Creating Upstream Change in Mental Health through Photovoice

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imagining Inclusion

Abstract

People with serious mental illness die an average of 25 years younger than the general population (Flanagan, et al., 2016). Social exclusion and stigma have been identified as being at the core of health disparities and barriers to meaningful community involvement for people with serious mental illness (Reid & Alonso, 2018). To address the complex and detrimental effects of stigma and social exclusion, *Imagining Inclusion* used Community Based Participatory Research methodology, Photovoice, to explore experiences of community inclusion, health and well-being for individuals with serious mental illness and will use the findings to foster organizational and societal change. With Photovoice research, participants take photos about their lived experience and speak about how they relate to themselves, community and society (Reid & Alonso, 2018).

In *Imagining Inclusion* Phase 3 we will examine the characteristics and outcomes of the Photovoice process, and the role of peers and therapeutic recreation in helping to create stigma resistance at the personal, peer, and public levels. We will develop an evidence-based toolkit that can be used to adopt and sustain the key elements of the Photovoice process across allied health and therapeutic recreation services for people with serious mental illness.

Goal and Research Questions

Goal:
The goal of *Imagining Inclusion* Phase 3 is to elucidate the most transformative characteristics of the Photovoice process for individuals with serious mental illness so we can adopt and sustain them across community mental health services in order to create the upstream change necessary for improving life expectancy, health, well-being and community inclusion of people with serious mental illness.

Research Questions:
1) What are the outcomes of involvement in a Photovoice process for individuals with serious mental illness?
2) What characteristics of the Photovoice process are most transformative for clients with serious mental illness?
3) How can we adopt these key elements and sustain them across community mental health services?

Literature Review

Social Determinants of Health, Disparities, Social Exclusion and Stigma

- Social determinants of health have more influence on our health than individual lifestyle choices (Adam & Potvin, 2017)
- Lived experience of discrimination, social isolation, primary care barriers, and lack of respect result in health disparities leading to early death (Becker, et al., 2014; Flanagan, et al., 2016)
- Stigma and exclusion are major barriers to recovery from mental illness (Reid & Alonso, 2018)
- Limited access to rights, resources, and capabilities for a healthy life (Adam & Potvin, 2017)
- Lack of meaningful involvement and a sense of belonging in community (Reid & Alonso, 2018)

Social Inclusion and Upstream Change

- Inextricably linked with improved health outcomes for people with serious mental illness (Reid & Alonso, 2018)
- Focus on systemic and structural barriers to active and meaningful participation in society (Reid & Alonso, 2018)

Photovoice, Peers, and Stigma Resistance

- CBPR research and social activism through use of photography to develop narratives around personally meaningful visual images (Reid & Alonso, 2018)
- Improved recovery and stigma resistance with PV and peer facilitation (Firmin et al., 2017)

**Allied Health/Therapeutic Recreation Professions**

- Use strengths-based person-first philosophies (Fenton et al., 2016; Reid & Alonso, 2018)
- The focus on individual health behaviours and biomedical approaches to improve quality of life is more effective when upstream factors such as stigma, social exclusion and disenfranchisement are addressed (Fenton et al., 2016 ; Reid & Alonso, 2018)
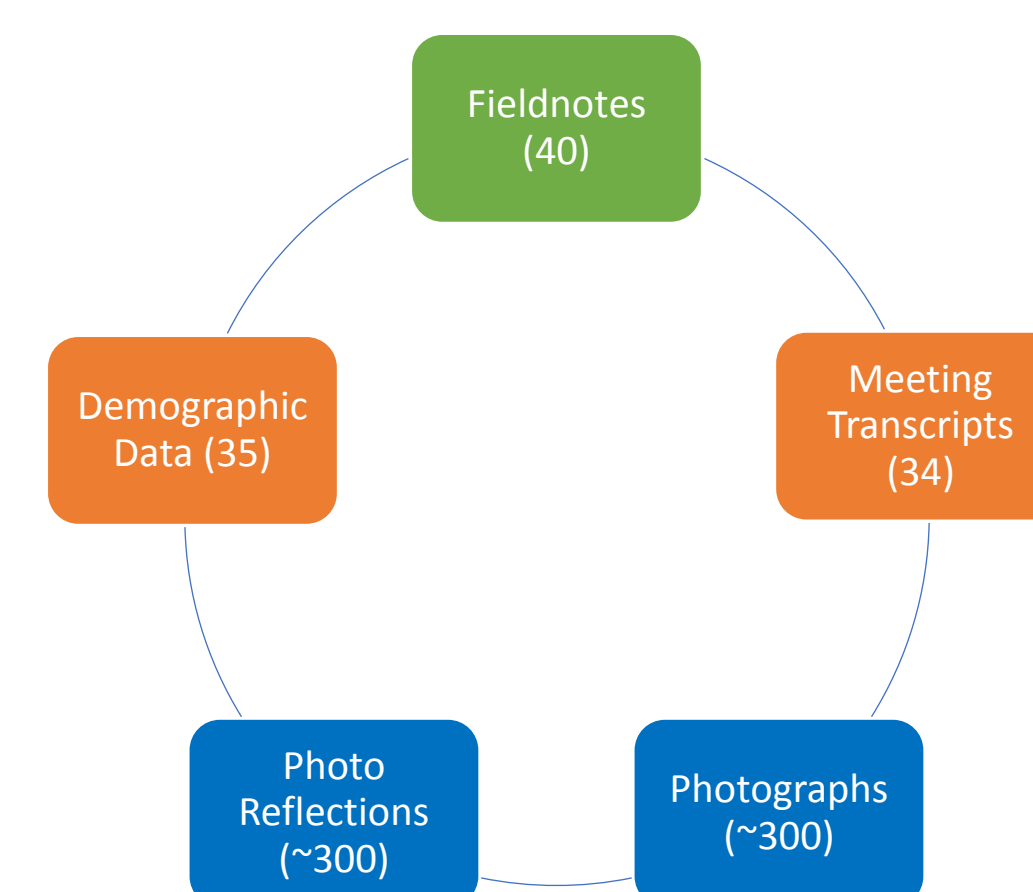
Context

Imagining Inclusion is a Vancouver research project with two phases (2013-2015 and 2016-2019) that is focused on discovering the reality of people with lived experience of mental illness and factors that contribute to community inclusion, health and wellbeing. Building on the first two phases, we turn our focus to Phase 3 in identifying the key components of Photovoice in personal transformation and adopting / sustaining this across all therapeutic recreation and allied health service delivery in community mental health.
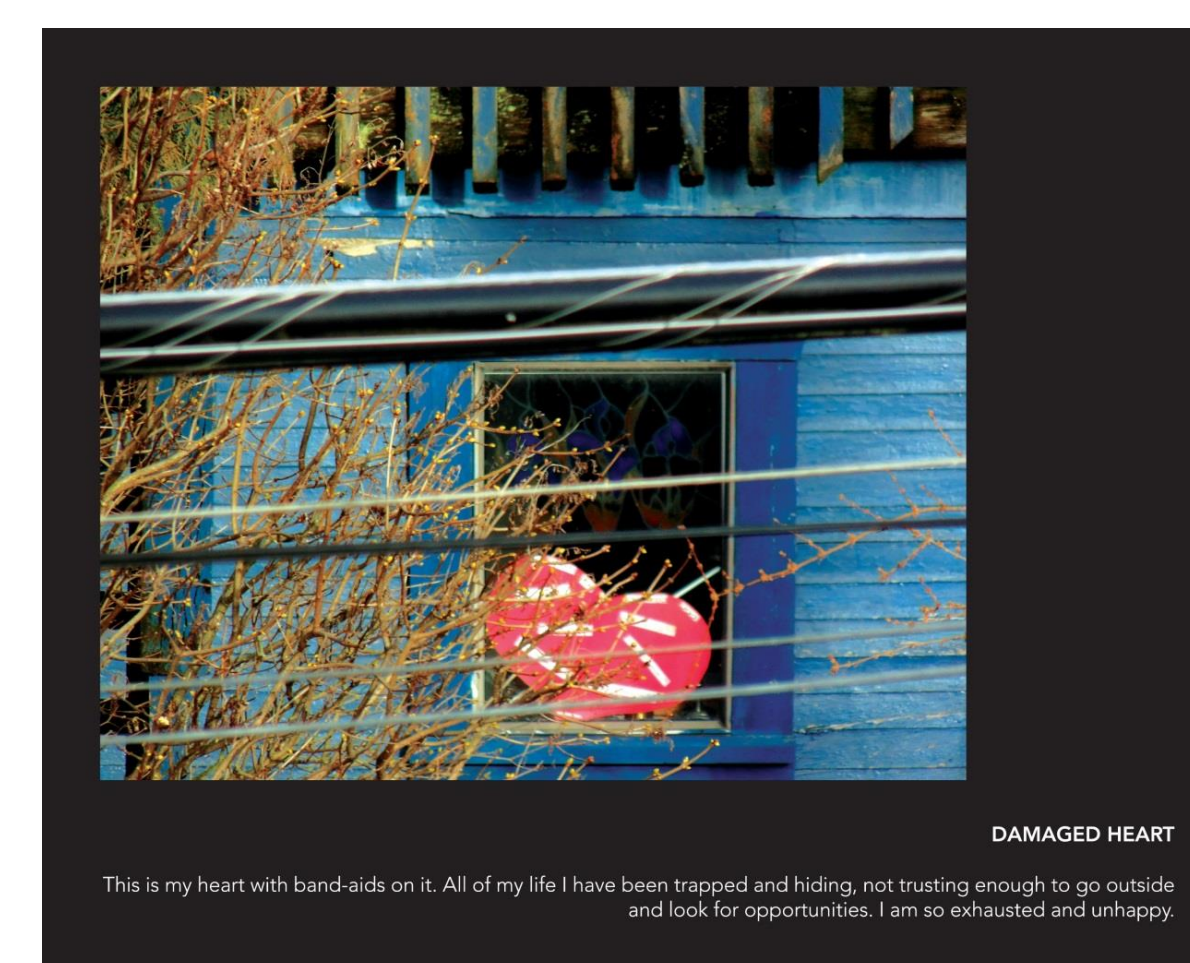
Project Phase 1
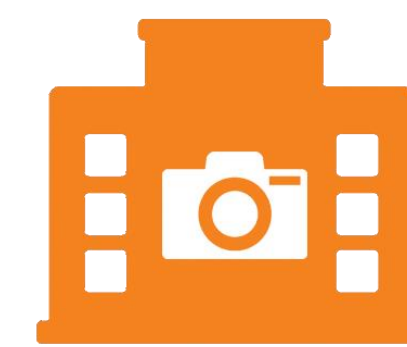
From 2013 to 2015, we explored experiences of community inclusion for people with lived experience of mental illness. Through collaborative involvement of research participants, we developed two models based on their individual, community and societal experiences. The data set for Phase 1 included:

- Fieldnotes (40)
- Meeting Transcripts (34)
- Photographs (~300)
- Photo Reflections (~300)
- Demographic Data (35)

Project Phase 2

From 2016 to 2019, we continue to explore lived experience of mental illness using the two models developed in Phase 1 to facilitate organizational change within the community mental health system as well as using peer leadership in all project activities.

ON HASTINGS FIELD THE LILIES GROW
By categorizing people with mental illness, it is easy for those in power to exploit, control, segregate, dehumanize, and discard people. Another example of "them and Us". People are born beautiful, but due to abuse, neglect, and abandonment many are discarded and thrown out.

DAMAGED HEART
This is my heart with band-aids on it. All of my life I have been trapped and hiding, not trusting enough to go outside and look for opportunities. I am so exhausted and unhappy

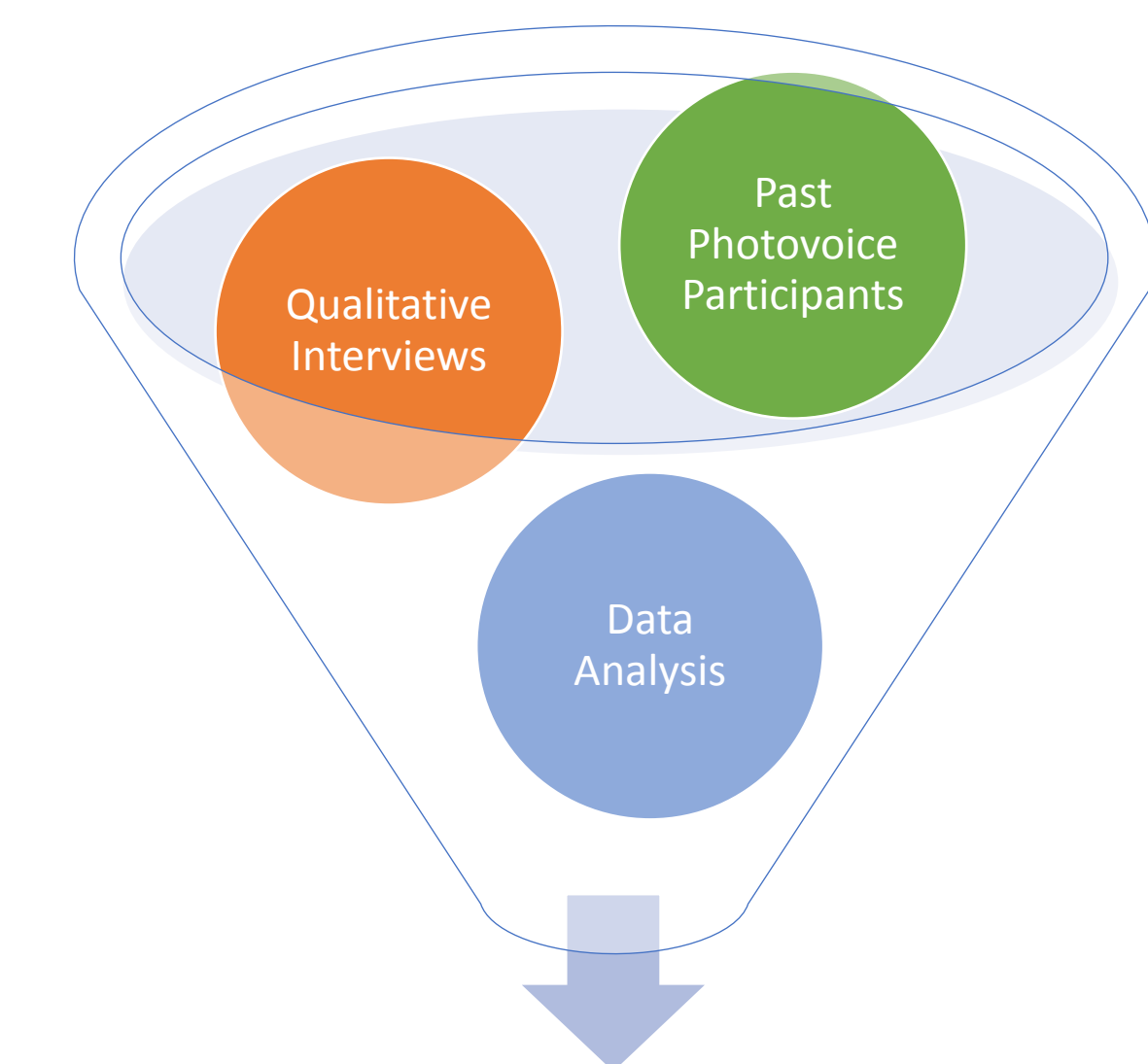## https://imagininginclusion.ca

Proposed Research Methods

- Small-scale community-based participatory research project
- Qualitative research study with 30-45 minute one-on-one semi-structured interviews

Recruitment
- Sample a sub-set of past Photovoice research participants (N=55)
  - Fifteen individuals with serious mental illness (n=15);
  - Three peer researchers who have facilitated Photovoice (n=3)
  - Two recreation therapists who have been involved in past projects (n=2)
  - Total (n=20)

- Formulate questions regarding:
  - Characteristics and outcomes of the Photovoice process and
  - How participation in Photovoice contributed to building participants' sense of self-efficacy, self-worth, self-awareness, agency, choice, and empowerment in developing stigma resistance

- Interviews conducted by peer researchers and audio-recorded, transcribed verbatim, thematically analyzed using NVivo 11 for data analysis and coding
- Results will be used to develop a program or project (toolkit) for recreation therapists and other allied health professionals to use in community mental health service delivery

Toolkit for community mental health services to create upstream change and stigma resistance

References

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