



*Impact du partenariat de soins sur l'amélioration de la qualité et de la sécurité des soins (PASS)*

### ACTEURS-CLÉ PLAN D'ANIMATION – GROUPE DE DISCUSSION

#### Déploiement du Partenariat de soins et de services Le partenariat patient

- Objet :** Participation des patients partenaires dans l'organisation et dans les soins et services, et participation des pair-aidants
- Participants :** 10 acteurs-clés en lien avec l'implantation de la participation des patients (patient-partenaires et pair-aidants)

#### MATÉRIELS REQUIS :

- Formulaires d'information et de consentement
- 2 enregistreurs + micro rond
- Formulaires d'indemnisation (pour patients)

#### CONTEXTE ET OBJECTIFS DE LA RENCONTRE

Ce groupe de discussion vise les objectifs suivants :

- Mieux comprendre **l'évolution de la participation** des patients depuis les débuts (création du Comité, introduction des patients-partenaires et pair-aidants et l'interaction entre ces deux approches).
- Mieux comprendre les **facteurs (organisationnels et contextuels) favorisant ou freinant** la participation des patients-partenaires et des pair-aidants
- Les **impacts et effets**

#### DÉROULEMENT DE L'ACTIVITÉ (Accueil, Questions et Mot de la fin)

##### ACCUEIL

- Présentation des participants :
  - Commencer par les personnes-ressources : qui fait quoi ?
  - Faire un tour de table et demander aux participants de se présenter
- Présentation du contexte et des objectifs de la rencontre
- Explications sur le déroulement de la rencontre (étapes du plan d'animation)
- Répondre aux questions des participants, le cas échéant.

## QUESTIONS D'ANIMATION

### OBJECTIFS :

- Valider notre compréhension actuelle
- S'assurer de BIEN comprendre l'arrivée de la participation, la nouvelle *vision / démarche citoyenne* et le Comité
- Est ce qu'il y a une connexion ?

### HISTORIQUE :

1. Nous avons identifié **TROIS mouvements de participation et d'implication des Patients**. Pouvez-vous **confirmer** notre **compréhension** ?

- **Implication du patient** vers 2008
- **De l'asile à l'Institut**, la structuration de la participation patient (Comité etc.)
- Le **mouvement des pair-aidants** (patient et famille)

### PATIENT-PARTENAIRE

2. **Préciser la création du Comité** (comité organisationnel pour la participation des patients) ?
  - Rôle du comité ?
  - Qui ? Pourquoi ? Comment ?
  - Facteurs facilitants ?
  - Défis et facteurs entravants ? (Statut, stigmatisation, rémunération)
  - Devenir DU Comité avec la transformation en CIUSSS ?
3. **Implication des patients-partenaires**
  - Recrutement ?
  - Formation ?
  - Participation ?
  - Suivi ?
4. Influence ou impact de **la création du Comité** sur la participation des patients-partenaires dans les diverses activités où ils ont été inclus ou sur d'autres aspects ?

### PAIR-AIDANT

5. Comment en est-on venu à **impliquer** des **pairs-aidants** dans l'organisation ?
  - Motivations ? Attentes ? Étapes ?
  - Acteurs-clés ?
6. Comment percevez-vous **le rôle et la fonction** du pair-aidant et la manière dont ils sont intégrés dans l'organisation (Formalisation) :

- Rôle ? Recrutement ? Formation ?
- Intégration dans les équipes ?
- Facteurs facilitants
- Défis rencontrés et facteurs entravant ?
- Limites ET défis ? (Statut, stigmatisation, rémunération)
- Évaluation de leur participation ?

**7. Impacts de l'intégration des pairs-aidants sur :**

- Les **équipes** de soins, les **pratiques** d'intervention ?
- Les **patients** et les **familles** ?
- **L'organisation** en général ?

## **INTÉGRATION**

**8. Comment sont intégrées les initiatives de patient-partenaire et de pair-aidant ?**

- **Synergie** ?
- Interactions et les pair-aidants (avant, après le Comité) ?

## **MERCI !**

## **MOT DE LA FIN**

- Présentation des faits saillants de l'activité par l'animateur.
- Donner des informations complémentaires quant aux suites à donner à ce projet.
- L'animateur remercie les participants.

## **FIN DE LA RENCONTRE**

