Community Engagement through the Lens of Intersectionality

by

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Abstract

Despite the growing interest in community engagement as an alternative way of building evidence in public health and its potential to address health disparities in marginalized populations, there is a dearth of knowledge and evidence of the ways in which participatory approaches, such as community-based participatory research (CBPR), engage and impact people with lived experience of mental illness. Although CBPR offers the promise of addressing factors associated with mental health inequity, it faces its own set of ethical and methodological concerns related to the authenticity of community participation and a lack of understanding of the ways in which active engagement in CBPR affects community members. For people with psychiatric diagnoses, mental health inequities are a reflection of persistent and intertwined social and structural inequities rooted in historical exploitation and ongoing systemic subjugation through psychiatrization, criminalization and stigmatization of mental distress. While people with lived experience of mental illness face similar mental health inequities, the way they experience or respond to oppression is contingent on the ways it intersects with different social locations, such as gender, social status or race and power relations, such as sanism. Thus, an exploration of engagement from the participants' perspective and a critical examination of multiple and intersecting social factors and underlying power relations are needed.

In this Master's thesis, I apply a critical lens of intersectionality to a CBPR case study (*Imagining Inclusion*) to examine the research question: "How do the intersections of social locations and systemic and structural processes shape the experience of engagement in CBPR for people living with mental illness?" Intersectionality-informed analysis of thirteen in-depth individual interviews with people living with a mental illness revealed three major themes: 1) definitions and dimensions of community engagement; 2) tensions around joining *Imagining Inclusion* and sustaining engagement; and 3) tensions around collaborative relationships. In this project, I contribute to the call for this type of consideration of engagement by employing an intersectionality lens to explore the term engagement and the experiences of engagement in *Imagining Inclusion* from the perspectives of people with lived experience of mental illness.

Keywords: community engagement; CBPR; intersectionality; mental health

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Chapter 1.   Introduction

Despite community engagement initiatives slowly becoming viewed as best practice within public health (O'Mara-Eves et al., 2013; Wallerstein & Duran, 2010), there is a lack of consistent definition of community engagement and a dearth of knowledge and evidence of the ways in which these initiatives engage and impact disenfranchised communities (O'Mara-Eves et al., 2013). One of the models of community engagement within public health that has gained popularity as a way of addressing complex health inequities in populations that face multiple forms of oppression, is community-based participatory research (CBPR) (Guta et al., 2013; Wallerstein & Duran, 2010). Researchers employing the CBPR approach aim at addressing health inequities by targeting unequal power relations. The challenging and never fully attainable aim of achieving equitable community engagement (Frisby, Maguire, & Reid, 2009) is facilitated by deconstructing power relations, democratizing knowledge, creating opportunities for community capacity building and creating spaces for political advocacy and action (Horowitz, Robinson, & Seifer, 2009). As CBPR collaborations between academic researchers, non-profit organizations and community members have been increasingly normalized as "socially just research" (Janes, 2016, p. 111), it is important to reconsider how CBPR ideals can be fulfilled in the face of unprecedented inequity (Frisby et al., 2009).The collaborative nature of relationships drives participatory research (Leeuw, Cameron, & Greenwood, 2012); thus critically exploring power relations within CBPR is of particular importance. Researchers utilizing CBPR are faced with several ethical dilemmas and methodological issues that, if left unexamined and unchallenged, might lead to false generalizations and further disenfranchisement of marginalized populations (Guta et al., 2013; Horowitz et al., 2009; Janes, 2016). As a result, the concept of community engagement as a way of addressing health inequities has received some criticism, including assertions that the recent call for active community engagement is more of an expression of neoliberal governance rather than a tool for addressing health inequities and facilitating change (Guta et al., 2013; Labonte, 2004; Miraftab, 2004). When utilized without attention to the socio-political context and power relations, community engagement can perpetrate oppressive social inequities. Moreover, the lack of systemic methods to examine and document community engagement, raises concerns regarding whose and how knowledge is amassed, documented and shared.

A lack of clarity and evidence in regard to how the process of community engagement is applied and what kinds of social, economic, political outcomes it produces for the community

members is particularly problematic within the context of mental health as the health inequities experienced by people with psychiatric diagnosis are embedded in a long history of abuse and discrimination of people with mental illness diagnoses and their ongoing subjugation within mental health research and care (Morrow & Halinka Malcoe, 2017). Moreover, mental health inequities are a reflection of persistent and intertwined social and structural inequities and systemic forms of oppressions, such as sanism[1] (Ingram, Wasik, Cormier, & Morrow, 2013; Perlin, 2002; Poole et al., 2012) that result in depletion of social, economic, and political resources (Friedli, 2009). As a result, vast differences in positions of power exist in community engagement in mental health, between community members and the outsiders entering the communities to facilitate engagement. Thus, initiatives that incorporate a community engagement approach within the context of mental health require a critical exploration of the experiences of community members in order to better understand what meaningful and sustainable community engagement within the context of mental health looks like (Morrow & Halinka Malcoe, 2017). Attention to the role of power relations in producing health outcomes, makes intersectionality a useful approach to exploring the complexities of academic-community collaborations within particular social and historical contexts (Bowleg, 2012; Hankivsky et al., 2010; Hankivsky, 2014; Hankivsky & Christoffersen, 2008). While it has been recognized as the most useful approach for critically exploring complex relationships between the determinants of health and the underpinning role of power in shaping mental health inequities (Ingram et al., 2013; Morrow & Halinka Malcoe 2017), intersectionality remains largely underutilized within the context of mental health (Morrow & Halinka Malcoe, 2017).

In this project, I contribute to the call for this type of consideration of community engagement within the context of mental health by exploring the potential of qualitative intersectionality-informed research to complicate the notion of community engagement in CBPR within the context of mental health. I employed an intersectionality lens to studying perspectives and experiences of peer researchers and research participants who took part in a CBPR project (*Imagining Inclusion*). Through the use of a case study of *Imagining Inclusion*, this study examined the research question: "How do the intersections of social locations and systemic and

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[1] Sanism is a term that describes discrimination directed towards individuals with lived experience of mental illness. What makes this form of bigotry particularly worrisome is that sanism is largely covert, frequently practiced and socially acceptable (Perlin, 1992). Some common intentional or unintentional microaggressions related to mental health, include being perceived as inferior, violent, threatening, incompetent, lazy, unable to make decisions. As a result, those deemed to have mental illnesses are often paternalized, feared and given low expectations (LeFrancois et al., 2013).

structural processes shape the experience of engagement in CBPR for people living with mental illness?" Specifically, I applied an intersectional lens in order to:

a) document the understanding of engagement from research participants' and peer researchers' perspectives;

b) investigate who engaged and sustained their engagement in *Imagining Inclusion* and why or why not;

c) identify the pertinent intersections of social locations that are relevant within the context of the *Imagining Inclusion* project;

d) document the impact of engagement in *Imagining Inclusion* on the research participants and peer researchers; and

e) identify structural and social processes that facilitated or hindered engagement in the four stages of the research entry process (pre-engagement; engagement; assessment, reflection and feedback; and ongoing maintenance;) (Ochocka, Moorlag, & Janzen, 2010) and within the context of peer researcher employment.

Imagining Inclusion was a CBPR project, co-led by Dr. Colleen Reid and Ms. Maya Alonso, that took place in Vancouver, British Columbia between September, 2013 and August, 2015. The initiative used two approaches to community engagement; it recruited people with lived experience of mental illness as research participants[2] and peer researchers[3]. I worked on *Imagining Inclusion* as a research coordinator and, as a result, I was intimately familiar with its research processes, research participants and peer researchers (I describe my role in more detail at the end of this chapter). The participants for this project were recruited from both groups; *Imagining Inclusion* participants and peer researchers. By recruiting participants who occupied diverse positions, I was able to explore the ways in which different approaches to

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[2] In *Imagining Inclusion,* research participants were recruited based on their lived experience of mental illness; there was no formal contract that bound their engagement in *Imagining Inclusion* other than a consent form that outlined the voluntary nature of engagement.

[3] In *Imagining Inclusion,* peer researchers were recruited in an employee capacity as paid research staff; they were recruited based on their lived experience of mental illness and their professional skills (e.g. group facilitation, communication and computer skills); their engagement in the project was defined by the formal employment contract; the contract outlined peer researchers' duties and responsibilities (e.g. participating in research team meetings; facilitating groups, providing an ongoing support to the participants; hours of work (12hours/week); and salary ($18/hour); as such they acted as both peers and research team members;

engagement (research participant vs peer researcher) might influence how people with lived experience of mental illness described and experienced engagement in *Imagining Inclusion*. In this project, an intersectional lens was applied to shape the research question and objectives, research design, the participants' recruitment process, data collection and analysis, and the narrative description of the participants' experiences. Qualitative methods of in-depth individual interviews were employed to collect data. The critical lens of reflexivity was applied throughout the research project to explore my own positionality vis a vis the participants and the research process and to ensure trustworthiness.

1.1. Background: *Imagining Inclusion*

Imagining Inclusion was a 2-year CBPR collaboration between the Therapeutic Recreation (TR) Department at Douglas College and Open Door Group's (ODG) Thrive program; a community-based mental health program in Vancouver that provides leisure and education services to people with mental illness diagnosis. *Imagining Inclusion* explored the experiences of community inclusion, health, and wellbeing of people with lived experience of mental illness through the lens of the social determinants of health. The project sought to answer two research questions: 1. How do individuals living with mental illness experience community inclusion, health and well-being? 2. What are meaningful, practical, and relevant ways to represent community inclusion, health, and well-being for those living with mental illness?

Imagining Inclusion participants were recruited from the Thrive program and identified with having lived experience of mental illness. They represented diverse ages and ethnic and educational backgrounds. The *Imagining Inclusion* research team, which included experienced CBPR researchers, peer researchers, mental health service providers, and students met regularly to plan, facilitate and reflect on the project's objectives and activities. All research team members were familiar with CBPR core principles and worked together to create opportunities for participants and research members to build capacity, engage in knowledge production and inspire reciprocal learning.

Imagining Inclusion employed a photovoice methodology to facilitate community engagement and data collection processes (Wang & Burris, 1997). Photovoice is CBPR methodology based on the assumption that experiential knowledge is important and critical to social change. Those employing photovoice position people with lived experience at the center

of critical inquiry, enable critical dialogue on lived experience, are concerned with role of the social determinants of health in shaping health inequities, and aim to achieve ongoing community engagement and outcomes of social justice (Wang & Burris, 1997). Those employing photovoice, utilize an art-based method of photo taking and reflection to facilitate creative expression, critical discussion and social action that are embedded in lived experience (Wang & Burris, 1997). A photo exhibit is often assembled at the culmination of the photovoice process to represent the individual and collective work of community members. Photovoice methodology has been found to be useful in exploring lived experiences of mental illness (Becker, Reiser, Lambert, & Covello, 2014; Han & Oliffe, 2016).

In *Imagining Inclusion*, data collection and community engagement processes were facilitated across four distinct stages of the project: 1. pre-engagement (Intake Interviews); 2. engagement (Photovoice); 3. assessment, reflection and feedback (Photovoice Evaluation); 4. ongoing maintenance (Peer Task Groups) (Ochocka et al., 2010); and within the context of employment (Peer Researchers) (see table 1).

The intake Interview stage involved signing consent forms and conducting 30-minute interviews with the research participants. The information collected during this stage was demographic in nature and there was no financial incentive for taking part in the intake interview. The photovoice stage took place over a period of 10 weeks. The research participants met with the research team members in small groups weekly to discuss photo guiding questions, share their photographs and engage in a discussion on lived experience of mental illness. The photovoice sessions were co-facilitated by the academic and peer researchers. The participants were reimbursed with a camera or $75 gift card for their involvement in the photovoice part of the project. The photovoice participants who demonstrated an interest in continuing their engagement with the project became involved in the Peer Task Groups (PTGs). Three PTGs were created: The Analysis PTG, the Newsletter PTG and the Exhibit PTG. The goal of the PTGs was to collaborate with the participants on data analysis (Analysis PTG) and on knowledge translation tasks (Newsletter and Exhibit PTG). The PTGs met for a year and were co-facilitated by academic and peer researchers and student research assistants. At the conclusion of the project's second year, a fourth PTG, called Speaker Series, was established in response to some of the participants' interest in learning how to do public speaking and engaging in mental health advocacy. Unlike the photovoice part of the project, there was no reimbursement for involvement in the PTGs, with a concession for the Speaker Series; participants of the Speaker Series were reimbursed $50 gift cards for their time travelling to and

speaking at different venues around Vancouver and Richmond. As a way of establishing a more sustainable and equitable community engagement in *Imagining Inclusion*, the photovoice methodology included hiring two community members as peer researchers (PR). The peer researchers worked alongside the other research team members throughout the life of the *Imagining Inclusion* project. The peer researchers were involved in diverse tasks, including co-facilitating photovoice group meetings, developing a photovoice manual, providing ongoing emotional and technical supports to the participants and participating in the research team meetings.

Type of community engagement	Intake Interview (II)	Photovoice (PV)	Photovoice Evaluation	Peer Task Groups (PTG)	Peer Researchers (PR)
Duration	1 day	10 weeks	1 day	1 year	2 years
Strategies to gather knowledge of lived experience	Formal interview	Personal narratives, photographs, semi-structured small group discussions	Formal survey, semi-structured focus group, large group evaluation activity	Semi-formal analysis sessions, semi-formal writing and exhibit planning sessions	Collaborating on planning, developing and facilitating research activities, formal evaluation survey
Number of community members involved	38	32	32	19	2

Table 1. Four stages of community engagement and peer employment in *Imagining Inclusion*

Most of the strategies employed in *Imagining Inclusion* had a dual purpose: to gather knowledge of lived experience and to create meaningful engagement for the participants. Within this context, implementing the photovoice methodology afforded the opportunity for creative expression (photo taking) and sharing personal and collective voices (photo exhibit), hiring community members as peer researchers which offered peer driven supports, and facilitating the peer task groups which offered opportunities for mutual learning and gaining research related skills. Furthermore, it is worth noting that the active engagement of community members in *Imagining Inclusion* was supported purposefully and extensively throughout the life of the project; through ongoing weekly follow-ups, debriefing sessions, reminder phone calls, financial

incentives and transportation costs and providing one on one technical and emotional support during and between the group sessions.

Working as a project coordinator on *Imagining Inclusion* alongside the participants and peer researchers, I witnessed the unique ways in which they discussed their lived experiences and the unique way in which their realities shaped how they experienced their roles on the project. This aspect of the project was difficult to fully understand and document at the time. Taking on this project as part of my Master's thesis, allowed me to fully explore experiences of engagement in *Imagining Inclusion*. What enticed me to investigate engagement through the lens of intersectionality was the way it demands a shift from a single category perspective to incorporate multiple categories, power forces and contexts and allows for new, more nuanced ways of understanding and critiquing community engagement. Moreover, an intersectional lens allowed me to explore the differences in the conceptual understandings of engagement, investigate systems of power influencing experiences of engagement and challenge the essentialist notion that people with lived experience of mental illness view and experience inclusive and participatory methods in the same ways.

My involvement as a project coordinator on *Imagining Inclusion* positioned me in a dual role as both insider and outsider on this project. My two-year position involved direct work with all *Imagining Inclusion* participants and included directly supporting the engagement of the participants and peer researchers in all stages of the project, co-facilitating photovoice sessions and Analysis Peer Task Group meetings, and collaborating on the development and implementation of the evaluation tools. Moreover, having ongoing support from the *Imagining Inclusion* co-leads, allowed me an opportunity to develop this case study and facilitated access to the potential participants. Although I used *Imagining Inclusion* as a case study, my work on this project was independent and additional to the work I completed for *Imagining Inclusion.*

Chapter 2. Literature Review

In this chapter, I provide an overview of the literature and concepts relevant to my research. I start by introducing the concept of community engagement within public health and CBPR as an example of a health promoting strategy and a way of addressing complex health inequities in disenfranchised populations. I then demonstrate how historical and ongoing subjugation of people with lived experience of mental illness has resulted in experiences of economic, social, cultural and political discrimination and wide-ranging mental health inequities. Next, I explore ethical and methodological issues within CBPR, with specific implications for CBPR initiatives applied within the context of mental health. Lastly, I explore the potential for feminist and intersectional research approaches for addressing these issues.

2.1. Community Engagement within Public Health

Utilizing community engagement as a way of addressing health outcomes has a long history with its roots in Kurt Lewin's participatory action research, Paulo Freire's work on adult literacy with oppressed communities in Brazil and, Orlando False Borda's work with peasant communities in Latin America. In addition, feminist and community development movements, and the actions of many communities have worked to improve the health of their members (Coghlan & Brydon-Miller, 2014; Wallerstein & Duran, 2008). In recent years, community engagement has been adopted and adapted into public health as a way of improving health outcomes and/or improving health care (Minkler, 2005; O'Mara-Eves, et al., 2013; Wallerstein & Duran, 2010). As a result, several community engagement models[4], toolkits[5], frameworks[6], and planning reports[7] have been developed to illustrate the role of community engagement in achieving health outcomes.

Within public health, community engagement is a contested term that is often used interchangeably with other terms, such as 'public involvement', 'community participation', or 'citizen engagement'. As such, the concept of community engagement carries many

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4 see CBPR Conceptual Model in Wallerstein et al. (2008)

5 See Health Canada Policy Toolkit for Public Involvement in Decision Making

6 see Community Engagement Framework - Fraser Health; Community Engagement Framework for Vancouver Coastal Health

7 see Action Table Report: Improving Mental Health Service Planning for Immigrant, Refugee; Ethno-cultural and Racialized Populations Executive Summary (2017)

overlapping, contradictory and conflicting meanings, such as a) involving patients in their care (e.g. Patients as Partners and Patient Voices Network B.C.; client-centered care); b) involving diverse stakeholders through the spectrum of participation (see Community Engagement Framework for Vancouver Coastal Health, 2006); or c) consulting with communities (see Community Engagement Framework - Fraser Health, 2009). Additionally, the relationship between community engagement and the social determinants of health, concrete strategies for community engagement implementation, and means of evaluating it are largely absent within these frameworks (NCCDH, 2013). The lack of a consistent definition of community engagement within public health and the ways it has been utilized to meet different organizational agendas makes it difficult to evaluate the overall impact of these initiatives on health (O'Mara-Eves et al., 2013).

2.2. CBPR as a Model of Community Engagement

One of the models of community engagement within public health that has gained momentum as a health promoting strategy and a way of addressing complex health inequities in disenfranchised populations is community-based participatory research (CBPR) (Guta et al., 2013; Wallerstein & Duran, 2010). It operates on the assumption that community engagement results in the improved health outcomes for community members.

Within CBPR, community engagement goes beyond the recruitment of the participants and involves multifaceted, ongoing, and transparent academic-community partnerships where the researchers participate in the community of focus and community members take an active part in all aspects of the research process (Ahmed & Palermo, 2010). Ochocka et al. (2010) define community engagement as a "research entry process" that goes beyond the recruitment of research participants and includes "a long-term relationship with community members that is 'continually negotiated', with power imbalances to be constantly navigated" (Sixsmith, Boneham & Goldring 2003, p.3). The authors propose a four-stage process for research entry in CBPR:

1. pre-engagement (initial contact with the community, i.e. information session);

2. engagement (negotiating roles and research objectives, hiring community researchers);

3. assessment, reflection and feedback (daily check-ins, ongoing evaluation and feedback);

4. ongoing maintenance (creating structures for ongoing engagement during the duration of the project).

For Ochocka et al. (2010), community engagement as a research entry process allows participants and researchers access to both the research process and its outcomes, emphasizing that the research itself is a "means for a change" (p. 3). Consequently, the outcomes of CBPR, such as knowledge attainment, capacity building and social change, rely on how successfully and meaningfully community engagement is facilitated (van der Velde, Williamson, & Ogilvie, 2009).

CBPR is an approach to health research that employs community engagement as a way of promoting health equity by targeting social as well as individual-level factors and underlying systems of power that affect disenfranchised communities (Wallerstein & Duran, 2006). Within the framework of CBPR, the challenging aim of achieving equitable community engagement is facilitated by centering knowledge of lived experience and sharing access to power and resources, such as decision-making power, capacity building opportunities and supports (Israel et al., 1994; Wallerstein & Duran, 2006). According to Wallerstein and Duran (2006), community engagement involves creating a space for reflection and action and is facilitated through an ongoing communication and dialogue between researchers and community members. As such, those employing a CBPR approach aim to do research *with* rather than *for* or *in* community. Furthermore, they utilize diverse strategies that aim at sharing responsibilities and power with community members; such as, accommodating diverse needs, encouraging a diversity of opinions and perspectives, actively involving community members across different research stages, including decision making regarding the focus of the research, ownership of data, and dissemination of the findings (Ahmed & Palermo, 2010). It is important to note that although principles of CBPR are often idealized in the literature, in a time of unprecedented inequities, these ideals are worthy goals that are never fully attainable (Frisby et al., 2009). In this project, I am particularly concerned with CBPR's claims to utilize community engagement as a way of achieving health equity for people with lived experience of mental illness.

Within mental health, CBPR offers an alternative to the predominant biomedical model of mental health, as it shifts attention from mental illness (biomedical approach) to health inequities (social determinants of health approach) (Morrow, 2013). Although a clear link between mental health and experiences of the social determinants of health, such as poverty, exclusion, sexism and racism has been well established, these experiences continue to be largely neglected in mental health policy, research and practice (Morrow, 2013). Unlike more traditional mental

health research that predominantly disregards the influence of social and structural factors on mental health, those applying a CBPR approach recognize that the social determinants of health play an important role in shaping people's experiences of mental health (Morrow & Halinka Malcoe, 2017

2.3. Mental Health Inequities

People with lived experience of mental illness have historically been exploited, devalued, stripped of their rights and discriminated against both within and outside of the mental health system (Minds that Matter, 2012; Morrow, Dagg, & Pederson, 2008). To this day, those who have or who are perceived to have a psychiatric diagnosis are systematically subjugated by processes of psychiatrization, criminalization and stigmatization of mental distress (LeFrancois, Menzies, & Reaume, 2013). As a result, they continue to lack access to power and control over knowledge, face significant barriers to resources (such as income, education, housing, employment, and relationships) and, as a result, experience unprecedented mental health inequities (Friedli, 2009; Minds that Matter, 2012; Morrow, Halinka & Malcoe, 2017; Morrow et al., 2008). Subsequently people with lived experience of mental illness face high rates of poverty, unemployment, homelessness and social isolation (Minds that Matter, 2012). Friedli (2009) highlights the effects of material deprivation on mental health and argues that "levels of mental distress among communities need to be understood less in terms of individual pathology and more as a response to relative deprivation and social injustice" (p.3).

For people with a psychiatric diagnosis, mental health inequities are a reflection of persistent and intertwined social and structural inequities and systemic forms of oppression, such as sanism (Ingram et al., 2013; Perlin, 2002; Poole et al., 2012). The term sanism, which describes a particular form of stigma and discrimination directed towards people who have a mental health diagnosis or have received mental health treatment, was coined by Morton Birnbaum and popularized by law professor and mental health advocate, Michael Perlin in 1992 (LeFrancois et al., 2013). Similar to other forms of bigotry, such as sexism and racism, sanism reflects prejudice and uneven power dynamics. However, what makes this form of discrimination particularly worrisome is that sanism is largely covert, frequently practiced and socially acceptable (Perlin, 1992). The term sanism is related to the concept of mentalism, coined by Judi Chamberlain (1978), in an effort to label the pattern of common communications and behaviours directed towards individuals with lived experience of mental illness (LeFrancois et al., 2013). Some common intentional or unintentional microaggressions related to mental

health, include being perceived as inferior, violent, threatening, incompetent, lazy, and unable to make decisions. As a result, those deemed to have mental illnesses are often paternalized, feared and given low expectations (LeFrancois et al., 2013). These sanist ideologies are not only evident at the micro level, but they also penetrate mental health policies and services. Furthermore, dominant and well embedded sanist beliefs shape the ways in which the perspectives of those with lived experience of mental illness are marginalized and dis-missed (Leblanc & Kinsella, 2016). Ingram et al. (2013) explain the distinctive impact that mental health diagnosis has on the experience of health disparities: "although the context and specific social and structural determinants for health can overlap with mental health, inequities in mental health also operate distinctly and are overlaid with the additional stigma and discrimination that often accompanies a mental illness diagnosis" (p. 8).

Morrow et al. (2008) argue that mental health policies and services driven by the biomedical model of mental health, reflect the underlying tension between the desires of support and control, which have guided the treatment of people with mental illness in society throughout the centuries. The authors (2008) further argue that the deinstitutionalization of people with mental illness in British Columbia has resulted, in some cases, in trans-institutionalization; whereby people with mental illness have been criminalized, institutionalized in correctional facilities, and forced into treatments. In Canada, all provinces/territories have their own mental health acts with differing levels of patient rights. In BC, policies, such as the British Columbia Mental Health Act (BC MHA) are used to deny ordinary liberties to people with lived experience of mental illness by legalizing mental health crisis intervention, which usually involves the use of coercion and force that can result in detention or involuntary medical intervention (Grove, 2011; Morrow, et al., 2008). The BC MHA gives authority to police officers, judges and physicians to commit the person perceived to be in crisis to involuntary treatment that can involve substituted decision making and various treatments such as seclusion, forced medication, and physical restraints (Grove, 201; Minds that Matter, 2012).

In Canada, police officers are frequently the first responders to people in psychological distress and are responsible for making critical decisions about whether the person will enter into the criminal or medical systems. Although the rate of violence among people with mental illness is low when compared with other groups, they are more likely to be arrested and prosecuted (Lamb & Weinberger, 2005). As a result, they are overrepresented in the BC criminal justice system (Lamb & Weinberger, 2005; Morrow et al., 2008). Although a relatively small percentage of these people will be subjected to involuntary treatment (Grove, 2011), the

devastating impact of the BC Mental Health Act is wide reaching and has an adverse effect on the whole mental health community.

Denying liberty to people experiencing mental distress is predominantly an ethical and human rights issue. However, involuntary treatment can have significant physical, psychological, or economic implications, such as psychological trauma and fear, physical pain and suffering, and loss of current and future employment (Morrow et al., 2008), often leaving those forced into treatment re-traumatized and re-victimized (Lamb & Weinberger, 2005; McSherry, 2012). Furthermore, although the BC MHA claims protection from self-harm, the intervention itself sometimes results in serious physical injury or even death of the person in crisis (Minds that Matter, 2012). Campbell (1994) noted that mental health law "institutionalises the idea that there is something about 'mental illness' itself, which invites a system of control and coercion" (p. 556). Since people with other illnesses are not forced into treatment, the purpose of the BC MHA appears to focus on the control of those who are stereotyped as 'deviant', 'volatile', 'incapable' or 'dangerous', as opposed to how best to provide the care and services that people experiencing mental distress need.

Although, the mental health system has been adopting recovery models of mental health within recent years (Mental Health Commission of Canada, 2009), the ways in which values of individualized and self-care, choice, autonomy, resilience and self-determination are understood and utilized within a neoliberal context results in tensions and obscures the ways in which people with lived experience of mental illness continue to be subjugated within mental health care (Howell & Voronka, 2012). For example, current mental health models situate experiences of mental distress and recovery within the realm of psychiatric services and positions consumers as being responsible for adhering to the prescribed treatment (Howell & Voronka, 2012). Furthermore, access to choice, autonomy and self-determination are conditional on adherence to the treatment and impeded through the use of coercive treatment (Howell & Voronka, 2012). As the mental health system driven by biomedical approaches continues to favour quantifiable measures of outcomes of recovery like employment (Howell & Voronka, 2012), the voices of those with lived experience of mental illness continue to be silenced (Morrow & Weisser, 2012).

2.4. CBPR and Mental Health Inequities

Although CBPR offers the promise of addressing factors associated with mental health inequities (Morrow & Weisser, 2012), it faces its own set of ethical and methodological concerns related to the authenticity of community participation and a lack of understanding of the ways in which active engagement in CBPR affects community members (Guta et al., 2013; Horowitz et al., 2009).

Ethical issues.

Within a CBPR framework, community is viewed as a social entity and members of the community are assumed to share a common identity and values (Israel et al., 1998). Although this definition presents a new broader definition of community that goes beyond shared geographical location, the assumption of shared social identity creates an ethical challenge as it may result in the perception of community as a homogenous group and in turn lead to misleading findings and stereotyping of people with lived experience of mental illness (Voronka, 2016; Voronka et al., 2014). Given that "people with mental health issues and addictions are a diverse group, and experience disability, impairment and societal barriers in many different ways" (Minds that Matter, 2012, p.8), it is difficult to achieve a representative sample of the larger mental health community. Who gets to participate in CBPR projects is particularly problematic because these initiatives often draw participants from members of community-based organizations. This means that people who are unable to or choose not to engage with these organizations are silenced within CBPR projects. In addition, some people reject the medical label of mental illness. Reasons for that include not wanting to be identified in relation to the psychiatric system, avoiding the stigma of mental illness and a failure of the label to fully reflect individual's experience (Minds that Matter, 2012).

Given the discrimination and oppression that people with lived experience of mental illness have been subjected to within mental health research, policy, and practice, the inherent tensions and power dynamics in the partnership process might be particularly evident in the mental health context (Morrow & Weisser, 2012). Despite good intentions and value-driven strategies, CBPR initiatives present risks for social, psychological, emotional and financial harm to individuals and the whole mental health community. For example, in order to join the project as participants or to apply for peer researcher positions, people living with mental illness are required to disclose their disability. Thus, rather than addressing power differentials, CBPR

might further stigmatize people by putting their 'shared marginality' front and centre (Guta et al., 2013). Although self-disclosure has been identified as "a first step toward successfully addressing the stigma associated with being mentally ill" (Hyman, 2008, p. 24), it also presents significant risks that might include: social exclusion, gossip, negative attitudes, and discrimination. People may also experience increased anxiety due to others pitying them or treating them differently (Hyman, 2008). Self-disclosure as a requirement to participate in CBPR also raises concerns around issues of privacy and confidentiality in regards to data dissemination and knowledge exchange activities. This issue draws attention to the importance of informed consent and transparency regarding the potential risks and benefits of community engagement within the context of mental health.

Successful relationships between academic researchers and community members have been identified as critical for initiating and sustaining meaningful community engagement in CBPR (Ochocka et al., 2010). However, given that historically relationships between researchers and people with lived experience of mental illness have been marked by exploitation, negligence and oppression, building trust and overcoming tensions related to negative past experiences with research can be particularly challenging (Morrow, Halinka & Malcoe, 2017). Community members might be suspicious about researchers' hidden agendas or ulterior motives and unsure about the possibility of an equitable partnership based on CBPR ideals of mutual respect, trust, and transparency (Ochocka et al., 2010). Furthermore, academic researchers and mental health community members often differ in terms of ethnicity, socio-economic status, and cultural background, which can create tensions between the partners presenting a risk for cultural misunderstanding, racism, and discrimination (Minkler, 2004). In addition, sanist beliefs that people with a mental health diagnosis are less capable or unreliable (Minds that Matter, 2012) might impact how rights and responsibilities are distributed within CBPR. Engaging in CBPR without recognizing differences in social locations and systematically interrogating sources of privilege and personal biases can result in silencing individuals and their collective community (Minkler, 2004). Thus, special attention needs to be given to critical self-reflection in order to evaluate implications for individual community members and a larger community (Oetzel & Minkler, 2017).

Furthermore, the popularization of community engagement as a means of addressing health inequities has led to criticism regarding co-opting and professionalizing community engagement to reduce costs of mental health services (Morrow & Weisser, 2012). Concerns have been raised that the recent call for active community engagement in public health is more

an expression of neoliberal governance and a new way to penetrate marginalized populations to gain compliance to maintain the status quo while depoliticizing mental health community activism, rather than serving a mechanism to facilitate meaningful change (Guta et al., 2013; Guta et al., 2014; Labonte, 2004; Labonte, Polanyi, Muhajarine, McIntosh, & Williams, 2005; Miraftab, 2004). For example, Costa et al. (2012) highlight the issue of mental health organizations co-opting stories of lived experience to meet professional and organizational agendas rather than striving for social change. They explain the ways that these increasingly common practices reinforce mental health inequities by shifting attention away from the political aspect of the personal narratives and instead creating what the authors refer to as "patient porn" (Costa et al., 2012, p. 91).

Methodological issues.

While meaningful and vital community engagement in all stages of the research process is desirable but rarely attainable (Frisby et al., 2009), ensuring research rigour while maintaining community engagement has been identified as one of the main methodological challenges in applying the CBPR approach (Cashman et al., 2008). Potential issues related to methodological rigour can arise from a lack of research skills amongst community members, and a lack of infrastructure and resources necessary to build community capacity and provide an ongoing support for community-engaged research. In addition, CBPR goals of embracing knowledge of lived experience, addressing community needs, and shifting roles and power relations might conflict with methodological aspects, formal administrative constrains and requirements of projects that are embedded in fixed timelines and budgets (Guta et al., 2013). Furthermore, there is a concern that the social justice orientation of CBPR can interfere with the trustworthiness of the findings as all partners see themselves as 'change agents' (Leeuw et al., 2012).

Navigating collaborative, trustworthy and meaningful community participation is a complex process that requires the transition from a professional-client relationship into a collaborative partnership and demands an ongoing effort from those who employ CBPR to actively identify and address power imbalances that contribute to negative health outcomes (Frisby et al., 2009; Knightbridge, King, & Rolfe, 2006; Mancini & Miner, 2013). In addition, skills, time, and effort are required to maintain relationships, sustain meaningful participation, create safeguards, and provide support for participants while maintaining research rigour is a balancing act that can present significant logistical challenges (Reid, Pederson, & Dupéré,

2007). Furthermore, shifting roles and power dynamics throughout the research process might contribute to a lack of clarity about responsibilities and result in tensions between the partners (Ochocka et al., 2010). Issues related to communication, power dynamics and trust often arise from differences in cultural and social backgrounds between the researchers and community members (Horowitz et al., 2009). Moreover, the focus on measurement and outcomes within CBPR helps to sustain 'client – professional' power relationships as well as professionals themselves (Guta et al., 2014). Thus, it is important that those taking on CBPR initiatives create relevant training, adaptations and support structures to promote meaningful community engagement and keep lived experience in focus while maintaining research rigour.

A failure to acknowledge and critically examine power relations and the potential adverse effects of community engagement on people with lived experience of mental illness, might result in CBPR unintentionally perpetuating the social inequities that it is trying to address (Guta et al., 2013; Ingram et al., 2013; Janes, 2016), or it might only benefit more privileged community members (Ingram et al., 2013; Miraftab, 2004). For example, community engagement strategies can also perpetuate mental health inequities if insufficient attention is given to the communication structures and the language used when working with mental health communities. Language used in reference to mental illness can maintain the inequities and the stigma of mental illness or break stereotypes and promote respect and social justice (Minds that Matter, 2012). For example, the use of a professional or academic jargon can exclude people from meaningful participation. Although those employing community engagement strategies work towards reducing health inequities, unrealistic promises can lead to feelings of exploitation along with compromised mental health. Keeping the process of community engagement open and transparent can help to ensure that shared goals and processes are clearly understood and agreed-upon.

Peer researchers.

One way of engaging community members in CBPR projects is through formal employment as peer researchers. Peer researchers are members of the target population who are hired and trained to work as members of the research team (Flicker, Roche, & Guta., 2011). This participatory strategy assumes shared positionality between participants and peer researchers who have similar lived experience and encourages people to capitalize on experiential knowledge (Guta et al., 2013). Although the peer research model of community engagement has become increasingly perceived as 'best practice' in CBPR (Roche, Guta, &

Flicker, 2011), to date there has been little research investigating the ways in which the peer researcher role is understood, negotiated and facilitated (Guta et al., 2013; Roche, Guta, & Flicker, 2011). As well, the potential social, emotional, and economic implications of having a perceived dual role of research team member and peer are also often over-looked (Hankivsky et al., 2010; Reid et al., 2007).

Tensions between lived experience and previously established systems of power might be particularly evident within the context of mental health, where overt and subtle forms of oppressions, such as sanism, influence the authenticity of community engagement, power relations and knowledge production. For example, current calls for an increased integration of peers within the mental health system (Mental Health Commission of Canada, 2009) intersects with the overt and subtle pressures on peer workers with lived experience of mental illness to conform to biomedical values and create a professional identity, thus compromising inherent values of being a peer (Morrow & Weisser, 2012). This leaves one to wonder whose goals and agendas are being realized through peer engagement.

While there are emerging CBPR best practice guidelines on implementing CBPR and involving peer researchers, issues and logistics related to participants and peer research support and supervision remain under examined (Roche, Guta, & Flicker, 2011). Leeuw et al. (2012) further caution that normalizing community engagement and promoting it as best practice when working with disenfranchised communities may discourage a critical evaluation of the impact that the integration of people with lived experience of mental illness into pre-existing structures might have on their lives, along with the authenticity of their engagement (Morrow & Weisser, 2012; Voronka et al., 2014). This in turn might result in tokenistic approaches to the role of peer researcher (Roche, Guta, & Flicker, 2011) and a failure to create opportunities for more meaningful and transformative engagement, which are inherent to CBPR. Thus, in order for CBPR to uphold its principles of social justice, it must always remain open to critique (Leeuw et al., 2012).

Voronka (2016) expands the critique of the position of peers within the participatory mental health research into querying the politics of experience and exploring the potentials and limits of experiential knowledge and power dynamics within research initiatives that promote inclusive and participatory processes. According to Voronka (2016) knowledge of lived experience has a potential for both; challenging or entrenching hegemonic power relations. In a discussion on the risks of using experiential knowledge as a means for social change, Voronka

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(2016) points out that within inclusive and participatory initiatives, lived experience comes to exist as a category of identity. Thus, the homogeneous approach to lived experience can lead to eradicating the differences in experiences of mental distress and intersecting forms of oppression, disregarding differences in philosophical and ideological positions, and solidifying a "difference as deficit" view of mental distress (Voronka, 2016, p.192). This is problematic as lived experience is not an 'explanation' per se but is a phenomenon that requires explanation (Voronka, 2016). The pursuit of a knowledge of lived experience is further complicated by the inequitable distribution of power; this is evident by the imbalance between the impact that the peer researcher has on the ways in which lived experience of mental illness becomes embedded and represented on the research initiatives and how her embodiment of lived experience on these projects justifies them as "inclusionary, diversified, and participatory." (p.198). To better understand the forces that shape the potential and limits of experiential knowledge, Voronka (2016) draws attention to broader socio-political contexts. She asserts that although lived experience remains relatively constant, what people can produce through the lens of their lived experience can vary widely depending on socio-structural factors as such knowledge derived from the same lived experience can either serve to critique, challenge or entrench existing systems of power (Voronka, 2016).

Although the mental health field recognizes the need for cultural and ethnic sensitivity and a more cohesive representation of social identities (van Mens-Verhulst & Radtke, 2008), critical analyses of the relationships between various social factors and underlying power relations, through which social and systemic structures produce social and health inequities in people with lived experience of mental illness, are required to fully understand their impact on health outcomes (Morrow & Weisser, 2012; van Mens-Verhulst & Radtke, 2008). As Guta et al. (2013) point out "shining a critical lens on CBPR makes it possible to resist its co-option and to imagine ways of engaging communities that better reflect their needs and aspirations" (p. 447).

2.5. Addressing Ethical and Methodological Issues in CBPR

A lack of sufficient scrutiny of the ways in which social locations and power relations shape community engagement within participatory research have long been critiqued by feminist scholars who call for a more nuanced operationalization of the concept of community (Coghlan & Brydon-Miller, 2014). Moreover, feminist scholars emphasize the issue of knowledge production within research and confront questions around the ways in which privilege and disadvantage shape knowledge production (Frisby et al. 2009; Reid, Tom, &

Frisby, 2006). Those taking a feminist approach to participatory research, such as Feminist Participatory Action Research (FPAR), aim to achieve these ideals by emphasizing gender, exploring the role of power relations, recognizing women's diverse voices and experiences, searching for different forms of action and representation, and practicing reflexivity (Frisby et al., 2009; Reid et al., 2006; Reid & Gillberg, 2014). Rooted in a long history of feminist social movements for pursuing social change by addressing structural factors, FPAR merges principles of participatory action research with feminist theories (Frisby et al., 2009; Ponic, Reid, & Frisby, 2010; Reid et al., 2006; Reid & Gillberg, 2014), and centers lived experiences of oppression to facilitate a sense of inclusion and inform social action (Reid & Gillberg, 2014). Ideas of reciprocity and sharing lived experience have been well established in feminist research as a way of fostering the inclusion of community members (Reid & Gillberg, 2014). Reflexivity involves a continuous process of researcher self-reflection with regards to the social context of the research project; this facilitates mindfulness of her privileges and "conceptual baggage", documents decision making and identifies possible implications of her power (Reid, 2004, p.11). Smith (2013) advocates going beyond self-reflexivity, as she believes it does little to undermine those privileges and suggests addressing privilege by purposefully changing oppressive power dynamics.

Although people with lived experience of mental illness face similar mental health inequities, the way they experience or respond to oppression is contingent on the ways it intersects with different social locations including gender, social status or race (Collins, 2002). Thus, it will vary how they define and experience structures and processes implemented to facilitate community engagement will vary. The exploration of experiences of engagement in *Imagining Inclusion* warrants an approach that goes beyond individual determinants of health, and for example takes gendered differences into account. An intersectional approach to CBPR allows for a critical inquiry of complex relationships between various social locations while underpinning the role of power relations in shaping health inequities (Hankivsky & Christoffersen, 2008; Hankivsky, 2014).

Intersectionality is a feminist sociological theory, framework, and methodology that has been slowly gaining recognition as an essential theoretical framework for public health and a way of improving the validity and relevancy of health research (Bauer, 2014; Bowleg, 2012). The term intersectionality was coined by Kimberly Crenshaw in 1989 in an effort to highlight the ways in which the oppression experienced by black women was shaped by the intersections of gender and race. The concept and principles behind intersectionality emerged much earlier

through the work of Black, post-colonial, queer, and Indigenous feminists, such Patricia Collins, bell hooks and Linda Tuhiwai Smith (Bowleg, 2012; Hankivsky, 2014). Intersectionality is a way of understanding the complexities of identity and their relationships to power. Intersectional theory helps to understand the ways in which intersecting identities of race, gender, disability, sexuality, class, and so on, are shaped through various forms of domination (such as sexisms, racism) that materialize as experiences of discrimination and privilege and shape people's experiences at individual and systemic levels (Crenshaw, 1991). According to those utilizing intersectional theory, people embody various social identities that are fluid and interconnected and occupy various levels of significance based on historical and social contexts (Hankivsky, 2014). Given that people identify with more than one social group, they can simultaneously experience oppression and privilege (Crenshaw, 1991). Academics employing intersectionality believe social identities intersect and interact with power relations to produce health outcomes, therefore human experience cannot be explained through the lens of a single social category such as gender, race, or social economic status (Bowleg, 2012). Therefore, researchers engaging in intersectionality-informed research are concerned with revealing and understanding the intersections of these social categories, identities, structures, and systems of oppression and privilege that contribute to health inequities and poorer health outcomes within marginalized populations (Hankivsky & Christoffersen, 2008).

An intersectional view of community engagement is similar to that proposed within the CBPR approach in that both approaches consider lived experience as a source of knowledge, view people living on the margins of society as having important knowledges and histories and position them in the center of critical inquiry as 'subject matter experts' (Hankivsky, 2014). Furthermore, both approaches are concerned with reflexive practices and critical analysis. For those taking on a CBPR approach to mental health research, intersectional approaches encourage exploring the historical roots of stigma and discrimination and the ways in which these power systems continue to use identity to exclude and privilege people on the margins of society (Crenshaw, 1991). While intersectionality has been recognized as the most useful approach for critically exploring complex relationships between the determinants of health and the underpinning role of power in shaping mental health inequities (Ingram et al., 2013; Morrow & Halinka Malcoe, 2017), it remains largely underutilized within the mental health context (Ingram et al., 2013; Morrow & Weisser, 2012; van Mens-Verhulst & Radtke, 2008).

Attention to overlapping social locations and power relations makes intersectionality a useful approach for scrutinizing the ways in which micro processes and mechanisms used

within *Imagining Inclusion* intersected with social locations and power relations to support or inhibit experiences of engagement of people with lived experience of mental illness.

Chapter 3.   Methodology and Methods

In this chapter, I describe intersectionality as methodology and present how utilizing an intersectional lens informed decisions around recruitment and data collection methods. I present a summary of the participants' demographic information and provide an in-depth account of the data collection process. Moreover, I describe how intersectional lens was applied to the data analysis process. I end this chapter by positioning myself vis a vis the participants and the research process.

3.1. Intersectionality

I introduce the critical lens of intersectionality as an approach to examine subjective experiences of engagement in *Imagining Inclusion*, a CBPR mental health initiative, in order to provide a more complex and nuanced understanding of community engagement and reveal the potentials and pitfalls of it within the context of mental health. Intersectional methodology was employed here as it has been recognized as the most useful approach for critically exploring complex relationships between the determinants of health and the underpinning role of power in shaping mental health inequities (Morrow & Halinka Malcoe, 2017).

Within the context of health research, intersectionality is not a methodology per se, but rather is a set of principles that guide the research process (Hunting, 2014). Those employing an intersectional approach to research are predominantly concerned with the lived experience of people living on the margins of the society (Hankivsky, 2014). Accordingly, they privilege experiential knowledges and regard them as legitimate and important. Furthermore, they seek to understand the lived experience through an exploration of identity formation (Hankivsky, 2014). The belief that knowledge is socially situated (Collins, 2002) demands consideration of social locations and the historical and sociopolitical contexts at play, such as economic, social, cultural and political oppressions. Another important principle of intersectionality is the belief that multiple social identities are more powerful as a whole than the sum of its individual parts, because these social factors are interconnected, fluid, and dependent on social time and place (Collins, 2002). This consideration also exposes the ways in which well-meaning approaches can produce exclusionary outcomes that harm individuals and communities and further perpetuate health inequity. According to van Mens-Verhulst and Radtke (2008) analyzing social factors as separate elements of human experience can lead to assigning characteristics

associated with a social group to an individual connected to this group. Consequently, this process of analysis paired with the tendency to generalize research findings might result in perpetuating old stereotypes, creating new ones, disregarding within-group differences, and pathologizing people that diverge from the norm (van Mens-Verhulst & Radtke, 2008). As social identities are formed through relationships, exploring lived experience through the intersections of social categories can reveal power relations (Hunting, 2014). Thus, researchers employing intersectional analysis utilize a non-additive approach to social categories. In addition, they view power as relational and employ the study of power to explore lived experience through multiple axes of intersecting social locations to consider issues of difference rather than essentializing categorical factors; for example, the category of women and Black (Crenshaw, 1991).

Moreover, intersectionality has been increasingly recognized as an effective approach to evaluating academic-community partnerships (Hankivsky et al., 2010). For example, historical and sociopolitical contexts can help us understand the connection between participatory approaches and health outcomes, as they impact how participatory practices are materialized within these projects. In addition, acknowledging and understanding the ways in which power differentials operate within these collaborations can be helpful in exposing: 1. how engagement strategies are experienced by the participants; 2. the ways in which forces of domination and subordination are being challenged and reinforced; 3. determining which voices are included and which ones are silenced and why; and 4. why participatory efforts might not always produce the envisioned outcomes. Furthermore, exploring the experiences of engagement of community members can reveal the ways in which micro and macro power forces operate within these initiatives. By virtue of being positioned on the margins of society, community members involved in these partnerships are more attuned to the shifting power relations and are better positioned to contextualize their experiences.

Another critical aspect of an intersectional approach to research is employing reflexivity (Collins, 2002). Reflexivity is a defining feature not only in an intersectional approach (Hankivsky, 2014) but also in CBPR (Hunting, 2014) and in qualitative research (Finlay, 2003). In an intersectionality-informed research, reflexivity plays a critical role in ensuring transparency and methodological rigour (Reid, 2004) as it allows the researcher to continuously examine her own positionality vis a vis the research participants and the research process. In this project, I used an intersectional lens to shape the research question and objectives, research design, the participants' recruitment process, the data collection and analysis, and the narrative description of the participants' experiences. In my dual role as a project coordinator on the *Imagining*

Inclusion project and a researcher on this project, I used reflexivity to examine the following: 1. power relations between myself and the participants; 2. my own assumptions about the participants' experiences within and outside *Imagining Inclusion*; 3. The ways in which my previously established relationships with the participants might have facilitated or hindered the interview process and influenced participant selection and the data analysis process.

3.2. Research participants

Recruitment. Participants for this study were drawn from the *Imagining Inclusion* research participants and peer researchers. The poster advertising the project was displayed at the Thrive program location (site of the *Imagining Inclusion* project). In addition, the Thrive program coordinator emailed invitations to participate in this study to the selected group of the Imagining Inclusion participants and peer researchers.

The following inclusion criteria were implemented to recruit the research participants from the *Imagining Inclusion* project:

1. over 18 years of age;

2. has lived experience of mental illness;

3. manages medications, addictions and harmful behaviours;

4. has been recruited as a peer researcher or a participant on the *Imagining Inclusion* project;

5. able to understand the nature of the project;

6. willing to participate in an hour and half long interview;

7. fit into one of the following groups:

- Participant in the intake interview only (II)

- Participant in the photovoice stage only (PV)

- Participant in the photovoice and the Peer Task Group(s) (PTG)

- Peer researcher (PR)

To gain multiple perspectives on ways in which diverse social locations, such as gender, race, income, and a mental health diagnosis interacted to shape engagement in *Imagining Inclusion*, this study used the maximum variation sampling strategy (Creswell, 2017) to identify

and recruit participants for the interviews. This sampling strategy involved purposeful selecting different selection of participants to ensure diversity of experiences and opinions within the sample (Creswell, 2017). Participants were purposefully selected based on their roles and the length of time of their engagement in the *Imagining Inclusion* project. I intentionally sampled participants from four distinct stages of *Imagining Inclusion*; (Intake Interview (II), Photovoice (PH), Peer Task Group (PTG); and Peer Researcher (PR)), to allow for categories of difference to emerge, to ground my analysis in diverse voices and to explore who was able and who was unable to continue their engagement in *Imagining Inclusion* and why (see Table 2 for demographic information).

Stages	Pseudonym	Age	Gender	Language	Education	Employment status	Income	Ethnicity	Diagnosis
INTAKE INTERVIEW	Lulu	62	female	English	some college or university	PWD CPP volunteering casual job	11 000 – 15 000	French Canadian	socioaffective disorder
	Susan	54	female	English	university degree	PWD volunteering looking for job	11 000 – 15 000	Australian-Finnish	Schizophrenia
PHOTOVOICE	Kelly	50s	female	English	university degree	Pension volunteering	less than 10 000	Canadian	major depression
	George	51	male	English	diploma or certificate	part time PWD, CPP	11 000 – 15 000	Caucasian	trauma
	Eagle	51	female	French	some college or university	part time	less than 10 000	African	personal
PEER TASK GROUP	Natasha	54	female	Chinese	some college or university	PWD CPP	less than 10 000	Chinese	Bipolar, anxiety OCD, personality disorder
	Emmett	35	male	Cantonese	diploma or certificate	part time	less than 10 000	Chinese	anxiety disorder past depression
	Elsbeth	55	female	English	diploma or certificate	PWD CPP	21 000 - 25 000	Caucasian	Major depressive disorder, PTSD
	Joe Bloggin	52	male	English	some HS	PWD volunteering	less than 10 000	Canadian born Asian	depression
	Trent Halliday	61	male	English	some college or university	PWD volunteering	less than 10 000	Canadian	chronic severe depression, AHDH

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Stages	Pseudonym	Age	Gender	Language	Education	Employment status	Income	Ethnicity	Diagnosis
	Sunny	46	female	English	some college or university	PWD	26 000 or higher	French, native Swedish	mood disorder
PEER RESEARCHER	Liza	45	female	English	University degree	Part time; Disability benefits	16 000 – 20 000	Mixed ; externally constructed as "black" or Dalit	Bipolar
	Susan Brown	47	female	English	University degree	Contract and part-time employment ; Disability benefits	16 000 – 20 000	Caucasian	Bipolar

Table 2. Participants' self-reported demographic information

3.3. Research Methods

This research project used qualitative methods of in-depth individual interviews to explore the understandings of the concept of engagement and the experiences of engagement in the *Imagining Inclusion* project. Qualitative methods are compatible with intersectionality, as both privilege knowledges derived from lived experience and are concerned with the contextual framing of research and explore researcher-researched power relations (Hunting, 2014).

In-depth interviews.

Face-to-face one-on-one semi-structured interviews were the data collection method as they allowed for in-depth probing while keeping the main issue in focus (Ormston, Spencer, Barnard, & Snape, 2014). Furthermore, they allowed for the observation of body language and nonverbal cues which can be of particular importance when seeking to understand the broader power dynamics at play and their implications for the experience of community engagement. Non-verbal cues, in addition to the participants' verbal responses, helped me to guide my use of probes. For example, when asked to describe an instance when she felt that her views were not valued in *Imagining Inclusion*, Natasha (PTG) looked at the floor and started to fidget. It seemed that she wanted to say something but was uncomfortable answering this question. I offered additional encouragement and reassured Natasha (PTG) that I was interested in learning about both positive as well as negative experiences, in order to better understand how she experienced engagement in *Imagining Inclusion*. After each interview, I documented my observations and my reflections in journal.

Thirteen interviews were conducted over a period of four months, between August and November, 2016. Written consent was obtained before each interview. Prior to the interview, I verbally went over the information in the consent form (see Appendix A) and answered any questions or concerns participants had about the study. All participants chose pseudonyms and were informed of the voluntary nature of the project and their right to withdraw from the project at any time. Interviews took place in a private room at the Thrive program location. At the beginning of each interview, the research participants received $25 cash as acknowledgement of their time and contribution. Three separate interview guides were developed to ensure that the questions asked were relevant to each group of the research participants: 1. Intake Interview; 2. Photovoice and Peer Task Group; 3. Peer Researcher, (see Appendix B, C, & D).

The interviews lasted from 30 to 90 minutes. Interviews with the research participants from the Intake Interview group were the shortest and the interviews with the Peer Task Group and Peer Researcher group members were the longest. As two Intake Interview participants did not continue their engagement in *Imagining Inclusion* beyond the 30-minute intake interview, they were asked to reflect on their experience in a recently attended community-based program that was important to them. Lulu (II) chose to discuss a skill-based program; a flower arrangement class, that was offered through continuing education and was not specific to mental health. In contrast, Susan (II) chose to focus on a walking program for people with lived experience of mental illness. It became apparent during the interviews that the interview questions that prompted rich reflections on experiences in *Imagining Inclusion*, did not provide the same depth of information regarding experiences in other programs. The responses of the II participants contained less detail and were overall much shorter. This might have been due to the nature of the programs discussed – being focused on teaching a new skill (a flower arrangement program) or facilitating an activity and social interactions among the participants (a walking program). As a result, experiences in these programs did not reflect the participants' definition of 'engagement' and the data gathered did not lend itself to an analysis of the intersections of social locations and power relations. Subsequently, I wasn't able to draw on the data collected from the II participants as much as I did from other participants.

Keeping a reflexive journal throughout the data collection process allowed me to become more cognisant of my insider knowledge about *Imagining Inclusion* and navigate my biases more effectively. Firstly, as I was involved in planning and facilitating most of the *Imagining Inclusion* processes and activities, I had to resist an urge to clarify or defend some of the decisions made by the *Imagining Inclusion* research team that the participants were referring to. Journaling about my 'experiential baggage' from *Imagining Inclusion*, allowed me to make a more conscious effort to put aside my own experiences and to focus solely on the participants' experiences. Secondly, I had a preconceived notion of the ways in which the participants will engage in this research. Writing about my assumptions regarding each participant prior to the interview, allowed me to become more aware of these biases and approach the interview process more openly. This also helped me avoid using leading questions during the interviews. On the other hand, my insider knowledge allowed me to facilitate a safer space for the participants. For example, my previous knowledge of the participants allowed for more effective interpretation of the nonverbal cues; as a result, I was able to attend to the participants needs during the interview more effectively, by offering a break, reassurance or encouragement.

All interviews were audio recorded and transcribed verbatim. The first two interviews were transcribed before conducting the subsequent interviews to allow for revisions to the interview guides. Subsequently, minor revisions to the interview questions were made between interview two and three to remove a repetitive question.

Secondary data sources.

I received written permission from the *Imagining Inclusion* co-leads to use demographic data from the *Imagining Inclusion* intake interviews associated with the participants of this study. Demographic data related to the peer researchers were collected during this project at the individual interview meeting. Emerging themes from the *Imagining Inclusion* project were used to support the objectives of this project and informed the interview guides.

Confidentiality.

A coded approach was used in the data collection process. Prior to the interview, each participant chose a pseudonym. Participants' names and other identifiers are stored separately from their research data. Participants were assigned numbers at the time of the recruitment and prior to data collection. Signed consent forms and any other data that can identify a participant were stored in a locked filing cabinet, which has only one key, in the principal investigator's home. Only the principal investigator has access to these data. Electronic data has been stored on the principal investigator's laptop. This data is password protected.

3.4. Data analysis

In this project, I applied an intersectional lens to data analysis to explore different standpoints on the concept of engagement and expose the intersections of social locations and systems of power shaping experiences of engagement in *Imagining Inclusion*.

NVivo 10 software was used to organize and manage data. All transcripts were analyzed using intersectional multi-stage coding and analysis with the purpose of revealing commonalities and patterns across the experiences of and understandings of engagement among the participants (Ormston et al., 2014). The analysis occurred in iterative cycles throughout the project and included inductive and deductive analysis (Reid, Greaves, & Kirby, 2017).

The data were analyzed with a specific focus on individual experiences of engagement in *Imagining Inclusion* and the ways in which these experiences reflected and were shaped by overlapping socio-structural inequities. I began the analysis process with an inductive coding of the transcripts, starting with open coding and then moving into axial coding, to search for patterns (Marshall & Rossman, 2014). The first draft of the codebook was based on the open coding and structured according to major sections of the interview guides. Descriptively coding the interview transcripts, I actively searched for indicators of power relations to embed experiences at the micro level within the broader context of power dynamics (Bowleg, 2008). In the first codebook, descriptions of social inequality were coded separately (Bowleg, 2008); for example, the descriptions of experiences of sanism and sexism were coded separately. As a result, during the first level of coding, some data was double coded (Reid et al., 2017). When all transcripts were coded descriptively, I moved to axial coding to identify intersections of oppressive relations (Hunting, 2014). For example, intersections of poverty and sanism emerged as relevant within the context of engagement in *Imagining Inclusion*. In order to reveal unique and intersecting experiences of the participants, I was attentive to the narratives that indicated a link between peoples' experiences of their social locations and power relations and their experiences within *Imagining Inclusion*. I purposefully focused on how people drew on different social categories to construct their definition of engagement and to describe their experiences of engagement. I further contextualized the intersections of oppressive power relations within the *Imagining Inclusion* process; for example, the ways in which sexism and sanism (power relations) intersected with sharing stories of lived experience (photovoice process) to shape how people experienced their roles of being a participant or a peer researcher.

During the coding of the data I was trying to be aware of my professional biases; such as my pre-conceived ideas about the kinds of intersections of oppression and privilege that shaped the participants' experiences in *Imagining Inclusion* or the outcomes that they might have experienced. Consequently, I made and made a conscious effort to allow the data to shape the direction of the analysis. For example, I used some of the participants' phrases to guide code and theme development. Furthermore, I used narratives of ideological and conceptual standpoints and critiques relevant to the projects research question to provide a framework for the analysis.

After completing the initial analysis, I set-up a meeting with the research participants to share and discuss the emerging themes. I was able to re-connect with all participants either

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through email or phone. Seven participants replied that they were unable to attend the meeting due to previous commitments; however, six of them emphasized that they would like to be contacted about the research developments in the future. The meeting with the research participants was held on May 26th, 2016 and was attended by six of the 13 participants (four from PTG group, one from PV group, and one from PR group). A Power Point presentation of the emerging findings was followed by a group discussion. The meeting included refreshments and lasted approximately 1.5 hours. Overall, the participants seemed very attentive during the session. During the presentation they often nodded in agreement and smiled when they recognized their pseudonym or their words in the presentation. The discussion after the session was dominated by three participants. Participants who were quiet during the discussion mentioned prior to the session various challenging circumstances that they were dealing with at the time of the meeting, such as a recent cancer diagnosis and housing issues. After the presentation, one participant questioned the findings that were contradictory to her own experiences with *Imagining Inclusion*. This was in relation to the finding representing a critique of *Imagining Inclusion*. I clarified that each study finding was not representative of everyone's experiences and that it was important to represent both, the benefits as well as the challenges, that people faced in *Imaging Inclusion.* Presenting complex academic terms and the projects' findings clearly and effectively to the lay audience was another challenge. Although I considered diverse language and educational needs of the participants while planning the presentation, when asked directly about the clarity of the presentation, one participant with ESL admitted that the language used in the presentation was "over his head." The participants left the session stating that they enjoyed updates on the progress of the project and demonstrated an interest in hearing about the project's future developments.

3.5. Study limitations

Although I recruited participants across a continuum of engagement in *Imagining Inclusion*, some might question the diversity of responses within each subgroup due to the small sample size. Moreover, my previously established relationships with the *Imagining Inclusion* participants might have affected who agreed to participate in my thesis project and their reasons for participating. For example, at the time of the recruitment I had known the PR participants for two full years while we were working closely together on *Imagining Inclusion*. Similarly, I had known the Analysis PTG participants for over a year through our weekly analysis meetings. It is possible that the participants who worked with me closely for an extended period of time might

have been more hesitant to critique the *Imagining Inclusion* project. Conversely, I had not seen the PV participants in a year and the II participants I had only met once prior to this project. Consequently, these participants might not have been as comfortable as PTG or PR participants in terms of sharing their personal experiences and opinions. Furthermore, a long period of time between their involvement in *Imagining Inclusion* and in this project might have affected what they remembered about their engagement in *Imagining Inclusion*. In addition, although the consultation with the participants regarding the emerging themes was facilitated, only half of the participants were able to attend it. Due to logistical reasons, I was unable to follow up with the rest of the participants.

3.6. Positioning myself

My identities as an ESL-speaking, middle aged, immigrant woman from an Eastern European country, having an uncertain grasp on the lower middle class, positions me alongside some of the intersectional experiences of the participants. Experiences of sexism, sexual violence, classism, labor exploitation, discrimination and poverty are also part of my story. Although I have some experiences of marginalization and exploitation similar to the participants, the strength of my cumulative privileges of being white, heterosexual, married, employed, English speaking and pursuing higher education have often protected me from having my moments of extreme distress psychiatrized and from experiencing the kinds of oppressions described by the participants. Throughout the project, I was directly and indirectly reminded of my many privileges. For example, when during the recruitment stage, I was approached by one of the potential participants, Lulu (II), about the project because she was "interested in earning $25." Lulu (II) explained that she was just released from the hospital (her second hospital stay that year) and as a result had lost access to $100 volunteering money. She did not know how she was going to survive until the end of the month. When I handed her $25 at the beginning of our interview, Lulu (II) looked straight at me and said, "you cannot imagine how much this means to me." This exchange and Lulu's directness about seeking an opportunity to 'earn' $25 gave me a small insight into the level of poverty some of the participants were forced to navigate.

Furthermore, my intimate knowledge of the project processes and my previously established relationships with the participants have influenced the power relationships between myself and the participants and ultimately shaped the breadth and depth of the data gathered through the interviews. Moreover, my work on *Imagining Inclusion*, and specifically the

relationships that I have established with the co-leaders, provided me with their ongoing support during the development, implementation and analysis stages of this project and facilitated access to potential research participants.

My extensive involvement, the participants' overall positive experiences in the project, and the trusting relationships established between the participants and the research team members, influenced and facilitated the recruitment process and allowed me to conduct the interviews with the participants from a place of deep trust, respect and safety. Generally, the interviews with the participants who continued with *Imagining Inclusion* beyond the Intake Interviews stage (PV, PTG and PR groups) were long, very descriptive and rich in examples. As a result, I was able to gather detailed descriptions of the concept of engagement and experiences of engagement.

On the other hand, my role as a project coordinator may have limited how people critiqued *Imagining Inclusion*. I openly invited constructive criticism; for example, I asked the participants to describe instances when they felt like their voices were not valued. They either said that they never felt unvalued or they associated negative experiences with the behavior of their peers rather than the project per se.

My privileged position of researcher vis a vis the participants on this project fluctuated during the interviews in tangible ways. For example, during an interview with one of the peer researchers, new dimensions of power became more salient over the course of the interview. Liza (PR) often drew on her extensive knowledge of feminist theories, and her embodied and lived experience that, at the time of the interview, were beyond my knowledge and understanding and increased my vulnerability. Furthermore, the power dynamics that emerged during the interviews with the participants complicated my position as an ally of people with lived experience of mental illness in *Imagining Inclusion*. Although I was often seen as a 'supporter' and 'helper' by the participants, Liza (PR) directly discussed the ways in which I was implicated in the oppression of people with lived experience of mental illness. She emphasized the fact that I was receiving material gains from a system that was implicated in the oppression of living with a diagnosis of mental illness. She told me: "if you were really interested in making the biggest impact on the mental health population you would have quit your job and gave your paycheque to mental health people." As poverty is one of the most dominant and pressing forms of oppression experienced by the mental health community, Liza (PR) felt removing myself as a resource 'broker' would produce more immediate and tangible benefits. Furthermore, she

emphasized the power differentials between us by highlighting the ways in which those perceived as 'sane' have been benefiting from having an unearned privilege of credibility "because they are not turned insane." This conversation complicated how I saw my role and my credibility in pursuing this research project, which left me with questions: How am I implicated in the oppression of people with lived experience of mental illness? Is removing myself from the context of mental health research the most noble act towards eroding mental health inequities? Although I still am not able to fully answer these questions, I see my role as more fluid and shifting between being an ally and acting as an oppressor. In addition to my many privileges of being constructed as white and heterosexual with access to employment and higher education, I continue to directly benefit socially and materially from being perceived as 'sane' and as a result 'credible' and by extension I am complicit in creating the Other and perpetuating the status quo. Furthermore, positioning the participants within this research project in a space where they are being investigated and probed about the oppression that I continue to construct, further refined the unjust power dynamics. The tension between acting as both an ally and an oppressor within the context of this research has guided how I approached the data gathered through the interviews and reassured me of the potential of applying a critical lens of intersectionality to shed light on the hidden power dynamics within the mental health research.

In my thesis, I do not intend to speak *for* people with lived experience of mental illness in *Imagining Inclusion*. Rather, my intention is to apply intersectional theory to their narratives of engagement in order to reveal intersections of social identities and macro and micro power relations relevant within the context of their experiences.

Chapter 4.   Findings: What does engagement mean to people?

"Engagement with life and not the psychiatrization business."
(Trent Halliday, PTG)

The findings from this project will be presented in 3 chapters around the major themes that emerged through the intersectionality informed analysis: Chapter 4: What does engagement mean to people? Chapter 5. Community engagement: benefits and challenges; Chapter 6. Tensions around collaborative relationships.

I began the interviews with the research participants by discussing their understanding of the concept of engagement and the ways in which they experienced it. This was important to explore as most accounts of community engagement are predominantly reported through the lens of academics.

4.1. Language of Engagement

When asked "When you hear the word engagement what comes to your mind?", a couple of the participants associated the use of the language of engagement with professional health care environments. Based on the health care posters promoting engagement initiatives, Emmett (PTG) concluded that the concept must be important, but admitted he did not fully understand what it entailed:

> It's actually [popular] within the mental health system and simply with the health system [...] because they actually put [a] poster about it (…) I found out when Vancouver Coastal Health used the same word [engagement] and I never understood what that meant. I went to work twice a week at the hospital and I saw the posters but it never came to me to ask "what the hell is engagement?" (Emmett, PTG)

Although within the framework of community engagement the term engagement indicates an active role for the community members, for Liza (PR) it seemed to be more relevant to the bureaucratic structures than to the participants' day-to-day realities. She explained:

> I definitely come across [the language of engagement] more in funding and research … I can't say that all my peers in mental health are talking about community engagement, they are not like "Liza, how can I be more community engaged? I really want to know…". No, nobody is saying that at all. (…) so I guess

> when we talk about community engagement like there is the looksy grant stuff, but there is a street credit like what and where there is a real engagement.

Liza's (PR) comments pointed out the division between what the system might consider to be community engagement – "the looksy grant stuff", and what community members considered to be a credible form of engagement – "a real engagement."

Interestingly, when asked to explain what the concept of engagement meant to them outside of their experiences in *Imagining Inclusion*, all five participants who were PTG members kept going back to examples from *Imagining Inclusion* to illustrate and further clarify their definition of engagement. This could have occurred because their experience in PTGs clearly exemplified characteristics of meaningful engagement or because for them *Imagining Inclusion* served as the only point of reference for defining this concept.

Furthermore, when asked to choose a term that was the most meaningful and best reflected their definition of engagement (words that were suggested as an example included: 'engagement', 'meaningful involvement' or 'participation'), most of the participants chose expressions such as "connection", "dialoguing as equals", "understanding each other" and "meaningful involvement". In fact, one of the participants suggested that he would like to use the word 'connection' interchangeably with 'engagement' throughout the interview. The preferred expressions highlighted the participants' desire for shifting power dynamics within the community engagement initiatives in order to experience connection and meaning.

4.2. Dimensions of Community Engagement

Conversations about the term *engagement* and the subsequent analysis revealed four broad dimensions of community engagement: 1) Collaborative; 2); Critical 3); Intersectional; and 4) Emancipatory.

Collaborative

Throughout the interviews, all participants spoke about the ways in which multiple and intersecting forms of oppression such as stigma of mental illness, poverty and sanism, experienced both within and outside of mental health system, resulted in experiences of rejection, isolation and exclusion. It was not surprising then that every participant defined engagement through the lens of relationships with others. Expressions such as "doing things

together with other people", "understanding each other", "connecting", "coming together", "communicating with each other", and "listening to each other", were used most often to describe when people felt the most engaged. Furthermore, markers of engagement identified by the participants, included feeling "wanted", "accepted", "included", "[feeling] not aside from everyone else", and "I trust them and [I am] being trusted." Similarly, when asked "how do you know when you are engaged?", the participants often spoke about the experience of being treated with respect and dignity by others. Natasha (PTG) explained the causal relationship between the experience of engagement and relationships with others: "It [engagement] doesn't happen just like that. It has something to do with people that are surrounding me, how they react to me." Defining engagement through a relational lens highlights the ways in which it is inherently intertwined with power relations.

Intersectional

Two participants discussed the concept of engagement through the lens of intersecting social locations and related power dynamics. Liza (PR) explained the ways in which social locations shaped the subjective understanding of engagement: "it [the experience of community engagement] depends on what you see as community and what [you] see is engagement, which is a reflection of your own relative demographics." Furthermore, she discussed ways in which engagement was fundamentally intertwined with access to power and resources: "if power is related to money and if people with money have more power than they are more engaged and people with less money are not as engaged or cannot get engaged as much" (Liza, PR). As such, the understanding and experience of engagement was contingent on social locations and power relations.

On the other hand, Kelly emphasized the importance of considering the issue of inclusion in engagement. When asked to describe the ways in which she would engage people with lived experience of mental illness in CBPR, Kelly (PV) said:

> I will, I would be honest and say, "we've got three quarters of the people here and this is not an honest sample, if one quarter aren't here, and what are their barriers? Is that possible to address their barriers? Is it that easy to exclude them? Or do we wanna have a- a more honest, uh, sample? And, uh, find out from them?" Because, you know, maybe I'm not the only one that was isolated because of the health issues. Maybe there was someone else because of a mental health issue or hassle with a spouse. You know, maybe it's family violence; who knows what barrier could be, so maybe that would have been better.

Kelly's (PV) example raised questions about how social inequities shape who gets to be included and who remains silenced within community engagement, and the connection between the issue of inclusion and community representation in community engagement initiatives.

Critical

Another key aspect of engagement identified by the participants was the opportunity to freely share their lived experience of mental illness. When asked to define engagement both participants from PV and PTG spoke about having the "freedom to speak and think or say the things I think" the "sharing of thoughts, feelings, ideas." Emmett (PTG) emphasized the importance of having a dialogue about mental illness while distinguishing different types of knowledge: "We can talk about it [issues important to community members]. We can, we can have more information about it [mental illness]. Not propaganda wise but from real-life experience". For Emmett (PTG), it was important for engagement to be centered around first-hand accounts of mental health community members – "knowledge from real life experience." Similarly, when asked what it mean for her to be engaged, Eagle (PV) explained: "it means I participate, I feel part of the project, I ask question, I share my personal experience.

Furthermore, two participants discussed the importance of centering engagement explicitly on issues that shape their day to day lives, such as poverty, unemployment or mental health stigma, and the ways in which they affect their daily lives. For example, Emmett (PTG) described engagement as having the opportunity to explore issues of social justice affecting mental health community members:

> If just the management try to understand what the patient need. Or the managers and the staff try to understand what the patient need. I mean respect (…) and other stuff that people want to talk about. Talking about human rights, equal opportunity, no sexism, no racism, that kinda stuff.

For Emmett (PTG), one of the markers of engagement was an opportunity to discuss intersections of oppressive power relations, such as sanism, racism and sexism that shape the day to day lives of people living with a mental illness diagnosis.

Many participants further explored the idea of engagement as a platform to tell their story of lived experience by discussing how their stories are received. Participants used words such as "understood" and "valued" to describe their feelings of having their stories heard and acknowledged. Eagle (PV) provided a context to her experience when she said: "(…) when you

have to share personal experience, it's painful because it's about mental illness but otherwise it [engagement] feels comfortable (…). I feel valued in what I'm doing when I feel engaged." Here Eagle (PV) explained how sharing her story of lived experience can be painful and rewarding at the same time. Kelly (PV) further explored the meaning behind the notion of being 'heard': "[…] it's [engagement is] not just being heard, not just [being] heard like a robot would listen but like... validation is big." Kelly's comment highlighted the difference between being listened to "like a robot" and having a story of lived experience acknowledged. Participants saw engagement as a way of gaining credibility.

Emancipatory

Another critical marker of engagement, identified by seven participants, was engagement as a means to create social change. As such, participants often discussed engagement as a "two-way relationship" that provides the opportunity for both social action and personal gain. For Trent Halliday (PTG) that meant "(…) deeds not words; it's not just the initial perception is the follow through that's important." Similarly, Kelly (PV) spoke about the inherent action-oriented nature of engagement: "I think there's a responsibility that it [engagement] goes someplace (…) it does something (…) influences policy change" (Kelly, PV). Both comments referred to engagement as bound by its commitment to social justice outcomes. For most participants it was important that engagement offered an opportunity to access socially valued roles and resources, such as, status, capacity building opportunities and financial compensation. Both participants who worked as peer researchers on *Imagining Inclusion* brought up the issue of the distribution of resources within the context of engagement. Liza (PR) said: "The real community engagement I find comes when you put out a meal for people." "Put[ing] a meal for people" was seen as a marker of "the real engagement", as it acknowledged and directly attended to poverty as a barrier faced by people with lived experience of mental illness. Similarly, Susan Brown (PR), identified material incentives, such as "snacks, honoraria, having their [participants'] name on the cover of the book, rewards...that kind of thing" as important in facilitating the engagement of community members. In addition, both peer researchers drew attention to engagement as having access to employment opportunities. Susan Brown described it as "just having more opportunities, money (…) opportunities for future jobs." The above comments raised an important issue of community members receiving tangible benefits for their time and efforts.

Within the emancipatory dimension, engagement was also seen as a means of shifting unjust power dynamics. This was raised by five participants from the PR, PV and PTG groups. George (PV) spoke about engagement as "find(ing) new ways of communicating, trusting". His comment highlighted engagement as an opportunity to establish new and more equitable ways of relating to one other. Liza (PR) further argued that the experience of engagement within the context of mental health was dependent on the redistribution of power when she said:

> [...] so in terms of facilitating engagement with people with lived experience basically you [people without lived experience of mental illness and in position of power] have to let people with lived experience be a little bit up and take some power and be willing to share that power and ... dialogue as equals [...].

Liza (PR) suggested that in order to reposition people with lived experience of mental illness from *less than* to *equal*, those without lived experience need to intentionally let go of their power locations and allow people with lived experience to step into positions of power. Similarly, Natasha (PTG) discussed the causal relationship between oppressive power relations and the experience of engagement. She said:

> [Engagement means] being included, accepted without being judged by whatever disability or anything I have. [...] Being accepted of who I am [...] rather than judging me "you are being lazy" or "you just don't want to do it or just making excuses" all that stuff.

For Natasha (PTG), sanism endured through the invalidation of an experience of mental distress, judgment and an expectation of conformity, diminished a sense of inclusion and ultimately compromised her experience of engagement. In fact, when sanism and other forms of bigotry are not addressed, community engagement can become a form of oppression. As one of the participants described it: "engagement with guilt, shame, and blame is like punishment" (Emmett, PTG).

Within the emancipatory dimension, key markers of engagement were more equitable power relations as evidenced by concrete efforts in counteracting oppressive power relations and pursuing social change and distribution of tangible resources, including employment opportunities.

4.3. Interconnections between inclusion and engagement

When asked about the potential role of inclusion in engagement specifically, all participants felt that inclusion and engagement processes were interconnected; as Kelly (PV)

explained: "engagement and inclusion ...seem like they are almost parallel, they are almost together […] if you do it wrong [engagement], and it often is done wrong, then you're only gonna have people with... less disabilities, less barriers, participating." Kelly's comment points out that attending to the issue of inclusion within the context of engagement of people with lived experience of mental illness can help to ensure a more just and intersectional representation of community members.

The participants spoke about the role of inclusion as critical in facilitating the engagement process and generally believed that "it's difficult to be engaged if there isn't a feeling of inclusion" (Elsbeth, PTG). Moreover, Elsbeth described the experience of engagement without a feeling of inclusion as being reduced to "a silent bystander"; positioning inclusion as an enabler of active engagement. Two other participants explained that inclusion enabled engagement by counteracting experiences of loneliness and exclusion. Susan Brown (PR) said:

> So being included, feeling included ... it helps people to be engaged in what they are doing, 'cause they are feeling connection with other people, they are not alone and ... they can make friends maybe or in the group, outside or [during] breaks, so there is social aspect to it.

According to Susan Brown (PR) having a sense of inclusion – "feeling connection with other people" - supported people's ability to engage.

The participants' descriptions of an interconnected causal relationship between engagement and inclusion, positioned inclusion as one of the markers of engagement.

4.4. Surfacing tensions: ideals vs practice

A common thread through the various narratives of the concept of engagement was an explicit and implicit reference to tensions between participants' ideals of engagement and their day-to-day reality of systemic subjugation.

Sense of exclusion

Both peer researchers spoke about the ways that sanism intersected with other forms of oppression as well as privilege to influence hierarchies within the mental health system. Liza (PR) said:

[…] especially not having money you know and being crazy yeah ... so I mean people whose voices get heard are often the more educated people or the people who are, the people that can communicate with less provoking, less anger and guilt you know, because there are many people in the system that […] that they are not less than staff or whatever but that's the way it kind of gets acted out, because of who gets paid and who has privilege and who has more entitlement […]

Liza (PR) explained the ways in which previously established power dynamics within the system, that Other community members and position them as "being less than staff", intersected with mental health inequities such as poverty and sanism, to influence who was perceived as having credibility and who was further silenced. The above reflection also exposed the ways in which systems of power sustain themselves by privileging those who are willing or able to conform to them.

Susan Brown (PR) shared a personal experience illustrating the ways that people with lived experience of mental illness were tokenized and silenced within the larger systems:

When I went to that knowledge transfer exchange thing, you weren't there, but [project co-lead] and [project co-lead] were there at the Centre for Dialogue at SFU and they were talking about the policy and Mental Health Commission stuff. They [organizers] didn't invite a single consumer or single person with lived experience there, and so I stood up and I said something [regarding] why are you making policy and talking about people with lived experience, when there is no one here except for me.... didn't you think to invite them?

Susan Brown's (PV) account of being a lonely voice in confronting the exclusion of people with lived experience of mental illness from spaces where discussions and decision making regarding policies and systems that directly affected their day-to-day lives, further exemplifies the systemic subjugation of people with lived experience of mental illness.

Experiences of exploitation

Two participants provided an explicit critique of the ways in which they have observed the concept of engagement implemented or realized within the larger system. Liza (PR) said:

[…] so for us who work in that area, who have been [mental health] activists all our lives ...so this [community engagement] is a trendy thing and people will definitely appropriate other people to rubber stamp whatever they are doing … it's already happening… engagement is one of the check boxes that you have to check off.

The above quote demonstrates a sense of dismay with the ways that engagement has been misappropriated within the system. Liza observed a superficial and tokenistic approach to the

inclusion of people with lived experience of mental illness within folds of the systemic power. These efforts seem to be driven by the desire to fulfil organizational agendas rather than social change.

Similarly, Kelly (PV) expressed a deep sense of disappointment with her engagement as a research participant:

> I mean I've been in BC for 13 years, we don't get a whole lot of engagement that goes anywhere. […] so, I'm used to a lot of dead end, so called [community] engagements, but [then]... it's nothing [nothing changes in the mental health system]. It's nothing. And I hear it, like a spark here and a spark there and you follow it through and you see all this is some kind of bullshit agenda.

Kelly's (PV) comment exemplifies her frustration with the initiatives that facilitate peer participation, but are lacking in community relevant agenda, social justice focus and sustainability planning. Furthermore, Kelly (PV) described the ways in which the voices of people with lived experience are often marginalized within the larger systems:

> I think an important thing is being heard. I find living in this poverty trap of BC in Vancouver, I find that people with mental illness are repetitive; they say the same story over and over and over. Some of those stories they've been saying for 4 of 5 years and it's dawned on me that they look crazy for repeating the same story. But [then] I realized, I guess in the last year; and it's because I'm doing myself now […] I've realized that people are not being listened to […] you keep repeating the story because nobody's listening […] that's why they're doing it and it looks like they're ruminating [being] obsessive, but it's because it's an important story (…).

Here, the sanist approach to the knowledge of lived experience of mental illness, results in the reproducing and deepening invisibility of the community members and psychiatrization of their advocacy efforts. The above accounts are illustrative of the ways in which sanism intersects with the efforts to include people with lived experience of mental illness within the larger systems of power to re-produce rather than challenge unjust power differentials within the context of mental health. As a result, engagement here functions as a means of oppression rather than a tool for social change.

Chapter 5.   Findings: Community engagement: benefits and challenges

> *"You see I have a number of challenges in my personal life (…) mundane sort of but there is so many of them, because you can't take your hands off the wheel of your own life without having a lot of cleaning up to do afterward."*
> *(Trent Halliday, PTG)*

A lot has been written about the tensions and ethical dilemmas experienced by academic researchers as they take on CBPR initiatives; however, less attention has been given to exploring tensions experienced by community members. For people who have been historically mistreated and silenced by mental health research and practice and who are weary of day-to-day survival efforts, engagement in a CBPR project can be both a promising and daunting experience. In this section, I explore a broad theme of tensions around joining and sustaining engagement in *Imagining Inclusion*. Specifically, I explore: 1) What motivated community members to join *Imagining Inclusion*? 2) What inhibited community members' ongoing engagement in *Imagining Inclusion*? 3) What motivated community members' ongoing engagement in *Imagining Inclusion*?

5.1. What motivated community members to join *Imagining Inclusion*?

Most of the participants who continued with *Imagining Inclusion* (PR, PTG, PV groups) saw it as an opportunity to pursue a personal interest and had a clear goal in mind when joining the project.

The ways in which the intersections of sanism (psychiatrization), mental distress and socioeconomic status influenced entry to *Imagining Inclusion* was twofold: on one hand it contributed to participants' feeling suspicious and apprehensive about the intentions of the researchers and more specifically about their role on the project; on the other hand, it provided a renewed sense of hope and was a source of motivation for the participants to join the project. George (PV) described his initial feelings about the project:

> so to have all these new people, all these ...and cameras, it just (…) I didn't really catch on [during the recruitment stage] (...) and that was the part that was a little difficult to comprehend, just like: what's going on? what's the motive? who is making the money? Who is ...what's ...who benefits? and why is it here? why is it now?

George's (PV) comment revealed initial uncertainty about the project and the suspicion around the projects' intent. George's (PV) sense of discomfort might be illustrative of a larger sense of distrust in mental health research that is rooted in the historical and ongoing oppression of those with lived experience of mental illness both within and outside of the mental health system. Despite an initial sense of uncertainty, George (PV) continued with the project and completed the photovoice stage.

Lulu (II), conversely, observed a sense of distrust among other potential participants during the information session:

> (…) when I found out the Inclusion project was photography I went to the meeting, but I found the people [other participants] who were there were highly suspicious of what the intent of the project was and I didn't feel it [the project] would ...well thrive … that it would go somewhere, so I didn't get involved in it, I thought it will be hung up by a lot of minor political kind of influences.

A sense of apprehension from the participants prompted her to withdraw from the project as she expected that the "political kind of influences" would inhibit the project and the development of any meaningful outcomes. The above quote demonstrates how historical and sociopolitical factors shaped the ways in which community members approached *Imagining Inclusion* with a sense of distrust and powerlessness; for Lulu (II), this resulted in withdrawal from the project.

Mental health advocacy

A strong theme of engagement as an opportunity to pursue mental health advocacy emerged in the narratives of all research participants, except for the participants from II group, regardless of their role and length of engagement. Having a platform to share and critically discuss lived experience of mental illness was identified as one of the key reasons for joining the project. Kelly (PV) said:

> I think it's because I asked "is there any kind of a critical analysis to this?" Or, you know, as opposed to, are we just gonna paint flowers today and make fridge magnets. But I actually asked and I got some feedback that it was, [so it] sounded like it could be a useful thing.

Kelly (PV) found the overall lack of initiatives within the mental health system that do not go beyond "painting flowers" and "making fridge magnets" problematic. Therefore, the promise of a critical dialogue on lived experience of mental illness convinced her that *Imagining Inclusion* had the potential to be a meaningful experience.

Moreover, Elsbeth (PTG) explained how the interface between her exploration of her own positionality and the objectives of *Imagining Inclusion* motivated her to join the project:

> [at the time of the project recruitment] I was starting to wrap my head around the fact that I was tired of being a victim of mental illness and I wanted to be a voice (…) So, just the two words: photo and voice jumped out at me.

Personal reflections on her own subjugated positon vis-à-vis mental illness diagnosis facilitated Elsbeth's (PTG) entrance to *Imagining Inclusion*. She saw the opportunity to tell her story as a form of resisting the domination.

Furthermore, others discussed desire to challenge stereotypes and sanist beliefs as a main motivation for joining the project. Joe Bloggin (PTG) explained:

> It [motivation to join the project] was something […] to show people that we are not just, you know, people that they want to ignore. (…) So, it's nice to show other people that mental health consumers do things besides, you know, hanging around the house, isolating themselves (…) I wanted to be part of it just because being able to illustrate certain things how we feel and (…) [that we are] just as normal as a normal person.

What motivated Joe Bloggin (PTG) to join the project was his intention to 'earn' acknowledgement from the dominant group by eradicating portrayals of people living with a mental illness diagnosis as lazy, unproductive and incapable by demonstrating productivity and proving normalcy – "[that we are] as normal as normal person."

Similarly, Sunny (PV) spoke about joining the project in the hope of dispelling the misconceptions and shame surrounding mental illness. She said:

> I wanted to participate and tell people in the community that it is okay if you do have a mental illness that there are ways you could, I don't know like, be functioning, and, you know, that you can live a productive life even though you have a mental illness. And I wanted to participate in the *Imagining Inclusion* project because I wanted to, I don't know, just...be a part of something that was gonna show people that...mental illness is not a scary thing. (Sunny, PV)

The desire to remove secrecy and fear out of mental illness were the main reasons for Sunny (PV) joining. Taking on an advocacy role and addressing issues of marginalization and underlying power relations related to lived experience of mental illness were equally important to two participants who worked as peer researchers on *Imagining Inclusion*. Liza (PR) explained: "I guess in the most kinda overarching way I wanted to somehow make a difference to basically to bring forward views of people that have been marginalized or silenced or discredited." Unlike

Kelly, Elsbeth, and Joe Bloggin that aimed at challenging sanist processes and beliefs within the larger systems of power, Liza's (PR) goal of taking on a peer researcher role was to dis power disrupt unequal power relations within *Imagining Inclusion*.

The above quotes demonstrated that the research participants recognized stigma of mental illness and unequal power relations as root causes of their marginalization and social exclusion. What was also clearly evident was the level of agency and intentionality with which most of the participants joined *Imagining Inclusion*. It seemed that the objectives and processes of the project were meaningful to the participants on personal and social levels from the start of the project and that most of the participants engaged with *Imagining Inclusion* as a way of fulfilling their personal goals.

Personal development

For most of the participants, joining *Imagining Inclusion* was seen as an opportunity to pursue personal and professional development. For Emmett (PTG), the motivation stemmed from the desire to have a new experience and to have an opportunity to gain more advanced skills. Joining the project was driven by a deep sense of dissatisfaction with his current life situation and the desire for change – "I don't want to stay with a life like that, life that I have now kinda sucks." He attributed his current situation to being sidelined and being given low expectations in the past – "no one challenged me and no one cared." Emmett (PTG) saw *Imagining Inclusion* as an opportunity unlike the ones he typically has access to. As learning photography skills was identified in the promotional materials as one of the benefits of joining *Imagining Inclusion*, the participants from PV and PTG groups often identified receiving a camera, learning how to use it and take pictures as initial reasons for joining *Imagining Inclusion*.

Explicit interest in experiential knowledge around mental health and photovoice methodology provided an initial motivation for one of the PRs to seek peer employment in *Imagining Inclusion*. Liza (PR) said:

> (…) some of the things were…you know I've done a lot of work in visual art but I can't work directly in visual art right now, so I was looking for ways to use those skills in a different way that is less draining to my mental health, so doing research, photography was very, very appealing to me as well as narrative [of lived experience of mental illness], [it] has been very appealing to me. Also it was a peer position and I am very interested in peer aspect of western medicine.

In the above quote, position of peer researcher was seen as a space that would allow for combining formal education and lived experience of mental illness. For Liza (PR), peer researcher positon offered potential to be professionally and personally fulfilling and supportive of her mental health needs.

Susan Brown (PR) on the other hand discussed the process of applying for a peer positon:

> It was just like applying for any other job I think, but just I didn't really have to disclose my disability, because you wanted people with disabilities right [laughing] so it made it a little bit easier; OK I might as well put down I have bipolar [diagnosis] and [I am] mentally ill because it's...that's whom they want, right? So it was a little bit easier that way, be-cause if you are applying for a regular job you might not want to disclose that, 'cause then maybe they think (…) [that] you will take a lot of time off for like...the stigma of mental illness might be there.

For Susan Brown (PR) having a lived experience of mental illness as one of the job criteria eliminated the dilemma of disclosure and as a result made the application process less stressful. In her experience, applying for the non-peer positions was accompanied by a fear of stigma and a sense that she might be discriminated against on the basis of having a diagnosis of mental illness.

Organizational and social change

Most of the participants spoke about the motivation to join *Imagining Inclusion* from an individual level, such as a desire to take on an advocacy role and gain new skills and fulfilling employment. However, two participants directly spoke about a desire to incite organizational change as a reason for joining. Kelly (PV) described why she saw *Imagining Inclusion* as a pathway to organizational change:

> I think change, you know, [I was] hoping that it would have some effect (…) improving things in the service [name of the mental health organization] (…) that's why I joined. I see a lot of lip-service. But, you know, I think I trusted this [*Imagining Inclusion*] more knowing it's coming from educational direction.

Kelly (PV) joined believing that the project had a potential to result in concrete organizational improvements at Thrive, as opposed to her experience of fruitless ideas - "I see a lot of lip-service". She attributed this new sense of hope for change to academic leadership within the project – "I think I trusted this [*Imagining Inclusion*] more knowing it's coming from educational direction".

5.2. What motivated community members' ongoing engagement in *Imagining Inclusion*?

All participants from the PV, PTG and PR groups identified benefiting from *Imagining Inclusion* as a key motivating factor for continuing their engagement with the project. The types of outcomes that the participants identified as motivators for continued involvement varied. For the research participants from the PV and PTG groups, opportunities for personal growth and forming meaningful relationships with peers and academic researchers were identified as key factors supporting their ongoing engagement throughout photovoice and PTG stages. For two research participants from PR group, on the other hand, motivation to continue engagement in *Imagining Inclusion* was driven by paid employment that was meaningful and rewarding.

Personal growth

Having opportunities for learning and a positive learning experience were strong motivating factors for ongoing engagement, as mentioned by several participants from the PV and PTG groups. Joe Bloggin (PTG) said:

> (..) because everybody learnt something, everybody gained something you know like some people gained little more confidence for instance, more communication skills, other people (…) are spending more time thinking about something instead of "oh, well I will just go into computer, watch television, listen to music" now they have something to think about because it means something to them , if this [*Imagining Inclusion*] didn't exist those thoughts wouldn't be there, so increased their creativity, their knowledge, their skills.

Learning new skills, gaining new knowledge and improving interpersonal skills were identified by Joe Bloggin (PTG) as important facilitators of an ongoing engagement. Trent Halliday (PTG) also identified the opportunity for personal development as a key motivating factor: "(…) each one of us had an opportunity, many opportunities really, to develop in the process, to develop our own understanding [of lived experience of mental illness] and to extend it (…)." For Trent Halliday (PTG) having opportunities to explore new perspectives and expand self- awareness kept him involved.

Meaningful role

Finally, Liza (PR) spoke about having a meaningful role as a peer researcher as a main reason for her ongoing engagement with the project. She said:

it's [research and feminism] a heartfelt issue for me, it's not just an academic issue, or intellectual issue, it really brings my lived experience and my body together with the concepts in my mind and I was kind of able to orchestrate those in a way that hoped will have some lasting benefits

For Liza (PR) the location of peer researcher was an emergent space in which theory and lived experience could come together. She valued the location of a peer researcher as it was a research position embedded in feminist values, which allowed for her theoretical ideas and her lived experience to be integrated and embodied through her work on the project – "it really brings my lived experience and my body together with the concepts in my mind and I was kind of able to orchestrate those in a way that hoped will have some lasting benefits."

A sense of meaningful engagement was also a deciding factor to continue engagement for Sunny (PV), who completed a photovoice stage and later returned to the project to join the Speaker Series PTG. She said:

It [being involved in *Imagining Inclusion*] just made me feel really good being involved in something that meant something for the mental health community. Doing something that was worthwhile and that would help people years to come. It just, it just made me feel worthwhile like I was actually contributing to society like, making a mark that hopefully [will live] for years to come. (Sunny, PV)

Being involved in *Imagining Inclusion* not only gave Sunny (PV) a sense of taking on an advocacy role for the mental health community but it also made her feel like she was a valued member of the society.

Relationships

Another common thread in the participants' narratives was the role of the relationships established in *Imagining Inclusion* that served as motivating factors to continue engagement. What gave value to these relationships was a sense that they were based in mutual recognition, trust, respect and were free of judgment.

Elsbeth (PTG) explained the connection between her relationships with the research team members and her ongoing engagement in the photovoice and Analysis PTG:

Because at that point I had gotten so much of out the experience and I felt a connection with the leaders of the program. Because it was clear to me that they were interested in hearing what we had to say and what we were going through (…).

Being perceived as a source of important knowledge and feeling acknowledged by others, allowed Elsbeth (PTG) to establish a deep sense of connection with the research team members, which ultimately motivated her to continue her engagement. A strong sense of connection with the research team members was also identified as a key motivator by Natasha (PTG): "I felt very equal. That's how I could continue doing what I was doing here." Furthermore, Trent Halliday (PTG) pointed out the unconditional nature of the respect given to the participants: "it was the respect that we were given (...) and we didn't have to be particularly eloquent or (…) entertaining, we were accepted."

Natasha (PTG) and Trent Halliday (PTG) experienced relationships with the research team members as non-discriminatory. Trent Halliday (PTG) further observed that the *Imagining Inclusion* participants were valued unconditionally regardless of their ability to articulate their story or their ability to present it in an engaging way. Although, the photovoice group discussions were guided by broad questions and facilitated in a way that allowed each participant to share their story, the researchers did not impose any preconceive ideas or assumptions on research participants nor did they present any additional expectations in terms of what specific topics to explore or how to present the personal narratives.

The ways in which the relationships established between the participants provided a motivation for continued engagement was explored by the participants; mostly within the context of their engagement in the photovoice stage of *Imagining Inclusion*. Three participants who took part in photovoice spoke about the ways in which their peers' acknowledgment and feedback were a source of support and encouragement and their active engagement in the project was an inspiration to continue. George (PV), who at one point was contemplating withdrawing from the project, explained what kept him involved:

> I probably wouldn't have [continued], I was very flipping - is that the word? I was very indifferent to it [*Imagining Inclusion*] (…) [but] I saw the commitment [of the] other members here and I saw the commitment [of] the people from Douglas College and the commitment by the staff at [name of the community mental health organization] and I realized that well [I will] give it a chance, I should give it a chance and I did (…) and it turned out pretty good.

Despite the initial lack of interest in continuing with the photovoice, the decisive moments that facilitated continued engagement for George (PV) were active engagement and the high level of commitment exhibited by the other participants, the research team members and the staff members at Thrive.

Healing experience

Finally, one participant spoke about a sense of healing experienced as a result of their engagement as a motivating factor for their continued engagement in the project. Natasha (PTG) said:

> It is big improvement in my mental health, (…) I feel that I could have a voice now, that I can openly talk about what's bothering me than just keeping all inside of me...and it's been...I don't feel as ashamed now as I did before of my illness, because I felt that other people, like you guys, now understand so much what we have, [I] mean what we suffer. I feel that you guys understand our illness more, so I felt that I've been, my illness been heard by you guys now, that more people understand we are not faking it, this is real.

For Natasha (PTG) being understood by others, was experienced as therapeutic and resulted in an improvement in her mental health.

5.3. What inhibited community members' ongoing engagement in *Imagining Inclusion*?

A common theme of tension between efforts to maintain ongoing and meaningful engagement and efforts to navigate marginalization emerged in the participants' narratives about factors that inhibited their engagement in *Imagining Inclusion*. Participants' engagement was shaped by the intersection between different social locations, such as mental health diagnosis, gender, socioeconomic status, and ESL, and related power relations, such as sanism, sexism and poverty, personal experiences of mental distress and organizational processes and structures embedded in *Imagining Inclusion*. These intersections and power relations often resulted in compromising the ways in which the participants planned to be involved.

Intersection of ESL and research processes

All three participants (1 from PV group and 2 from PTG group), who identified with ESL, spoke about the ways in which it influenced their engagement in *Imagining Inclusion*. Eagle (PV) explained the ways in which having ESL limited her ability to explore some of the nuances of her story of lived experience of mental illness during the photovoice sessions: "[ESL limited my engagement] because I would discuss less...I would say few words and I would stop, because I was feeling I don't have enough words ...I didn't have enough vocabulary to say more details." It

is interesting to note however that although all three participants with ESL identified language to be a barrier in their day to day lives, only two participants identified language as a factor affecting their engagement in the photovoice stage of the project. Furthermore, two participants, who continued to volunteer with the project past the photovoice stage and attended weekly meetings with the Analysis PTG over the yearlong collaboration, did not believe that ESL limited their engagement.

Gendered oppression and mental illness

Both research participants from PRs group referred to their gendered social location as a factor influencing their engagement and specifically their role as a Peer Researcher and described the ways in which their experiences of stigma and sanism were compounded by sexism. Susan Brown (PR) spoke about the ways in which oppression experienced at the intersection of her identities influenced her direct work with the *Imagining Inclusion* participants while co-facilitating photovoice sessions:

> [listening to women's stories of lived experience] makes you think about your own situation and your own life a little bit (…) sometimes it (story of lived experience) would trigger things in me. I have post-traumatic stress and bipolar, (…) I am mentally ill, so that naturally makes me more vulnerable than the rest of the population for abuse or for poverty (…) [and] I guess traditionally women are exposed more, they are more vulnerable, more likely to be sexually abused, experience violence (…) more likely to be poor, more likely to be diagnosed with mental illness, so those are all I guess factors that I have experienced and I know that a lot of the participants have had that too.

Susan Brown (PR) explicitly illustrated the ways in which her intersecting identities of being a female and having lived experience of mental illness, marked by experiences of sanism, sexism and gendered violence created an additional challenge that opened her up to being potentially re-traumatized while facilitating discussions on lived experience of mental illness with the research participants.

Social precariousness

When asked about the factors that impeded their engagement in *Imagining Inclusion*, a couple of the participants described the ways in which their social precariousness resulting from multiple intersecting social locations and power relations, such as psychiatrization, sanism and

poverty, inhibited their engagement. Trent Halliday (PTG) comprehensively described the precariousness of life at the intersection of multiple marginalities:

> Well, because...because we are marginal...one little element like a rent increase or something or physical attack by somebody can change the whole picture...of course it happens with people in the mainstream too, but with people who are, whose existence is so precarious there [is] a dosage of medication and all of the sudden you can't understand the guy.

Living at the intersection of multiple marginalities amplified the impact of influences that otherwise might have been experienced as inconsequential by Trent Halliday (PTG). However, within the context of lived experience of mental illness, he saw them as life changing - "one little element like a rent increase or something or physical attack by somebody can change the whole picture."

When asked to describe the challenges that he faced in order to continue his engagement in *Imagining Inclusion*, Trent Halliday (PTG) explained how the multiplication and intersection of inequities, that might seem mundane when faced individually, had resulted in him experiencing a deep sense of despair. He said:

> Dread [silence] and the feeling of congestion, you see I have a number of challenges in my personal life […] I'm struggling to organize my life so that what they call benefits which are really attempts to correct deficits ... I'm dealing with the system so I got this big challenge (…) standing in lines or going to the food bank for a year in order to scrape up enough money in order to see her [mother] before she died so I was quite [...] for a while I was more medicated than usual, it seemed to be necessary in order to get through those first few weeks [grieving mother's death] and then of course I had a feeling of impatience that I couldn't get back to the project because I had all these other things to do and there were other things … I should've been looking for accommodation, because I'm in a SRO [single room occupancy] and I still haven't put my name on the list … yes single room occupancy complete with bugs, so I need to get out of that and then I have to deal with financial problems that occurred during my laps into defeatism … those kind of things ...mundane sort of but there is so many of them, because you can't take your hands off the wheel of your own life without having a lot of cleaning up to do afterward.

The above quote speaks to the synergistic and domino effect of the multiple inequities that Trent Halliday (PTG) experienced during his engagement and the ways in which they influenced his ability to sustain engagement in the project. Interestingly, Trent Halliday (PTG) seemed to have a profound sense of self-responsibility for these inequities; he referred to them as his "laps into defeatism" and assumed responsibility for tackling them.

Co-occurrence of marginalization and privilege

Although all of the participants interviewed for this project identified as experiencing wide-ranging and intersecting forms of inequities, further analysis revealed that for three participants it was a co-occurrence of marginalization with some form of privilege that was the key intersection in shaping some of their experiences. For Liza (PR) and George (PTG), intersection of lived experience of mental illness and 'being educated' facilitated ongoing and more meaningful engagement. George (PTG) said:

> At [name of mental health community organization] I feel, because I feel like I am at the top of the food chain, I'm sort of like ... I function very high here ... in comparison to others perhaps and so, there is less of the threat for me to be vulnerable here (…) so it's safer for me here, which is really nice.

George (PV) explained how the intersection of marginalization and seeing oneself as having educational privilege within the context of *Imagining Inclusion* – "I function very high here" - allowed him to assert more control over his role – "[being] at the top of the food chain" - and has provided him with a sense of safety.

For Elsbeth (PTG), on the other hand, the co-occurrence of marginalization with socioeconomic privilege resulted in her questioning her group membership during the photovoice sessions. She said:

> (...) When I would see... pictures of the downtown East Side [in Photovoice sessions] and [understand] that this was peoples' reality. Or, a garbage pile full of rotten tomatoes, and that they were picked through to offer at meals for others; I was just so horrified that people…like those photos were right in your face; brought those issues right to the fore-front. I and I know that...my shame just made me quiet (…) to hear those stories and know that that was not part of my reality. I would go home and really struggle with that. Well I would take it home with me and, you know, feel guilty. And then think, do I be-long in this project? And then I thought, well, there is one common denominator, we all have mental illness. And, it covers or it shows itself amongst all social scales.

In view of the other participants often discussing experiences of poverty and food and housing insecurities during the photovoice sessions, Elsbeth's (PTG) socioeconomic privilege made her feel embarrassed and uneasy. She struggled to reconcile her intersecting experiences of socioeconomic privilege, which did not seem to fit with the group membership criteria, with her experience of marginalization as a person with lived experience of mental illness. She was able to resolve this ambiguity by focusing on experiences of mental distress as a "common denominator".

Sanism: fear and invisible struggle

The ways in which the participants' experiences of mental distress intersected with the project processes that resulted in tension between the hope of eradicating sanist beliefs and the fear of reinforcing sanist representations was most evident in the narratives of three participants who were involved in the Analysis PTG. The Analysis PTG was focused on the technical aspects of conducting data analysis, such as reading transcripts of the photovoice sessions, generating initial codes, drafting and updating codebook, and identifying major themes and subthemes.

For example, Natasha (PTG) spoke about her dilemma of whether to attend the research sessions when experiencing symptoms of mental distress when she said:

> There may be days when we [are] perfectly talking to you and another day that we could [be] coming but really not [be able to] get involved in anything … just sit there, really not do anything ... but not because we [are] just lazy or anything, we really cannot function, but yet we want to show up to support it, yet we cannot really work it; like sometimes I really have no choice, I say to myself "Should I go there and not [be] able to really functioning or can I go there. I like to go there, but yet my brain is not really working", like I sometimes have a hard time deciding if should go, but if I go there and I am not doing anything, it's kind of wasting your guys' time, so….

On the one hand, Natasha (PTG) wanted to ensure, through regular attendance, that she was demonstrating her commitment to the project. On the other hand, she was worried that attending the group when experiencing symptoms of mental distress might result in her becoming a burden on the Analysis group. Furthermore, Natasha (PTG) was wary about the ways that her work was perceived by others vis-à-vis experience of mental distress. It was important for Natasha to note several times during the interview that contrary to common sanist beliefs; that people living with mental illness diagnosis are lazy, incapable or unreliable; the instances in which she did not attend or left the session early were due to her "not being able to function."

Elsbeth (PTG) also described experiencing physical, cognitive and emotional symptoms that interfered with the work on data analysis:

> Having days when thinking clearly, um, would be very, very frustrating because, um, I'd really want to be able to do a good job... do, uh, fulfilling the task that day. But feeling very, very frustrated because, I knew what my mental or emotional limitations were. Could be that I was reading something [part of the transcript] that

really struck a chord with me and would trigger something in me or just having such brain fog that reading something, trying to process it and then analyze it would be very difficult (...) if I felt ashamed it was my … that was about me but I was never made to feel embarrassed or ashamed [by others in the group].

Elsbeth described experiencing occasional difficulties with concentration while working on data analysis. She attributed the lack of concentration to being triggered by the narratives from the photovoice transcripts– or experiencing a temporary inability to think clearly. As a result, Elsbeth (PTG) felt disappointed with herself and "ashamed"; however, as she pointed out, these were internally triggered feelings.

Furthermore, I recall a couple instances during which one of the participants was either falling asleep or feeling particularly sleepy and unable to focus during the session. These events were later explained by the participant as the side effects of psychiatric medications or the effects of night medication being taken in the morning by accident.

Emmett (PTG), on the other hand, described his experience of learning how to conduct data analysis tasks at the beginning of the Analysis PTG. He said:

And at the beginning [of] the data analysis unit we are new, we don't know what to expect and I never did something like that before, so I'm scared, I don't know what to do. Sometimes I might go there and feel lost. Like, for example, at the beginning of the data analysis group we are doing data analysis and it's not quite clear what we can do (…) and then I start to worry; am I doing it right? I worry about if I missed certain data that [was] important for the group and anxiety kick[s] in and then you might not...and then people may feel your anxiety and people might feel you are not friendly to work [with]. And then things get worse after that.

Although Emmett (PTG) often spoke about enjoying the challenges of learning new skills in *Imagining Inclusion*, the learning experience was also a source of anxiety for him. What was particularly worrisome for Emmett (PTG) was the fact that his anxiety could compromise his relationships with other group members and lead to further negative experiences – "people may feel your anxiety and people might feel you are not friendly to work [with]. And then things get worse after that."

One of the participants from the PV group spoke about the challenges of taking part in the photovoice process. Eagle (PV) said:

It's required attention for a long time to hear everybody what they try to say, so it was difficult that way, but part of the work, it was like work it wasn't easy. So we have to hear everybody what they did, what they said (…) it very consuming...at the end of day I was tired.

Eagle (PV) found maintaining focus for a long period of time intense and challenging and as such she experienced engagement in the photovoice as "work."

It is important to note that although the research participants sometimes described research tasks as challenging and draining, none of the participants identified them as a reason for withdrawing or missing the sessions. All participants who discussed the challenges of working on the research tasks also spoke about the ways in which they were able to overcome these challenges, often attributing their ability to navigate the challenges to support provided by the *Imagining Inclusion* research team. For example, Natasha (PTG) said:

> Because of the encouragement that you guys gave me, the day before or whatever, the time I come here even though I [told] you, I [am] really not there, my brain is not there, you the guys just [said] "do what you can do", accept[ed] us the way we are, that was wonderful, that keeps me continue to this far.

The above quote speaks about the kinds of supports that the research participants found helpful. What allowed Natasha (PTG) to sustain her engagement was the support systems that she experienced as ongoing, flexible and non-judgmental.

Overall, the participants spoke about feelings of disappointment when they were unable to attend the sessions due to dealing with health or other personal issues and experiencing embarrassment when unable to participate in the way that they had anticipated. These experiences were especially evident in the narratives of the participants who took part in the PTGs. Is there a quote missing here?

5.4. What enabled community members' ongoing engagement in *Imagining Inclusion*?

"… turning the rocks over and [discovering] what is underneath." (Trent Halliday, PTG)

For most of the participants of this project, taking part in *Imagining Inclusion* was their first experience with CBPR. As a result, most of the participants found themselves simultaneously navigating social and institutional inequities and personal challenges, and learning how to engage with the research process (e.g. how to work with others within the CBPR process; learning and practicing photography and research skills) both as participants and co-researchers. Discussions about the ways in which the research participants were able to overcome these challenges, revealed three structural processes embedded within *Imagining*

Inclusion that were key in supporting community members' ongoing and meaningful engagement with the project: 1. Peer researcher approach to research; 2. Exploration as empowerment.; and 3. Building capacity.

As the project examined the experiences of an historically marginalized community that has been systematically oppressed, there was an understanding among the research team members that the community members would have unique needs and required different kinds of supports to sustain an ongoing and active collaboration (than those without lived experience). Thus, from the start of the project, the research team members planned and implemented multiple strategies aimed at optimizing community engagement. Two peer researchers were contracted to join the research team during the planning stages of the research project and their ongoing engagement in the subsequent stages of the project were supported by equitable wages ($18/hour), access to training opportunities and flexible supports and accommodations, such as a flexible work schedule and work tasks. Strategies developed to create a safe and supportive environment for the research participants included: regular check-ins, follow-ups and reminder phone calls; small group format for the participants' meetings; one on one supports during and between the meetings; and capacity building activities, such as photography lessons and data analysis information sessions. Moreover, approaches to data collection, data analysis and knowledge translation were co-facilitated by the peer researchers and included opportunities for critical reflection, creative expression of lived experience, personal development and social action. Interestingly, those who intended to continue with the project were participants who had a clear goal for joining the project and whose goals aligned with the project's objectives and tasks.

Peer researcher approach to research

One of the key roles of the peer researchers on *Imagining Inclusion* was co-facilitating photovoice sessions. The participants, who took part in this stage (PV and PTG groups), often emphasized the ways in which having peer researchers as co-facilitators facilitated their engagement and sense of inclusion.

Eagle (PV) spoke about the ways in which having a peer researcher as a facilitator, helped her navigate the photovoice process:

> (…) the peer support work was helping [with learning how to participate in the photovoice] too and to answer questions (…) [with peer researchers] we were

feeling at the same level.... she was like a peer exactly...and she was able to understand and ...she was also ...sometimes she was participating, so it was giving us idea how to participate.

The above response indicates that Eagle (PV) saw the peer researcher as both a peer and a role model within the photovoice context. The ways in which the peer researcher facilitated the photovoice session enabled Eagle (PV) to relate to her and made her feel like she was "like a peer exactly." It may also be important to acknowledge that Eagle (PV) and the peer researcher in question shared intersecting categories of gender and ethnicity and were the only Black women in *Imagining Inclusion*. However, Eagle (PV) did not explicitly identify this factor as a foundation of shared social location - "feeling at the same level."

Similarly, Natasha (PTG) spoke about the ways in which shared experience of mental illness between herself and the peer researcher enabled her engagement:

I think so, because they are part of us that have gone through the lived experience too. So it's not just anybody that come from the street that without going through the same thing that we going through. It helps a lot. […] They kinda know what we are talking about. They kind of sometimes like could help us back up what we are saying, because they are going...have gone through the same thing too so they feel for us (…) that was encouraging, because they know what I am talking about.

For Natasha (PTG), it was not only shared experience of psychiatrization, but also the ways in which the peer researchers incorporated it into the facilitation process, that made her feel genuinely understood and validated.

Similarly, Trent Halliday (PTG) reflected on the ways in which the peer researcher approach was a unique and innovative way of establishing a professional relationship in the Newsletter PTG:

I was quite impressed with the more humanistic approach that was being used [in the Newsletter PTG], particularly when [Liza (PR)] used the phrase "peer to peer", I was wondering "what does she mean?", "was she serious!?", because I always assumed that there would be certain chauvinism inherent in the therapeutic relationship, the other person has more knowledge, is more psychologically stable or something, better at some sort of advantage.

The ways in which Liza (PR) positioned herself vis-à-vis the participant within the working relationship emphasized equalizing power relations - "peer to peer"- and was recognized by Trent Halliday (PTG) as ground-breaking and "more humanistic." Trent Halliday (PTG) perceived the peer researcher as someone holding more power and believed that being treated as equal within the context of a mental health intervention was a special privilege. Clearly, this

reveals deeply embedded inequality between those who are positioned as 'users of mental health services' and those who are perceived as professionals.

Exploration as empowerment

A common thread through different reflections of PV and PTG participants was the ways in which the exploratory nature of the project served as an enabler of meaningful engagement. This was particularly evident in references to the photovoice stage of the project. All participants who were photovoice participants (PV and PTG groups) felt most engaged when sharing their stories of lived experience. Eagle (PV) said: "I felt engaged when I was describing my social interaction with the world (…) because to be engaged you must share personal; it must be personal experience...to exchange it with the group." For Eagle (PV), who earlier spoke about sharing personal narratives of lived experience as the most difficult aspect of her engagement in *Imagining Inclusion*, recognized the process of "describing my social interaction with the world" as an integral part of feeling "engaged."

Furthermore, Trent Halliday (PTG) observed that in the exploratory nature of the photovoice process: "we didn't come with a whole volume already written we were in the process of examining [own lived experience]." Photovoice structure that was characterized by absence of a preconceived agenda and included photo taking and group discussions guided by broad questions, allowed Trent Halliday (PTG) to become an active agent in exploring and making sense of his own experience. The common thread of photo taking and sharing as an enabler of exploratory process emerged in the narratives of the photovoice participants (PV and PTG groups).

Generally, those who were participants in the photovoice (PV and PTG groups) discussed photo taking and sharing as the processes that enabled them to share their lived experience. Many participants understood the purpose of taking photos during the photovoice as "to show different aspects of mental health", "to express my feeling of mental illness" or "[to express] symbolic or instructive [meaning] concerning our own struggles as mental health consumers". Two participants described the role of the photos as being a "catalyst" for sharing lived experience or "jump off points for conversations". George (PV) said:

> it was really good, because it [sharing photos and reflections] allowed people to see who they are, for me, and I'm sure probably for others, it's like you reveal yourself without even knowing that you are revealing yourself until after you've

shared; it's kind of like going to see a counselor, you talk about something and you just keep talking and then you got all figure it out, because the counselor might not say anything but hearing oneself … what's on my mind … just hearing myself verbalizing, saying then "Ok, I got it figure it out" and so too with this project it was like ...the catalyst was the photographs and it allowed people probably to feel safe to talk about their feelings and experiences.

George (PV) compared the photo sharing process to counseling in which the therapeutic benefits are achieved through expressing personal experiences, feelings and thoughts in order to achieve clarity and uncover new insights. Although the photo sharing facilitated safety and allowed for vulnerability, George's comment – "you reveal yourself without even knowing that you are revealing yourself until after you've shared" – does create an ethical dilemma around consent in regards to participants being fully aware of how much they disclose in a moment during the photovoice group meetings.

Another element that supported the exploratory nature of the research, identified by a few of PV and PTG participants, was applying a critical lens to the stories of lived experience of mental illness. Kelly (PV) said:

I think maybe the bigger part too was the communication and getting to talk intelligent (…) because we don't get a lot of that. (…) While people try to survive and find food they use idiotic statements like in bread lines you get the poor bashing and insulting the mentally ill. (…) so there's a lot of stupid statements going on. And I think that it [sharing photos and reflections] meant something, because it gave the opportunity for more intellectual feedback and validation for peoples' pictures and I feel really good about that; that people actually grew from that.

Similarly, Trent Halliday (PTG) reflected on the ways in which a critical approach to discussing photographs and stories of lived experience during the photovoice shifted his understanding of the meaning behind the participants' narratives:

So for a while I just went to the room and just "blah, blah, blah, blah..." but listening analytically and providing feedback makes it interesting. It sounds mundane "I went to the store and I bought quart of milk and I got home and it was sour, so I went back there but she knows I am mental ill patient" or something like that, these experiences seem trivial unless you put them in context and you try to work with them intellectually (…) often was absolutely astonished, I seemed to be seeing something beyond ...a whole different level of reality.

Embedding the stories of lived experience within the larger context of social, economic and cultural forces – "put them in context and you try to work with them intellectually"- allowed for a new important meaning to emerge from the everyday stories that otherwise seemed "trivial" to Trent Halliday (PTG).

Building capacity

Most of the participants from PV group and all participants who were part of the Analysis PTG spoke about supported learning as an enabling factor for ongoing engagement with *Imagining Inclusion*. The participants reported feeling incompetent at the beginning of the photovoice stage and at the beginning of the Analysis PTG then gradually gaining competency as the result of supportive processes, such as having an opportunity to learn new skills while contributing to the project and having a choice in how to apply their skills. Emmett (PTG), who did not have any previous knowledge or experience with data analysis, participated in weekly meetings from the start of the group until its culmination (18 months). He reflected on the factors that enabled his engagement with the Analysis group:

> at the beginning [of] the data analysis I [did] not feel comfortable (…) then after a while I start to get a hold of how the patterns should be used and then I start to get [something] out of it. It [learning while participating] was really helpful, but (…) some jobs they let you sit on it for a while, but some job they don't. Like the job from the temp[orary] agency they may not do that, and then some other jobs they fire people pretty quickly but at the same time the mental health service providers, sometimes they just give you very basics and people never move forward.

Emmett (PTG) was able to maintain his engagement with the group as a result of having an opportunity to learn and practice new skills in a supportive environment. He juxtaposed this experience with his struggles with obtaining adequate on the job training and sustaining employment, and with limited work-related development opportunities through mental health services – "they give you very basics." He further observed that as a result of this barrier, people with lived experience of mental illness struggle to develop work related skills and "never move forward." The other two Analysis PTG members, Elsbeth (PTG) and Natasha (PTG), who similarly did not have any previous experience with data analysis, also attributed their ongoing engagement with the Analysis PTG to supported learning process.

Eagle (PV), on the other hand, reflected on her learning experience in the photovoice part of the project:

> it [photovoice] was a learning process … I was learning how to do that [participate in photovoice] and with the time I was able to learn that (…) yes it changed … at the end I was able to ... I was feeling more comfortable (…) I was judging myself right, because I was feeling more and more competent, it's a matter of competency … at the beginning I was not feeling competent in what I was doing, at the end I was feeling more competent (…) by observing and hearing what other people were saying (…) it [people listening, asking questions and making comments] made me

feel I was contributing about something even though I was not very competent by still I felt [that].I was contributing somehow

Having the opportunity to learn new skills while contributing to the project enabled Eagle's (PV) ongoing engagement in the photovoice. Interestingly, for Eagle (PV), it was the group context of the photovoice sessions that facilitated both the experience of learning and the sense of contribution. Eagle (PV) was learning new skills "by observing and hearing what other people were saying" and the acknowledgment of her lived experience by other group members made her feel that she was contributing to the group work, even during the times when she was lacking a sense of competency.

Supports for capacity building opportunities also meant that participants could choose how to apply their skills. For Emmett (PTG) it meant "being given tools and freedom to use them". Emmett further explored his sense of agency within the project by describing his engagement with the Speaker Series PTG:

Like doing the public speaking, they [RT members] just gave us tool [writing a story of lived experience and public speaking skills], they didn't force me as what to do, like in some sort of communist country where they want you to do certain thing and then say certain thing, it's not. You are more empowered when you can choose what you want to say within the framework.

For Emmett (PTG) gaining skills in *Imagining Inclusion* was associated with being given a framework for building capacity and freedom to integrate his own sense of agency within it. For Emmett (PTG), this approach was experienced as a feeling of empowerment.

Generally, when discussing factors that enabled or supported their ongoing and meaningful engagement in *Imagining Inclusion*, the participants predominantly highlighted organizational structures and processes that challenged unjust power relations and counteracted mental health inequities. Additionally, factors that enabled ongoing engagement for PV and PTG groups, included: small group process, an environment free of stigma; emotional support and encouragement; constructive feedback; and lived experience incorporated into the research team work.

Chapter 6.   Findings: Tensions around collaborative relationships

"(…) I was given a text of alternative to the mainstream ... and it reinforced my feelings that there shouldn't be coercion, force, involuntary medication, involuntary hospitalization." (Trent Halliday, PTG)

The participants often used a relational lens to describe their experiences of engagement in *Imagining Inclusion* and generally spoke about the relationships they formed in Imagining Inclusion as embedded in respect, trust and support. In fact, it seemed that the strength of these relationships established early on in *Imagining Inclusion* between the participants and the research team members, kept people involved throughout the photovoice process and the subsequent stages of *Imagining Inclusion*. However, within the context of historical and ongoing oppression of people with lived experience of mental illness, collaborations formed within the context of CBPR are inherently marked by profound inequities and intersecting asymmetrical power relations. As the result, the participants, who all identified as experiencing wide-ranging forms of disenfranchisement, often talked about experiencing both a sense of gratefulness and sense of injustice when describing their experiences in *Imagining Inclusion*. It is also possible that the power dynamics associated with my role on *Imagining Inclusion* may have prevented some participants from discussing negative experiences. When asked specifically about the instances when they felt disengaged or not valued, overall the participants took longer to answer, or answers were significantly shorter and often included responses, such as "I don't know" or "I can't think of any."

In this section, I examine the ways in which intersections of wide-ranging health inequities and participatory processes and structures enacted 1. Participants' engagement as a humanizing experience; 2. Researchers as allies; and 3. Stigmatized identity as an asset.

6.1. Participants' engagement as a humanizing experience

All three participants, who took part in the Analysis PTG juxtaposed their experiences of microaggressions and being Othered in their day to day lives with the experiences in *Imagining Inclusion* as being seen as having potential, "not being set aside", and being included and acknowledged without judgement. For example, Emmett (PTG) contrasted his experiences of discrimination and microaggressions, such as the assumption of inferiority and incompetence while seeking employment, with his experience in Analysis PTG. He said:

(…) there's a really bad stigma, we're stigmatized too for example. They [society] expect you, you're a mental health consumer, so you will be only available doing work maybe two hours per week or doing only sweeping on the street, something like that. No, we need more than that because we have more ability than that. And they never let us try. Because they don't give us higher expectation. (…) But this one [*Imagining Inclusion*] is more like equal opportunity. (…) you let us do certain stuff that you expect normal people to do; people with autonomy able to do. (…) I can do stuff that, according to my abilities and at the same time I can do what I can and hopefully I can do it in the future with other people. Or gain full employment. But other people just give up on you, when things go wrong.

Having the opportunity to gain research skills in *Imagining Inclusion* was experienced by Emmett (PTG) as having access to "equal opportunity" that does not discriminate on the basis on mental illness diagnosis. Furthermore, for Emmett (PTG) "equal opportunity" meant that he was seen as someone who has a potential to grow and develop higher level employment skills as opposed to being seen through the lens of stigma of mental illness and set aside as different and incapable.

Similarly, Natasha (PTG) and Elsbeth (PTG) both spoke about the experience of being accepted rather than Othered when experiencing cognitive difficulties during the Analysis PTG. Natasha (PTG) said:

but you guys doing great job, many times I come here I just sit there really, not doing much of anything, but you just accepted that we ...I cannot say anything more than, much more ...you guys are just wonderful...I mean if this happened more in other places it would be great (…) I think the most important things that what kept me going was the people that were involved in this project, people that worked in this project were...so human. I mean in terms human, how do I say this...they just don't judge us, they didn't set us aside as different kind of people.

Being welcomed in the sessions and accommodated regardless of how much she was able to contribute to the research tasks when she felt unwell or was experiencing cognitive difficulties made Natasha (PTG) feel understood and included in the project. Clearly, the relationships established in the project played a critical role in facilitating Natasha's (PTG) ongoing engagement. Moreover, her response indicated that the relationships experienced in *Imagining Inclusion* had unique characteristics when compared to the relationships experienced elsewhere in the mental health system.

Although several participants spoke about connecting with peers on a new, deeper level, one participant, Trent Halliday (PTG), described more explicitly how listening to stories of lived experience allowed him to challenge his perception of another participant as the Other. He

illustrated this by describing the turning point that he experienced during one of photovoice sessions:

> I remember there was one lady who was talking about her experiences and she was barely coherent and she's always been like that and I looked around the room she was talking about how difficult it was for her to relate to people, she was doing all the right (…) making all the right moves (…) and doing this activity and that activity and the other activity and yet she had such a towering, formidable obstacles including the way she spoke to people (...) the way she spoke to people (…) most people would just turn around and walk away, they wouldn't consider even worthwhile trying to establish any kind of rapport ... and yet I found when I started speaking to her and asking her about the various projects she was in, she became coherent, all she needed was somebody to sit down and listen to her and it was as though complete adjustment had been made and then I realized a lot of people [with lived experience of mental illness] are like that, one way or another they're either grand standing and being provocative in order to attract attention ...or they are falling back and not even bothering ... it was the intensity of the experiences

Having an opportunity to listen to and interact with one of his peers that he wouldn't otherwise choose to engage with, shifted Trent Halliday's (PTG) perception of her. This experience provided him with a new perspective on how his peers engaged with the world around them. The above quote illustrated how sharing lived experiences revealed points of connections in the common pursuit of achieving a collective voice, recognition and acknowledgment.

6.2. Researchers as allies

Regardless of their role or length of their engagement (with exception of participants from II stage of the project), all the research participants spoke extensively about the high level of respect, support and trust they experienced in *Imagining Inclusion*. However, as these relationships were embedded within broader social inequities, equalizing and engagement efforts materialized as experiences of tension between sense of gratitude and injustice.

For example, Liza (PR), who identified as experiencing multiple intersecting forms of oppression, expressed gratitude for her employment in *Imagining Inclusion* positioning it within a broader context of social and structural oppressive power relations:

> I think one of the first things is employment, because the people with lived experience have a lot of challenges with employment, like even for me being quote on quote 'crazy' and 'black' and 'female' does not make me the most employable person right of the bat, you know in terms of popular prejudices (...) you know for someone who has so ...I mean I have such a vast ability to be underemployed I

think you know that I really appreciated employment where I can bring this much of myself to the table, you know I do appreciate it [employment on the project].

Liza (PR) embedded her sense of appreciation for an employment opportunity within the context of her multiple intersecting marginalized identities; as a black woman with lived experience of mental illness that was related to the power dynamics inherent in sanism, racism and sexism. This points out the ways in which intersections of social categories and socio-structural factors influenced how participatory processes are experienced.

Overall spaces and relationships created within *Imagining Inclusion* were perceived to be inclusive and welcoming. George (PTG) explained how experiences within *Imagining Inclusion* disrupted the sense of exclusion experienced by people with lived experience of mental illness:

> One of the things that people trying to achieve or get over or I'm having trouble wording things, but one of the things people with mental illness have in common is trying to trust others is very difficult thing, because most people with mental illness have experienced tremendous rejection ... [silence] ... so this [*Imagining Inclusion*] countered this really nicely (…).

However, when specifically referring to the researchers without lived experience of mental illness, the participants often hinted at the power imbalance by using dichotomous statements, such as "healthy", "sane", and "those with credibility" when referring to the researchers. Additionally, the researchers were often perceived as having charitable qualities. As such, attempts to facilitate inclusion and engagement were met with a sense of gratitude. For example, Emmett (PTG) expressed a sense of gratefulness for being part of the Analysis PTG by noting that "You allowed me inside your circle, in the professional circle and see what I can do." His statement indicated that the Analysis group remained a "professional circle" and the power to "allow into" this circle remained with the academic researchers.

Furthermore, a closer analysis of the power relations between the participants and the *Imagining Inclusion* researchers without lived experience of mental illness revealed a tension between a sense of gratefulness and feeling of injustice. The issue of sustainability of community engagement was raised by both the peer researchers and a couple of PTG members. For example, when reflecting on employment opportunities that emerged for the research team members as a result of their engagement on *Imagining Inclusion*, Liza (PR) observed:

I don't know if [name of the other peer researcher] and I kind of benefited economically to the same scale or if we had as much obvious capacity step forward, like none of the participants got jobs out of this research you know so... (Liza, PR)

Liza's (PR) reflections challenged the notion of a 'charitable researcher.' Within the context of continuity of employment, she felt disadvantaged. It is also important to point out the role of broader social factors, such as formal education in creating these employment opportunities. For example, the student researchers who were studying to be therapeutic recreation professionals, were able to access employment at Thrive in addition to their role on *Imagining Inclusion*. Another aspect of this is the MH system's emphasis on the peer employment rules and the fact that they are almost entirely temporary and poorly paid.

Similarly, Natasha (PTG) brought up the issue of having access to engagement opportunities as she referred to *Imagining Inclusion* being a "one off":

(...) the negative side of it is also because I don't continue doing this research kinda thing, it kinda takes away some of the... almost like a medicine that kept me continue to get better, because I [am] disconnected from you guys now. (...) it has been taken away now, I'm sure I will go back to old self again." (Natasha, PTG)

The above concerns reflect a larger challenge of sustainability of community engagement as a way of addressing mental health inequities within the systems that offer short-term, 2-3 year grants, for doing this kind of work.

Another important consideration that emerged for the research participants from the PTG group was issue of compensation. Two participants discussed how they observed other PTG members bringing up issue of compensation Joe Bloggin (PTG) said:

I hate to say it, but some people wanted the money [laughing] it was either the camera or the gift certificate and fortunately some people really felt that way, cause I did hear a few people "I can wait to get that money" you know "I can't wait to get that gift card" and I thought "that's not what it's about, it's to be in this project to show the public", not to say "I want to be part of this project, cause I can benefit.

Joe Bloggin (PTG) quote reveals an interesting ethical and methodological issue of compensation within the context of CBPR research. In the above quote, moral superiority was given to engagement as altruistic endeavor to educate others over engagement as a pursuit of tangible outcomes and benefits. Similar sentiments were shared by Natasha (PTG):

I do see some really sincere to putting their time to really want to help to … to help us to find out like how we are suffering this and that...so you guys can put it in the

book and say this is how people are suffering this, what they are going through in life. But then there are other participants who are not really there for that they are just for a reason of something than just getting to get involved. (…) Because it takes time to do this and some people think time costs money, so all they think about is like "if I do this I should get paid"... and all that stuff. (…) And I don't feel that way [that participants should get paid for all their engagement], I feel that you guys are doing this for our own good in the future, to help us to improve into whatever treatment we are going to get in the future. But to some people, because the time I am spending here I should get paid for this, blah, blah, blah...

It was interesting to observe that although both research participants brought up an issue of compensation around the work on PTGs, neither one of them presented the issue as their personal consideration. On the contrary, both participants offered harsh critique of engagement as driven by financial gains. These comments raised questions around the values introduced within CBPR projects and the ways in which the principles of social justice are communicated to and utilized by the community members. Are projects focused on promoting values of social justice and equalizing power relations inadvertently create a sense of guilt and shame around expectations for compensation for engagement?

6.3. Stigmatized identity as an asset

The intersections of sanism, ableism and historical oppression and research structures and processes shaped the ways in which the peer researchers experienced their role in *Imagining Inclusion*. Although both participants from the PR group appreciated the opportunity to incorporate their lived experience of mental illness into their employment, they found the position to be ambiguous. Liza (PR) said:

(...) there were some more superficial things like general questions about using 'crazy' as an asset to you in your work you know: How do you dress to match crazy? What does the crazy look like? What does crazy wear to work every day? … so there were just practical issues: What does the peer researcher do? What does the peer researcher look like? What makes a competent peer researcher? What makes an excellent peer researcher? The lay of the land there is not too studied yet, it is still a little bit unexplored, so there is some creativity (...) it's not really established professional niche yet so there isn't [a] manual to go with it.

Liza (PR) discussed her uncertainty in regards to when and how she was expected to use her lived experience of mental illness to inform the research processes and structures within the project. By referring to those with lived experience of mental illness as crazy she emphasized the power differentials that are inherent within the context of a peer researcher

position and her struggle to transform her stigmatized identity into an asset within *Imagining Inclusion*.

When asked specifically to describe their position in *Imagining Inclusion*, the two peer researchers presented their role in relation to different structures of the project. Liza (PR) predominantly spoke about her role vis-à-vis the work of the research team, whereas Susan Brown (PR), described her role in relation to the work of the participants. When describing her work, Liza (PR) positioned herself as a "native informant":

> generally, what I've been hired like to give information from the point of view someone's with lived experience it's often because someone wants to use me as a native informant … so I am generally kind of hiring myself out as a native informant (…) it's ironically appropriate thing to come though my voice as well or to facilitate in that way, because I certainly know mental health blues but I also know what is (…) age, race, gender, sexual orientation, like know all of those blues so I am quite a large palette of intersectionality...

The above quote explains the intersection between Liza's lived experience of mental illness and her role on the research team. According to Liza (PR) her wide range of intersectional lived experiences of "mental health blues" and "age, race, gender, sexual orientation [blues]" as well as her ability to articulate these experiences in a way that informed her work on the project, made her uniquely suited to act as a bridge between the community members and the research team. She furthered explained:

> When we were going over the photovoice images and the narratives definitely all the information within me helped me to facilitate the externalization of that experience into something that could be observed and quantified or analyzed, so the peer researcher was kind of needed as a native informant for that major piece of the research in a way… if there was no native informant, it might have been more difficult to secure trust or secure information or cooperation even.

The above quote highlights that Liza (PR) saw her role as key in establishing safe environment for the participants, collecting rich data and facilitating ongoing engagement of the participants during data collection stage of *Imagining Inclusion*.

By positioning mental health as a social justice issue, Liza (PR), who self-identified as "externally constructed as black", drew a parallel between lived experience of mental illness and racial segregation: "we still live in the time when there are no really civil rights for mental health people, right... so we are way back in a day like we are still in segregation times pretty much so." Furthermore, she saw herself as someone well positioned to disrupt imbalanced power relations between those with and those without the lived experience of mental illness:

> I felt like there was certain diplomatic element to it [her role as a peer researcher] in terms of coordinating non-lived experience people and lived experience people ... because it's really easy to exclude less creditable view kind of thing...also in terms of diplomacy there is also a big basically class divide between [people] doing the research and people being studied [and] I tended to be very aware of that ... and giving information I guess you could say like I have a very extensive background in 'the blues' as the person that I am so you know to be developing you know a research blues for mental health in relation to community...

In her role as a peer researcher in mental health, Liza (PR) saw herself as someone who was positioned in-between those with and those without lived experience of mental illness. As such, she acted as mediator of knowledges – someone whose task was to navigate unequal power relations to ensure that knowledge of lived experience is visible, sustained and utilized within the research sphere. According to her response, her lived experience of mental illness was a source of both marginalization and privilege. Her response further suggests that the role of a peer researcher within the context of mental health has not been fully conceptualized and those taking on peer researcher positions act as trailblazers and pioneers.

On the other hand, Susan Brown (PR) spoke at length about the ways in which she worked with the *Imagining Inclusion* participants to support their active, meaningful and ongoing engagement:

> (…) [I] supported people, helped them write their reflection forms and just offer them support if they were having a bad day and being empathic to them and just helping them out and like with the exhibit group trying get them confident enough to go out to businesses and ask for sponsorship and venues and [to] find prices for getting pictures developed and with the Speaker Series … just helping people prepare for public speaking and standing in front of the crowd and telling their stories about their experiences with photovoice. (…) Calling people [*Imagining Inclusion* participants] to remind them to come or emailing them and then just checking in with people throughout the project and just being supportive, encouraging to people.

In relation to the participants, Susan Brown (PR) saw herself as an ally, who provided the participants with emotional support and technical assistance. The ways in which Liza (PR) and Susan Brown (PR) described their roles on *Imagining Inclusion* revealed the multifaceted nature of peer researcher positon. Their responses indicated a strong connection to the research participants and mental health community as a whole. Thus, both peer researchers found their positons on the project personally rewarding.

Chapter 7.   Discussion

The findings in this project revealed that in the view of the research participants, community engagement was understood as 'engagement with power.' All four broad dimensions of engagement: collaborative, intersectional, critical, and emancipatory, revealed the role of power in shaping experiences of engagment. For example, experiencing a strong sense of trust and respect were indicators of relational power. Indeed, the theme of relationships crosscut all four dimensions of engagement. Thus, a sense of inclusion was seen by the participants as a precursor of engagement and one of the key markers of collaborative dimension. Attending to the issue of inclusion and intersectional experiences of community members was seen as a way of ensuring equitable community representation. As such, engagement was contingent on social locations and power relations. Engagement as a means of gaining credibility by sharing and critically exploring stories of lived experience was an important marker of critical dimension. Finally, engagement was viewed as a site for pursuing social action and personal gain. Gaining access to capacity building opportunities, material resources, including sustainable employment, and working towards more tangible changes, such as policy change, were all seen as a way of achieving more equitable power relations. Within this context, relationships formed through engagement were viewed as spaces of possibility for shifting power relations and an important marker of emancipatory dimension of engagement. It was remarkable how much the characteristics of engagement identified by the participants' aligned with approaches to community engagement advocated by feminist scholars (Ponic et al., 2010; Reid & Frisby, 2008; Frisby et al., 2009). Based on the participants' narratives, engagement was seen as a 'bottom-up' approach to collaboration that is utilized as a catalyst for meaningful social change. Attending to issues of power relations within participatory approaches have been raised by Frisby et al. (2009) and Ponic and Frisby (2010) who advocated for cultivating *power with* rather than the paternalistic *power over* approach (Lord, 1989) within community-academic partnerships. The research participants' definition of engagement was also consistent with photovoice (Wang & Burris, 1997) and intersectional (Hankivsky, 2014) methodologies and CBPR (Wallerstein & Duran, 2010) approach to research that aim to expand and deepen spaces of influence of community members within collaborative initiatives. What makes experiences of community engagement unique within the context of mental health is how experiences of psychiatrization of mental distress and sanism intersect with other forms of oppression (Morrow & Halinka Malcoe, 2017; Ingram et al., 2013) and influence the ways in which power relations becomes materialized within these initiatives.

The findings further revealed that when it came to community engagement within the context of mental health, language mattered. Most of the participants could either not relate to the term 'engagement' or did not understand its meaning. Although the language was an important consideration, what was more problematic in the eyes of the participants, was the ways in which community engagement initiatives were utilized within the larger systems of power. Generally, the research participants experienced them as oppressive; hens contributing rather than addressing mental health inequities (Morrow & Weisser, 2012).

Another finding was that the research participants' experiences of engagement in *Imagining Inclusion* were negotiated and constructed at the intersections of multiple mental health inequities and power relations, such as sanism (Morrow, 2013; Ingram et al., 2013) and participatory processes. These intersections were experienced as tensions. For example, belief systems grounded in sanism, compelled some participants from PTGs to weigh their interests before attending the sessions when experiencing symptoms of mental distress or side effects from medications fearing that what they 'produce' through their engagement when feeling unwell might reinforce sanist beliefs and representations. Furthermore, experiences of sanism have resulted in participants utilizing *Imagining Inclusion* as a way of pursuing credibility and humanization by resisting sanist representations and seeking acknowledgement and recognition. In this context, their efforts became a pursuit of 'normalcy.' However, Voronka (2016) warns that the pursuit of 'normalizing' the difference and inclusion into the privileged group cannot be a goal in itself, as it perpetuates the creation of the Other. This highlights the need of employing participatory methods as a means of disputing 'normalcy' rather than using a community engagement framework as a way of normalizing the difference (Voronka, 2016).

The findings also suggested that within the context of CBPR, co-occurrence of oppression and privilege (Crenshaw, 1991; Collins, 2002; Hankivsky, 2014) is an important consideration as it can either support or inhibit experiences of engagement. For example, 'being educated' emerged as a privileged identify that facilitated greater access to power and allowed one of the PR participants to assert more control over her role in *Imagining Inclusion*. Moreover, 'being educated' aided one of the PV participants in navigating experiences of disenfranchisement and maintaining ongoing engagement. On the other hand, intersecting identities of having lived experience of mental illness and living 'above the poverty line', resulted in another PV participant experiencing internal conflict and questioning her group membership. Here, conflicting identities emerged within a participant when a privileged social identity – 'living above the poverty line' - was exposed through the photovoice and stood in a stark contrast to

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the extreme poverty experienced by other community members. These findings raise several questions: What social categories and forms of oppression constitute legitimate group membership within the context of mental health? To what degree a sense of group membership is dependant on shared social locations? Which unique intersections of oppression and privilege facilitate and which ones inhibit community engagement within the context of mental health? How do community members reconcile conflicting social locations in order to maintain their engagement in CBPR initiatives? How does one kind of oppression(s) becomes privileged over others within the context of community membership?

The findings further indicated that, within the context of *Imagining Inclusion*, utilizing methodologies, such as photovoice and peer research, as a way of counteracting unjust power relations, was effective in: 1. Transforming researcher-researched power dynamics; 2. Supporting ongoing, meaningful, and relevant engagement of the community members throughout a project's lifecycle, and 3. Supporting pursuit of personal goals. Engagement in the photovoice stage of *Imagining Inclusion* was generally associated with transforming power relations between the photovoice participants as it allowed the participants to connect with each other on a deeper level and see themselves and their peers in a new, different light. This process was facilitated by a critical exploration of the lived experience of mental illness and by a small group setting of the photovoice sessions. The transformative nature of the researcher-researched relationship in *Imagining Inclusion* was most evident and most central in the narratives of the research participants from the PTG group. The equalizing nature of these relationships was generally attributed to three main factors: 1. Peer research approach; 2. Capacity building opportunities; and 3. Accessible supports and adaptations. Although the power relations within *Imagining Inclusion* were experienced as transformative at the individual level, the ways in which they these experiences were shaped by broader social inequities resulted in some participants experiencing feelings of gratitude for equalizing efforts and capacity building opportunities and a sense of injustice associated with lack of access to sustainable and equitably reimbursed engagement opportunities. Based on the above findings, we can conclude that CBPR agendas need to address individual level outcomes that go beyond opportunities for sharing stories of lived experience and capacity development, and include research processes and resources that allow for just recognition and reimbursement of the community members.

In contrast to Gregor and Smith (2009) assertions that positioning community members as 'subject matter experts' within CBPR often results in community members being hesitant to contribute beyond their lived experience, this project found that roles that incorporated interests, strengths, talents, and competencies and allowed for skills development (PTG and PR) were experienced as more fulfilling than the roles that were based solely on sharing stories of lived experience (Photovoice). This was especially true for PR, who found employment that combined experiential knowledge with the professional skills fulfilling, inspiring and personally rewarding. Consistent with Gregor & Smith (2009) were the findings that engaging communities who are systemically marginalized requires recognition that, by the virtue of their lived experience, they will have unique needs and require different supports than those without lived experience. The findings from this project indicated that ongoing, flexible, and non-judgemental supports and adaptations were helpful in meeting emotional, physical and technical needs of the research participants. What made these supports particularly effective in supporting ongoing and meaningful engagement, was the fact that they were driven by trusting and mutually meaningful relationships.

One of the ways in which power relations are materialized within the CBPR initiatives is through the roles and positions that are occupied by the community members. The findings in this project indicated that peer positions that were experienced as personally meaningful, justly compensated, and adequately supported, were similarly influential as other social categories, such as gender or socioeconomic status, in facilitating access to power. Within the context of *Imagining Inclusion*, the peer research approach was seen as an "alternative to the mainstream" and a potential blueprint for establishing more equitable client-professional relations within the mental health system. Participants from PV and PTG groups, viewed *Imagining Inclusion* peer researchers as playing three overlapping roles: 1. Acting as peers who by virtue of their lived experience can offer unique empathy; 2. Serving as role models who have an insider knowledge of the research processes and structures; and 3. Acting as allies who have shared lived experience of mental illness and are positioned within the folds of larger systems of power. It is important to point out that different dimensions of the peer researchers 'roles' were seen within *Imagining Inclusion* as not mutually exclusive, meaning that depending on the context, the peer researchers were able to act as peers, role models or allies. This was possible due to flexibility and the strategic use of supports and resources dedicated to implementing the peer research methodology. Although larger structures and power relations within which CBPR are embedded limit the ways in which they can transform larger systems of power and sustain meaningful

engagement of people with lived experience of mental illness, they have the potential to enable and support community members' advocacy efforts, produce outcomes that are meaningful and transformative at the individual level, and offer a blueprint for community engagement that is more equitable and meaningful. The peer research approach holds the biggest potential for transforming structures and power relations within the larger systems, as it can embed the community members in roles that are influential, relevant, meaningful, and sustainable.

Voronka (2016) urges us to look at lived experience of mental illness not as an 'explanation' but as a phenomenon that we seek to explain. She emphasizes that consuming stories of lived experience through an individualistic lens results in perpetuating mental health inequities. In this project, an intersectional lens helped seek an 'explanation' of the research participants' understandings and experiences of community engagement in the following ways: 1. It allowed for the contextualization of understandings of engagement within the broader historical and socio-political factors; 2. It legitimized prioritizing stories of lived experience and resisting essentializing and pathologizing knowledges derived from them; and finally 3. It revealed research participants as actors in pursuit of human rights and health equity rather than passive recipients of services.

Contextualizing conceptual and ideological understandings of the term engagement revealed a vast disparity between the participants' ideals of engagement and their experiences within the mental health system and exposed the ways in which sanism infiltrates the mental health system to produce services that exploit, Other, tokenize and subjugate bodies and knowledges of people with lived experience of mental illness. Moreover, it positioned interests and motivations of the research participants as politically driven. At a time of great concern over the efforts to depoliticize community engagement within the larger systems of power (Guta et. al, 2014; Labonte et al., 2005; Miraftab, 2004), including within a mental health context (Costa et al., 2012; Morrow & Halinka Malcoe, 2017; Fabris in LeFrancois et al., 2013; Voronka, 2016), utilizing an intersectional lens to illuminate and prioritize the political interests of community members can ensure that engagement initiatives are embedded in socio-political contexts and are accountable for their social justice agendas (Morrow & Halinka Malcoe, 2017). This is particularly important within the context of CBPR as one of its key principles is utilizing research as a means for social change (Ochocka, 2010).

On a practical level, using an intersectional approach legitimized prioritizing the perspectives of the research participants. According to Leblanc and Kinsella (2016) systemic

dismissal of the perspectives of people with lived experience of mental illness constitutes a human rights violation; therefore, by extension, engaging with knowledges of lived experience of mental illness can be seen as an act of social justice. However, there is a growing concern that utilizing lived experience as a category of identity within CBPR might lead to a homogenous understanding of mental health community, consequently eradicating differences in experiences of mental distress and intersecting forms of oppression (Voronka, 2016). Drawing upon intersectional theory helps to resist essentializing and pathologizing knowledges derived from lived experience (Crenshaw 1991; Hankivsky, 2014). In this project, emerging intersections of categories of identity and power relations provided a framework for embedding stories of engagement in *Imagining Inclusion* within broader power relations, consequently emphasizing nuanced differences in which different social locations related to gender, SES, and race intersected with sanism and other relevant power relations to shape the understandings and experiences of engagement.

Finally, an intersectionality informed analysis allowed for an illumination on micro and macro goals and actions of the research participants as political efforts aimed at dismantling dominant power relations at individual and societal levels. As the intersections of social categories and oppressive power relations shape experiences of discrimination and subordination at the individual and systemic levels (Hankivsky, 2014), actions that people take to resist unequal power relations can also occur at both micro and macro levels (Reid & Tom, 2006). For the research participants, motivating factors to join and maintain engagement in *Imagining Inclusion* reflected both individual and collective needs. Regardless of the nature of the goals, be it individual or systemic, the participants often embedded them within broader social and political contexts thus, revealing themselves as active actors in pursuit of human rights and health equity.

7.1. Recommendations

Based on my research, I recommend that those taking on CBPR initiatives within the context of mental health apply an intersectional lens to reflections on the research process to gain a better understanding of the different ways in which community members can view and experience inclusive and participatory methods. By considering collaborative, critical, intersectional and emancipatory dimensions of the concept of engagement, those facilitating community engagements can help to expose and attend to unjust power differentials that drive mental health inequities. Moreover, in an effort to facilitate meaningful and sustainable community

engagement, it is worthwhile to consider roles for the community members that go beyond sharing stories of lived experience and utilize opportunities that incorporate people's interests, strengths, talents, and competencies that allow for development of skills, competencies and personal growth. In addition, consideration needs to given to the research processes and resources that allow for just recognition and reimbursement of community participants. One approach that has potential for meaningful, sustainable, and equitable engagement is hiring community members as peer researchers. Employing community members as research staff in roles that are personally meaningful, justly compensated and adequately supported might be the most effective way of establishing more equitable relationships between research and community collaborators in CBPR. However, in order to effectively work on addressing mental health inequities, those taking on CBPR projects need to approach community inclusion and engagement not as an end in itself but as a way of disputing notions of "normalcy" and working towards a more equitable society.

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Appendix A

**Informed Consent Form for Participants of the
"Community Engagement through the Lens of Intersectionality" project**

        Principal Researcher: Anna Landy, Graduate Student, Health Sciences, SFU

        Senior Supervisor: Dr. Marina Morrow   Supervisors: Dr. Colleen Reid
                                                                      & Dr. Wendy Frisby

        This informed consent form is for people with lived experience of mental illness who were involved in the *Imagining Inclusion* project.

Information Sheet

Background Information for the Study:

Community-Based Participatory Research (CBPR) operates on the assumption that community engagement results in improved health of community members. For people with lived experience of mental illness, who have historically been oppressed and discriminated against and to this day remain highly stigmatized population, community engagement offers promise of capacity building, knowledge co-production and community level action.

Although the benefits and potential of community engagement are well recognized, lack of critical exploration of the processes and structures inherent to CBPR and a dearth of systematic methods to examine and document experiences of community engagement of people with lived experience of mental illness, create uncertainties as to whether initiatives applying participatory approach lead to authentic community participation, increased community capacity and better health outcomes in people with lived experience of mental illness. Thus, an exploration of engagement from participants' perspective and a critical examination of multiple, intersecting social factors and systems, and underlying power relations are needed.

Project Description:

This project uses the *Imagining Inclusion* initiative as a case example to critically explore ways in which individual, social, and structural inequities and systems of power shape engagement of people with lived experience of mental illness in CBPR.

In this research I will:

(a) document the understanding of engagement from research participants' and peer researchers' perspectives

(b) investigate who engaged and sustained their involvement in *Imagining Inclusion* and why or why not

(c) identify the pertinent intersections of social locations that are relevant within the context of the *Imagining Inclusion* project

(d) document the impact of engagement in *Imagining Inclusion* on the research participants and peer researchers

(e) identify structural and social processes that facilitated or hindered engagement in the four stages of the research entry process (pre-engagement; engagement, reflection and feedback; ongoing maintenance; and employment)

Research Procedures:

People with lived experience of mental illness (participants and peer researchers) involved in the *Imagining Inclusion* project are invited to participate in this project.
You may participate in this study if you:

  a) are over 18 years of age;

  b) have lived experience of mental illness;

  c) manage medications, addictions and harmful behaviours;

  d) are able to understand the nature of the project;

  e) willing to participate in an hour and half long interview;

  f) have been recruited as a peer researcher or a participant on the *Imagining Inclusion* project;

  g) fit into one of the following groups:

  1. Participant in the Intake interview only

  2. Participant in the Photovoice stage only

  3. Participant in the Photovoice and the Peer Task Group(s)

  4. Peer researcher

You are asked to participate in a 90-minute-long individual interview. The interview will take place at the thrive program location and will be audio-recorded.

Benefits

There will be no direct benefit to you, but your participation is likely to help me find out more about how to facilitate community engagement strategies for people with lived experience of mental illness.

Reimbursements

You will not be provided any incentive to take part in the research. However, you will receive $25 cash at the beginning of the interview as a compensation for your time and travel expenses.

Confidentiality

Principal investigator and the supervisory committee members will know your identity. However, your confidentiality will be maintained in the following ways. All supervisory committee members will be required to sign a confidentiality agreement. The interview will take place in a private room at the thrive program location. After the interview, audio-recordings will be transferred to principal investigator's laptop (password protected) and the interviews will be erased from the recorders. All the identifying information will be removed during the transcription of the interviews. Pseudonyms will be used to identify the participants. Your name will not be included on any written materials. This includes fieldnotes, transcripts, and socio-demographic data sheets. Data that allows linking pseudonyms with participants' identities will be stored in a locked filing cabinet, which has only one key, in the principal investigator's home. Only principal investigator will have access to these data.

Alarming information, such as intention to harm self or others and child abuse, will be reported to your worker at ODG. Data from this project will be stored in a locked safe at the principal investigator's home for up to 5 years. It will be destroyed no later than January 2020.

Right to Refuse or Withdraw

Your participation in this research project is entirely voluntary and you will not be penalized or adversely affected in any way should you decline to participate, withdraw from the study at any time (even after giving initial consent), or refuse to answer particular questions. During the

interview, if you choose to not answer one of the questions, you may say so and we will move to the next question. You can leave the interview and withdraw from the study at any time and without giving any reasons for your decision. This will not in any way compromise your participation or employment in the *Imagining Inclusion* project.

If you decide to withdraw, all associated data collected will be immediately destroyed wherever possible. This is a minimal risk study; I do not expect any adverse effects for any research participants.

Sharing the Results

The results of this study will be disseminated in several ways:

- publish academic articles
- present results at conferences

The data from this project will be used to raise awareness about ways in which structural and social processes can facilitate or hinder engagement of people with lived experience of mental illness in CBPR initiatives and develop recommendations for ethically sound CBPR in mental health

Who to Contact

If you have any questions regarding this project or the methods used in the study, please contact Anna Landy (phone # and email: [...]@sfu.ca) and/or Dr. Marina Morrow, Senior Supervisor, SFU (phone # and email: [...]@sfu.ca)

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you may contact Dr. Jeffrey Toward, Director of the Office of Research Ethics, jtoward@sfu.ca, 778-[…]

CERTIFICATE OF CONSENT

By signing this document, you indicate that you have read the foregoing information, or it has been read to you. You have had the opportunity to ask questions about it and any questions you have asked have been answered to your satisfaction. You consent voluntarily to be a participant in this study.

Print Name of Participant _____   Signature of Participant   _____

Date _____

      Day/month/year

Appendix B

QUESTIONS FOR THE *IMAGINING INCLUSION* PARTICIPANTS [1]
(INITIAL INTERVIEW STAGE)

Opening Questions

---

1. **What made you sign up for the *Imaging Inclusion* project?**
- What was your goal for joining the project?

2. **Can you describe some of the activities you participated in?**
- Can you provide more details?
- How often did you participate?
- What was your participation level?

 3. **What made you withdraw from the project?**
- Could you tell me more about that?

Engagement – concept

[As you know this project explores experiences of *engagement* in the *Imagining Inclusion* project. For a moment, let us reflect on the concept of *engagement*.]

4. [Try not to think too much about this] **When you hear the word *engagement* what comes to your mind?**
- What does it mean to you?
- Can you take a stab at defining engagement?

5. **What is it like when you are engaged?**
- For example, think about an activity that you got interested in – how does it feel when you are performing in that activity?
- How does it happen?
- How do you know when you are engaged?

6. **Is participating and being engaged the same or different?** In what way?

7. **What role if any does inclusion play in engagement?**
- In what way? Can you give me an example?
- For example: Are these concepts/ feelings interconnected/ dependent on one another? In what way? Can you feel included and not feel engaged and vice versa?

Experience of engagement within the Imaging Inclusion project
[or another activity/ project]

8. **When you think of your involvement in the *Imagining Inclusion* project or another activity/ project], is the word *engagement* or another word that comes to mind?**
- E.g. participation. Which one is the most meaningful to you?

9. **What words describe your *engagement*[8] in the *Imaging Inclusion* project [or another activity/ project]?**
- You mentioned _____ tell me what does it mean to you.
- Can you give me an example?

10. **Think of the specific time when you felt *engaged* in the *Imagining Inclusion* project [or another activity/ project] and describe it in as much detail as possible.**
- Could you walk me through this event?
- What about that experience was important to you?

11. **What encouraged or motivated you to continue your *engagement* in the project [or another activity/ project]?**
[As you might remember, we spoke about that in the focus groups]
- What helped you to continue your *engagement*?
- Has having peer researchers on the team played a role? In what way? Why was that?
- What made your *engagement* easier?
- What made it more difficult to *engage*?
- What could have made your *engagement* more fulfilling/ meaningful?

12. **Tell me about the challenges you had to face in order to *engage* in the *Imagining Inclusion* project [or another activity/ project]?**
- Where you able to overcome these challenges? If yes, how did you achieve that? What was helpful?
- *What I mean by challenges is individual barriers as well as some bigger, social factors. For example, some Imagining Inclusion participants discussed ways in which dealing with poverty, bureaucracy within the mental health system, or stigma of mental illness presented an additional challenge when trying to engage in health supporting activities.*

13. **Have you personally experienced any changes due to your *engagement* in the project [or another activity/ project]?**
- What kind?
- Can you provide specific examples?
- Why do you think that happened?

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[8] Or another word preferred by the interviewee – I will change the word *engagement* throughout the interview based on people's preferences

- For example: Some participants in the Imagining Inclusion project also discussed various ways in which engagement in the project had impacted their sense of inclusion or supported their recovery.

14. **In general, how do you think being a woman/men with lived experience of mental illness has shaped your *engagement* in the *Imagining Inclusion* project [or another activity/ project]?**

Experience of disengagement within the *Imagining Inclusion* project [or another activity/ project]

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15. [Thinking back to the *Imaging Inclusion* project - or another activity/ project] **While you were in the group, where there any specific times when you felt *disengaged*?** Can you describe it in as much detail as possible?
- Can you give me an example?
- How did that make you feel?
- How did you feel like when you were disengaged?
- Why do you think that happened?

16. **What are some of the obstacles that you experience in your day-to-day life as a woman/ man with lived experience of mental illness that played a role in your *engagement* in the project [or another activity/ project]?**
- Can you think of an example of the situation during which your engagement was compromised and why?
- What are some additional, specific factors that contributed to you feeling disengaged?

Closing question

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17. [Let us suppose you were organizing a community-based participatory research or another activity/ project.] **How would you *engage* people with lived experience of mental illness?** – *spend time exploring this question*
- What would be the most important to think about? What resources are crucial?
- What researchers need to be mindful of?
- What else?
- Can you give an example?
- What would be your recommendation for the next project with people with lived experience of mental illness?

Appendix C

QUESTIONS FOR THE *IMAGINING INCLUSION* PARTICIPANTS [2]
(PHOTOVOICE, PV10, AND PEER TASK GROUPS)

Opening Questions

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1. **What made you sign up for the *Imaging Inclusion* project?**
- What was your goal for joining the project?

2. **What motivated you to continue with the project?**
- Could you tell me more about that?

3. **How would you describe your role on the *Imagining Inclusion* project?**
- What tasks were you involved in?
- Can you describe some of the activities you participated in?
- Can you provide more details?
- How often did you participate?
- What was your participation level?

Engagement – concept

[As you know this project explores experiences of engagement in the *Imagining Inclusion* project. For a moment, let us reflect on the concept of engagement.]

4. [Try not to think too much about this] **When you hear the word *engagement* what comes to your mind?**
- What does it mean to you?
- How would you define it?

5. **What is it like when you are engaged?**
- What does that feel like?
- How does it happen?
- How do you know when you are engaged?

6. **What facilitates engagement?** In what way?

7. **What role if any does inclusion play in engagement?**
- In what way? Can you give me an example?
- For example: Are these concepts/ feelings interconnected/ dependent on one another?

In what way? Can you feel included and not feel engaged and vice versa?
In terms of feeling included and feeling engaged, do you think that they can exist-.are they interconnected? Or do you feel like they can, you can be engaged in something but do not feel included?

Experience of engagement within the Imaging Inclusion project

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8. **When you think of your involvement in the *Imagining Inclusion* project, what word comes to mind?**
- E.g. participation, meaningful involvement, engagement etc. Which one is the most meaningful to you?

9. **What words describe your *engagement*[9] in the *Imaging Inclusion* project?**
- You mentioned _____ tell me what does it mean to you.
- Can you give me an example?

10. **Think of the specific time when you felt *engaged* in the *Imagining Inclusion* project and describe it in as much detail as possible.**
- Could you walk me through this event?
- What about that experience was important to you?

11. **What encouraged or motivated you to continue your *engagement* in the project?**
[As you might remember, we spoke about that in the focus groups]
- What helped you to continue your *engagement*?
- Has having peer researchers on the team played a role? In what way? Why was that?
- What made your *engagement* easier?
- What made it more difficult to *engage*?
- What could have made your *engagement* more fulfilling/ meaningful?

12. **Tell me about the challenges you had to face in order to *engage* in the *Imagining Inclusion* project.**
- Where you able to overcome these challenges? If yes, how did you achieve that? What was helpful?
- What I mean by challenges is individual barriers as well as some bigger, social factors. For example, some Imagining Inclusion participants discussed ways in which dealing with poverty, bureaucracy within the mental health system, or stigma of mental illness presented an additional challenge when trying to engage in health supporting activities.

13. **Have you personally experienced any changes due to your *engagement* in the**

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[9] Or another word preferred by the interviewee – I will change the word *engagement* throughout the interview based on people's preferences

project?
- What kind?
- Can you provide specific examples?
- Why do you think that happened?
- *For example: Some participants in the Imagining Inclusion project also discussed various ways in which engagement in the project had impacted their sense of inclusion or supported their recovery*.

14. **In general, how do you think being a woman/men with lived experience of mental illness has shaped your *engagement* in the *Imagining Inclusion* project?**

15. [As you remember, most of the work done in the *Imagining Inclusion* project was done in a group setting] **How was it like for you to be working with others?**
- In what ways if any being in a group with others enhanced or compromised your *engagement*? Why do you think that happened? Can you give me an example?

16. [Let's now reflect on some your observations of other group members] **What are your observations of the level of *engagement* of other group members?**
- Have you noticed different level of *engagement* between the group members? Why do you think that was?
- For example, did you notice different level of *engagement* between men and women or people with fluent English and those with English as a second language?
- In your opinion what enhanced participants' engagement? What inhibited it?

Experience of disengagement within the *Imagining Inclusion* project

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17. [Thinking back to the *Imaging Inclusion* project.] **While you were in the group, where there any specific times when you felt *disengaged*?** Can you describe it in as much detail as possible?
- Can you give me an example?
- How did that make you feel?
- How did you feel like when you were disengaged?
- Why do you think that happened?

18. **What are some of the obstacles that you experience in your day to day life as a woman/ man with lived experience of mental illness that played a role in your *engagement* in the project?**
- Can you think of an example of the situation during which your engagement was compromised and why?
- What are some additional, specific factors that contributed to you feeling disengaged?

Closing questions

 [As you know the *Imagining Inclusion* project was a community-based participatory research initiative that brought together people with lived experience, service providers, students, and academics. By engaging in this type of research, the researchers often try to shift power away from the researcher as an expert in order to create a space for the voice of people with lived experience.]

19. **Can you think of a specific time when your experiences or views were valued?**
- What is the evidence of that? Can you give me an example?
- Why do you think that happened?
- How did it feel?
20. **Can you think of a specific time when your experiences or views were not valued or documented?**
- Can you give me an example?
- Why do you think that happened?
- How did it feel?

21. [Let's suppose you were organizing a community-based participatory research.] **How would you *engage* people with lived experience of mental illness?**
- What would be the most important to think about? What resources are crucial?
- What researchers need to be mindful of?
- What else?
- Can you give an example?
- What would be your recommendation for the next project with people with lived experience of mental illness?

22. **What will you take away from your *engagement* in the *Imagining Inclusion* project?**

Appendix D

QUESTIONS FOR THE *IMAGINING INCLUSION* PARTICIPANTS [3]
(PEER RESEARCHERS)

Opening Questions

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1. **What made you apply for the peer researcher position on the Imaging Inclusion project?**
- What was your goal for joining the project?
- Tell me more about the application process. What was your experience like?
- What made the process of applying for the position easy/difficult?

2. **You have been with the project for almost 2 years - What motivated you to continue with the project?**
- Could you tell me more about that?

3. **How would you describe your role as a peer researcher on the *Imagining Inclusion* project?**
- What were your responsibilities as a research team member?
- What kinds of tasks were you involved in?
- Can you describe some of the activities you participated in?
- Can you provide more details?

Engagement – concept

[As you know this project explores experiences of engagement in the *Imagining Inclusion* project. For a moment let's reflect on the concept of engagement.]

4. [Try not to think too much about this] **When you hear the word *engagement* what comes to your mind?**
- What does it mean to you? How does it happen?
- How would you define it?

5. **What is it like when you are engaged?**
- What does that feel like?
- How do you know when you are engaged?

6. **What facilitates engagement?** In what way?
7. **What role if any does inclusion play in engagement?**
- In what way? Can you give me an example?

- For example: Are these concepts/ feelings interconnected/ dependent on one another? In what way? Can you feel included and not feel engaged and vice versa?
- In terms of the feeling included and feeling engaged, do you think that they can exist...are they interconnected? or do you feel like they can, you can be engaged in something but do not feel included?

Experience of engagement within the Imaging Inclusion project

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8. **When you think of your involvement in the *Imagining Inclusion* project, is the word *engagement* or another word that comes to mind?**
- E.g. participation, meaningful involvement etc. Which one is the most meaningful to you?

9. **What words describe your *engagement*[10] in the Imaging Inclusion project?**
- You mentioned _____ tell me what does it mean to you.
- Can you give me an example?

10. **Project activities shifted over the length of time you were part of the project, have you found some of the activities more engaging than others?**
- Which ones?
- Why do you think that happened?

11. **Think of the time when you felt *engaged* in the *Imagining Inclusion* project and describe it in as much detail as possible.**
- Could you walk me through this event?
- What about that experience was important to you?

12. **What encouraged or motivated you to continue your *engagement* in the project?**
[As you might remember we spoke about that in the focus groups]
- What helped you to continue your *engagement*?
- Has having peer researchers on the team played a role? In what way? Why was that?
- What made your *engagement* easier?
- What made it more difficult to *engage*?
- What could have made your *engagement* more fulfilling/ meaningful?

13. **Tell me about the challenges you had to face in order to *engage* in the *Imagining Inclusion* project.**
- Where you able to overcome these challenges? If yes, how did you achieve that? What was helpful?

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[10] Or another word preferred by the interviewee – I will change the word *engagement* throughout the interview based on people's preferences

- What I mean by challenges is individual barriers as well as some bigger, social factors. For example, some Imagining Inclusion participants discussed ways in which dealing with poverty, bureaucracy within the mental health system, or stigma of mental illness presented an additional challenge when trying to engage in health supporting activities.

14. **Have you personally experienced any changes due to your *engagement* in the project?**
- What kind?
- Can you provide specific examples?
- Why do you think that happened?
- For example: Some participants in the Imagining Inclusion project also discussed various ways in which engagement in the project had impacted their sense of inclusion or supported their recovery.

15. **In general, how do you think being a woman with lived experience of mental illness has shaped your *engagement* in the *Imagining Inclusion* project?**

16. [As you remember, most of the work done in the *Imagining Inclusion* project was done in a group setting] **How was it like for you to be working with others on the research team?**
- In what ways if any being in a group with others enhanced or compromised your *engagement*? Why do you think that happened? Can you give me an example?

17. [Let's now reflect on some of your observations of participants] **What are your observations of the level of *engagement* of participants?**
- Have you noticed different level of *engagement* between the group members? Why do you think that was?
- For example, did you notice different level of *engagement* between men and women or people with fluent English and those with English as a second language?
- In your opinion what enhanced participants' engagement? What inhibited it?

Experience of disengagement within the *Imagining Inclusion* project

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18. [Thinking back to the *Imaging Inclusion* project.] **Where there any specific times when you felt *disengaged*? Can you describe it in as much detail as possible?**
- Can you give me an example?
- How did that make you feel?
- How did you feel like when you were disengaged? Why do you think that happened?
19. **What are some of the obstacles that you experience in your day to day life as a woman with lived experience of mental illness that played a role in your *engagement* in the project?**
- Can you think of an example of the situation during which your engagement was

compromised and why?

- What are some additional, specific factors that contributed to you feeling disengaged?

Closing questions

[As you know the *Imagining Inclusion* project was a community-based participatory research initiative that brought together people with lived experience, service providers, students, and academics. By engaging in this type of research, the researchers often try to shift power away from the researcher as an expert in order to create a space for the voice of people with lived experience.]

20. **Can you think of a specific time when your experiences or views were valued?**
- What is the evidence of that? Can you give me an example?
- Why do you think that happened?
- How did it feel?

21. **Can you think of a specific time when your experiences or views were not valued or documented?**
- Can you give me an example?
- Why do you think that happened?
- How did it feel?

22. [Many researchers are interested in the notion and the value of 'engagement'] **How do you understand the current interest in the notion of engagement of people with lived experience of mental illness?**

23. [Let's suppose you were organizing a community-based participatory research.] **How would you *engage* people with lived experience of mental illness?**
- What would be the most important to think about? What resources are crucial?
- What about engaging people with lived experience of mental illness as peer researcher?
- What researchers need to be mindful of?
- What else?
- Can you give an example?
- What would be your recommendation for the next project with people with lived experience of mental illness?

24. **What will you take away from your *engagement* as a peer researcher in the *Imagining Inclusion* project?**