USER INVOLVEMENT AT PEPP-MONTRÉAL

A Research Proposal from a Mad Standpoint

ABSTRACT

The aim of this research proposal is twofold. First, it reviews literature to try to understand from a patient standpoint how equitable collaboration between mental health researchers, practitioners and service users can happen. Second, it proposes the broad outlines of a community-based participatory research platform to establish this equitable collaboration at PEPP, with a focus on the housing program.

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Introduction

How can patients collaborate equitably with professionals considering the power imbalance? This is the general question that motivated this proposal. The standard view across the lived-experience literature from mad, consumer, survivor and ex-patient (MCSX) activists is that the problem of psychiatry is not chemical imbalance but *power imbalance*. Anger is what makes MCSX activists feel compelled to engage in collective action aimed at making mental health care better or altogether different. Fundamentally, they are seeking back their self-pride, their confidence, their individual and collective voices. Patients want professionals to listen to them. From a patient standpoint, this is what user involvement means: having a strong voice and being proud of it.

As the author of this proposal, I am socially located at the intersection of several communities of belongings and corresponding sets of often competing interests. As both an ex-patient of the PEPP-Montréal clinic and a current researcher at PEPP, I try to respond to the MCSX community as well as to my research supervisors, in that order. As a psychiatrically-labeled person, I identify to a marginalized group, the Mad. However, as a Western white male, former investment analyst and aspiring scholar, I have been and remain in a dominant social position. Aware of this diversity of standpoints that makes my identity, I certainly don't pretend to live up to the positivist ideal of "unbiased" scientific objectivity. Rather, in a social constructionist spirit, my goal is to offer a fair-minded representation of the standpoint and interests of the constellation of identity groups to which I experience primary belonging: the MCSX.

Mandate

The mandate to which this research proposal aims to respond is to open a path forward for user involvement and peer support at the PEPP-Montréal clinic, with a focus on the housing program. This research will work if stakeholders own it and make it theirs. To me, this is the key challenge: to foster ownership in this research proposal among PEPP's stakeholders now so that we can foster shared ownership and equitable partnership in mental health care among PEPP's stakeholders in the future.

Why I do this

This research at PEPP is an important part of the fieldwork on which I will support my doctoral dissertation in organizational sociology at HEC Montréal. For the inquiry that will lead to my

doctoral dissertation, I use participant observation and semi-structured interviews as ethnographic methods to understand how clientele activism contributes to change in professional practices. So, this research at PEPP is an important part of my doctoral work. But for me this is about much more than obtaining a degree. Beyond any scholarly considerations, I do this because I care deeply – because I want those who will ask for help at PEPP after me to receive better care than what I received. I do this because I know that, although it already does some good things, the PEPP team has the skills, the potential and the interest to do much better *with* its clientele than what it does *for* its clientele. Because I have the conviction that such improvements are to be found in the nurturing of a clinical culture of inclusion and reciprocity. A clinical culture of listening to and valuing the diversity of stakeholders' perspectives. A culture of equitable partnership with service users, relatives and surrounding community organizations at all stages of the process, from the design to the delivery and evaluation of research and clinical practices.

Draft review: Feedback and revisions

An earlier version of this document was circulated to 10 reviewers representing different stakeholder groups but predominantly composed of PEPP staff. In a SurveyMonkey electronic questionnaire, reviewers were asked to evaluate their level of agreement on a 1-5 scale for each section and to write their thoughts in a comment box. A total of 5 submissions were received on the electronic survey plus two reviewers who did not submit but shared their thoughts with me verbally in extensive discussions. Electronic plus verbal, this makes for a 7/10 response rate. The sample of reviewers was selected through "purposeful sampling," which means that I chose people around that may be interested in my proposal and may accept to review it. In positivist terms, we would see it as a biased sample. But in constructionist terms, I see it as representative of the standpoint of those in favor of user involvement.

The reviews received were immensely helpful and much of the credit goes to the reviewers as I trust that their feedback dramatically improved this document. The earlier draft contained similar sections as this one, but the first section was much different. Overall, the average level of agreement was around 3/5 for section 1 and at or above 4/5 for sections 2, 3 and 4. Although they agreed with some of the content of section 1, reviewers were uncomfortable with the format that read more like an opinion piece than a "scientific" discussion. The consensus opinion of reviewers was that the tone of section 1 was too oppositional, accusatory or "self-righteous" in the words

of a reviewer. That initial version of section 1 was written out of sheer anger. It was predominantly articulated around the topic of pharma influence on mental health care research and clinical practices. Reviewers were concerned that this tone would hinder the build-up of a collaborative relationship between service users and professionals.

In response to this key concern of the reviewers, I carved out that former version of section 1 and turned that material into a distinct paper on my personal experience as a former patient of PEPP based on an autoethnographic methodology. To replace that earlier draft of section 1 with a different and more substantiated discussion, I tapped into the existing MCSX lived-experience literature to discuss the role of my own anger and that of marginalized actors – such as the mad, disabled, women, or racial and sexual minorities – who engage in social movements to challenge unfair institutional arrangements.

In this new version of the proposal, the reviewers' wise comments invited me to make the pragmatic decision of not addressing the issue of pharmaceutical money and its detrimental influence on mental health care research and practice. However, it must be clear that I would officially dissociate myself with this project if pharma money were to be involved in support of it; and I do hope that out of goodwill, a decision will be made against that orientation. Participation in such a context would contradict my strongly-held belief that pharmaceutical companies should not be allowed to influence mental health care because their interests may diverge from those of service users. This stand, I am not taking out of any oppositional or accusatory purposes, but simply to be true to myself and my beliefs.

Structure of the report

The first section looks at peer support and user involvement through the prism of anger and self-pride among MCSX activists and members of other marginalized groups. It explores how anger drives mobilization in collective action to change unfair institutional arrangements. Section two, three and four propose a community-based participatory research platform, a definition of expected outcomes, and a tentative timeline for the work.

Funding acknowledgements

and $3,000 for AQRP peer support training and other expenses for this research. I also enjoy the recurring support *of Fonds de recherche du Québec société et culture* (FRQSC). This offers me the privilege of intellectual freedom, which I intend to exercise fully. I am grateful to the Douglas Institute's Dr. Iyer and Dr. Joober for their financial, intellectual and moral support.

By building up an ownership in this CBPR platform that is shared across stakeholders, I do trust that we can achieve results that we will all have reasons to be proud of.

Now, let's turn to the role of anger in the MCSX movements.

1. Anger, Self-Help and User Involvement from a Lived Experience Standpoint

How can the clients of a public service collaborate equitably with the providers of the service when the providers command much of the power in the jurisdiction? How can we build equitable collaboration between stakeholders that are set apart by anger and ideology? Through a review of literature on the topic from a lived experience standpoint, this section will attempt to address those interrogations.

Patients, ex-patients, consumers, psychiatric survivor and mad people are different terms that have been used to refer to mental health service users and former service users. Each of these terms refer to a distinct identity which is attached to a particular component of the larger movement. Members of the movement have identified themselves in different ways over the decades and per their distinct claims. Therefore, it would be more exact to conceptualize MCSX as a constellation of movements rather than as a global and unitary movement. MCSX movements are constituted of a variety of groups that are typically locally-situated and have developed in an atomized and decentralized fashion over time (roughly since the "deinstitutionalization" period around the 1960s), along geographical and ideological lines.

However, some common discussions and core claims (voice, legitimacy, inclusion) generate connections between groups, which creates somewhat of a network of groups with various claims and agendas. Activist and researcher Linda Morrison (2005: 2-3), uses the acronym "C/S/X" to refer to consumers/survivors/ex-patients' movements. To reflect the recent growth of the "mad pride" movement and resulting emergence of a distinct "mad" identity, I will henceforth use the

acronym MCSX to refer to the diverse strands of the constellation of mad, consumer, survivor and ex-patient activist groups.

> [A]s they have identified themselves thus far, mental health consumers do not speak with one voice over whether their ultimate goals are to eliminate and de-emphasize their commonalities until assimilation is achieved, or to emphasize and valorize them. (p. 2) … The differing connotations of "survivor" (with its implicit critique of the care received); "consumer" and "service user" (stressing commonalities with other recipients of goods and services); and "mad pride," with its impulse to rehabilitate and valorize, reflect profoundly different attitudes. (p. 3)

Activists identified as "consumers" have tended to promote reformist claims in a spirit of collaboration with mental health professionals, while "survivors" and "ex-patients" have tended to formulate more radical critiques of psychiatry and to advocate for the development of alternatives outside of a "mental health system" seen as oppressive, illegitimate and harmful. The recent emergence of the "mad" identity, "mad pride" movement and "mad studies" academic literature (see for instance LeFrançois, Menzies & Reaume 2013, eds.; Burstow, LeFrançois & Diamond 2014, eds.; Burstow 2015, ed.) typically combines an uncomplacent critique of psychiatry with an attempt to explore solutions both outside and inside of the mental health system. Also, as madness is being reconceptualised as a socially constructed disability – that is, a set of limitations imposed by society to the individuals that are defined as disabled – the mad movement and literature are increasingly drawing inspiration from and sharing common discussions with the disability rights movement and disability studies (see for instance Spandler, Anderson & Sapey 2015, eds.).

Yet, what consumers, survivors, ex-patients and the mad have in common is their claim to "lived experience," that is, they claim to have gained valuable knowledge through having gone through experiences of psychological, emotional and/or social distress. They use this experiential knowledge to critique the services offered by the mental health system, to contribute to the improvement of available solutions within the mental health system and/or to the development of alternative solutions outside of the mental health system. Above all, what consumers, survivors, ex-patients and the mad (MCSX) share is their common belief that their voices should be expressed and listened to, and that their views should be considered both valid and valuable.

1.1. Anger and the Mobilization in Collective Action

In the introduction of her landmark self-help manifesto "*On our Own: A Compelling Case for Patient Controlled Services*," Judi Chamberlin, an early leader of the ex-patients' movement, laid the key notions around which much of the later user-led literature would be articulated. In this part, Chamberlin (1977: xiii) speaks forcefully about the role of anger as a motivation to engage in collective action ~~aimed at changing arrangements seen as unfavorable (the source of the anger).~~

> In the mental patients' liberation movement, we have examined the ways in which we were treated when we 'went crazy.' Occasional instances of kindness and compassion stand out in sharp contrast with the overwhelming isolation and contempt imposed by most forms of 'treatment.' We came together to express our anger and despair at the way we were treated. Out of that process has grown the conviction that we *must* set up our own alternatives, because nothing that currently exists or is proposed, fundamentally alters the unequal power relationships that are at the heart of the present mental health system.

These claims, which had been initially formulated ~~about~~ four decades ago by Judi Chamberlin and other early activists of the "mental patients' liberation movement," have motivated MCSX movements ever since until today as Radden (2012: 1) aptly summarizes: "Those in mental health-related consumer movements have made many of their demands clear, including the demand for humane treatment and basic civil rights, an end to stigma and discrimination, and a chance to participate in their own recovery."

More broadly, throughout the theoretical and empirical literature on social movements, and particularly in the literature on social movements spawning from marginalized groups (ethnic minorities, women, gays, disabled, etc.) the role of anger in inducing the drive to engage in collective action runs as a foundational assumption (see Fligstein & McAdam 2012). In the MCSX literature, this anger is typically triggered by the sentiment of being systematically silenced, discredited and excluded from sites where decisions that affect them are being made.

Contested realities: Madness versus mental illness

As Chamberlin expresses, since the early days of the movement the sentiment of anger at being dismissed and patronized ~~by~~ psychiatric services has been a powerful driver for individual service users to engage in movements destined to challenge and/or reform psychiatric practices. The recent literature in what has come to be known as "mad studies" shows that this anger is still well

alive today ~~and~~ is felt in the daily lives of mental patients and is regularly discussed in their grassroots organizations (Starkman 2013). Later in that same introduction, Chamberlin (1977: xv) goes on to observe the visceral distrust of many ex-patients for "mental health" service providers, and the reasons she perceives to explain this distrust:

> Many ex-patients are angry, and our anger stems from the neglect, indifference, dehumanization, and outright brutality we have seen and experienced at the hands of the mental health system. Our distrust of professionals is not irrational hostility, but is the direct result of their treatment of us in the past. We have been belittled, ignored, lied to. We have no reason to trust professionals, and many reasons to fear them.

In their application of the notion of disability to the context of madness, Wallcraft and Hopper distinguish between a medical model and a social model of disability. They show that the "medical model" is but one paradigm to explain disability or madness, and that alternative paradigms (or explanatory systems) do exist. The authors (Wallcraft & Hopper 2015: 84) first define the medical model of disability/madness.

> The medical (or biomedical) model considers disability to be a problem of the individual that is directly caused by a disease, an injury, or some other health condition and requires medical care in the form of treatment and rehabilitation. In contrast to the social model, impairment is thus synonymous with disability. This model attributes the problem to the individual, who has a condition that is unwanted and that places him or her in the 'sick role' (Parsons & Fox 1952). This model is 'normative' – that is, it is the duty of the sick person to try to get well, and compliance with this expectation is part of the social bargain struck in exchange for dispensation from the ordinary responsibilities.

The medical model of disability/madness is founded on positivist epistemological assumptions that support a "hierarchy of knowledge" often referred to as the "evidence-based" paradigm. ~~Per~~ this paradigm, systematic reviews of randomized controlled trials constitute the most valid form of "evidence" while experiential and practical knowledge is considered the least valid form of evidence (Glasby & Beresford 2006: 270-1); truth is to be found in scientific objectivity, which can be attained through remoteness from the object of study. Such assumptions typically lead to the adoption of quantitative measurements aimed ~~to prevent~~ the subjective biases of researchers and/or of subjects from contaminating scientific results with subjective understandings. The core postulates of the evidence-based paradigm support the belief that direct involvement in a phenomenon prevents one from acquiring objective knowledge on that phenomenon. In our

context, the evidence-based paradigm provides a basis for the epistemic disqualification of the mad as legitimate knowers (Glasby & Beresford 2006; Liegghio 2013).

This experience of being disqualified and invalidated parallels the process exposed decades before by Chamberlin, of mental patients being belittled, ignored and dehumanized. This process of delegitimation is further analyzed by Liegghio, as she recounts her experience of seeing her mother being psychiatrized against her will in palliative care. Based on a modern "mad" framing of the problem, Liegghio (2013: 122) writes:

> [A]t the core of this … are my personal experiences of the ways psychiatrized people are denied their voices and, ultimately, their very existence as legitimate knowers. Based on my experiences, I propose that madness refers to a range of experiences – thoughts, moods, behaviours – that are different from and challenge, resist, or do not conform to dominant, psychiatric constructions of 'normal' versus 'disordered' or 'ill' mental health. Rather than adopting dominant psy constructions of mental health as a negative condition to alter, control, or repair, I view madness as a social category among other categories like race, class, gender, sexuality, age, or ability that define our identities and experiences.

In support of Liegghio's analysis, Wallcraft and Hopper (2015: 84) describe the "social model" of disability/madness as labeling imposed on individuals determined to be deviant or abnormal as per certain criteria defined by powerful social institutions.

> The social model of disability draws an important distinction between impairment and disability, stating that 'impairment' exists in the real physical world, while 'disability' is a social invention, defined through language and practice within a complex system of shared meanings, discourses and limitations imposed by the environment at a particular time and place. It thus has its philosophical foundations in social constructionism.

Whereas the medical model of disability/madness (e.g. the evidence-based paradigm) defines madness as an individual and objective problem, the "social model" sees madness as a collective, socially constructed, and thus a subjective (and intersubjective) phenomenon. Based on her lived experience, Liegghio (2013: 122) describes her understanding of the phenomenon of madness as follows:

> Our experiences of madness inform and construct the ways we see, feel, think, interpret, and make meaning of ourselves, of others, and of the physical and social worlds around us. In addition, our 'mental health' is constituted by the ways certain experiences, subjectivities, and subjects are privileged over other within society and the practices, psychiatrized people are disadvantaged against

constructions of 'normal mental health' and experience their identities as pathologized and devalued, and their humanity denied.

Therefore, while the medical model of madness is founded on positivist epistemological assumptions that postulate reality as unitary and objective, the social model of madness is supported on a social constructionist epistemology which sees reality as multiple, intersubjective, and contingent on the observer's standpoint. This epistemological position, which takes roots in Austrian and German phenomenological philosophy (Husserl 1928/1964; Schutz 1932/1967; Mannheim 1936/2015), has found a modern formulation in Berger & Luckmann's (1966) influential essay in social phenomenology, *The Social Construction of Reality*. What Chamberlin (1977), Liegghio (2013) and Wallcraft and Hopper (2015) all denounce in different ways can be likened to what Berger and Luckmann (1966: 121) ~~coined~~ "symbolic monopoly."

> There is first of all, perhaps paradigmatically, the possibility of the universal experts holding an effective monopoly over all ultimate definitions of reality in a society. ... Such a monopoly means that a single symbolic tradition maintains the universe in question. To be in the society then implies acceptance of this tradition. The experts in the tradition are recognized as such by virtually all members of the society and have no effective competitors to deal with. ... This does not imply that such societies have no skeptics, that everyone has without exception fully internalized the tradition, but rather that what skepticism there is has not been socially organized to offer a challenge to the upholders of the 'official' tradition.

This notion of symbolic monopoly is developed by Radden (2012), who prefers the term of "master narratives," which she conceptualizes as meta-stories that define relations of epistemic dominance/submission among interacting groups. These notions of "symbolic monopoly" and "master narratives" are proximate to what symbolic interactionist Erving Goffman (1974), and then theorists of social movements (see Benford & Snow 2000) refer to as "frames of reference."

> Master narratives are an expression of the power of a dominant group; it is a power so great as to create conditions for non-recognition or misrecognition of marginalized groups such as, in our case, those bearing psychiatric diagnoses. (Radden 2012: 4)

The perception of being subjected to "dehumanization" (Chamberlin 1977: xv) and "impairment" (Wallcraft & Hopper 2015: 84) or of being "denied their voices and, ultimately, their very existence as legitimate knowers" (Liegghio 2013: 122) can be understood as a pervasive perception that only the paradigm that favors the group in power – the mental health service providers – is attributed legitimacy while the paradigm through which disenfranchised actors – the service users

– perceive reality is being systematically invalidated and discredited. ~~Following~~ Berger and Luckmann (1966: 123), "When a particular definition of reality comes to be attached to a concrete power interest, it may be called an ideology." After having offered this definition of ideology, Berger and Luckmann proceed to define ideological pluralism.

> The pluralistic situation goes with conditions of rapid social change, indeed pluralism itself is an accelerating factor precisely because it helps to undermine the change-resistant efficacy of the traditional definitions of reality. Pluralism encourages both skepticism and innovation and is thus inherently subversive of the taken-for-granted reality of the traditional *status quo*.

In many ways, what both MCSX authors and disability activists denounce is the persistent tendency of the dominant social group in the mental health system, the service providers, to repress ideological pluralism by invalidating the service users' perception of reality. This epistemic invalidation enables the monopoly of the "medical" epistemic paradigm, which closely aligns with the interests of the social group in power in the jurisdiction of mental health care: the service providers (for comprehensive theoretical studies of the epistemic oppression of marginalized groups, see Medina 2013 and Fricker 2007). Adame and Leitner (2008: 147) expose the mechanisms whereby epistemic hegemony is enforced by delegitimating and silencing alternative theorizations of the generic phenomenon of madness.

> Many researchers and psychologists (e.g., Boyle, 2002b; Breggin, 1991; Fisher, 2003; Gosden, 2001; Karon, 1992; Read, 2004; Warner, 2004) have challenged the claim that serious psychological disturbances (e.g., schizophrenia, bipolar disorder) are biologically based illnesses and have written about the ways in which this dominant narrative is perpetuated in public and professional discourses. Currently, the main areas of clinical research tend to center on genetic and neuroanatomical abnormalities as well as neurochemical imbalances. Most mental health professionals operate under the framework of the medical model, and thus their interventions typically address biological and cognitive processes that are deemed sick, dysfunctional, and delusional. However, the medical model underemphasizes issues such as social conditions, political oppression, family systems, interpersonal relationships, spiritual crises, and the trauma of physical and sexual abuse that are experienced by many people seeking help.

Then, Adame and Leitner (2008: 147) proceed to explain how these efforts to enforce epistemic hegemony and suppress alternative theorizations ~~of~~ "mental illness" are supported by powerful and deeply entrenched institutional, professional and commercial interests.

Boyle (2002a) discusses the various ways that alternatives to the medical model are silenced and highlights the roles of financial power, medical authority, and biologically reductionistic discourses that largely determine who gets to define the nature of psychopathology. There is a considerable financial investment for the pharmaceutical companies as well as the field of psychiatry to promote these beliefs (Fisher, 2003; Gosden, 2001). Especially in the field of psychiatry, people's jobs literally depend on the ability to prescribe pills to control the patterns of thoughts and behaviors that are labeled as psychotic (e.g., hearing voices, disorganized thought and speech). Any criticisms or oppositions to the medical model are threatening to the psychiatrist's professional credibility and thus are vehemently fought against and often dismissed as ignorant, misinformed; or it may be argued that the patient lacks insight into the reality of his or her disease. In fact, it has been argued that *lack of insight* may be reinterpreted as "simply having a theory which is different to that of the relevant mental health professionals and at variance with the prevailing scientific paradigm of the psychiatric establishment" (Day & Bentall, 1996: 251).

Yet, despite the dominant influence of the medical paradigm of mental illness, a flourishing literature of first-person accounts based on lived experience of mental distress and mental health care supports counter-narratives in resistance to, and in the aim of liberating the mad from, the medical epistemic hegemony.

Resisting epistemic hegemony through lived experience narratives

MCSX activists are angry at being silenced and delegitimated and they engage in collective action to challenge those oppressive dynamics. In an enlightening article on recognition rights in the context of MCSX movements, Radden (2012: 2-3) offers a synthesis of the griefs of mad people against the hegemonic dominance of the medical model of mental illness.

What [people with psychiatric diagnoses] have suffered has ben a notably systematic and damaging *misrecognition*. Mental disorder has been allied with otherness, with irrationality, lack of competence, deficient agency, identity and even humanity. Its sufferers have also been the victims of what has been described as epistemic injustice – deprived of semantic authority and credibility (see Fricker 2007). (p. 2) ... The mad have been excluded from the epistemic as well as the social community, their voices disregarded and dismissed as meaningless. Their struggle must include being believed as credible knowers, as well as merely being heard. (p. 3)

Based on his lived experience of psychiatric treatment, Mel Starkman (2013: 106) uses the Bourdieusian notion of "symbolic violence" to explain how epistemic power dynamics contribute to the reproduction of structural inequalities.

> Coined by sociologist Pierre Bourdieu as a way of critiquing domination, symbolic violence refers to "the subtle imposition of systems of meaning that legitimize and thus solidify structures of inequality" (Wacquant 2006: 3). Symbolic violence is difficult to recognize because its practices are deeply ingrained in everyday activities. The benefit of using this concept is that it shows the subtlety of violence, its possibility of occurrence without actors' intentions and/or realization (Shubert 2002), and its systemic nature as an institutionalized form of violence

Then, Starkman (2013: 106) proceeds to show how symbolic violence occurs in mental health care, and then goes further to observe how the medical understanding of madness has become pervasive throughout Western societies.

> According to Crossley (2004), "one of the key injuries which both psychiatry and the wider society might be said to inflict upon [psychiatric patients] is the symbolic violence of disqualification and stigmatization" (p. 172). Because the power of psychiatry and the mental health system depends on symbolic power to define reality and to categorize the distress people experience, the violence and other harm it can cause are also symbolic by nature. Especially nowadays, "[m]ental distress is pre-defined in [W]estern culture by the discourses of psychiatry, whose reach has extended beyond the realms of a professional clique into the domain of everyday discourse" (Crossley 2004: 162).

Here again, an early and witty formulation of epistemic injustice and symbolic violence was offered by Judi Chamberlin as she exposes, based on her lived experience of psychiatric treatment, the process through which "mental patients" are disabled and oppressed by the psychiatric system through the routine assumption by service providers of their incompetence, and related invalidation of their experiential knowledge. Moreover, Chamberlin (1977: 1) shows how this process of epistemic delegitimation is used to justify coercive and inhumane treatments.

> People labelled mentally ill are usually presumed to be incapable of exercising their decision-making power in their own best interest. The compulsory psychiatric treatment of people labelled mentally ill usually involves confinement in a mental hospital, which is widely perceived as an unpleasant and undesirable fate. Mental patients who protest such confinement are seen as being unable to understand their own best interest; and often, once someone has been so diagnosed, even the perception of his or her place of confinement as undesirable or unpleasant is considered a sign of mental illness.

Drawing from postcolonial studies, Liegghio (2013: 123-4) calls "epistemic violence" the process by which mental health service users are not only silenced and assumed incompetent, but are "disqualified as legitimate knowers at a structural level through various institutional processes and practices." On how these processes and practices not only dismiss the individual, but

invalidate knowledge gained through lived experience – the primary epistemic approach through which mental patients interpret their reality, Liegghio (2013: 126) specifies:

> The epistemic violence is not the dismissing of the person, voice, or perspective as disordered. It is rather the denial of the person as a legitimate knower. Dismissed as incompetent, the psychiatrized person cannot get their knowledge, the content of their experiences, or their ways of knowing recognized and heard as legitimate. Alternative experiences of reality – defined as 'psychosis or 'hallucination' – become the rationale for the denial of their legitimacy as a knower. Rendered incompetent, persons are disqualified as legitimate knowers and lose their epistemic agency, specifically losing their ability to speak on their own behalf and to be heard on their own terms and in their own styles (Dotson 2011).

First-person narratives of lived experience of madness have been used for decades to unfold a counter-narrative to the dominant paradigm of madness-as-mental-illness. Despite hegemonic pressures to delegitimate interpretations of reality alternate to those that align with the interests of the dominant group, Radden (2012: 5) shows that MCSX and members of other marginalized groups have shared their subjective accounts of lived experience to promote alternate theorizations of madness – alternate theorizations that rehabilitate and revalue their stigmatized identity belongings.

> Counter-stories [or counter narratives] have been described as those that resist an oppressive identity and attempt to replace it with one that commands respect; they challenge unjust assumptions implicit in the master narrative and identify their subjects "more accurately and fairly" as the result (see Nelson 2001: 6).

Along this line of thinking, Gerald Jordan's ongoing doctoral work at McGill University's department of psychiatry, drawing from disability and mad studies, gathers testimonies of psychiatric patients and ex-patients to show how psychosis can be a positive learning and life-redefining experience. Through his inspiring work, Jordan (2016: 23) shows that "[p]eople can experience positive, transformational change following a first episode of psychosis through negotiating adversity, navigating resilience, [and] healing (p. 23). In his own words, Jordan (2016: 24) proposes "[a] counter-narrative to that of the sick patient in an endless cycle of remission and relapse." Jordan's work invites those in all positions to listen the first-person accounts of service users, consumers, survivors, patients and ex-patients as a method to understand their reality.

First-person accounts by service users of the meaning that they, themselves, attribute to their experiences has been a form of resistance to the medical narrative, a way for psychiatrized people to liberate themselves from the epistemic hegemony of the "chemical imbalance," and the "sick role" created for them by the "mental health" ideology promoted by service providers and their state and industry backers. As but one example of many such first-person accounts, psychiatric survivor Ji-Eun Lee (2013: 105) reflects on the importance of Mad Studies by and for Mad people to her subjective story:

> What do Canadian Mad Studies have to do with someone like me who lives in Canada as an international student from Korea? While I am usually hesitant to be so "out there" with this part of my identity, I am, indeed, a psychiatric survivor who survived the Westernized Korean mental health system. Locating myself this way, it is certainly not a surprise that because of my own lived experience, I have become passionate about Mad Studies by and for Mad people, which led me to write my undergraduate dissertation... Basically, reading people's stories about their painful struggles and sense of powerlessness in the face of powerful political actors, such as psychiatrists and the medical establishment, was one way to make sense of my own traumatic experience. Furthermore, it is interesting how, regardless of the variance in health care in different countries, there is much similarity. So I analyzed the stories of my peer survivors, and my own story is much implicated in them.

Rice et al. (2015) recount how disabled people have creatively used digital (audio-video) stories to share their personal narratives.[1] Correspondingly, Radden (2012: 1) discusses the importance of first person accounts in the negotiation of contested meanings that needs to happen to challenge hegemony of the medical understanding of madness:

> First person accounts of mental disorder expose conceptions of insight and meaning at odds with the precepts and assumptions to be found in the 'master narrative' of medical psychiatry. In light of these contested realities, ... the reconstructive task will involve negotiation over the contested meanings involved.

Adding to this line of analysis, Radden (2012: 4) also highlights the needed participation of "non-consumers," including mental health caregivers, in the collective task of bringing about epistemic justice for mental health service users.

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[1] PEPP-Montréal's Manuela Ferrari is a co-author in this article.

Only consumers themselves can provide testimony and bear witness *in this way* [through first person "madness narratives"]. However sympathetic and knowledgeable they might be, non-consumers are differently positioned, with obligations lying elsewhere. As allies, non-consumers must acknowledge, honor and attend to these first person narratives of survival, recovery, and experience with disorder, psychiatric diagnosis, and mental health care, and remain open to the potential cultural transformation they can bring; they must confer credibility on consumers as knowledge claimants. In addition, as we shall see presently, non-consumers and particularly mental health caregivers may need to participate in a negotiation over the contested realities that are revealed by some of this writing.

We have seen that, at an individual level, mental patients use first person narratives to affirm the validity and the value of their lived experience in understanding the phenomenon of madness. In the next segment, we will see how the anger of being unfairly treated acts as a powerful motivator for individuals to engage in collective action through social movements aimed at changing institutional arrangements ~~which they perceive as hurtful to their interests~~.

From anger to pride: Self, identity and MCSX movements

The American sociologist Erving Goffman conducted an extensive empirical study of a psychiatric institution. In *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963: 2) defines his concept of "social identity."

Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. Social settings establish the categories of persons likely to be encountered there. The routines of social intercourse in established settings allow us to deal with anticipated others without special attention or though. When a stranger comes in our presence, then first appearances are likely to enable use to anticipate his category and attributes, his "social identity – to use a term that is better than "social status" because personal attributes such as "honesty" are involved, as well as structural ones, like "occupation."

Based on this conception of social identity, Goffman (1963: 3) then proceeds to describe "stigma" as a social process that forces a person who possesses a specific attribute into a marginalized social position.

While a stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute

is a stigma, especially when its discrediting effect is very extensive; sometimes
it is also called a failing, a shortcoming, a handicap.

Building further on Goffman's conception of stigma, Kaplan and Liu (2000: 215) elaborate on the attributes that render a person vulnerable to the social process of stigma and associate stigma with deviance from socially accepted norms: "The attributes and experiences contributing to a stigmatized personal identity may include deviant behaviors, membership in objectionable groups, physical stigmata, or past experiences (such as having been institutionalized) that are intrinsically disvalued or from which objectionable qualities may be inferred." After describing stigma as a social process contingent on a person's deviance from accepted norms, Kaplan & Liu (2000: 220) proceed to suggest that a person's desire to fight or reverse the deleterious effects of stigma on self-worth may motivate deviant behaviors, or non-compliance with the norms of mainstream social institutions.

> If the person is unable to evaluate himself or herself positively, then the person will be motivated to behave in ways that will increase feelings of self-worth and decrease the feelings of psychological distress that are associated with self-rejecting attitudes. If a person perceives an inability to achieve the attributes, perform the behaviors, and enjoy the experiences he or she has been taught to value as the basis for the overall positive self-evaluation through conventional behavior, then the person will be motivated to behave in deviant ways that offer promise of gaining a feeling of self-worth.

While stigma may result from certain attributes perceived as abnormal with regards to socially accepted norms, Britt and Heise (2000: 234) suggest that many isolated individuals disenfranchised through stigma may be incentivized to associate with each other in order to engage in collective action aimed at challenging institutional arrangements ~~perceived as detrimental by members of their identity group~~.

> Individuals who experience pervasive rejection and failure in the context of conventional membership groups, although the source and the nature of the specific experiences may differ widely, represent a latent collectivity that is predisposed to protest against the social structure in the context of which self-derogating experiences and consequent spoiled identity emerged. The diverse self-discontent individuals have the potential for affiliating with any of a variety of crosscutting social categories that similarly have reason to resent, distrust, and desire to change the social structure in which the person came to experience highly distressful negative self-feeling (Spencer 1994).

In support of this argument, the activist literature ~~abundantly~~ shows that the mad, disability, gay, feminist and civil rights movements have tended to cross-pollinate. The recent emergence of the

mad pride movement certainly bears many resemblances with the gay pride movement. Conceptual framings and activism tactics and strategies developed in disability, feminist and civil right movements have been taken up by ex-patients, survivors and the mad. The social constructionist epistemology and standpoint theoretical framing appear to run as a constant throughout most of the work constituting these literatures. Kaplan and Liu (2000: 223) observe this cross-pollination and the common motivation of persons with stigmatized identities to engage in collective action.

> The evolution of individual stigmatized identities into a collective identity community along with accompanying dispositions to social action has been studied recently in a variety of deviant contexts including those relating to drug abuse (Anderson 1994), physical disability (Bat-Chava 1994; Brathwaite 1990; Groch 1994), transgenderism (Gagné and Tewksbury 1996), racial status (Porter and washington 1993), and gay and lesbian status (Anspach 1979; Kaugman 1966; Krouse 1994; Tajfel 1978a, 1978b; Troiden 1993). Thus, the notion that stigmatized identities are implicated in the process leading to participation in many social movements has resurfaced in many different forms as a viable hypothesis.

In other words, challenging institutionalized oppression is the common project of marginalized actors that engage in social movements. Observing the transition process contained in the "identity shift" from the individual to the collective level and from shame to pride, Carr (2007: 270-1) summarizes this perception of social movements as vehicles that transform marginalized individual identities into proud and self-affirming collective identities.

> The functioning of collective identities in groups of people with common experiences of oppression and political aims has been a powerful means for action, resistance and change. People have acted together in reaction to shared lived realities of exclusionary social, economic and environmental structures. In many cases, service users have developed collective power rather than remaining as isolated, relatively powerless individual consumers: 'participation is seen as both a personal and a collective process that enables poor and excluded people to collectively organise and engage in action and negotiation (with power holders) for the purpose of improving their own lives and living environments' (Beresford and Hoban, 2005: 27).

Identity shift is a process through which stigmatized individuals are motivated to engage in collective action to challenge unjust arrangements through a sequence of emotions from shame to fear, anger and then pride. This emotional process, argue Britt and Heise (2000: 257), is situated

at the root of the claim formulated by social movements constituted of marginalized actors such as the gays, women, disabled or mad.

> As social movements spread the ideological position that particular identities are not inherently deviant or bad but are defined as such by society and therefore may be challenged, stigmatized individuals are likely to replace feelings of fear with feelings of anger. Not only is the system explicitly held accountable for defining specific attributes as 'deviant,' but movement ideology also unambiguously denies the personal focus of socially constructed images of inherent inferiority, immorality, or illness. By modifying the frame from one of innate deviance to one of oppression, individuals may come to feel angry not only because the system is unjust but because they have been made to feel ashamed. ... The activated feeling of anger propels stigmatized individuals into public space to behave collectively, and feelings of pride emerge.

"Anger, a powerful and active emotion, creates pride by booting participants out of hiding and into a public arena of collective action," write Britt and Heise (2000: 259). In other words, anger is the emotion that motivates marginalized actors to engage in collective action aimed at improving their social position and that of their peers. Similar forms of grassroots collective action emerging from disenfranchised social groups (women, gay, ethnic minorities, mad) who want to challenge their disadvantaged social position in the institutional order is largely discussed in the academic literature on identity politics, as observed by Britt & Heise (2000: 262).

> Processes involved in identity politics have an impact on each of these factors, and thereby identity politics not only change shame to pride but also transform sequestration into solidarity. First, social movement writings and activities clarify that someone with the stigma is not an idiosyncratic individual but rather a member of a definable plurality. There are others with the characteristic, and all can identify with their commonality when they get together.

Later in that article, Britt and Heise (2000: 265-6) expose the social process through which isolation and shame are transformed into a solidary construction of positive selves through mobilization in collective action, that is, how anger gives birth to social movements.

> Hidden stigma is associated with shame. Ideological campaigns by social movements transform the emotion of shame into fear and anger, thereby creating activated and dominant participants disposed to join collective actions. These individuals get pulled into demonstrations through network ties and crowd contagion. The collective public display of their stigma develops empathic solidarity and pride.

In the terminology of identity politics, this process of morphing identities to move to a different social position is known as "identity shift." Britt and Heise (2000: 265-6) shed light on the identity

shift that happens in the transition from shame to pride and from stigmatized to esteemed identities.

> The emotional transformation likely does not end with pride. Pride may be regenerated repeatedly through collective public displays, and that may be necessary to erase earlier feelings of shame, but ultimately individuals come to accept the stigmatized identity as simply another component of the esteemed self. Pride is a prerequisite to incorporating the identity into the positive self and the threshold to the identity's deemotionalization.

We have explored in this segment the process through which the anger felt by marginalized actors gives birth to social movements that challenge dominant ideological paradigms and the institutional arrangements they legitimate, and how through such challenges, social movements enable marginalized actors to shift from stigmatized to esteemed identities. We have seen that through ideological challenges and identity shifts, marginalized actors aim to modify the institutional order and/or to improve their social position within the prevailing institutional order (see Strauss et al. 1963, 1964; Goffman 1983; Fligstein & McAdam 2012). In sub-sections 1.2 and 1.3 respectively, we will see how the claims and agendas formulated by MCSX movements vary from seeking alternatives to mental health care (*peer support*, sub-section 1.2) to promoting collaboration between mental health professionals and service users to render services more inclusive and responsive (*user involvement*, sub-section 1.3).

1.2. Peer Support: Beyond and Within Mental Health Care

In this sub-section, we will explore experiential knowledge as the epistemic foundation of peer support. We will also see that different types of peer support coexist, ranging from by-and-for approaches (mutual assistance groups and user-led organizations) to professionalized peer support. I will briefly explore the benefits, paradoxes and risks inherent to professionalized peer support.

Experiential knowledge and peer support

A simple definition of experiential knowledge as "truth based on personal experience with a phenomenon" was proposed by Borkman (1976: 445) in her early discussion on the role of experiential knowledge in the context of self-help groups. She suggests that "The two most important elements of experiential knowledge are (1) the type of "information" on which it is

based and (2) one's attitude toward that information" (p. 446). Borkman has this to say on those two constitutive elements of her definition of experiential knowledge (p. 446-7):

> The type of information is wisdom and know-how gained from personal participation in a phenomenon instead of isolated, unorganized bits of facts and feelings upon which a person has not reflected. This wisdom and know-how tends to be concrete, specific and commonsensical, since they are based on the individual's actual experience, which is unique, limited, and more or less representative of the experience of others who have the same problem.
>
> The second critical element of the definition is the certitude that what one experiences becomes indeed knowledge. Thus the term "experiential knowledge" denotes a high degree of conviction that the insights learned from direct participation in a situation are truth, because the individual has faith in the validity and authority of the knowledge obtained by being a part of a phenomenon. Self-help groups frequently strengthen this faith among their members.

To synthesize this argument, the two constitutive elements of experiential knowledge identified by Borkman are the know-how gained from lived experience, and the confidence in the value of this know-how, which allows to translate knowledge into purposive action. Reflecting on how experiential knowledge influences the power dynamic between the patient and the treatment providers in the context of chronic illness, Morrison (2005: 3) makes the following observations.

> As the illness continues over time, patients develop increasing knowledge and awareness of both the illness itself and its management in their particular case. Meanwhile, as physician involvement decreases over time, opportunities for patient autonomy and self-direction of care increase. Mutual respect for differential expertise may change the balance of power, knowledge and practice in the relationship: the physician's role changes from director of care to supportive assistant, providing the technical resources needed for treating the patient's condition. Meanwhile, the patient's power and authority are enhanced in the newly-defined relationship.

Experiential knowledge is epistemic the foundation of peer support among mental patients. Based on Mead and MacNeil (2004), Repper & Carter (2011: 394) suggest that "[a]t its core, the peer support 'approach' assumes that people who have similar experiences can better relate and can consequently offer more authentic empathy and validation." In line with this conception of peer support, Mead, Hilton & Curtis (2001: 135) offer a formal definition.

> Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about

> understanding another's situation empathically through the shared experience of emotional and psychological pain. When people identify with others who they feel are 'like' them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to 'be' with each other without the constraints of traditional (expert/patient) relationships.

In their extensive review of the literature on peer support, Repper and Carter (2011: 393) invoke Davidson et al. (1999) who distinguish between "three broad types of peer support: informal (naturally occurring) peer support, peers participating in consumer or peer-run programmes and the employment of consumers/service users as providers of services and supports within traditional services." In the remainder of this sub-section, we will briefly touch on the last two types of peer support identified above: self-help alternatives and peer support workers.

Based on both a review of the literature and consultations with service users, Faulkner & Basset (2012: 41) comprehensively document the benefits to service users from engaging in peer support, which they synthesize as follows: "The findings suggest that there are many benefits to service users from engaging in peer support. These include: shared identity; development and sharing of skills; increased confidence; improved mental health and wellbeing; and the potential for challenging stigma and discrimination." Faulkner & Basset's is but one example of a large and growing body of studies that document the many benefits of both the informal and professionalized types of peer support (for instance, Rose et al. 2003; Solomon 2004; Corrigan 2006; Mead & MacNeil 2006; Gates & Akabas 2007; Richard et al. 2009; Repper & Carter 2011; Repper 2013; Rose et al. 2014).

Self-help alternatives outside of mental health care

For decades, patient activists disenchanted by mental health care have explored and developed alternatives outside of the professionalized mental health system. Throughout her forceful advocacy in favor of by-and-for alternatives to "mental health," Chamberlin (1977: 68) and other early leaders of MCSX movements have inspired the collective endeavor of patient activists to retake ownership of the meaning and solutions to their struggles.

> The alternative programmes ... are different, because their underlying philosophy is different. Nonprofessional, client-controlled services don't divide people into 'sick' and 'well,' 'helper' and helped.' They see every person as having a combination of strengths and weaknesses, and the need for help in one area does not negate the ability to help others also. But in order to achieve these

ends, people have to recognise their own strengths and abilities. They have to discover that sometimes there are no 'experts' to turn to. People who seek out the alternatives, have experienced the harm that the 'experts' and their methods can cause.

Then, Judi Chamberlin reverts to the topic of anger to explain how this powerful emotion has guided this collective research and development of alternatives. Here, Chamberlin (1977: 69) highlights the importance of confidence and self-esteem to the undertaking of collective action by groups whose knowledge and competence are routinely dismissed, which echoes Borkman's second constitutive element of experiential knowledge relative to the self-confidence in lived experience as a valid and valuable form of knowledge.

> These alternatives have begun in a spirit of anger and frustration, by people who have had firsthand experience with unresponsive, unhelpful mental health 'care.' But more than anger and frustration is necessary to enable people to set up functioning alternatives. People also need confidence in their own abilities – confidence that has often been damaged by contact with the mental health system. So, side by side with the work of setting up the alternative has gone another essential activity – building up the confidence and self-esteem of all the people involved in the work.

Discussing the by-and-for approach of user-run (or "consumer-operated") services and programs, Corrigan (2006: 1493) insists on the critical importance of the reciprocal relationship implied in that approach, which he terms the "helper principle," where every participant is simultaneously giver and receiver.

> Consumer-operated services are programs largely developed by people with psychiatric disabilities for people with psychiatric disabilities (Davidson et al. 1999; Mowbray et al. 2002; Solomon & Draine 2001). Peer support is a prototype service of this kind. Essential to these programs are actions that foster the "helper principle." Namely, people feel better about themselves not only when they receive support and resources from peers but also when they are able to give and be of assistance to others. This kind of help can boost the self-esteem of participants, which in turn can suppress self-stigma that might worsen a person's experiences of mental illness (Corrigan & Watson 2002; Watson et al., in press). People who believe they are personally empowered about most facets of their life are less likely to experience the self-stigma of mental illness (Corrigan & Watson 2002).

It is implied that the presence of a concerted effort across stakeholders to support the development of an independent by-and-for ecosystem of peer support outside of the boundaries of the mental health care system is key to the preservation of the "helper principle" evoked above

by Corrigan. Along those lines, Hodge (2005: 177) highlights "the importance of promoting, at a local level, the role of independent, user-led organizations through which individuals might engage with the kind of issues that are off the agenda for most user involvement initiatives."

Thus, we see that patient activists have explored and developed alternatives to mental health care outside of the system. Yet, some service users have also sought to play a role within the mental health system, as professionals of peer support, that is, as colleagues of service providers.

Peer workers within mental health care

In many countries, such as but not limited to the United Kingdom, the United States, Australia, New Zealand, France and Canada, the hiring of peer support workers in mental health clinics and facilities has been speeding up over the last decade or so and has been increasingly supported or even mandated by state-related regulatory and funding agencies. From a Canadian health policy standpoint, Richard et al. (2009: 2-3) discuss this trend at lengths.

> There is an increasing movement in mental health care towards hiring individuals with personal experience with mental illness as Peer Support Workers (PSW) to support and assist current mental health clients in their recovery process. The involvement of PSWs in the system is one of the most visible examples to other service users, their families, and professional services providers that the respective mental health system is committed to inclusion, partnerships with clients, and the adoption of a recovery-oriented mental health system.
> (...)
> The simultaneous implicit recognition by clients and their families of working with, or alongside, a peer is that, regardless of their current symptomology, clients can, and do, lead fulfilling and rewarding lives, build relationships and partnerships, and find employment... In addition to supportive relationships with family members/friends and mental health professionals, mental health consumers identify supportive relationships with peers as ... sources of inspiration, education, and support (Mancini, Hardiman, & Lawson, 2005).

Again, from that Canadian health policy standpoint and based on the medically-oriented assumptions and methods that typically underlie this standpoint, Richard et al. (2009: 3) list many benefits of employing peer support workers both for the health system and for the peer worker.

> Benefits for the health system include increasing resources, helping clients, decreasing stigma, and promoting PSW (Mowbray, Moxley, & Collins, 1998). Some of the personal benefits identified by PSWs include facilitating recovery, social approval, professional growth, skill development, mutual support,

receiving money and work, job security, career direction, and positive feedback (Mowbray, et al., 1998; Salzer & Shear, 2002).

Related to client benefits, … a systematic review showed that peer staff, compared to non-peer staff, had more client contact, fewer professional boundaries, and more outreach opportunities (Simpson & House, 2008). Clients receiving peer services were shown to also have improved quality of life and social functioning, fewer life issues, less family burden, longer durations before hospitalization, fewer hospitalizations, and shorter hospital stays, although nonpeer staff had lower employment turnover rates (Simpson & House, 2008). In a separate study, the majority of clients receiving peer counseling were positive about the experience and would recommend the service...

In many respects, by-and-for (mutual support groups and user-run organizations) and professionalized types of peer support are based on similar assumptions and values. The key difference of professionalized peer support is the distinction of status it operates between "giver" and "receiver" and resulting clientele relationship (see Mauss 1925/2012; Abbott 1988), while in by-and-for types of peer support participants are all givers-receivers. Based on this, Repper & Carter (2011: 394-5) highlight the important distinctions to be aware of between by-and-for and professionalized peer support.

In both mutual support groups and consumer-run programmes, the relationships that peers have with each other are valued for their reciprocity; they give an opportunity for sharing experiences, both giving and receiving support and for building up a mutual and synergistic understanding that benefits both parties (Mead, Hilton, & Curtis, 2001). In contrast, where peers are employed to provide support in services, the peer employed in the support role is generally considered to be further along their road to recovery (Davidson, Chinman, Sells, & Rowe, 2006). Peers use their own experience of overcoming mental distress to support others who are currently in crisis or struggling. This shift in emphasis from reciprocal relationship to a less symmetrical relationship of 'giver' and 'receiver' of care appears to underpin the differing role of peer support in naturally occurring and mutual support groups and PSWs employed in mental health systems (Davidson et al., 1999). It appears therefore that the degree of reciprocity expected from PSWs varies depending on the approach being adopted. Nevertheless, it appears that whatever be the setting, reciprocity is integral to the process of 'peer–to-peer support' as distinct from 'expert worker support'.

Building further on this giver/receiver conceptualization, Faulkner and Basset (2012: 44) discuss challenges implied in the "dual identity" and limitations attributable to the subordinated occupational status of peer support worker (PSW) in the mental health jurisdiction.[2]

> Most of the challenges of peer support identified during the consultations focused on the development of intentional [professionalized] peer support roles. Training, support, and supervision took on a greater significance for PSWs, as did employment and issues surrounding maintaining a dual identity. There were other challenges too, though, extending beyond the immediate role of PSW. Groups could be asked to change their role by funders or to sustain themselves against a backdrop of reduced resources. Some saw the new model of intentional peer support to be a challenge in itself, a threat to the informal nature of peer support on offer in their own and other user groups.

In this sub-section, we have seen that experiential knowledge, the epistemic foundation of peer support, is constituted by the know-how gained through lived experience and by the confidence in the validity of that knowledge. We have also seen that there is an important distinction to make between by-and-for (giving-receiving reciprocity) and professionalized (giver/receiver distinction) forms of peer support.

1.3. User Involvement as Citizenship: Nothing About Us Without Us

Professionalized peer support is certainly a form of user involvement, where service users seek a position within the mental health care system to participate in it and influence it from within. But the trend toward user involvement in mental health services is much broader than that, includes many approaches and draws inspiration from several related movements of identity politics.

The trend toward user involvement in mental health

Greater user involvement in mental health research and clinical practice has become a noticed trend that has taken increasing importance over the last few decades, and is becoming an expectation and even in many cases a requirement of state actors across the Western world. Discussing this growing trend, Beresford & Menzies (2014: 77) argue that:

> we need to gain a better understanding or two recent and related developments. These are: first, the emergence of 'service user involvement' in and beyond psychiatry, and second, moves beyond professional, to more

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[2] On professional jurisdictions and occupational dominance/subordination, see Abbott 1988.

inclusive partnership-based and collaborative approaches to opposition to psychiatry. In recent years, there has been an increasing international interest in including the perspectives, comments, and presence of 'mental health service users' in both academic and policy settings. This has been framed in different ways in different countries, for example, as 'user' or 'consumer' involvement, 'community engagement,' and 'empowerment.'

Further to this, Beresford & Menzies (2014: 78-9) observe the emergence of international service user movements at the intersection of the "disabled" and "mad" identities, and they explore the common claims for the inclusion of their voices and for the democratization of health care put forth by the disability and mad movements.

> … [T]he emergence of international 'service user' movements, most conspicuously the disabled people's movement, but also notably the mental health service user/psychiatric system survivor movement. While these movements have varied, between different countries and between different groups of service users, they have generally been underpinned by a central concern to have more say, to act on their own behalf, and to democratize policy and practice. Generally rights, rather than being welfare based, they have developed their won cultures, histories, ideas, theories, struggles, and collective action and have begun to impact on wider policy and thinking (Oliver and Barnes 2012).

Correspondingly, as Mead, Hilton & Curtis (2001: 135) observe this trend toward user involvement, they call for the exploration of diverse research methodologies to enable the equitable participation of service users to mental health research and practice.

> At the same time peer support programs are developing, they must participate in the design of research and evaluation processes that are drawn from the rich evolving nature of what we are learning. Some of these research methods might include action research (Rogers & Palmer-Erbs 1996); narrative research (Polkinghorne 1988); ethnography (Denzin 1997); life story models (Hertz 1997); empowerment research (Fetterman, Kaftarian & Wandersman 1996); measures of 'healing cultures' (Mead & Curtis 2000) and quantitative studies that show patterns of recovery that challenge traditional prognoses (Harding, Zubin & Strauss 1992).

However, on a note of caution, Sarah Carr (2007: 274), a mental health service user and research analyst at the Social Care Institute for Excellence in London, invites attention on the challenges arising from the resistance of powerful actors to the meaningful sharing of power and evolution in epistemic positioning that is necessarily implied in the social process of user involvement.

> Analysis of power dynamics in Western democratic and public institutions suggests that 'dominant perspectives may be policed through disallowing the

> possibility of alternative viewpoints that might undermine the construction of the oppressors' superiority, or suggest a continuity of common experiences between ''us'' and ''them'' (Tew, 2005: 77). Crucially, when organizations suppress service user ideas and expressions of experience what they are doing is resisting the opportunity to explore and benefit from any commonality between 'us' (professionals) and 'them' (service users) or vice versa.

This invitation to prudence formulated by Carr resonates with the whole discussion on the medical epistemic hegemony that we have explored in sub-section 1.1. As a collective effort to counter the epistemic hegemony used to silence their voices and exclude them from sites where decisions that affect them are made, disability and mad activists have rallied around the slogan "Nothing about us without us" to reclaim the legitimacy of their voices and the necessity of their inclusion as active participants from the conception to the delivery of mental health care.

Nothing about us without us: Shared claims among the disabled and the mad

In an international qualitative study on disability oppression titled *Nothing About Us Without Us,* James Charlton (2000: 17), an influential activist of disability rights, synthesizes the core claims of disabled activists as they challenge the stigma and marginalization attached to a disabled status.

> [A] growing number of people with disabilities have developed a consciousness that transforms the notion and concept of disability from a medical condition to a political and social condition. "Nothing About Us Without Us" requires people with disabilities to recognize their need to control and take responsibility for their own lives. It also forces political-economic and cultural systems to incorporate people with disabilities into the decision-making process and to recognize that the experiential knowledge of these people is pivotal in making decisions that affect their lives.

In her doctoral thesis on the politics of peer work from a mad activist standpoint, Jijian Voronka (2015: 142) at Ryerson University in Toronto explains how the rallying cry "Nothing about us without us" has been taken up by mental activists reclaiming that their voice be included and listened to in psychiatric/mental health research and practice.

> A popular mantra used by the disability rights movement, "Nothing about us without us," urged for social, political and policy changes that allowed for disabled people to "*speak for themselves* instead of other groups speaking on their behalf. Here the primary concern has been with empowerment, the redistribution of power and people gaining more say and control over their lives" (Croft & Beresford, 1996, p. 186).

Through the "Nothing about us without us" rallying cry, as both Charlton and Voronka show, mad and disability activists pursue shared claims. In her comprehensive historical review of mental patient's movements in the United-States, consumer activist and scholar Linda Morrison (2005: 58) summarizes the core claims shared by the diverse strands of the movement.

> Over its history, the c/s/x [consumer/survivor/ex-patient] movement has focused on several core claims in regard to people who have been labeled and treated by psychiatry (psychiatrized). The movement claims that: (1) psychiatrized individuals must have an authorized voice in their treatment and the system of care; (2) they must have access to information and knowledge related to treatment decisions, legal rights, and other issues; (3) they must have protection of their rights to freedom from harm; (4) they must have the power of self-determination; and (5) they must have access to choice in their treatment and in their lives. In summary, the c/s/x movement claims that psychiatrized persons should have the same rights as any other human being."

Then, Morrison (2005: 59) focuses on the claim of c/s/x to gain a greater voice, a claim that has we have seen again and again in our brief review of the literature from a lived experience standpoint: "One of the movement's major goals is to provide a forum for the voices of people in the mental health system (psychiatrized people) to be heard. The emphasis is on the freedom to speak, to express the truth of one's experience with psychiatry, not to be silenced or spoken for by others." Fundamentally, what Morrison and many other authors in this literature review highlight through this core claim for gaining voice is that user involvement begins with offering service users a seat at the table and an open ear.

User involvement as citizenship

Mad and disability activists often use theories of citizenship to conceptualize user involvement in services. A useful citizenship framework is proposed Nira Yuval-Davis, a scholar of political sociology invested in feminist standpoint theory. Yuval-Davis (2008: 204) builds on the notion of community of belonging to theorize the phenomenon of belonging to a political community as a form of citizenship.
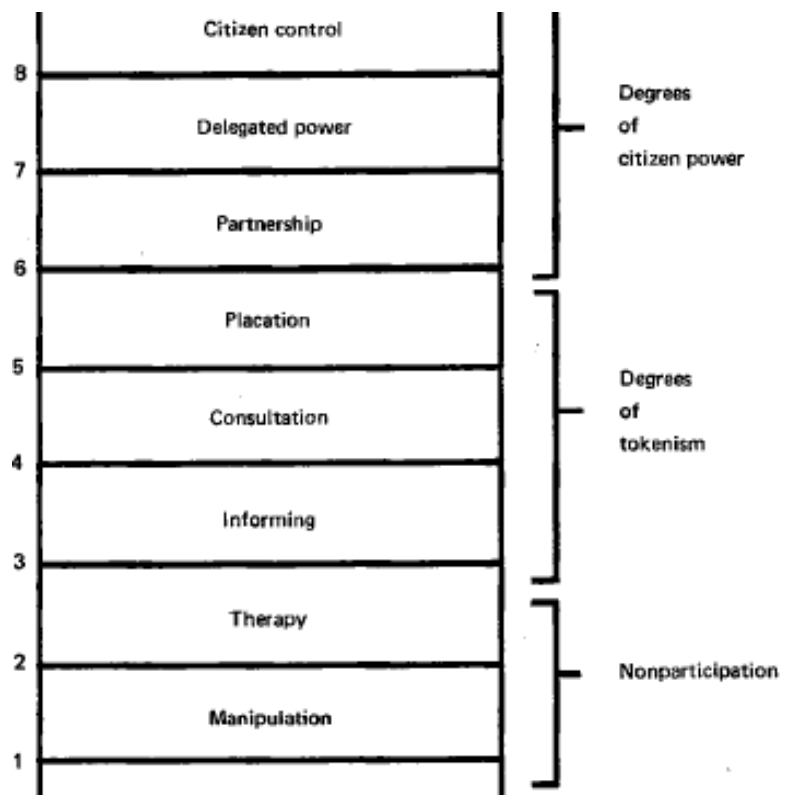
> John Crowley defined the politics of belonging as 'the dirty work of boundary maintenance'. The boundaries that the politics of belonging is concerned with are the boundaries of the political community of belonging, the boundaries that separate the world population into 'us' and 'them'. The author later observes (p. 206) that "Communitarian theories of citizenship ... see citizens not only as owing loyalty to the political community but also as its products, as organic parts of that community .... T. H. Marshall, the ... communitarian theorist of

> citizenship ... defin[es] ... citizenship as being 'full membership of the community, with all its rights and responsibilities.'

In the imagery of Yuval-Davis, user involvement thus consists of opening the boundaries of the community to service users and their relatives so that they become agentic citizens of the PEPP community. This also means that the driving principle of the community begins to switch from 'by-us,-for-them' to incorporate elements of peer support's 'by-us,-for-us' (by-and-for, for short). It is my hope that understanding this switch in principles may facilitate the transition.

Arnstein (1969: 217) developed a much-cited concept of "ladder of citizen participation" (see graph below) in which she defines eight levels of citizen participation, that she ranks from the lowest to the highest level of citizen participation. Right now, the level of citizen participation offered by the PEPP Clinic to service users is likely located somewhere around the rungs one to four of the ladder (between "nonparticipation" and "tokenism"). Genuine exercise of citizenship power begins at Arnstein's ladders six, seven and eight: "partnership," "delegated power," and "citizen control." At those rungs in the ladder, service users actively exercise citizenship in a shared community of care. Based on Arnstein's analogy, user involvement means climbing up the ladders of citizenship participation.

Figure 1 – The Ladder of citizen participation (integrally reproduced from Arnstein 1969: 217)

The cooptation of user involvement

Until now, the framing of user involvement in mental health care adopted here has mainly mobilized the "citizenship" model. Beresford and Menzies (2014: 79) explain that a "consumerist" model of user involvement also exists, and discuss some key distinctions of the two models.

> Involvement based on consumerist consultation is very different from involvement based on a democratic model committed to changing the distribution of power between services, services, and professionals and increasing service users' say and control. While one is essentially concerned with feeding into dominant professional understandings with the locus of decision-making remaining unchanged, the ambition of the other is to develop different user-led discourses and user knowledge based on direct experience, with the aim of changing where power lies and understandings and responses to the personal and political situation of service users (Beresford 2010, In Beresford & Menzies 2014: 79)

In the classic study in organizational sociology *TVA and the Grass Roots*, Philip Selznick (1949/2015: 217) wrote, on the notion of "cooptation," that the "absorption of nucleuses of power into the administrative structure of an organization makes possible the elimination or appeasement of potential sources of opposition." In the terms of Yuval-Davis (2008), cooptation is thus a form of participation in a community of belonging that denies the participant citizenship in the community. It is this notion of cooptation that lies behind Beresford and Menzies' description of the "consumerist" model of participation. The cooptation of user participation is discussed in greater details by Carr (2007: 267-8), who warns of the risk that service providers instrumentalize user involvement for purposes of institutional legitimation – a risk that she sees as substantial given the radical power imbalance between the protagonists.

> The lack of organizational responsiveness and political commitment to service user participation is a critical issue. Difficulties with power relations were found to underlie the majority of identified problems with effective user-led change. Exclusionary structures, institutional practices and professional attitudes can affect the extent to which service users can influence change. It appears that power sharing can be difficult within established mainstream structures, formal consultation mechanisms and traditional ideologies. In some cases there is a risk of user participation initiatives being conducted as externalized consultation exercises to approve of professional service planning and policy proposals, rather than enabling service users to be integral partners for their formulation.

In support of Carr's invitation to beware cooptation in user involvement, Harrison and Mort (1998: 60) argue that user involvement "can be used as a "technolog[y] of legitimation" ... by which managerial legitimacy is maintained in the context of an increasingly pluralistic policy arena." A relevant example of this type of cooptation is documented by Costa et al. (2012: 86), who show how patient testimonies are instrumentalized by mental health care organizations that seek to strengthen their "brand."

Sharing experiences through stories or "testimonies" by people who self-identify as having psychiatric disabilities has been central to the history of organizing resistance and change in and outside the psychiatric system (Church, 1995; Cresswell, 2005; Morrison, 2005; On our Own, 1980-1990). In the last decade, however, mental health organizations have begun to use and rely on personal stories from users of mental health services—people who are often homeless or struggling to survive below the poverty line. It is now commonplace for mental health organizations to solicit personal stories from clients—typically, about their fall into and subsequent recovery from mental illness. These stories function to garner support from authority figures such as politicians and philanthropists, to build the organizational "brand" regardless of program quality, and to raise operating funds during times of economic constraint.

As section 1 comes to an end, we have now gone through a review the literature on anger and the MCSX movements from a lived experience standpoint. We have seen that anger motivates mobilization in collective action aimed at challenging oppressive institutional arrangements, and that such movements promote a variety of claims and pursue a diversity of agendas, from seeking alternatives to the mental health system to advocating for the inclusion of service users in the design and delivery of mental health care. In section 2, I will draft the outlines of a community-based participatory research proposal that aims to structure a multi-stakeholder exploration of how user involvement could and/or should unfold at the Douglas Institute's PEPP-Montréal Clinic with a suggested focus on the housing program.

2. User Involvement: A Community-Based Participatory Research

This section proceeds in four steps. First, a brief review of the literature on inclusive and participatory research methods is presented. Second, some educational activities destined to share knowledge among stakeholders and create initial engagement among the groups that will later be invited to the community-based participatory research (CBPR) platform. Third, I propose a CBPR platform focused on the topic of user involvement and peer support at the PEPP Clinic, with a focus on the Housing Program. And fourth, the content of the work done in previous steps will be synthesized and an actionable implementation guide will be submitted to the representative members of all involved stakeholder groups.

2.1. An Overview of the Literature on Participative Research Methods

Much of the literature reviewed in section 1 supports the view that mental health research and clinical practice has traditionally been predominantly informed by the perspective of one main stakeholder group: service providers, and leans heavily toward medical explanations of madness. This dominance of one stakeholder's perspective over others enables the reproduction of the epistemic hegemony of "madness-as-mental-illness," as discussed in section 1. Ideological dominance allows for the silencing and invalidation of perspectives held by other stakeholder groups such as service users, their relatives and surrounding community organizations. In this sub-section, I argue that the adoption of a CBPR multi-stakeholder approach can contribute to the reduction of this power imbalance, in order to allow for the equitable expression of the perspectives of stakeholders that occupy a diversity of epistemic standpoints.

The participative turn in health care research[3]

In recent decades, we have witnessed the emergence of a significant evolution in research paradigms and in primary models of care in the direction of a participative vision of relationships between patients and health research and clinical environments. This "participative turn" has been supported by arguments around the adoption of best research and clinical practices as well as by increased preoccupations for the redistribution and the sharing of power through the democratisation of health care and research (INVOLVE 2013; Pollard et al. 2015; Baum et al. 2006). In Canada, an important indicator of this turn has materialized through new funding strategies and programs such as the Canadian Strategy for Patient-Oriented Research (SPOR) which aims to strengthen research capabilities that correspond to this approach (CIHR 2016). Ochocka et al. (2002: 379) highlight the importance this "participative turn" in the specific context of mental health care, where dynamics of stigmatization, epistemic invalidation and institutionalized exclusion have been, and remain to this day, particularly acute.

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[3] Except for the quote from Ochocka et al. (2002) which I have inserted, the three paragraphs of main text contained in the segment titled "The Participatory Turn in Health Care Research" are translated from French (my translation) and reproduced with minor adaptations from Tremblay, Bush and Pluye (forthcoming). This use has been permitted by Marie-Claude Tremblay, first author of the draft document and member of the OPRAM team at McGill University. I had access to the draft document through my participation as patient co-researcher in the consultative process being conducted in the context of the OPRAM research.

In recent years, the community mental health system in some communities has undergone a major paradigm shift in terms of our understanding of who has both the right and the experience and knowledge to participate in decision-making processes (Carling 1995; Nelson, Lord & Ochocka 2001; Traynor, Pomeroy & Pape 1999). There is an increasing recognition that people with mental health problems can and should actively contribute to planning and evaluating support services intended to be helpful to them. Calls for such participation are grounded in the belief that people with mental health problems, many of whom call themselves 'consumer/survivors,' are a disadvantaged group, and that participation is one vehicle for consumer/survivor empowerment (Lord & Dufort 1996). Consumer/survivors often experience a lack of power and control, are stigmatized and excluded from community life, and live in conditions of poverty, unemployment, and poor housing (Nelson et al. 2001).

Organizational participative research involving patients is a research approach through which researchers, representatives of health care organizations (decision-makers, professionals and clinicians), as well as patients undertake a collective research process as equal partners. It is a type of research conducted with and by health care organizations and service users rather than on or for health care organizations and service users (Baum et al. 2006; INVOLVE 2013; University of the West England 2011). Different levels of participation are often distinguished as consultative, collaborative, and user-led (INVOLVE 2013; Oliver et al. 2008). For example, a *consultative* project collects and integrates the perspective of patients at certain stage of the research, a *collaborative* project is conducted in partnership with patients at several stages of the research process, whereas a *user-led* project is primarily controlled by service users at all stages of the process (INVOLVE 2013; Oliver et al. 2008).

The research platform proposed here promotes a "collaborative" type of approach, where service users are full members of the research team and bring skills, experiences and forms of knowledge that are different and complementary to those of traditional researchers. Therefore, the proposed research platform is based on a conception of researchers and service users as equals, and on a conception of scientific, clinical and experiential forms of knowledge as being of different nature but equal and complementary value.

A CBPR multi-stakeholder approach to epistemic diversity

As Megan Pope (2016: 15) importantly highlights in her master's degree dissertation recently completed at PEPP-Montréal, "[s]ince varying perceptions of responsibility across stakeholder

groups could shape the extent and type of support received by these individuals, this is an important knowledge gap that must be addressed." Based on this observation, Pope adopts qualitative methods to index and understand the diverse perspectives expressed by distinct stakeholder groups involved in the care and recovery process of service users at PEPP-Montréal. Pope's inspiring effort to render the multiplicity simultaneous validity of perspectives resulting from the distinct standpoints of stakeholders in interaction in the context of mental health care inspires the approach promoted here.

The present research proposal assumes that there is an interest at PEPP-Montréal to engage in a process leading to greater and more meaningful user involvement in the research and practices related to the services offered by the Clinic. It also assumes that in the past, the perspective of service providers has tended to dominate research and practice at PEPP, and that consequently, the perspective of community-based stakeholders (service users, social relatives and community-organizations) has tended to be under-represented. Existing research such as Case et al. (2014: 397) support this assumption and suggest the adoption of CBPR to fill this gap.

> Historically, consumers of mental health services have not been given meaningful roles in research and change efforts related to the services they use. This is quickly changing as scholars and a growing number of funding bodies now call for greater consumer involvement in mental health services research and improvement. Amidst these calls, community-based participatory research (CBPR) has emerged as an approach which holds unique promise for capitalizing on consumer involvement in mental health services research and change.

As many other authors adopting a lived experience perspective do, Case et al. (2014: 398) root their suggested recourse to CBPR in protest to the silencing and epistemic invalidation to which service users are routinely subjected.

> Historically, the mental health system's relationship to consumers of its services is one that has been described as ''paternalistic'' (Chamberlin 2005; Craig 2008). Persons diagnosed with severe mental illness, as a result of their conditions, were believed to lack the capacity to truly appreciate the seriousness of their problems and the need for treatment (Chamberlin 2005). This led to a silencing of this population in the decisions that affected their lives and powerlessness within a system meant to address their needs (Ochocka et al. 2002).

Based on these assumptions (medical epistemic dominance and under-representation of the perspectives of community-based stakeholders), I suggest the adoption of a CBPR methodology to mitigate the power imbalance between stakeholders and to allow all standpoints to be represented equitably. Along the process of user involvement, Ochocka et al. (2002: 380) discuss the critical importance of building trust between service providers and service users, a heavy challenge in a context of radical provider/user power imbalance.

> To move toward more desired relationships between mental health professionals and consumer/survivors, several strategies for change have been suggested in the literature. First, changes in professional ideology and practice can be facilitated by educating professionals about shifts in their roles and ongoing interactions with consumer/survivors in order to build understanding and trust (Constantino & Nelson 1995; Ochocka et al. 1999; Stewart, Banks, Crossman & Poel 1994). Second, increased participation and involvement in decision-making in mental health policy, planning, service delivery, and research by consumer/survivors has been suggested to reduce power imbalances (Church 1992; Trainor et al. 1999). Power and control (of knowledge and resources) are critical dimensions of the relationship between professionals and consumer/survivors (Lord & Dufort 1996).

The framing proposed implicitly divides the stakeholder groups into two categories: (1) the service providers as the incumbent group in control of the social order in the jurisdiction of mental health care; and (2) community-based stakeholder groups as institutional challengers who wish to change institutional arrangements experienced as detrimental to their interests (see Fligstein & McAdam 2012). As explained above, it assumes that the first stakeholder category (service providers) has typically been in an epistemologically dominant position while the second stakeholder category (community-based actors) has tended to be marginalized and silenced. This divide could also be framed as one between professionals (service providers, in possession of the valid knowledge) and lay people (community-based actors, lacking valid knowledge). But to be able to discuss community-based stakeholder groups, we first need to understand what is a "community." Minkler & Wallerstein (2003: 29) synthesize four different conceptions of the notion of "community:"

> Communities have been defined as (1) functional spatial units that meet basic needs for sustenance, (2) units of patterned social interaction, and (3) symbolic units of collective identity (Hunter 1975). Eng and Parket (1994) add a fourth political definition of community: people coming together to act politically to make changes. (p. 29)

Community-based participatory researchers frequently refer to Paolo Freire as a foundational inspiration in the elaboration of participatory research methods. In his influential work *Pedagogy of the Oppressed*, Freire (1968/2004) insists on the imperative that education be used an emancipatory force that empowers disenfranchised actors to reclaim their voice and their epistemic legitimacy. Minkler & Wallerstein (2003: 29) explain how Freire's emancipatory educational aims are rooted in the core phenomenological assumptions (Husserl 1928/1964; Schutz 1932/1967; Mannheim 1936/2015) that underlie the social constructionist epistemic paradigm (Berger & Luckmann 1966) adopted here.

> Exiled Brazilian philosopher Paolo Freire ... influenced the transformation of the research relationship from viewing communities as objects of study to viewing community members as subjects of their own experience and inquiry. Freire's notion was that reality was not an objective truth or facts to be discovered but 'includes the ways in which the people involved with facts perceive them. ... The concrete reality is the connection between subjectivity and objectivity, never objectivity isolated from subjectivity' (1982: 29).

What this proposed research exercise requires of mental health service providers is an acceptance to leave the experienced comfort of positivist objectivity in order to engage in an intersubjective exploration of the multiple meanings of reality that derive from a plurality of stakeholders' standpoints (on the "hierarchy of knowledge" and epistemic diversity, see Glasby & Beresford 2006). Discussing the epistemological implications of participatory research methods, Israel et al. (1998: 176) identify three distinct paradigms: "post-positivism," "critical theory et al.," and "constructivism."

> Guba & Lincoln (1994) describe three alternative inquiry paradigms, 'postpositivism,' 'critical theory et al' (a blanket term for several alternative paradigms, e.g. feminism, participatory inquiry), and "constructivism." The latter two paradigms are particularly applicable for community-based research. From the critical theory et al perspective, a reality exists that is influenced by social, political, economic, cultural, ethnic, and gender factors that crystallize over time; the researcher and the participant are interactively linked; findings are mediated by values; and the transactional nature of research necessitates a dialogue between the investigator and participants in the inquiry (Guba & Lincoln 1994). From the constructivist paradigm, there exist multiple, socially constructed realities that are influenced by social, cultural, and historical contexts; the inquirer and participant are connected in such a way that the findings are inseparable from their relationship; and the methods used emphasize a continual dialectic of iteration, analysis, assessment, reiteration, and reanalysis (Guba & Lincoln 1989).

The key distinction between critical theory and constructivism, in my understanding of the point made by Israel et al., is that critical theory is more structurally-focused (structural inequalities as motivation for collective action) while constructivist is more culturally-focused (frames of reference and taken-for-granted understandings). But actually, the structuralist argument on class inequities complements the cultural argument on identity and anger, and in two arguments are in fact often made together. On purpose, the post-positivist paradigm is scarcely represented in the literature reviewed earlier.

Embarking in this CBPR exercise requires from service providers an acceptance to share some of their power with service users, their relatives and surrounding community organizations (see Beresford et al. 2010). A key challenge of this research proposal is that the subjectivist philosophy behind CBPR approach is hardly reconcilable with any purist form of positivism. In some cases, this may require from service provider a willingness to work from epistemic assumptions that some medically-oriented researchers and practitioners may not be familiar with. Also, in citizenship terms, the implementation of this research proposal may require from service providers a readiness to open the boundaries of their clinical community and create some "free space" where community-based stakeholders can fully express their beliefs and needs and have them heard (see Yuval-Davis 2008). Israel et al. (2003: 54) elaborate further on the critical importance of power-sharing and equitable partnership to community-based participatory research (CBPR).

> Community based participatory research in public health is a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute 'unique strengths and shared responsibilities' (Green et al. 1995: 12) to enhance understanding of a given phenomenon and the social and cultural dynamics of the community, and integrate the knowledge gained with action to improve the health and well-being of community members (Hatch et al. 1993; Schulz, Selig & Bayer 1998).

We have seen that CBPR situates research at the intersection of theory and practice, and at the intersection of professional and lay knowledge, promoting an ideal of equitable collaboration in the collective exploration of diverse perspectives on truth. Building on these intersections in the context of health research, Wallerstein & Duran (2003: 28) discuss the goals pursued by CBPR and identify three distinct and interconnected goals: research, action, and education.

> Community-based participatory research (CBPR) ... takes the perspective that 'participatory' research involves three interconnected goals: research, action, and education. As part of collaborative democratic processes, shared principles include a negotiation of information and capacities in both directions: researchers transferring tools for community members to analyze conditions and make informed decisions on actions to improve their lives, and community members transferring their expert content and meaning to researchers in the pursuit of mutual knowledge and application of the knowledge to their communities (Hatch, Moss & Saran 1993).

Later in the article, Wallerstein & Duran (2003: 45) acknowledge and discuss the paradox that lays in the potential for social change inherent to CBPR, a methodology that purports to guide "scientific" research, when the prevalent positivist ethics in mental health research from a service provider standpoint promote the ideals of logico-deductive objectivity (see Popper 1959/1992).

> Ultimately, CBPR is about knowledge creation and the value of practical and critical reason for understanding power dynamics, for recognizing the interconnections between the personal and social and between life worlds and system worlds, and for identifying the barriers and facilitators of human agency and participation toward the goals of action and social change. This can be a daunting and contradictory task but one full of promise and hope as we engage with community to promote democracy in a more just society.

Now that we have explored the philosophical foundations of CBPR in ethics and epistemology, let's take a brief look at some of the benefits and practical implications of CBPR in physical and mental health care.

Some benefits and practical implications of participatory research

Participatory research is increasingly considered as a "best practice" in health care and promoted as such by funding agencies, organizational decision-makers and academic researchers. For instance, Justin Jagosh (2012: 312), a former postdoctoral fellow at the Center for Participatory Research at McGill University who is now based at the University of Liverpool, makes the following synthesis of arguments made by proponents of participatory research (Jagosh et al. 2012: 312).

> For health intervention research, proponents argue that PR [participatory research] strengthens relations between the community and academia; ensures the relevancy of research questions; increases the capacity of data collection, analysis, and interpretation; reduces the "iatrogenic" effects of research; and enhances program recruitment, sustainability, and extension (Cargo and Mercer 2008; Israel et al. 1998, 2005; Macaulay et al. 1998; O'Fallon and Dearry 2002). PR is believed to increase communities' capacity to identify and solve their problems (Gaventa and Cornwall 2006; Macaulay et al. 1999) and decision

makers' and service providers' ability to mobilize resources, improve policies, and enhance professional practices (Minkler and Wallerstein 2008).

In a later article on the specific topic of community-based participatory research (CBPR), Jagosh et al. (2015: 10) highlight the ways in which CBPR can contribute to the nurturing of an environment of trust between health professionals and community-based actors facilitating systemic transformation.

> [C]omplex health improvement efforts can be addressed by a partnership approach involving shared decision making and equitable co-governance across the stages of research. ... [T]rust building and maintenance can make significant contributions to sustainability and systemic transformation which are key to both increasing the knowledge of factors supporting successful community-academic partnerships and transforming contexts to improve the conditions and motivations that determine health status.

Beyond the functional necessity of trust-building, Hancock et al. (2012: 218) expose the moral case made by patient activists in favor of inclusion of service users at all stages of service provision from the conception to the delivery of mental health care.

> Addressing the ethical or moral argument, consumer rights activists, using the slogan of 'nothing about us without us' have argued that inclusion is a human right and a social justice issue (Epstein & Olsen, 1998; Nelson, Ochocka, Griffin & Lord, 1998). Of growing prevalence within the literature is the argument that consumers on research teams improve the quality of the research (e.g., Faulkner, 2009; Goodare & Lockwood, 1999; Kim, 2005) by enhancing relevance, methodological sensitivity, accuracy of data collection, validity and consumer ownership of results. Consumers also report satisfaction and skill development as positive consequences of their involvement as researchers (Kim, 2005; Letcomte, Wilde & Walace, 1999).

Discussing the Photovoice method, an applied CBPR methodology that facilitates the active participation of marginalized actors to multi-stakeholder research processes, Shalini Lal and colleagues (2012: 181) observe that "[a] participatory approach to research occurs through partnership and collaboration with study populations across various stages of the research process. This approach necessitates a focus of attention on the power dynamics that exist between researchers and participants as well as consideration of the types of research methods that are used. Applying participatory methods can help researchers create knowledge that is more closely centred on the experiences of individuals with illness and disability (Letts, 2003) and their interactions with the environment." Further discussing the Photovoice method, Gervais and Rivard (2013: 496) show how such applied CBPR approaches can help "engage and empower"

disenfranchised actors, in their case, rural Rwandan women, "in the production of information about what is most relevant to them" and enable them to "reach and engage practitioners and officials" who typically do not consider the perspectives of such disenfranchised actors in the determination of policies and practices that affect them.

Sub-sections 2.2 to 2.4 propose a set of specific, applicable and integrated measures for the PEPP Clinic to meaningfully progress in that direction, not only in discourses, but especially in concrete initiatives and actions aimed at fostering user involvement, learning on and encouraging peer support. Three interrelated measures are formulated as part of this research proposal: (1) Make your marks at PEPP; (2) Sharing knowledge talk series; (3) Library on inclusive mental health practices; (4) Multi-stakeholder CBPR platform, and (5) Synthesis of the work done and practical implementation guide.

2.2. Education: Marks, Talks & Library

In this first stage of the platform, three concrete measures are proposed to provide everyone access to the material and knowledge needed to learn and educate themselves on user involvement and peer support: (1) Make your Marks at PEPP; (2) Sharing Knowledge Talk Series; and (3) Library on Inclusive Research and Clinical Practices.

Make Your Marks at PEPP

Dans la rue, a community organization that helps street youth in the Hochelaga neighborhood, have offered their service users the opportunity to paint the interior walls of the main building in which services are delivered. This is a quick and easy first step to engage the clientele. It contributes to creating a safe space that 'looks like' the clientele and is an efficient measure to strengthen the service users' sense of collective ownership in the Clinic. This may be especially important among youth, as the presence of meaningful opportunities for symbolic expression of their subjectivities responds to the key developmental need to define their identities in personal and positive terms; the need of young adults to express themselves in their own terms: to find who they are and be themselves. Such an initiative sends a clear message that the Clinic belongs to its service users and values their subjective expression.

The PEPP Clinic will launch a similar initiative. It could be named "Make Your Marks at PEPP." This initiative had been discussed in the past and was supported by Srividya Iyer and Ina Winkelmann,

who back then were the Coordinator and the Clinico-administrative Chief of the clinic. A few months later, the coordination of the Clinic changed and we were informed that the initiative could not be realized because the PEPP Clinic was preparing to move to a different building. As this move is apparently not in the plans anymore, the "Make Your Marks at PEPP" initiative can be launched as a first symbolic step toward engaging the clientele. This will be relatively easy and cheap to realize and will send a strong message to the clientele that the Clinic welcomes the diversity of its expression and is determined to strengthen its partnership with service users. A group of current and former service users of the Clinic can be assembled. With the supervision of a professional artist, this group will cover the walls of the waiting room at the Wilson Pavilion with artwork of their creation.

MU is a not-for-profit organization whose mission is to "beautify the city of Montreal by creating murals that are anchored in local communities. At the heart of its approach is the desire to see and experience art on a daily basis, to trigger a social transformation and to turn Montreal into an open-air art MUseum!"[4] MU can assist PEPP's service users in the creation of a beautiful collective mural which will foster their sense of ownership in the physical space of the PEPP Clinic.

This will create a colorful, creative and engaging physical environment that will foster the patients' sense of ownership in the Clinic and will send the message that the Clinic encourages collective expression of its service users' subjectivity and talents.

Sharing Knowledge Talk Series

Over the Winter of 2017, a series of lunchtime conferences will be scheduled. Staff, service users and their relatives will all be invited. Every second week, one or a few speakers will be hosted to share their experience with user-led initiatives, partnership of care, peer help groups and peer support. This will give clinicians, service users and their relatives access to a wealth of experience and contacts to learn first-hand on how such measures are implemented elsewhere, what are the obstacles, challenges, opportunities and benefits of these approaches. We can invite people from the PEPP program and other stakeholder groups to introduce the speakers and facilitate the discussions, as another way of engaging many stakeholders in the process.

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[4] See online at http://www.mumtl.org/en/ (retrieved on October 27th, 2016).

Each lunchtime talk will have a length of about 1 hour each, divided evenly between presentation and discussion. A tentative schedule for the Peer Talk Lunch Series is proposed below.

Table 1 – Proposed schedule for the Sharing Knowledge Talk Series

Speaker(s)	Relevant Experience	Tentative Date
Jean-Félix Hébert Collette & Dr. Amal Abdel-Baki	Jean-Félix is certified peer specialist, former JAP's service user and peer worker at JAP since March 2015 Amal is Director of JAP, a FEP Clinic at CHUM-ND, hired Jean-Félix as peer worker	Thursday, Jan. 12th, 2017
Richard Breton	Richard is certified peer specialist, peer worker at Pinel, Co-founder of Projet Avatar and animator of three voice-hearers' groups in Montreal	Thursday, Jan. 26th, 2017
Dr. J. Bruno Debruille & Bertrand Poupart	Bruno is psychiatrist at Douglas Institute and Writers' Club co-founder at Café Coop Bertrand is a Writer's Club regular participant, contributing artist at Les Impatients and member of Café Coop's management committee	Thursday, Feb. 9th, 2017
Annie Bossé	Annie is one of the first certified peer specialist in the Province of Quebec with 8 years of experience in peer work, she is peer worker in adult psychiatry at CHUM-ND and co-founder of Projet Baromètre	Thursday, Feb. 23rd, 2017
Marie-Claude Tremblay & a Patient Co-researcher	Marie-Claude is a researcher attached to the Organizational Participatory Research at McGill University (OPRAM) who coordinates a committee on researcher-patient partnership in health research A patient co-researcher participant in OPRAM will be present with her	Thursday, Mar. 9th 2017
Frances Skerritt & Mireille Valois	Frances is a peer worker with 8 years of experience at Wellington Center Mireille is IPS Coordinator at Wellington Center and works with PEPP's housing program	Thursday, Mar. 23rd, 2017
Eliza Chandler	Eliza Chandler is a Post-Doctoral Fellow in the School of Disability Studies at Ryerson University in Toronto. And a practicing disability artist. She will talk about art, disability and the Crip community.	Thursday, Apr. 6th, 2017
Annie Beaudin	Annie is coordinator of Programme Pair Aidant Réseau at Association pour la Réadaptation Psychosociale (AQRP), the community organization which delivers the Peer Specialist Certification in the Province of Quebec	Thursday, Apr 20th, 2017

Sharing-Knowledge Library

Dr Joober has generously offered a budget of $500 to assemble a library of books and manuals on user involvement, peer support and inclusive research and clinical practices in mental health care. I will match that amount and provide an additional $500 from my research budget to contribute to putting together a comprehensive and diversified library of books and manuals on inclusive and holistic mental health practices. This library will be assembled over the course of the Winter

2017 season. The library will be installed in a location at the Wilson Pavilion that is accessible to both staff and service users/relatives. The best location to make the library accessible to all is likely around the waiting room at the Wilson Pavilion. PEPP staff and service users/relatives will be entitled to borrow books and manuals on display in the library. The library will work much like a public library, where you register your borrowings to the receptionist and must bring them back within a limited period.

The library will make a rich and diversified array of published resources available for everyone to consult and learn on user involvement, peer support and partnership of care. Anyone who wants to learn and educate themselves on inclusive practices and on the diversity of existing perspectives on mental health care, recovery and strength-based approaches and user-led research and practices. Tom Holmes, a walking encyclopedia on such matters, has kindly accepted to suggest a list of references. Many other PEPP staff and clientele members should also consulted to make sure that this library is representative of a variety of views.

2.3. Design: A Community-Based Participatory Research Platform

The multi-stakeholder CBPR platform constitutes the centerpiece of this research proposal. Lysanne Rivard and Manuela Ferrari have generously shared their methodological expertise to inform the elaboration of this CBPR platform and they deserve much credit for this. Dr. Jean-François Pelletier has also been consulted and his expertise on CBPR methodologies has informed the design of this platform. My active participation in the ongoing work of a committee initiated by Organizational Participatory Research at McGill University (OPRAM), and which has for purpose to elaborate guidelines for best practices in participatory research (i.e. research in which patients are considered co-researchers) across McGill University and its affiliates has significantly informed the design of the CBPR platform proposed in this section. The methodological material and references shared by Marie-Claude Tremblay, post-doctoral researcher in the OPRAM team, have also been very helpful to the process.

The platform drafted below constitutes general framework proposed as a starting point to be fine-tuned and adapted in months to come in relation to the feedback and recommendations that stakeholders' representatives will be invited to provide. As the author of this proposal, I do not expect that my instructions will be closely followed, but rather that the diverse participants

involved will take ownership of the general spirit and framework proposed and adapt it to their visions, needs and objectives to make it their own. This draft therefore constitutes the starting point of what should be a collectively-owned and plurally-influenced endeavour.

The implementation of the CBPR platform, which is planned for May 2017 (see proposed timeline in section 4), may require involved researchers to obtain project approvals from the boards of ethics in research of McGill/Doulas and/or HEC Montréal. The earlier stage of the work (presented in section 2.2, *Education: Marks, Talks & Library*) planned to begin in mid-January 2017 should not require ethics approvals other than the one I already have for HEC for participant observation in the context of my fieldwork. This should leave us with enough time to seek and obtain the necessary ethical approvals before implementation of the CBPR platform begins in May 2017.

The objective of this CBPR platform is to give an equal voice to all stakeholders to lay the foundation for a culture of reciprocal partnership between PEPP staff, service users, their family members and close relatives, and community organizations providing complementary services in the area. Measures of the "education" stage will be implemented prior to the launching of the multi-stakeholder CBPR platform. The purpose of this timeline is to make all forms of knowledge, academic, clinical and experiential, available to all stakeholders, and to foster a culture of collaboration prior to the start of the CBPR process.

The design of the research platform is based on the guiding principles of reciprocity and equitable partnership. The facilitation of the work will be done to allow each stakeholder group to elaborate its distinct vision, needs and recommendations related to the implementation of concrete user involvement and peer support measures at the PEPP Clinic. The research platform will include four stakeholders:

- PEPP research and clinical staff, including some staff attached to the Housing Program;

- PEPP current and former service users, including some users of Housing Program services;

- Family members and close relatives of PEPP service users, including family members and close relatives of users of Housing Program services;

- Representatives of community organizations providing complementary services to those offered at the PEPP Clinic in the geographical area where the Clinic's service users live.

Each of the four representative stakeholder groups should be composed of about 8 participants and be diverse in its composition as it relates to gender, age, role, socio-economic or professional status, background, opinions, etc. The platform will develop in two subsequent stages.

Stage 1: Work in Separate Stakeholder Groups. The working groups will work separately in a 'safe space' that will allow its participants to feel that they are working in an environment that allows them to be fully independent and to express their views, opinions and recommendations to their fullest extent and without restriction. Given the exploratory nature of this project, an attempt will be made to maximize different opinions by inviting different people with different experiences to join the working group. Using snowball technique, we will ask people (service users, providers family member) who do you have important things to say or opinion on the topic, who should be involved in the working group, etc. In this first stage, the working groups will meet three times. Each working session will be of a length of about 2 hours. A common set of questions will be developed by the participants of each stakeholder groups for each of the three sessions under the general theme of user involvement, peer support and equitable partnership of care. The formulation of these questions will be determined through the inputs of a diversity of representatives of varied stakeholders. Here are a few examples of such discussion questions, which I provide only to start the thought process, with the expectation that the final questions used will be those chosen by the participants rather than the ones proposed here:

- Session 1: What is mental health for us? What are our needs? What do we like, and what do we not like about the current services offered at PEPP?

- Session 2: What is our vision of the future of services at PEPP? What objectives do we want to achieve together out of this research-action platform?

- Session 3: What do we need in physical, economic, social, and cultural terms to achieve our objectives? What are our concrete and applicable propositions to advance user involvement and peer support at PEPP?

Group meetings will unfold in the following format: (1) review confidentiality/consent forms (first meeting); (2) welcome and introduce facilitator, participants, and the space (first meeting); (3) review the purpose of the Working Group (first meeting); (4) review ground rules and work out new rules together (first meeting); and (5) group discussion. Examples of ground rules are: This is

an environment where people are free to share their honest thoughts. There are no right/wrong answers—only different points of view. You don't need to agree, but you must listen respectfully. Try to use "I statements." For instance, "I disagree" rather than "You're wrong." Do not use other people's names or unique identifiers (addresses). Turn off cell phones.

Stage 2: Multi-Stakeholder Plenary Session. Once all stakeholder groups have completed their separate working sessions, the four stakeholder groups will gather for a plenary session of a length of about 3 hours. Each group will have 30 minutes to share its distinct perspective, vision, and propositions to advance user involvement and peer support at the PEPP Clinic. Service users will present first. Families and relatives will present second. Community organizations will present third. PEPP staff will present last. This order is proposed to ensure that groups whose voices tend to be suppressed or excluded can be fully heard, and that PEPP staff stakeholder, who is typically in the position of authority and control of the research and clinical process, should first listen to its clientele before it communicates its views and propositions.

All work sessions in Stage 1 and Stage 2 will be facilitated by two experienced facilitators. Facilitators have been chosen for the relevance of their experience as well as to project an image of neutrality and diversity. I propose Annie Bossé and Manuela Ferrari as workshop facilitators. *Annie Bossé* is a peer worker with 8 years of experience at CHUM-Notre Dame and other mental health organizations and she is a skilled animator of discussion and help groups. *Manuela Ferrari* is a qualitative researcher in Srividya Iyer's team with solid experience in community-based and participative methodologies. As PEPP's support for this research project, I suggest that Manuela Ferrari be 'lent' for this work by her employer as a researcher attached to the Douglas Institute, and that Annie Bossé be remunerated 50$/hour as an independent facilitator, as this is the rate typically offered by *Organizational Participatory Research at McGill University* (OPRAM) and *Direction collaboration et partenariat patient* (DCPP) at Université de Montréal to remunerate similar 'experiential knowledge' consulting work.[5]

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[5] For additional information on compensation practices for "patient partners," you may contact André Néron at DCPP (http://medecine.umontreal.ca/faculte/direction-collaboration-partenariat-patient/) and Marie-Claude Tremblay at OPRAM (http://pram.mcgill.ca/). If you want to know more on this, please let me know and I will gladly introduce you to them.

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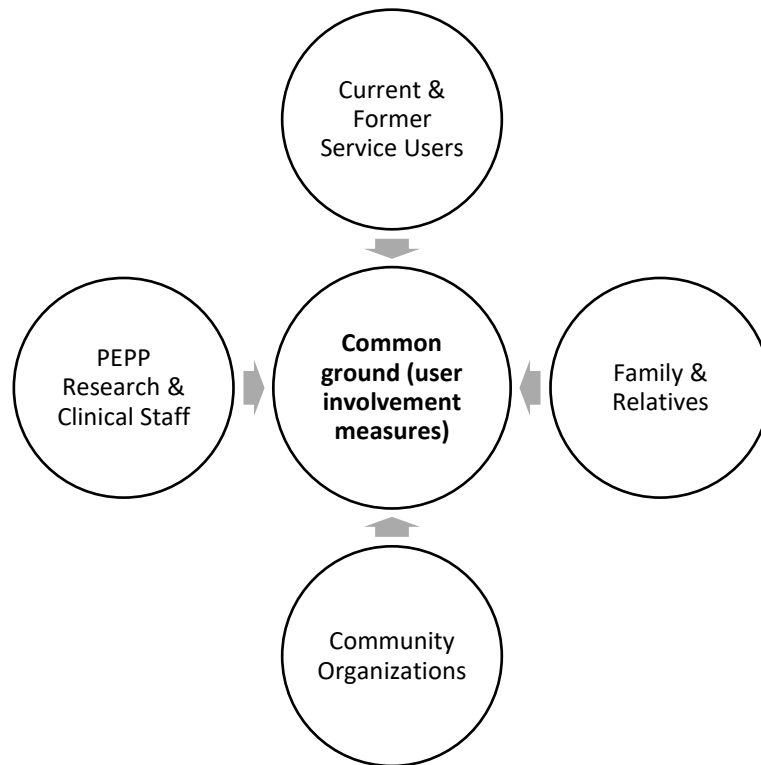
2.4. Action: Synthesis and Implementation Guide

Thematic analysis will be used to identify, analyze (patterns or themes within data), and report the data collected from the Working Group meetings. A second coder should be invited to participate in the thematic analysis in order to discuss, code the raw data and iteratively arrive at a final thematic framework. Dr. Srividya Iyer's research team contains several skilled qualitative researchers who would be habilitated and hopefully interested to participate in that capacity. Thematic analysis will be data driven, rather than theoretically driven, based on an inductive approach, as the themes to be identified will be emerge from the data itself rather being used to validate initial hypotheses. We will follow Braun and Clarke's (2006) steps of thematic analysis by: (1) familiarizing ourselves with our data (transcribing data, reviewing transcriptions for accuracy, reading transcriptions over and over, and noting initial ideas); (2) generating initial codes and searching for themes (collating codes into potential themes); (3) reviewing and redefining themes (exploring how strong the identified themes are by assisting the relationship between first [code]

and second [theme] levels of analysis, generating a thematic map of the analysis); and (4) writing the findings along the lines of the themes identified.

Based on the collective work and interaction that will have occurred in stages 2.1 to 2.4, we will consult the participants and draw from the data gathered to synthetize the work done, the distinct perspectives and common recommendations developed and shared by the stakeholder working groups. Based on this data, we will formulate specific and actionable measures. The second coder should continue to play a role here as well. At this step, we will ask for the feedback and additional inputs of representatives of all stakeholder groups to stay true to the spirit of equal partnership and participatory action-research promoted in this research proposal. At the outset of this process, a practical implementation guide will be submitted to the leadership of the PEPP Clinic and shared with all representatives of the stakeholder's working groups.

3. Expected Outcomes

The expected outcomes of this research proposal can be sorted out in three subsequent categories corresponding to the three stages of the proposed CBPR platform:

1) Education.
2) Design.
3) Action.

3.1. Education

Expected results in the first stage focus on encouraging ownership and epistemic diversity. The Make Your Marks event aims to generate a sense of ownership in the clinic in service users who will decorate the space according to how they want to express themselves. The Sharing Knowledge Talk Series will allow staff to listen to many actors from different horizons who have first-hand experience with user involvement and peer support. The Sharing Knowledge Library will give all of those who go to PEPP – staff, users, relatives and other partners in care – access to the best printed resources to become familiar with the diversity of standpoints that range from mad activism to biological psychiatry. The overall objective at this stage will be to foster engagement and ownership through creative expression and knowledge sharing.

3.2. Design

The methodological framework proposed in section 2 is intended as a starting point for a collective process of taking collective ownership in the process and adapting it to fit the needs and desires of all stakeholders. Because of the inductive nature of the participative methods proposed, the results of the design phase are not known in advance. The design of user involvement measures at PEPP will emerge at the intersections of the respective zones of interest of all stakeholder groups throughout their collective work. The objective at this stage is to generate a list of actionable measures to foster user involvement and peer support at PEPP that responds to the perspectives and to the interests of all stakeholder groups.

3.3. Action

Once the education and design phases are completed, it will be time to put the ideas developed into action. Implicit to this research proposal is the expectation that this collective endeavour will have practical implications that will result in a progression of the clinic toward participative research and clinical practices that involve service users, their relatives and surrounding community organizations. The overall vision of this proposal is to create together a shared and equitable environment of care that celebrates the diversity of standpoints. An environment of care where members of all stakeholder groups – staff, users, relatives and social surroundings – have a meaningful voice in research and clinical activities at PEPP-Montréal and in its housing program.

4. Proposed Timeline

Week of	Validating & Submitting Proposal	Stage 1 - Education			Stage 2 - Research	Stage 3 - Recommendations
Jan. 9, 2017	Validating & Submitting Proposal					
Jan. 16, 2017						
Jan. 23, 2017		Make Your Marks at PEPP	Peer Talk Lunch Series	Library on Inclusive MH Practices		
Jan. 30, 2017						
Feb. 6, 2017						
Feb. 13, 2017						
Feb. 20, 2017						
Feb. 27, 2017						
Mar. 6, 2017						
Mar. 13, 2017						
Mar. 20, 2017						
Mar. 27, 2017						
Apr. 3, 2017						
Apr. 10, 2017						
Apr. 17, 2017						
Apr. 24, 2017					Preparing the Platform	
May 1, 2017						
May 8, 2017						
May 15, 2017					Multi-Stakeholder PAR Platform	
May 22, 2017						
May 29, 2017						
Jun. 5, 2017						
Jun. 12, 2017						
Jun. 19, 2017						
Jun. 26, 2017						Debriefing, Writing & Submitting Report
Jul. 3, 2017						
Jul. 10, 2017						
Jul. 17, 2017						
Jul. 24, 2017						

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