



PEER RESEARCHER TRAINING PARTICIPANT MANUAL

A program created to teach skills in Community Based Research to people with lived experience of mental illness.

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Sessions

Week 1	Introduction to Community Based Research
Week 2	Planning a Research Project
Week 3	Literature Map and Research Participants
Week 4	Research Methods – Part One
Week 5	Research Methods – Part Two
Week 6	Managing, Analyzing and Organizing Data
Week 7	Finalizing Data and Knowledge Translation
Week 8	Program Evaluation
Week 9	The Peer Context
Week 10	Review and Celebration (No module)

Module One:

Introduction

to

Community Based Research

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Learning Objectives

- Gain a basic understanding of Community Based Research (CBR)
- Understand the guiding themes of Community Based Research (CBR)
- Understand the difference between traditional research and Community Based Research (CBR)
- Understand foundational research ethics
- How to engage in reflexivity

Content

- Research and Community Based Research (CBR)
- Traditional Research vs Community Based Research
- Research Steps
- Ethics
- Reflexivity

Research

Research is the process of discovering or uncovering new knowledge about the world. It involves identifying a topic you are interested in, reading up on the area, and focusing in on a research question. In our daily lives, we regularly collect, process, and analyze information in order to understand the things around us. We search online to find the best restaurants in town, we watch the news to help decide which party to vote for in an election, and we might even compare every can of chicken soup in the grocery store to find the best deal.

Formal research is distinct from our everyday musings and problem solving because it involves a systematic inquiry into a phenomenon of interest. Research aims to contribute to what is known about a phenomenon, while also aiming to contribute to action and social change. Formal research uses specific frameworks and systematic processes to collect, process, and analyze information. It



usually focuses on a specific issue and works to contribute new information that was not previously known. During this process every step, setback, mistake, strength, weakness, and tool used is documented. In formal research, ethics also plays a major role in

ensuring that everyone's participation, identify, and contributions are respected.

What is *good* research?

Research does not need to be done on a large scale or cost a lot of money in order to be considered valid and useful. In fact, it is more about the considerations that are made during the process - how do the steps you take, and the tools you use, contribute to the results that you find.

Having a deep understanding of the strengths and limitations of your study, as well as what the results imply, are the most important parts of good research.

Research is a form of transformational learning that increases the 'stock of knowledge' that provides people with the means to engage their lives more effectively. This does not necessarily mean fundamental changes in worldview or cultural orientation...but includes the small 'ah-ha's' that enable people to see themselves, others, events, and phenomena with greater clarity or in a positively different way (Stringer & Genat, 2004, p. 3).

Community Based Research

Community Based Research has been described as “social research for social change” (Greenwood & Levin, 2007). In traditional research, in-depth insight into the lives of community members is usually not available. Often, researchers observe the research participants from an outside perspective, with the research participants as passive test subjects. In Community Based Research



(CBR), community members participate not only as research subjects, but as active research collaborators and agents of change.

CBR takes research out of the ivory towers of academia and into the general community, involving and empowering community members as *partners in knowledge production*. CBR is geared toward generating evidence and mobilizing change on issues that are important, as identified by members of the community. CBR is becoming increasingly popular in the fields of health and mental health. Because of this, more and more Peers are being invited to be involved in research (Access Alliance, 2011).

According to Schneider (2012), three primary goals of CBR are to:

1. Produce practical knowledge through the collection and analysis of data
2. Take action to make that knowledge available (i.e. knowledge translation, discussed later in the course)
3. Be transformative both socially and for the individuals who take part



There is a mental health service user research movement in CBR, in which people with experience of using services in the mental health system take part as active partners in the research process, rather than simply as research subjects. Through this involvement, through actively working to generate knowledge that will improve mental health services and change public perceptions of people with mental health diagnoses, service users can achieve a sense of personal empowerment, promote positive change in mental health treatment and in their own lives, and take their place in society as people with the right and ability to speak about issues that concern them (Schneider, 2012, p.153).

Guiding Themes of CBR

SOCIAL JUSTICE. A political and philosophical concept which is based on the idea of creating a fair



and just society is one where everyone enjoys the equal rights and access to housing, health, income security and opportunity. In order to commit to social justice, we must be aware of the ongoing imbalances of social power in society, as well as our own positions of power, privilege, and oppression. Reason and Bradbury

(2006) suggest a strong component of CBR is to “liberate the human body, mind and spirit in the search for a better, freer world” (p. 2).

INCLUSION. At the Centre of CBR is the idea that everyone has the right and ability to be *included* in research for which they are a member of the population under study. When communities are



included in research, there is richer information to be found and a more accepting environment to be created. Inclusive research involves looking at all sides of a community, all sides of a problem, and all sides of the solution. It allows everyone to be a part of the process and include their own opinions, experiences, and ideas.

SOCIAL DETERMINANTS OF HEALTH. A set of factors that individually and collectively influence one's physical, social, and mental health. These factors often begin even before we are born (e.g., the level of education our parents have; what type of health care is available in our community). Social determinants of health are not the personal reasons why we get sick, such as unhealthy eating, but the *overarching societal reasons* for our overall health.

For example, instead of an individual being overweight simply because they overeat – the social determinants of health consider their genetic background, environmental influences, poverty and upbringing. This framework explains that *there is no one*



single reason why people develop illnesses or become unhealthy, but that there are many factors that intersect and interact with each other that influence health over a lifetime.

A Closer Look: Social Determinants of Health

Claire has had a really bad cough for almost two months... *why?*

Because she has bronchitis... *why?*

Because she lives in an old, moldy building... *why?*

Because it is the only place that she can afford... *why?*

Because she receives minimum wage at her part-time job... *why?*

Because she was never able to graduate high-school... *why?*

Because she stayed home and took care of her ill mother, and was not able to put time into her school work.



Always ask why... There are some situations we face in life that are beyond our control.

We make the best out of what life gives to us, but these social determinants of health can often be the underlying reasons why we face health issues throughout our lives. Our life situations are rarely ever the result of one single factor.

Traditional VS Community Based Research

The following table outlines the major differences between traditional research and Community Based Research. Notice the difference in level of involvement on behalf of community members.

	Traditional Research	Community Based Research
Research Objective	Issues identified based on epidemiologic data and funding opportunities.	Full participation of community in identifying issues of greatest importance.
Study Design	Design based entirely on scientific rigor and feasibility.	Community representatives involved with study design.
Recruitment & Design	Approaches based on scientific issues and “best guesses” regarding reaching community members and keeping them involved.	Community representatives provide guidance on recruitment and retention strategies and aid in recruitment efforts.
Instrument Design	Instruments adopted/adapted from other studies; tested chiefly with psychometric analysis method.	Instruments developed with community input and tested in similar populations.
Intervention Design	Researchers design interventions based on literature and theory.	Community members help guide intervention development.
Analysis and Interpretation	Researchers own the data, conduct analysis and interpret the findings.	Data is shared; community members and researchers work together to interpret results.
Dissemination (i.e., “Getting the Word Out”)	Results published only in peer-reviewed academic journals.	Community members assist researchers in developing a knowledge translation plan, and identify appropriate ways to disseminate results; results are also published in Peer-reviewed journals.

(Hartwig, Calleson & Wallace, 2006)

Research Ethics

Research ethics are a set of principles, policies and practices that are followed by research teams to ensure that their research is conducted in ways that do not harm participants. Research ethics promote understanding, inclusion, transparency, and confidentiality of the researchers and participants. Conducting research ethically involves understanding what the risks might be for those participating, responding responsibly to those risks, and conveying information about the risks to the research participants, so they can make an informed decision about whether or not they would like to participate in the research.



An **ethics review** is a formal process that involves reviewing proposed research project ideas, and ensures that the *ethical principles of CBR* are upheld in any given research project. An **ethics review board** is comprised of a diverse group of individuals who are affiliated with a university, hospital, health authority, or private agency.



Ethical principles provide a guideline for values and behaviors to keep in mind when conducting research. The following are a number of ethical principles to keep in mind when conducting CBR:

RESPECT FOR RESEARCH PARTICIPANTS. Every person should be respected regardless of *gender, race, social class, ethnicity, nationality, sexual orientation, religion, age, mental health, physical disability, mental illness* and *physical illness*. This principle ensures that vulnerable persons, groups, and communities will not be taken advantage of or abused in any way. In CBR, this principle includes



advocating for communities and individuals who have or currently experience barriers.

MAXIMIZE BENEFITS AND MINIMIZE HARM TO PERSONS AND THE COMMUNITY.

Harms and risks can be decreased by proper planning and through consulting community members at all stages. Potential harms are discussed in an *ethics review* (discussed later) that is conducted before the research begins.

OBTAIN VOLUNTARY AND INFORMED CONSENT. Every participant for a research study must



be given the opportunity to understand the purpose of the study, the potential harms or risks, and how the data will be conducted and used. They must also be made aware of their right to not participate or to withdraw from the study at any time, and the process of doing so.

MAINTAIN CONFIDENTIALITY. The participant's identity, information and experiences are not shared with anyone outside of the research team, and information shared by study participants is not reported in a way that the person who shared the information can be identified. In some cases, it may not be necessary or appropriate for all members of the research team to know the identities of the participants. Confidentiality also includes the researchers' responsibility to securely store any research materials, including data obtained from research (more on managing data in Module Six).



Reflexivity

In CBR, researchers have high standards of openness and transparency about the study being conducted. Reflexivity is a method used by researchers to critically examine and better understand how their own assumptions, underlying values, and social positions might impact the research produced (Reid, Brief & Le Drew, 2009).



Reflexivity allows you to harness your awareness and understandings to guide your conduct when engaging in research. Practicing reflexivity can empower you to remain open-minded to a diverse range of responses and outcomes, even those that are completely unexpected or with which you may have initially disagreed. With reflexivity, you are able to explore your insights and knowledge, what inspires you and what frustrates you, and to appreciate the magical "*ah-ha!*" moments you are bound to encounter in your research.

Why we practice reflexivity in Community Based Research

1. While traditional research typically favors professional distance and objectivity, CBR favors engagement and subjectivity. Reflexivity can help researchers find their passion for a research topic, and can thus help researchers develop their *research question*.
2. Researchers may find that they are personally invested in a particular outcome of the research. Reflexivity can help researchers become aware of these biases, consider alternative outcomes, and thus discover information that would have otherwise been hidden to them.
3. *Qualitative research methods*, discussed in a later module, require researchers to draw conclusions from their own subjective knowledge and experience. Through reflexivity, a researcher can truthfully explain how and why they made certain decisions throughout the research process; this explanation can increase the integrity and truthfulness of the research, further discussed in later modules (Finlay & Gough, 2008).

Reflexivity involves:

- *Journaling*
- *Being curious and asking questions*
- *Paying attention*
- *Challenging assumptions and expectations*
- *Remaining open to possibilities*
- *Bringing your "voice" to your ideas*
- *Recording observations*
- *Documenting frustrations*

In order to monitor and critically examine engagement and subjectivity in CBR, researchers maintain a **research journal**. In the journal, researchers write out and reflect on their own personal thoughts, feelings, behaviours, knowledge, attitudes, and lived experience.



- What is my own personal understanding of the topics being studied?
- What are my reactions to the information I am gathering?
- How do my own *social determinants of health* affect my understanding of the data?

Homework

Journal Questions

Answer any of the following questions in your journal:

1. What are some of my experiences with mental health or mental illness that I'd like to learn more about?
2. What would I like to see done differently in the mental health system?
3. What topics interest me in terms of research in mental health?
4. What does the word "Peer" mean to me?
5. What are my passions?
6. Why am I interested in doing research?
7. How do I see myself as a Peer Researcher?
8. Why am I becoming a Peer Researcher?

Need to Know Readings:



Reid, C., & Alonso, M. (2018). Imagining inclusion: Uncovering the upstream determinants of mental health through photovoice. *Therapeutic Recreation Journal*, 52(1), 19-41. doi:10.18666/TRJ-2018-V52-/1-8461.

- **Read pages 20-22:** "Literature Review" section



Reid, C., Greaves, L. & Kirby, S. (2017). Chapter 5: Literature Review. In *Experience, Research, Social Change: Critical Methods, 3rd Edition* (pp. 107-131). Toronto, ON: University of Toronto Press.

- **Read pages 107-111**, and familiarize yourself with the following terms:
 - Peer-reviewed literature
 - Grey literature

References

- Access Alliance Multicultural Health and Community Services. (2011). *Community Based Research Toolkit: Resource for Doing Research with Community for Social Change*. Toronto: Access Alliance Multicultural Health and Community Services
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- Schneider, B. (2012). Participatory action research, mental health service user research, and the hearing (our) voices projects. *International Journal of Qualitative Methods*, 11(2), 152-165. doi:10.1177/160940691201100203
- Stringer, E., & Genat B. (2004). *Action Research in Health*. Upper Saddle River, NJ: Merrill Prentice Hall.

Module Two:

Planning a Research Project

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Learning Objectives

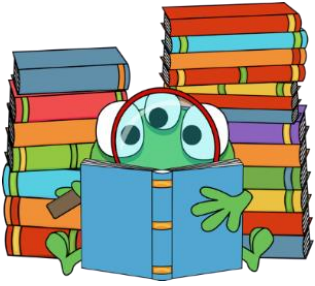
- Explore the research and practical application of the research that has been done on a topic
- Distinguish between different kinds of information (e.g., Peer-reviewed; grey literature)
- Different methods to search for information (e.g., literature review; environmental scan)
- Why literature reviews and environmental scans are done in research contexts
- Develop strategies for finding information that is relevant to a research question

Content

- Developing a Research Question
- Searching for Information
 - Peer-Reviewed Literature
 - Grey Literature
- Environmental scans
- Searching for Information
- Literature Map
- Documentation and Rigor

Literature Review

A **literature review** involves looking for information on a topic in order to gain better understanding of what research was already been done. Literature reviews can also expose possible gaps in literature that your research could potentially address. Literature reviews also provide insight



into previously used methods and approaches that may be beneficial to the research you are conducting. A thorough literature review will show what is already known/what is not known about a particular topic. It is a good way to find out what still needs to be investigated. It is best to find articles published

in the last 5 years, but you may be required to use articles up to 15 years old.

A literature review provides a framework for answering the following questions:

1. How much information **already exists** for this topic?
2. **Who** is writing about it? Are there authors **with multiple publications** on the topic?
3. What **kind** of research is it (traditional research or Community Based Research)?
4. What are the **relationships between studies**? Do two or more of the studies report similar findings? If not, what are the differences between the studies?
5. Do the authors identify **potential areas** where more research is needed?
6. Can you identify any **gaps** in the literature where additional research may be helpful?

Peer-Reviewed Literature is work that has been assessed by other academics or “experts” in the field before publication, usually in an academic journal along with other pieces of work of similar caliber. Peer reviewed methods are intended to uphold quality, integrity and credibility of the information contained in the pieces of work. Peer reviewed literature has traditionally been known as being the “most legitimate” or “reliable” sources, because they have been evaluated by other reputable members in the field, presumably negating any false claims, errors, and biases (Reid, Greaves & Kirby, 2017).



Grey Literature is any literature that is not published in peer-reviewed journals. Grey literature can be government reports, blogs, websites, newspaper articles, books. By using both peer-reviewed and grey literature, you will gain a more in-depth understanding of the issue you are exploring. It is important, however, not to rely on grey literature *exclusively*. Although grey literature can provide a greater reflection of the community outside academia and may be beneficial information that may not be reflected through studies, sole reliance on grey literature will decrease the validity of your work. In the

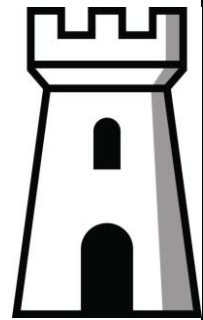


research field, it’s important to combine grey literature with peer-reviewed literature (Reid et al., 2017).

Many people do not have unrestricted access to peer-reviewed literature. Often, one must be a student or professor at an educational institution to have free, unlimited access to academic articles – that, or have a lot of disposable income, as some articles can cost over \$100 each!



As discussed in Module 1, CBR values social justice and inclusion, and considers knowledge from all sources to be important, especially knowledge held by individuals who are marginalized in society. In order to hear from individuals who are outside of the “ivory tower” of academia, another source of information that is important to consider is grey literature.



Environmental scan is a tool used to investigate external factors that are seen as the keys to the success of an organization. Environmental scans can reveal information about what is currently happening in the field you are studying. Current, short-term and long-term trends in social, economic, technological, and political contexts that are impacting the area of study can be discovered, and this information can be applied to how the research you are doing could benefit the population served (e.g., policy-making; changes in services; etc.) (Graham, Evitts, & Thomas-Maclean, 2008).

Environmental scans include both looking at internal and external sources. **Internal**



assessments may look at an organization's meeting minutes, personal communications, and other documents to see how they are applying information from research that has been done. **External assessments** look

more at different contexts that affect the organization such as political, social, shifts in the economy, and technological changes (e.g. the use of social media in providing information on free or low-cost resources for mental health care).

Developing a Research Question

The research question aims to seek answers to the key issues you want to investigate. It is best to keep your research question narrow and specific to allow for more focused research (Reid, Greaves & Kirby, 2017). One way to develop your research question is to approach it from different angles.

Real World Example: Planning Your Research Project - Imagining Inclusion

Topic: Community inclusion, health and wellbeing of people with lived experience of mental illness



Problem: Lived experience of mental illness is often marked by stigma of mental illness, economic insecurity, social exclusion and sense of isolation, experience of being silenced

Purpose: to document how individuals living with mental illness experience social isolation, poverty, and stigma in their daily lives; the importance of community inclusion, health and well-being from the perspective of individuals living with mental illness

Research Question: How do individuals living with mental illness experience community inclusion, health and well-being?

Searching for Information

Whether you are writing a formal academic literature review, a review that integrates Peer-reviewed and grey literature, or an environmental scan, you will need to *find information*. For instance, you may be interested in understanding the phenomenon of “women who are older and have a psychiatric diagnosis accessing mental health services”. You will find a wide range of terminology when you begin searching, so before you do you will need to consider your options.

It is also crucial for researchers to refer to the population with the *proper terminology*. For example, it would be disrespectful and politically incorrect to describe your population as “Schizophrenic Women,” and more appropriate to use person-first language, such as “Women living with Schizophrenia”. Using person-first terminology will allow you to find more focused information on your population that will contribute to defining what your topic is, and will also likely lead you to articles that are from a more social justice-oriented perspective.



At first, you may not know what the proper terminology is for your population, but by perusing academic articles and noticing the language that is used, you will gain a better understanding as to what terminology is relevant to your research question.

Example: Brainstorming Key Search Terms

Key terms:	Women	Who are older	Schizophrenia	Accessing	Mental health services
Terms you may use for search:	Female	Senior	Psychotic disorder	Participating	Community mental health
	Gender	Elderly	Mental illness	Using	Clinical
		Retired	Psychosis	Barriers	Mental health teams
		Geriatric	Psychiatric disorder	Consumer	Health services

Open Source Databases

Online:

- <https://scholar.google.ca/>
- <https://doaj.org/>
- <http://plos.org/>
- <https://www.hindawi.com/>
- <http://www.frontiersin.org/>
- <http://www.mdpi.com/>
- <http://www.biomedcentral.com/>

In-person:

- Local public libraries
- Hospital libraries
- University libraries

An **annotated bibliography** may be a helpful tool to implement as you conduct a literature review. In annotated bibliographies, all of the main points of the article are recorded -- including any limitations -- for easy future reference. An annotated bibliography may also include the following:

- A brief summary of the article
- The article's strengths and weaknesses
- The article's conclusions
- How the article is relevant to your research

- How the article relates to other studies
- Information about the author's background, if available
- Your personal conclusions about the source
- Any suggestions the authors make for future research

(Adapted from Niseteo, 2018)

Real-World Example: Annotated Bibliography

Pegg, S., & Moxham, L. (2000). Getting it right: Appropriate therapeutic recreation programs for community based consumers of mental health services. *Contemporary Nurse*, 9(3-4), 295-302.



Pegg and Moxham (2000) describe ways in which the process of deinstitutionalization in Australia has left mental health consumers largely underserved. The authors advocate for a consumer-driven Therapeutic Recreation services as a way of addressing some of the gaps in community-based mental health services. They suggest that having opportunities for mastery and perceived leisure control may play a valuable role in enhancing the success and life satisfaction of community-dwelling consumers. This paper illustrates the changes to therapeutic recreation programming and training of professional staff necessary to empower mental health consumers. Finally, the authors suggest that a need exists for other health-care staff to recognize the importance of therapeutic recreation programs for consumers living with a mental illness in the community.



Caution: Avoid plagiarism! When conducting research, it is important to give credit where it is due. If you find information from another source, it is important to *cite that source!* Failure to cite a source implies that the idea is an original thought of your own. It's completely fine to build on an idea, but you must always cite the original source – just like we do in this manual! (Reid et al., 2017).






Documentation and Rigor

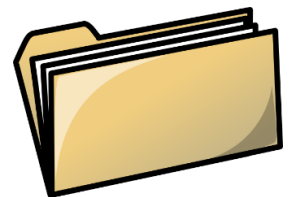
Documentation is very important for researchers to keep track of all the steps taken within the research process. In research, it is important to establish a system to keep information organized.





Organization is especially important when working on a research team with multiple people: the team must have an efficient system for organizing data so that any member can easily find and access it.


Documentation Tips!

-  Create folders on a USB or online storage program that are password protected.
-  File everything; be organized, diligent, and consistent.
-  Label your data in ways that make it easy for you to identify.
-  Name the files as something that makes sense to you with the date in the title.
-  Keep similar items in folders of a common name (e.g., keep all sources from literature review in PDF form in a folder called "Literature Review," each file labelled with proper APA citation).



 Be consistent in your labelling and filing.

 Back-up the files regularly. You can back-up your data onto a web-based storage: Google Drive, iCloud, Dropbox and others, on desktop applications (e.g., Word) or storing on a USB stick, external hard drive, etc.

 Keep your data confidential. You may choose to store your raw data on a password protected USB. (Reid, Brief, & LeDrew, 2009.)

Rigor in qualitative research is associated with being open-minded to your data and what can be gathered from it. When searching for information, it is important to take into consideration all perspectives and viewpoints, and to read each article with the same care and attention (Reid et al., 2017).



In other words...

Do not only select articles that 'agree' with your perspective.

Homework

Literature Review

1. Choose 2 or more articles that are the most relevant to your topic.
2. Write an *annotation* for each article (revisit “annotated bibliography” in this module).
3. How have your articles helped you conceptualize or further solidify your research topic?
4. What did you discover about your research topic that you didn’t know before?



Conduct an environmental scan on your topic:

1. What are some of the programs and practices undertaken by organizations that are related to your research question?
2. How do you think these programs and practices can be improved?

Need to Know Reading:



Reid, C., & Alonso, M. (2018). Imagining inclusion: Uncovering the upstream determinants of mental health through photovoice. *Therapeutic Recreation Journal*, 52(1), 19-41. doi:10.18666/TRJ-2018-V52-/1-8461.

1. How did the researchers recruit research participants?

Nice to Know Reading:



Ejiogu, N., Norbeck, J. H., Mason, M. A., Cromwell, B. C., Zonderman, A. B., & Evans, M. K. (2011). Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the healthy aging in neighborhoods of diversity across the life span study. *The Gerontologist, 51*, S33-S45. doi:10.1093/geront/gnr027

1. What were the barriers that affected participation?
2. What were the solutions to addressing the barriers?

References

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<https://www.lib.sfu.ca/help/cite-write/citation-style-guides/annotated-bibliography>.
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Reid, C., Brief, E., & LeDrew, R. (2009). *Our Common Ground: Cultivating Women's Health through Community Based Research*. Vancouver BC: Women's Health Research Network.

Reid, C., & Alonso, M. (2018). Imagining inclusion: Uncovering the upstream determinants of mental health through photovoice. *Therapeutic Recreation Journal*, 52(1), 19-41. doi:10.18666/TRJ-2018-V52-/1-8461.

Reid, C., Greaves, L. & Kirby, S. (2017). *Experience, Research, Social Change: Critical Methods, 3rd Edition*. Toronto, ON: University of Toronto Press.

Module Three:

Literature Map and Research Participants

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Learning Objectives:

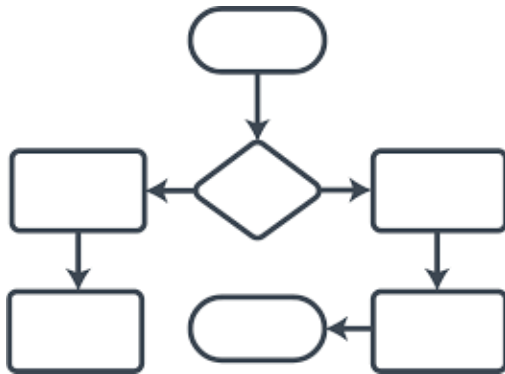
- How to organize information obtained from literature review in the form of a literature map
- Things to consider when choosing research participants
- Relevant information to include in a “face sheet”

Content:

- Literature Map
- Participant criteria
- Recruitment strategies
- Face sheets and demographic information

Literature Map

Mapping exercises provide a higher level of understanding of the literature you have covered. A **literature map** can be a useful tool to organize your literature review. It can also be effective for people that like to visually organize and understand what they are reviewing. After reviewing your



literature through a mapping exercise, the research question or topic can be revisited and possibly adapted. After conducting a literature map, you may realize you are missing information or need a bit more clarity on certain concepts.

Steps to creating a literature map:

1. Write your research question or topic at the **top of the page**. If you write your research question in the middle of the page you will have a more circular or relational map.
2. **Determine subtopics**. This will help you move towards a more specific research design. For example, a major concept you may be interested in examining is "health." When you refer to health, do you mean mental health, physical health, quality of life, or well-being?
3. Consider which areas provide the **most valuable knowledge, and which areas are lacking**. Do the gaps indicate that this information is not available? Double-check your search



strategies to ensure that you haven't missed a section of the literature. The level of detail is up to you depending on how you want to use the map and the kinds of information you want to write about. (Reid, Greaves & Kirby, 2017)

Research Participants

Now that you have more of an idea of what your research question is, it's time to figure out who your research participants are. Specific participant criteria will strengthen your data, so think about what sociodemographic characteristics your research participants will have. Take time to map out who could potentially be affected by your research.

Characteristics to consider when choosing your research participants include:

Age	Gender	Race, Culture and Ethnicity	Ability
Geographical Location	Sexual Orientation	Income and Socioeconomic Status	Membership status (if applicable)
Rapport	Identity	Communication	Accessibility

(Adapted from Engel & Schutt, 2017; Reid, Brief & LeDrew, 2009).

- **Demographics and experience:** Consider similar demographics, experiences, communities, and locations.
- **Accessibility:** Are the participants willing to share their experiences and information?
- **Identity:** Consider whether the participants identify with the population you are studying

- **Communication:** Does the language and terminology match with the level of understanding research jargon among the participants?
- **Rapport:** Creating a strong relationship is a key component of communication

Recruiting Research Participants

There are many different types of strategies that will help you recruit participants for your research. It is recommended to get interested participants to contact the study's researchers and not the other way around. You can advertise your study through social media, community posters, flyers, or a third party.

The following are different ways research participants can be recruited:

1. Convenience sampling: The researcher recruits *easily accessible participants* in public (e.g., standing outside of a subway station)
2. Cluster sampling: The researcher chooses participants who share a geographical space (e.g., surveying all the students in a classroom).
3. Extreme case sampling: The researcher seeks participants who are known to *currently exhibit* the characteristics wishing to be studied.
4. Intense sampling: The researcher chooses participants who experienced the characteristics over a *historical period of time*.
5. Maximum variety sampling: The researcher looks for both *common and uncommon experiences* to round out the description of the focused characteristics of the study.
6. Snowball sampling: The researcher asks whoever is being surveyed or interviewed to *identify another person* who may be interested to contact (i.e., "pay it forward").

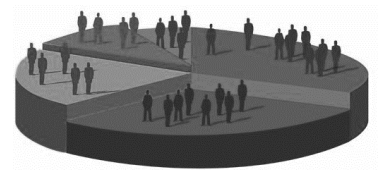


7. Purposive sampling: The researcher uses criteria of a group to select those in a unique position that are "*most*" *representative*.
8. Quota sampling: the researcher chooses participants based on a *percentage of the total population* who experiences a certain situation.

(Adapted from Engel & Schutt, 2017)

Face Sheets and Demographic Information

Face sheets are a form of record keeping, and a way to keep track of the information for all of the participants of a research study (Reid, Greaves & Kirby, 2017). Face sheets can be used for: gathering *baseline data* about participants so that you can describe your 'sample' (e.g., age, gender, ethnicity etc.); documenting *participants' progress* throughout a research process, such as attendance in a program; analyzing and interpreting data (e.g., it may be useful to know if men were more receptive to the program than were women.)



Real-World Example: Face Sheet (Reid et al., 2016)

INTAKE INTERVIEW

Pseudonym:	Consent form signed? Yes <input type="checkbox"/>	Participant Number:	Cluster Group Number:
	No <input type="checkbox"/>		
Photo identifiers:			
First name:		Last name:	
Phone:	Email:	Best way to contact you:	
Socio-demographic Information			
Age:	Gender:	First language spoken:	
Highest level of educational attainment: <input type="checkbox"/> Some high school <input type="checkbox"/> High school <input type="checkbox"/> Some college or university <input type="checkbox"/> College certificate or diploma <input type="checkbox"/> University degree <input type="checkbox"/> Some postgraduate <input type="checkbox"/> Postgraduate	Current employment status (check all that apply): <input type="checkbox"/> none <input type="checkbox"/> part-time <input type="checkbox"/> full-time <input type="checkbox"/> disability benefits PWD <input type="checkbox"/> PPMB <input type="checkbox"/> social assistance <input type="checkbox"/> volunteering <input type="checkbox"/> pension plan CPP <input type="checkbox"/> TVP <input type="checkbox"/> other: -	Current living situation: <input type="checkbox"/> with family <input type="checkbox"/> with roommate <input type="checkbox"/> alone <input type="checkbox"/> with partner <input type="checkbox"/> with partner and child(ren) <input type="checkbox"/> supported housing <input type="checkbox"/> group home <input type="checkbox"/> other: _____ <input type="checkbox"/> pets: _____	
Domestic Status: <input type="checkbox"/> Single <input type="checkbox"/> Partnered / common-law <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widow/widower <input type="checkbox"/> Other: _____	Average annual income: <input type="checkbox"/> less than \$10 000 <input type="checkbox"/> \$11 000 - \$15 000 <input type="checkbox"/> \$16 000 - \$20 000 <input type="checkbox"/> \$21 000 - \$25 000 <input type="checkbox"/> \$26 000 or higher	Ethnicity :	
		Religion or spirituality:	

Homework

Journaling Questions

1. How do I feel about embarking on this research? What else would help me feel more prepared to conduct research?
2. Have I checked in with my own self-care plan? What do I need to pay attention to as I move forward?
3. What do I need to be mindful of in terms of self-care, as I move forward in this training program? Is there anything the facilitators or my classmates can do to help?



Need to Know Reading:



Croft, B., Ostrow, L., Italia, L., Camp-Bernard, A., & Jacobs, Y. (2016). Peer interviewers in mental health services research. *The Journal of Mental Health Training, Education and Practice*, 11(4), 234-243.

1. What were the benefits of having Peer Interviewers on a research team?
2. What were the challenges faced by Peer Interviewers?
3. What were strategies did the team use to address the challenges?

References

- Croft, B., Ostrow, L., Italia, L., Camp-Bernard, A., & Jacobs, Y. (2016). Peer interviewers in mental health services research. *The Journal of Mental Health Training, Education and Practice*, 11(4), 234-243.
- Engel, R.J. & Schutt, R.K. (2017). *The Practice of Research in Social Work*. Thousand Oaks, California: SAGE.
- Ontario Women's Health Network (2009). *Guide to Focus Groups*. Toronto: OWHN.
- Reid, C. (2016). *Intake Interview*. Douglas College, Canada.
- Reid, C., Greaves, L., & Kirby, S. (2017). Chapter 9: Analyzing Data. In *Experience, Research, Social Change: Critical Methods, 3rd Edition* (pp. 239-253). Toronto ON: University of Toronto Press.
- Walsh, C. A., Rutherford, G., & Kuzmak, N. (2010). Engaging women who are homeless in community-based research using emerging qualitative data collection techniques. *International Journal of Multiple Research Approaches*, 4(3), 192-205.

Module Four:

Research Methods

Part One

Table of Contents

Learning Objectives

- The difference between qualitative and quantitative research methods
- How to prepare a questionnaire for research participants to answer
- How to plan and conduct an interview with a research participant

Content

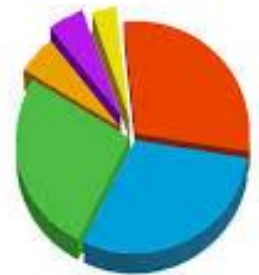
- Qualitative vs. Quantitative Research Methods
- Questionnaires
- Interviews

Research Methods

When conducting research, the tools used to collect information are referred to as **research methods**. Research methods are “tools in the toolbox:” they are used to ensure that information is collected in the same way, and anyone else should be able to replicate the same research and get the same results.

There are two main types of research methods:

1. **Quantitative research methods** are used to measure variables based on numbers and statistics (e.g., a researcher might administer a *questionnaire* to single mothers, collecting information such as their race, age and gender).



2. **Qualitative research methods** help you to understand the meanings people attach to things or their lived experiences and are based on text or visual data, such as transcripts of interviews, focus groups and photographs. A researcher might conduct interviews with single mothers to find out how they experience motherhood, what social factors affect them, and what they believe contributes to successful motherhood.



Method 1: Questionnaires

A **questionnaire** is a set of questions available online or through printed documents. Questionnaires can be *qualitative* and/or *quantitative*, depending on what information you want to collect. Questionnaires are constructed around the major concepts in regards to the research question.



Open-ended questions allow the respondent to reply in their own words, to process their thoughts out-loud, and to elaborate on certain points, which can lead to new insights. **Closed-ended questions**, on the other hand, tend to garner a “yes” or “no” answer, preventing the person from further explaining the reasoning for their answers.

“Attractive” questionnaires typically contain the following:		
Multi-paged	Instructions given <i>clearly</i> for how to answer each question	Lots of <i>blank space</i> between questions
Booklet-form presented on legal-sized paper	Proper path <i>clearly identified</i> with arrows	Response choices listed <i>vertically</i> rather than horizontally
Printing on both sides of paper	Uniform formatting	Provide a <i>neutral response</i> option
Have response choices that are <i>mutually exclusive</i>	Have response choices that are <i>exhaustive</i>	

(Engel & Schutt, 2017)



Activity: Questionnaires

In small groups, brainstorm ideas for your research question.

What questions would you like to ask your research participants?

1. What types of questions are better asked in an open-ended form?
2. How could a closed-ended approach lead to understanding?

Method 2: Interviews

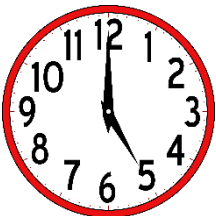
Interviews in a research context are often one-to-one interactions between researcher and



research participant. The researcher asks questions related to the research question, and records their answers. Interviews can be an effective method to gain insight on what you cannot see, such as thoughts, opinions, beliefs and specific lived experiences.

Conducting an Interview

Before the Interview:



- ✓ Determine a day, time and location of the interview.
- ✓ Inform the interviewee of the purpose of the interview and how long the interview will take.

- ✓ Ask permission to take notes and to audio/video record the interview.

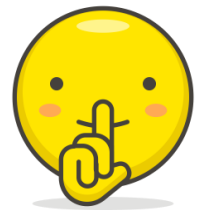
Warm-Up:

- ✓ Before the interview begins, facilitate a comfortable, relaxed environment by engaging in small talk with the interviewee.
- ✓ Reiterate the purpose of the interview and how the data will be used.
- ✓ Review consent form, and obtain participant's signature.
- ✓ Offer to address any questions the interviewee may have before the interview officially begins.



Main Section of the Interview:

- ✓ **Turn on the audio/video recorder!** It is easy to forget, so make sure the audio is recording before you begin recording.
- ✓ State the time, day, names of interviewer and interviewee.
- ✓ When asking questions to interviewee, keep questions short and sweet! Avoid asking "long-winded" questions (e.g., I know that weather can affect how people feel, especially when it is rainy. On nice days, I tend to feel much better. The rain really gets me down. On that day that you did the thing, would you say it was a nice day outside?)
- ✓ Ask one question at a time. Avoid "double-barreled" questions that contain more than one question (e.g., Asking "Would you say it was a nice day outside? How were you feeling? What else did you do that day?" without a break between questions for the person to answer).



- ✓ Allow silence for the participant to *fully* answer the question. Count to ten before jumping into the next question since the interviewee may begin to share more thoughts.
- ✓ Repeat the question if necessary to ensure the participant understands.
- ✓ Ask additional *probing questions*, if the answer given is not clear (e.g., "Can you say more about that?").

Cool-Down:

- ✓ Briefly summarize what was covered in the interview.
- ✓ Ask the interviewee if they would like to revisit any previous questions, or if there is anything else they would like to add.
- ✓ Let the participant know that the interview is about to end.



Closing:

- ✓ Thank your interviewee for their time and determine if a follow-up is needed for *member-checking* (more on member-checking later).
- ✓ Explain what the next steps will be for using their data.
- ✓ Provide interviewee with your contact information should they wish to follow-up with you about anything related to their participation in the research.



Debrief:

- ✓ **Keep the audio/video device recording!** Sometimes, the most valuable parts of an interview are captured in the moments after the interview is completed.
- ✓ Ask the interviewee how they feel about the interview, and if they have any questions or concerns.
- ✓ Leave the interview on a positive note 😊



Structured to Unstructured Interviews

	Structured Interviews	Semi-Structured Interviews	Unstructured Interviews
Types of Questions	Closed-ended questions with a <i>very specific</i> topic	Questions that have the flexibility to delve further into a particular topic and gain further insight	Many open-ended questions; “go with the flow” style of interviewing; covers a <i>broad</i> topic(s)
Variability in Questioning	No variability in questioning	Some variability in questioning	High variability in questioning

(Engel & Schutt, 2017; Reid, Greaves & Kirby, 2017)

Real-World Example: Interview Questions



Research Question: How do individuals living with mental illness experience community inclusion, health, and well-being?

INTERVIEW QUESTIONS* (*Imagining Inclusion* example)

1. What does community inclusion mean to you?
 - a. Specifically, what does it look like? What does it feel like? What does it mean in terms of access to resources / services / programs?
 - b. When you hear the term "community inclusion," do you think of inclusion in the MH community or the broader community?
 - i. [If MH community only] Why is this so? What do you feel are the barriers to feeling included in the broader community? Why does the MH community offer you a greater sense of inclusion?

So, for the purposes of this interview we'll define community inclusion as: _____ and "community" as: _____. Has your understanding of community inclusion changed over time? If yes, how?

2. Is feeling included in the community an important goal for you?
 - a. What impact would feeling more included have on you?
 - b. Would feeling more included in the community have an impact on your health, your wellbeing, or your recovery?
 - c. Which term is most meaningful to you?
3. Which changes do you personally need or want to make to be / feel more included in the community?
 - a. "Access to relationships", "participation" or "having a voice"
 - b. These are changes that can be supported by or pursued within current services and programs.

4. Which other kinds of change need to happen for you to feel more included in the community?
 - a. This can include changes to your living situation (income, education, employment, housing, stigma, exclusion).
5. What helps you feel included?
6. When you think of your recovery [or health or well-being], is feeling included in your community an essential part of this?
7. Is a greater sense of inclusion only possible once you have recovered [or feel healthier or a greater sense of well-being]?

Homework

Journaling Questions

1. What are your thoughts regarding self-disclosure?



Need to Know Reading:



Reid, C., & Alonso, M. (2018). Imagining inclusion: Uncovering the upstream determinants of mental health through photovoice. *Therapeutic Recreation Journal*, 52(1), 19-41. doi:10.18666/TRJ-2018-V52-/1-8461.

1. Read "Methods" section (pp. 22-23).
2. Review the photos and their descriptions on pages 28 to 34.

Nice to Know Readings:



Walsh, C. A., Rutherford, G., & Kuzmak, N. (2010). Engaging women who are homeless in community-based research using emerging qualitative data collection

techniques. *International Journal of Multiple Research Approaches*, 4(3), 192-205.

1. How could you use each one of the creative data collection methods described in this article into your research (e.g., digital storytelling; creative writing; design charrette; Photovoice)?
2. What do you think are the advantages of using creative research methods? What are the disadvantages?
3. Can you foresee any barriers to participation on behalf of your research participants? If so, how would you address them?



Mayes, D. (2009). When being bipolar gets you the job: *Service user research. Mental Health Practice*, 13(2), 26.

1. How does the author navigate self-disclosure?
2. What does the author identify as the pros and cons of being a Peer on a research team?

References

- Engel, R.J. & Schutt, R.K. (2017). *The Practice of Research in Social Work*. Thousand Oaks, California: SAGE.
- Mayes, D. (2009). When being bipolar gets you the job: *Service user research*. *Mental Health Practice*, 13(2), 26.
- Reid, C. & Alonso, M. (2018). Imagining inclusion: Uncovering the upstream determinants of mental health through photovoice. *Therapeutic Recreation Journal*, 52(1), 19-41. doi:10.18666/TRJ-2018-V52-/1-8461.
- Reid, C., Greaves, L. & Kirby, S. L. (2017). *Experience, Research, Social Change: Critical Methods, 3^d Edition*. Toronto ON: University of Toronto Press.
- Reichert, R. (2017). *Factors in Mental Health Advocacy*. Douglas College, Canada.
- Walsh, C. A., Rutherford, G., & Kuzmak, N. (2010). Engaging women who are homeless in community- based research using emerging qualitative data collection techniques. *International Journal of Multiple Research Approaches*, 4(3), 192-205. doi:10.5172/mra.2010.4.3.192

Module Five:

Research Methods

Part Two

Table of Contents

Learning Objectives

- Observational documentation
- Introduction to creative research methods
- Tips on planning and conducting a focus group

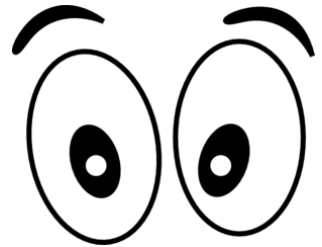
Content

- Observations
- Creative Research Methods
 - Digital Storytelling
 - Creative Writing
 - Photovoice
- Focus Groups

Research Methods

Method 3: Observations

Observations are an everyday skill that you may not realize transfers over to research. Observations involve a researcher's focused attention on observing individual and group behaviour, evidence of the behaviour, and what those behaviours or actions mean to the participants (Engel & Schutt, 2017).



When making observations, the researcher takes detailed notes of what they are observing and their reactions to their observations. **Fieldnotes** are written documentation of what the researcher



sees, hears, and experiences while observing something related to their research.

Field notes can be taken during interviews, programs, team meetings, focus groups, and any other setting related to the research. They provide the research

team with detailed notes that allow for patterns and overarching concepts to emerge. As observers, verbal and non-verbal behavior are recorded (Reid, Graves & Kirby, 2017).

In order for observations to be the most accurate, it is important for the researcher to build rapport and develop trusting relationships with members of the group.

Why it's *Awesome* to Be A Peer Researcher



An advantage of being a Peer Researcher is that you may already be a member of the group being studied, so a trusting relationship between you and your research participants may already be established.

The researcher can either participate in the activities, or observe them. In CBR, it is common for a researcher to assume a combination of participating and observing in the research activities. The Peer Researcher decides where and when it is more appropriate to be an observer and when to be a participant.

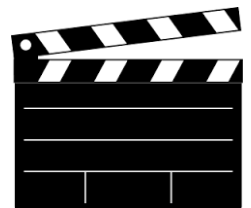


Observation should never be done in secret (i.e., "covert"). It is generally considered *unethical* to hide the researcher's identity. In CBR, it is important to be honest and transparent with the research participants about who is – and isn't – involved the research in which they are participating (Engel &

Schutt, 2017).

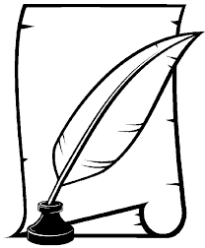
Method 4: Creative Research Methods

Digital Storytelling is often employed as an educational or community development strategy. This method involves a combination of digital media to tell a story with images, text, and music from the perspective of the first person. Digital storytelling is often employed as an educational or community development strategy. Digital storytelling allows an



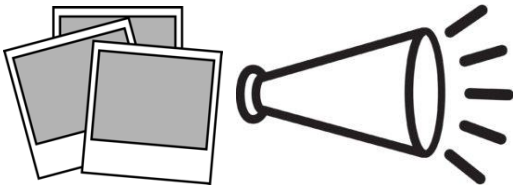
individual to creatively express their experiences. Digital storytelling can be an effective strategy for advocating for change, as can create a powerful emotional response in the viewer (Walsh, Rutherford & Kuzmak, 2010).

Creative Writing involves the use of qualitative methods to identify strengths and assets as well as concerns and problems. Creative writing has been used by many to describe trauma and illness as a way to improve quality of life and psychological well-being. Examples of creative writing methods include: poetry, personal essays, memoirs and speeches. Poetry is a type of creative writing used in this creative research method however, its validity is sometimes questioned when being used



as data. However, there are arguments that it provides individuals with a deeper understanding of participant's subjective experiences. Creative writing can be used to promote change and social action. Additionally, engagement in creative writing often results in participants experiencing therapeutic benefits (Walsh et al., 2010).

Photovoice involves combining photographs with written descriptions of the photo by the photographer (research participant). Similarly to digital storytelling and creative writing methods,



photovoice involves a narrative or story-telling process that results in creation of story of lived experience. Derived from health promotion, this method is described as participatory data

collection for individuals who are often excluded from decision-making processes. Photovoice typically has three goals (i) to enable participants to record and reflect upon strengths and concerns (ii) to promote and develop dialogue and knowledge about community issues and, (iii) to help create change by communicating information to policy makers (Walsh et al., 2010).



Remember: It's important for the researcher to practice *reflexivity* and document their thought processes as observations are recorded. This will bring the researcher's awareness to any biases, assumptions, or inferences they may make with regard to others' behavior (Reid et al., 2017).


Method 5: Focus Group

A focus group is qualitative research method that involves unstructured group interviews, whereby a group facilitator(s) encourages, guides and focuses discussion among participants on a particular topic of interest that is related to the research project (Engel & Schutt, 2017). Participants of focus groups are often members of the population in which the research is being conducted. During a *focus group*, participants are welcomed to discuss open-ended questions, and are given the opportunity to provide in-depth responses.



Focus groups are often employed in CBR, as they allow the researchers to gain a deeper understanding of participants' experiences, views and ideas (Reid et al., 2017). Focus groups typically last 1-2 hours, to allow time for group participants to process the questions, and to build off of each other's' responses. In order to get the best answers that can be used for greater a greater sense of

generalizability and consistency, a researcher should conduct several focus groups on the same topic with different groups of people (Engel & Schutt, 2017).



Why it's *Awesome* to Be A "Peer Researcher"

Having Peer Researchers as facilitators/co-facilitators of a focus group can contribute to a felt sense of safety among participants, and can allow freer expression of thoughts and feelings that can be sensitive in nature.

Planning a Focus Group

GOALS: Create a plan for the focus group session(s) and determine what goals you want to accomplish (e.g., feedback for improving a program).



QUESTIONS: Ensure that you have a variety of questions prepared to facilitate a meaningful discussion. Open-ended questions tend to gather more detailed responses than closed-ended



questions. Ask specific but open-ended questions that really get at the root of what the group is trying to accomplish. Keep in mind that focus groups tend to be more *unstructured* in nature, and, depending on the way the conversation unravels, you may

not have the opportunity to ask all of the questions you had prepared.

RECRUITMENT: You may have to recruit participants in different ways, such as through their previous research involvement, flyers, or by sending out emails. When contacting potential participants, ensure that you are clear about dates, times, consent, and expectations of their involvement in the focus group. We will discuss the recruitment of research participants more in Module 5.



DOCUMENTATION: As with interviews, ask permission of group participants to audio and/or video record the focus group. Continue recording until all research participants have exited; this way, you won't miss any important insights or information that may arise after the focus group has ended! Having another member of the research team in the room to take *field notes* (discussed later in this module) may also be helpful.



PARTNERING WITH CO-FACILITATOR(S): If possible, have two facilitators during a focus group. Divide up the roles before the focus group and ensure that each facilitator understands their role; it is important to ensure you are all on the same page. Spend time before the session reviewing the questions, while also being prepared to allow room for flexibility. Assist one another with time-keeping to ensure the group starts and ends on time. Allow time from one question to the next to ensure each topic is given equal attention. Debrief with your co-facilitator within two days after group to reflect on the session, to review that happened, and to identify strengths



and areas for improvement for the next time the focus group is to be run. Discuss any similarities between this focus group and other ones you have conducted on the same topic(s).

(Adapted from Engel & Schutt, 2017)

Facilitating a Focus Group

A key role of the facilitator is to promote constructive discussion among group members and encouraging group interaction and group involvement. This can be done most effectively by following the key features below:

INTRODUCTION: Always begin a focus group by introducing yourself, the purpose of the focus group, and how long the session is expected to last. Gain informed consent from all focus group participants, and provide information about how the data from the focus group will be used.



DOCUMENTATION: Ensure that data is being collected through field notes, audio recordings, or visual recordings. Focus groups may not be the best choice of data collection if there is a chance that participants may argue or there may be significant conflict; it is also worth considering that some participants may be less likely to speak their thoughts in group settings, so there are times when individual interviews would be more appropriate.



LISTENING: Convey your understanding of others' words by applying active listening skills (e.g., paraphrasing; clarifying; body language; verbal and nonverbal encouragers). Active listening, combined with empathic responses, can be particularly powerful. Probing questions can also encourage participants to elaborate on what they have said (e.g., "Tell me more").



ENCOURAGING PARTICIPATION: If you notice some people are contributing to the dialogue more than others, encourage those who are quieter to share their opinions. They may be quiet because they have nothing to say, or they may be waiting for a time when no one else is talking. Invite individuals who have been more on the quiet side to offer their opinion.



CREATING A SAFER ENVIRONMENT: Although there is no such thing as a truly "safe" environment, there are things you can do to contribute to a *safer* environment. Help participants and/or group members to become comfortable with one another by modeling appropriate group behavior, demonstrating confidentiality, and identifying and intervening when group dynamics become tense or unpleasant. Ensuring group guidelines are followed, and intervening when the group has strayed from them, also helps participants feel safer.



If the conversation drifts away from relevant topics:

1. State that you have noticed that the conversation has gotten off-track.

2. Remind the group of the goal of the focus group, as well as the group guidelines.
3. Gently guide the conversation back on-track, perhaps with another question.





Adapted from Engel & Schutt, 2017

Benefits of Peer Facilitation

For the Facilitator

-  Increased self-esteem and confidence
-  Improved access to work and education
-  More friends, better relationships, more confidence in social settings
-  Reduced self-stigmatization
-  Greater hopefulness about own potential
-  Improved problem-solving skills
-  Increased sense of empowerment
-  More positive feelings about future

For the Group

-  Peer facilitator can serve as a positive role model and a source of motivation
-  Greater feelings of acceptance and understanding
-  Peer facilitated groups provide space for sharing knowledge and experience
-  Peer facilitator can help group participants gain new skills important to self-growth

(Adapted from Mood Disorders Association of BC, 2009)



The 5Ws and an H

Drawing from the first worksheet “Planning Your Research Project,” answer the following questions on the handout, “5Ws and an H”:

WHAT do you want to know? Finalize your research question(s).

WHY is your research important? Clarify the need for your research, drawing from the literature review. This also relates to the problem that you identified earlier.

WHO will participate? Participant criteria and recruitment strategies. (We will cover this in more depth in Module 6, but here jot down some ideas to get started).

WHERE and **WHEN** will they participate? Other essential research ‘logistics’ to consider. This also relates to feasibility and other kinds of support you will need to do the research.

HOW will your research participants participate? What method(s) are most appropriate and why?

Homework

Journaling Questions

The following are additional considerations or detail to consider as you explore your research project:

1. How did you go about choosing your research method(s)?
2. Why did you choose the research methods you did?
3. How did the 5Ws and an H worksheet help you further conceptualize your research and solidify your research question?



Need to Know Reading:

Reid, C., Greaves, L. & Kirby, S. L. (2017). Chapter 9: Analyzing Data. In *Experience, Research, Social Change: Critical Methods, 3rd Edition* (pp. 239-253). Toronto ON: University of Toronto Press.

1. Write a short definition for the following terms:
 - a) Code
 - b) Bit
 - c) Satellite
 - d) Theme
 - e) Codebook

Nice to Know Reading:



Walsh, C. A., Rutherford, G., & Kuzmak, N. (2010). Engaging women who are homeless in community-based research using emerging qualitative data collection techniques. *International Journal of Multiple Research Approaches*, 4(3), 192-205.

1. Read **pages 197-201**: "Data Analysis," "Results and Discussion" sections
2. What methods did the researchers use to analyze their data in this article? Do you see any terms you are familiar with?

References

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- Reid, C., Greaves, L. & Kirby, S. L. (2017). Chapter 9: Analyzing Data. In *Experience, Research, Social Change: Critical Methods, 3rd Edition*. Toronto ON: University of Toronto Press.
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Module Six:

Managing, Analyzing and Organizing Data

Table of Contents

Learning Objectives:

- Making sense of the data that's been collected
- Transcribing recordings of interviews and focus groups
- Analyzing qualitative data
- How to create a codebook and/or spreadsheet

Content:

- Transcription
- Data Analysis
- Codebooks and Spreadsheets
- Trustworthiness

Managing Data

In Module Two, we discussed organizing data in relation to gathering preliminary information for planning a research project, as well as for the information found in your literature review.

In this module, we discuss managing *data* collected via the research method. Data, as you learned in the previous modules, may be *qualitative* (e.g., verbal and/or behavioral information contained in field notes, or in audio or video recordings), or *quantitative* (e.g., numerical or categorical information gathered from questionnaires). Managing data involves transcribing and member-checking (Reid, Greaves, & Kirby, 2017).

A **transcript** is the product of an interview or focus group, based on the data from the audio/video file that was recorded. The researcher can choose to transcribe verbatim for the entire recording, or to summarize and condense parts that have little relevant information. Transcribing audio can be quite time consuming, especially when some participants are quieter, or have more challenging speech patterns (Jensen & Laurie, 2016).



When tasked with transcribing, it is important to consider the following:





- What software or devices can I use that will help me save time?
 - Digital recorders can reduce or eliminate the need for transcribing, but need to be investigated for accuracy, efficiency and cost.
- How much time will I need to transcribe an interview?
 - Researchers should allow approximately at least five hours of transcribing time per one hour of interview.

- Who should transcribe recordings?
- How will I store the tapes or digital files?

Transcripts should contain the following elements:

- Date and time of the interview
- Identification of interviewer
- Identification of interviewee with either a letter, a number, or a **pseudonym** (Reid et al., 2017).

Tips when transcribing:

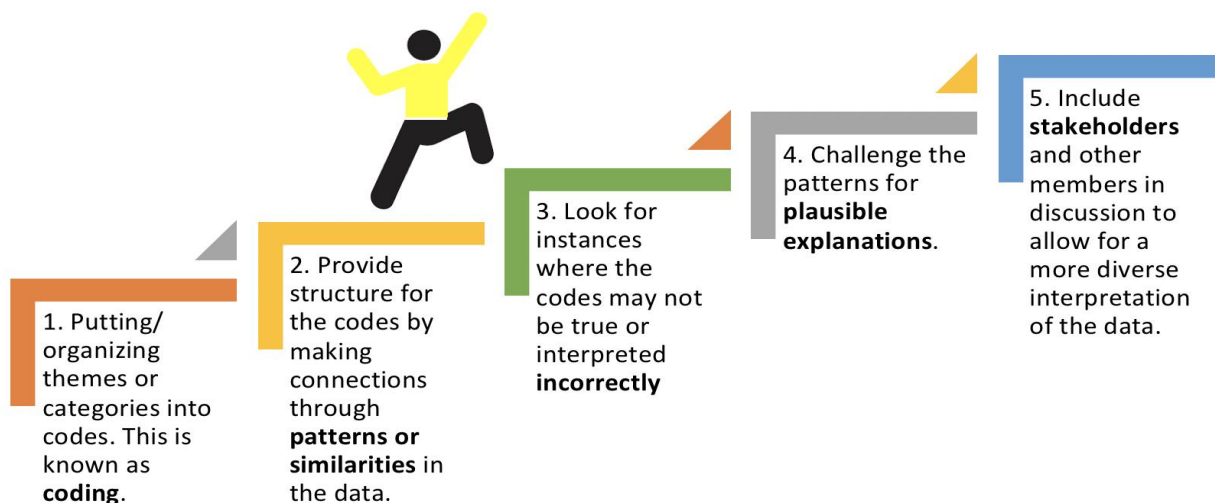
-  Listen to the interview fully once, without transcribing – especially if you did not conduct the interview. While listening for the first time, record *field notes* about your overall impressions, ideas, and inferences.
-  After you have listened to the interview once, then begin transcribing.
-  Make sure the transcript is single spaced with two lines between each speaker.
-  After you have finished transcribing the interview, re-listen to the interview while reading the transcript; this will help catch any mistakes you may have made (Reid et al., 2017).

Analyzing Data

It is important, particularly in community-based research, to involve members of the community in the data analysis process (Cashman, Adeky, Allen, Corburn, Israel, Montano, Eng, 2008). **Data analysis** allows researchers to better interpret and understand data and how the data are related to each other. Analyzing data reveals themes, explanations, and patterns within your research. Once you have completed your data analysis your major themes or ideas should, in some way, connect with the field review you conducted. Depending on the type of data you gathered, you will use different methods to analyze your data (Reid et al., 2017b).



The Actions of Data Analysis



Coding helps researchers find commonalities between research participants. *Coding* refers to assigning a word or a phrase that describes a section of text data that captures the essence of the attributes contained in the data (e.g., transcriptions; fieldnotes).



Themes represent important features of the data that might be relevant to answering the research question. Once *themes* are found within data, *codes* will be created based off of similarities within certain *themes*. *Codes* help readers understand *themes* that exist in data, and how *bits* may be grouped together based on these commonalities (Reid et al., 2017).

Real World Example: Themes



Theme 1: Lived experience of mental illness and recovery

Codes: active participation + experience + recovery

Theme 2: Experience of advocacy

Codes: standing up + experience as an advocate


Theme 3: The importance of social supports and understanding

Codes: support network + understanding

Theme 4: Barriers to advocacy

Codes: stigma + barriers + housing/income

Bits are words, sentences, or paragraphs of text that make sense even when separated from the data gathering context (e.g., segment of transcript; piece of information from fieldnotes; a section of a document; words written on a sticky note by a researcher that captured salient information). A **code** is a characteristic of a bit. Codes emerge as commonalities are found in *bits* of data. Additionally, a *bit* may have more than one *code*. (Reid et al., 2017b).

Real World Example: Coding a Transcript 	
Transcript	Codes
<p>M: I think people who have a lived experience are more likely to be an advocate for mental health just because they've had that experience and they know what it's like and what they want to change, and that's like not just people that have experience like that have lived with mental illness but those who have watched mental illness around them or relation, but I think it takes a certain confidence in what you know to be true to be an advocate, if you're unsure about things you're kind of still in that blurry middle zone where like that it's hard to advocate anything from that state.</p> <p>R: Do you feel that it is important to have advocacy in the mental health system?</p> <p>M: I think it is just because right now in society there is still a lot of stigma and misconceptions about mental health and within the mental health system like there is certain thing that that are barriers to people who have mental illness and I feel like it's important to continuously bringing those issues to the forefront and trying to change them.</p>	<p>Experience as an advocate</p> <p>Mental illness experience</p> <p>Stigma</p> <p>Barrier</p>



Real World Example: Codebook

Codes	Bits
Experience as an advocate	<p>being willing to go out and stand up or be a voice for others that are experiencing</p> <p>I think this is a lot of people are doing really good things in this field and continuously getting better the key to any kind of change in mental health cause people advocating for change</p>
Stigma	<p>stigma is the huge underlying fog underneath all this stuff</p> <p>think stigma loses its power when you realize what it is it's not real or true, but it's just a warped perception, I think, I think that stigma, becomes less of a barrier</p> <p>more people are talking about it and that stigma is defiantly a lot less that it is in the past, but then again it is still there</p>
Barriers	<p>barriers to people who have mental illness and it's important to always bring those issues to the forefront and try to change them</p> <p>cause it's hard to be vulnerable and if you don't think you can handle the repercussions of that then it's probably wise to be aware of what you can and can't handle</p>

maybe it's not all for nothing going through all the barriers in the system and the very real pain of having a mental illness when that experience can be useful to try and make other people's lives better or make something better for someone somewhere

Satellites are parts of a text that do not have similarities to other bits of coded information, so they



do not seem to fall under any of the codes. *Satellites*, however, may still be important

to the research, whether it be analysis for the same research project, or for providing

insight into the limitations of the research project, and inspiring ideas for future

research questions (Reid et al., 2017b).

Why it's *Awesome* to Be A Peer Researcher



As a Peer Researcher, you may have insights into the data that has been collected that are unique to the research team. Your contributions can potentially lead to discoveries that otherwise would have gone unnoticed.

Organizing Data

Spreadsheets are tools used to organize data. Although spreadsheets are most easily created in Microsoft *Excel*, they can also be kept track of in other programs (e.g., Word; Google Sheets), or written on paper. Spreadsheets enable the researcher to see all of their data in one place, and easily compare and analyze their results. Quantitative data (ex. numbers, survey answers) can be imputed into spreadsheets to provide the researcher with a document that shows all of their data and how it compares (Reid et al., 2017a).

For example, a spreadsheet could be created that has all of the answers to the demographic questions asked in a survey (ethnicity, gender, etc.); it might look like this:

Participant #	Birthplace	Age	Gender	First Language
1	Canada	48	Male	English
2	United States	53	Female	English
3	Canada	51	Female	English
4	Spain	53	Female	Spanish

A spreadsheet might also have all of the data from one specific question, so it is easy to see the most common answers or identify patterns; it might look like this:

Question #1 – How would you currently rate your level of physical activity?	
I never exercise	3
I exercise a few times per month	7
I exercise at least 1 time per week	4
I exercise more than 3 times per week	2

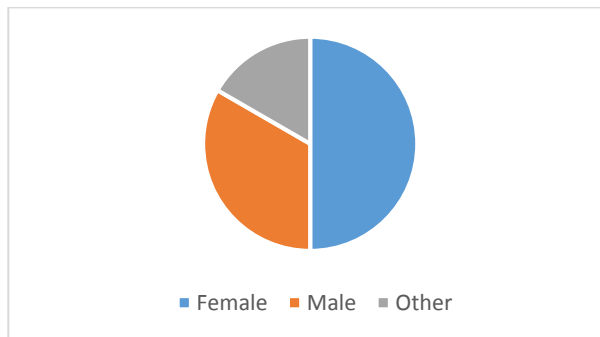
The first spreadsheet contains all of the answers for each participant:

Participant #	Q1 - What gender do you identify with?
1	Female
2	Female
3	Male
4	Female
5	Other
6	Male

The next has all of the answers added up:

1. What gender do you identify as?	
Female	3
Male	2
Other	1
	Total: 6

Additionally, figure can be made to visually show the results.



Things to Consider when Organizing Data:

- What system will be used to retrieve data files easily on the computer?
- How will other members know which documents are the current/active documents?
- How will I ensure information is backed up on the computer?
- Do the other team members have compatible software programs?
- How will a system for integrating different sources of data be created?

- How will emerging ideas and insights be tracked, documented and recorded?
- How will the data's confidentiality be protected (e.g., computer password; locking cabinet)?
- Ethically, is there an obligation to destroy data upon completion of the project?
 - If so, who is responsible for this and when will it be done?

Trustworthiness

Trustworthiness demonstrates that no matter who conducted the research, the final



findings would have been the same. Trustworthiness promotes credibility of the research data and strengthens the overall research work. There are eight different strategies to examine credibility of the data:

1. Negative Case Analysis: Looking for elements of the data that contradict explanations or patterns.
2. Triangulation: Using different research protocols to gather information from the same or similar types of participants.
3. Saturation: Where data is consistent with previous understandings and does not provide new insights.
4. Member-Checking: Providing data to research participants to verify accuracy.
5. Reflexivity: The researcher reflects on how their personal biases, views, and beliefs may be shaped by the research process.
6. Descriptive Statistics: Using numerical data.
7. Log Book or Audit Trail: A description of the steps taken from beginning of research to end.
8. Peer Debriefing: Involving Peers allows for other insights and interpretations of data

(Reid et al., 2017b).

Homework

Journaling Questions

4. What would I still like to learn in this training?
5. What would I like to change about this training?
6. What would help me participate more fully in this training?



Need to Know Reading:



Bilsker, D., Petermann, L., & Goldner, E. M. (2012) *Innovation to Implementation: A Practical Guide to Knowledge Translation in Health Care*. Calgary, Alberta: Mental Health Commission of Canada

1. Flip through the pages of this guide and begin to answer some of the questions.
2. Bring it to the class next week since we will be discussing it in depth.

Nice to Know Reading:



Walsh, C. A., Rutherford, G., & Kuzmak, N. (2010). Engaging women who are homeless in community-based research using emerging qualitative data collection techniques. *International Journal of Multiple Research Approaches*, 4(3), 192-205.

1. What strategies do the researchers use to demonstrate trustworthiness of the data?

References

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- Cashman, S. B., Adeky, S., Allen, A. J., III, Corburn, J., Israel, B. A., Montano, J., Eng, E. (2008). The power and the promise: Working with communities to analyze data, interpret findings, and get to outcomes. *American Journal of Public Health, 98*(8), 1407-1417.
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Module Seven:

Finalizing Data and Knowledge Translation

Table of Contents

Learning Objectives

- Writing a final report based on findings from the research
- Disseminating results of the research in a planned, systematic way

Content

- Finalizing data
 - Report writing
- Knowledge translation
 - I2I Workbook

Finalizing Data

A **final report** is a written overview of the research you have conducted. The report should provide readers with an in-depth explication of why your research matters. Below is a general outline for writing a final report:



Introduction	Research question; research goals and purpose; researcher’s orientation to the research; rationale for research
Literature Review	Review of research and findings; what is already known; what you are adding to the literature on the topic; how the literature review informed the research question; mention gaps, biases, limitations of extant literature
Research Methods	Qualitative research methods (e.g., observations; interviews; focus groups; Photovoice) Quantitative research methods (e.g. questionnaires)
Research Participants	Number of research participants, demographics, social determinants of health, identities, recruitment strategies, etc.
Recruitment Strategies	How did you recruit your research participants?
Analyzing Data	Findings Links between findings and literature coding Trustworthiness
Conclusion	Overview of research question, rationale, findings and restatement of why your research is important
Appendices	Budget, timeline, documents, forms, codebooks and spreadsheets

(Adapted from Reid, Greaves, & Kirby, 2017)

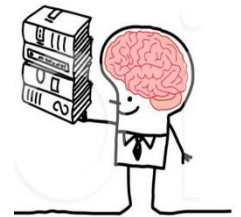
Knowledge Translation

Knowledge translation (KT) is about developing a strategy to share the knowledge that's been discovered by the research. As social change and action are often motivators for community based researchers, KT is about figuring out how the research will impact the world. KT strategies make



research results available and useful in a timely manner, and help knowledge-users access and implement new knowledge, "closing the gap between what we know and what we do" (Bilsker, Petermann, & Goldner, 2012, p.4).

In the health care system, specifically, there is a huge gap between research and its implementation in practice – often 10-15 years between knowledge acquisition and implementation (Bilsker et al., 2012). Healthcare systems and hospitals are complex, bureaucratic organizations that have been carefully constructed to meet a diverse range of needs and are also highly resistant to change. KT strategies help new knowledge reach potential knowledge-users, bypassing bureaucratic processes and procedures that can undermine innovation.



Why it's *Awesome* to Be A Peer Researcher



Stories about lived experience provide context and bring information to life. As a Peer, you are someone whose life is directly impacted by the research. Your experience may inspire someone to become a knowledge-user of your research findings, thus effecting positive change in the lives of others.

Knowledge Translation

The Mental Health Commission of Canada has developed a step-by-step guide to KT, "*I2I: Innovation to Implementation*" (Bilsker, Petermann & Goldner, 2012).



- As a large group, we will make your way through the workbook, drawing parallels to the *Imagining Inclusion* research project, as well as to your research question. This activity may inspire you by offering a different perspective, and possibly providing new insights into the work you have done.

A word about stakeholders: It is important for **stakeholders** to be involved in research from the very beginning, helping identify the purpose of the evaluation. Even though there may be

consensus in regard to the overall research goals, there may also be differences in opinion as to how to achieve them. In order to ensure that multiple perspectives and supports are included in the research process, the KT plan should *clearly outline when and how key stakeholders will be consulted and updated throughout the course of the research* (Ontario Centre of Excellence for Children and Youth Mental Health, 2013).



Homework

Journal Questions

Answer the following questions in your journal



1. How has the Knowledge Translation Workbook helped you understand your research process?
2. Have you gained any new insights as a result of using the workbook?

Need to Know Reading:

Koyne, K. & Cox, P. (2006). *A SMART Fund Guide to Design & Manage Community Health Activities*.

Calgary, AB and Vancouver, BC: Plan: Net Limited.



1. Briefly review the content in this document. We will be going over it in more detail next week.
2. Make sure you review the *Logic Model* on **Page 28, Appendix 3**

Nice to Know Reading:



Ontario Centre of Excellence for Child and Youth Mental Health (2013). *Program Evaluation Toolkit*. Ottawa, Ontario: Author.

References

- Bilsker, D., Petermann, L., & Goldner, E. M. (2012) *Innovation to Implementation: A Practical Guide to Knowledge Translation in Health Care*. Calgary, Alberta: Mental Health Commission of Canada
- Koyne, K. & Cox, P. (2006). *A SMART Fund Guide to Design & Manage Community Health Activities*. Calgary, AB and Vancouver, BC: Plan: Net Limited.
- Ontario Centre of Excellence for Child and Youth Mental Health. (2013) *Program Evaluation Toolkit*. Retrieved from:
http://www.excellenceforchildandyouth.ca/sites/default/files/resource/toolkit_program_evaluation_tools_for_planning_doing_and_using_evaluation.pdf
- Reid, C., Greaves, L. & Kirby, S. (2017). *Experience, Research, Social Change: Critical Methods, 3rd Edition*. Toronto, ON: University of Toronto Press.

Module Eight:

Program Evaluation

Table of Contents

Learning Objectives

- Understand how a logic model can help with evaluation
- Learn basic strategies for developing a program logic model
- Identify short, intermediate, and long-term outcomes related to a specific program

Content

- Steps of Program Evaluation
- Consulting with stakeholders
- Logic models
- Evaluation methods

Program Evaluation

Program evaluation (PE) is a form of CBR which focuses on the systematic collection and analysis of data. PE is often conducted in an effort to determine the effectiveness of a particular program, and to inform program-related decisions. PE is not about gathering a large amount of data; rather PE is about organizing, interpreting and making changes based on this information. PE can be particularly helpful in examining the relationship between efforts and outcomes of a particular program; as such, PE can help you identify whether the expected outcomes of your program have been achieved, and to what extent the program outcomes can be attributed to the program activities (Ontario Centre of Excellence for Children and Youth Mental Health, 2013; Taylor-Powell & Henert, 2008).



There is no “cookie cutter” approach to program evaluation; what may work for one organization may be damaging and counterproductive in another (Canadian Mental Health Association, n.d.). Although program evaluations vary depending on factors such as: complexity of the program, purpose of the evaluation, and approach in program delivery, there are *several essential steps to program evaluation* that you need to consider in order to ensure that the information you collect is accurate and useful (Adapted from: Ontario Centre of Excellence for Children and Youth Mental Health, 2013).

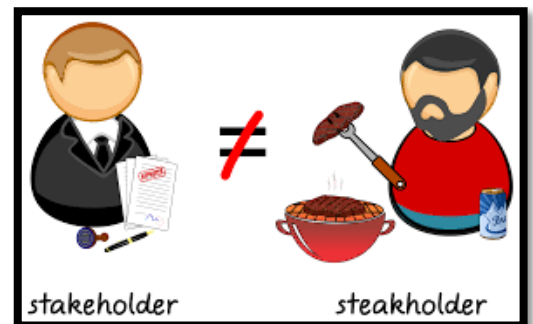
Program Evaluation Steps

1. CREATE A DETAILED DESCRIPTION OF THE PROGRAM. Before you identify a detailed evaluation plan, it is vital that you generate a clear description of your program. Describing the following aspects of the program that you intend to evaluate; will help you create a comprehensive picture of the program:

- Problem addressed by the program
- Purpose and objectives of the program
- Program participants
- Program's origin and organizational structure
- Main elements of the program
- People involved in program planning and delivery
- Funding source(s)
- Program's Budget



2. INVOLVE STAKEHOLDERS. Just like in CBR, **stakeholders** are individuals that have an interest in evaluating the effectiveness of the program. Program stakeholders might include program funders, participants, program providers or others interested in understanding if the activities implemented produce the intended results. Identifying and consulting with the key stakeholders is an important step in an evaluation process as different



stakeholders might have different visions for the program and different motives for conducting

PE. Questions to consider regarding stakeholder involvement:

- Have all those who have a stake in the project and its evaluation been identified and contacted?
- Is there a consensus of support for the idea of evaluation?
- Are there additional ways stakeholders could be included in the planning phase of the evaluation, as well as throughout the duration of the evaluation?

Creative Ways to Involve Stakeholders

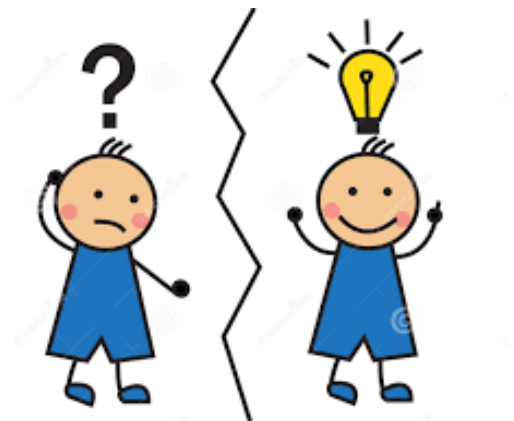
- Helping to build logic models
- Wisdom-sharing with evaluators
- Pilot-testers for data collection tools
- Co-presenters of findings at public events and conferences
- As participants in a "data analysis forum"



3. IDENTIFY A PROGRAM EVALUATION QUESTION. Identify a broad evaluation question, for

example: *What impact is the project having on its participants and its staff?* It is important to be clear about

WHY you are conducting the evaluation and WHAT you want to know about the impact of the program.

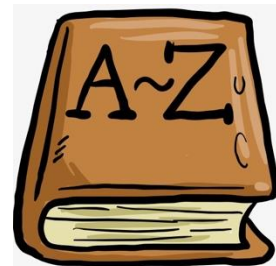


4. EXPLAIN YOUR “THEORY OF CHANGE” WITH A PROGRAM LOGIC MODEL. A **theory of change** is a way of clearly explaining exactly how your PE will lead to positive change. A **logic model** is a tool used by funders, managers, and evaluators of programs to evaluate the



effectiveness of a program. It provides a graphic illustration of the program and the connection between the investments and the outcomes. The logic model can be helpful in focusing a program evaluation by identifying intended outcomes (CMHA, n.d.; Taylor-Powell & Henert, 2008)

- **Inputs** are resources that you invest to run the program.
- **Outputs** describe activities and participation resulting from your program - what you do and whom you are able to reach.
- **Outcomes** are changes (e.g. in skills, behaviours, policies) achieved as a result of your program/intervention; generally, your program will be able to measure only short- and medium-term outcomes.
- **Impacts** identify long-term effects of your program and generally cannot be measured by the program as they take years to achieve
(socrates.berkeley.edu/~pbd/pdfs/Logic_Model_Terminology.pdf)
- **Indicators** are specific, observable and measurable accomplishments that demonstrate progress toward achieving a specific outcome. They answer the question: “What information



will tell us that change occurred, that the program has been delivered in the intended manner, or that the intended target population has been reached?" (Ontario Centre of Excellence for Children and Youth Mental Health, 2013, p. 11)

- **Activities** are the *concrete things you do within your program*.

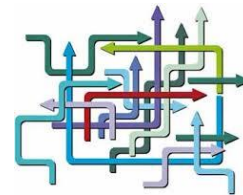
Why use a logic model?

Creating a logic model can be a time consuming and demanding process, so why should we invest time and energy into creating one? Developing a logic model can be useful for the evaluation process, as it can:



Provides a roadmap of exactly how and why you expect certain outcomes to occur, so you know where to look for evidence of success

Serves as a simplified representation of your program



Helps you correctly link specific activities with specific outcomes

Provides a common language between team members and stakeholders

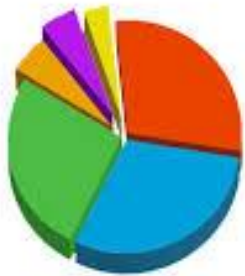


Helps you identify outcome indicators

5. SELECT EVALUATION METHODS. Once you have confirmed your outcomes and indicators, you will need to select **evaluation methods** to gather data.

Evaluation methods are the same as research methods. Refer back to modules 4 & 5.

It is important to be realistic about what can be done at the organization, and to stream-line this process as much as possible. For instance, if you plan to gather data for one output through designing a questionnaire, is it possible to use this same questionnaire to gather data for several



other outputs? Strategies for gathering comprehensive and accurate data that are not too onerous for the organization will have the greatest likelihood of being sustained into the longer-term.



5. COLLECT AND ANALYZE DATA. A timeline is useful in determining when data collection should occur. Often, it is helpful to have one person responsible for this so that they can remind team members about the need to gather evaluation data. Before the evaluation begins, identify who is responsible for data analysis and devise strategies for effectively and efficiently analyzing data. There are a number of online programs that can help with analysis such as online survey forms (e.g. SurveyMonkey or SurveyPlanet) as well as Microsoft Excel.



7. DISSEMINATION OF RESULTS. As discussed in Module Seven, it is important to determine your knowledge translation strategy of a program evaluation. It is advisable to follow exact guidelines from management or program funders who provided the funding for the program to run in the first place.



8. ACT ON RESULTS. An important aspect of CBR is the action that follows as a result of the research. What kind of change is feasible to make the program more effective to achieving its goals?



Homework

Journaling Questions

You may work with an organization where you would like to conduct an evaluation, or you may be affiliated with an organization (as a Peer support worker or consumer) that could benefit from an evaluation. Choose an organization with which you are familiar and to which you have some kind of professional or personal connection, and respond to the following questions:

1. What is the vision, mission and mandate of the organization?
2. What needs is the organization trying to meet?
3. Who will benefit? Who are possible partners/ funders/clients?
4. What research methods would be appropriate for evaluating the organization?
5. What are some skills and resources available in or outside the organization?



Need to Know Reading:



Mayes, D. (2009). *When being bipolar gets you the job: Service user research*. *Mental Health Practice (through 2013)*, 13(2), 26.

1. What does the author describe as the pros and cons of being a Peer researcher?
2. What does it mean to you to be a valued member of the research team?

Nice to Know Reading:



O'Hagan, M. (2009). Leadership for empowerment and equality: A proposed model for mental health user/survivor leadership. *The International Journal of Leadership in Public Services*, 5(4), 34-43. doi:10.5042/ijlps.2010.0110

1. What feelings come up for you in the discussion of User/Survivor Leadership?
2. What resonates with you?

References

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Module Nine:

The Peer Context

Table of Contents

Learning Objectives

- The value of Peer leadership and community partnerships
- Basic understanding of applying for grants
- Advocating at individual, community and systemic levels
- Understand more about working as a “Peer” on a research team
- Practicing self-care and setting boundaries at work and in your personal life

Content

- Peer leadership
- Change at the systemic level
- Grant writing
- Advocacy
- Partnering with community agencies
- Working as a “Peer” on a research team
- Self-Care and Boundaries

Peer Empowerment: A Brief History

Prior to the 1950s, people who developed mental illness were separated from their communities, and forced to live in hospitals. Between the years of 1950-1970, a number of psychotropic medications were discovered that were thought to be promising treatments for mental illness. With this discovery, the mental health system embraced “deinstitutionalization,” discharging mental health patients from hospitals, into the community to receive treatment.

Despite receiving treatment and taking medications, people still live with mental illness today, and people are still coerced into receiving treatment against their will. The consumer/survivor



movement of the 1970s had a goal of achieving patient empowerment. Tomes (2006) defines empowerment as “having the right to make one’s own health care choices” (p. 720). The movement’s goal was not to restructure the mental health system, but to give patients treatment *options*. The consumer/survivor movement opposes what it sees as a historically oppressive mental health system, and promotes a

patient’s rights and empowerment approach to treatment and recovery. The following is an excerpt from Tomes (2006, pp. 722-723):

The early survivor movement drew heavily from the intellectual traditions of the antipsychiatry movement. [...] [E]x-patient activists portrayed madness not as an illness, but as an alternative state of being, one that frightened and challenged the sane/straight community, much as feminism frightened male chauvinists and gay rights frightened homophobes. [...] [T]hey celebrated “mad pride,” suggesting that the route to wholeness lay

in accepting their uniqueness and changing society so that their differences could be accepted, rather than used as grounds for involuntary confinement and repressive "treatment" regimens.

As the consumer/survivor movement evolved, there emerged disagreements among activists (Tomes, 2006):

1. Some activists focused on more "upstream" change, reducing stigma and promoting a more tolerant society, while others focused on more "downstream" change, choosing to intervene at the individual level.
2. Groups differed in their opinions as to whether to involve non-Peer mental health professionals and other individuals in their groups.
3. Groups differed in the degree to which they accepted or rejected the medical model of mental illness, and the value and efficacy of their treatment.

The consumer/survivor movement has gained momentum in the past 40+ years, as Peers become increasingly more involved in the mental health system (Chamberlin, 1990). Peers have been offered new employment opportunities in the healthcare system; however, when compared with other powerful key players in policy settings -- the medical profession, the insurance industry, the pharmaceutical industry, and the hospital industry -- Peer/consumers have significantly less power when it comes to lobbying for changes in policy and legislation (Tomes, 2006).

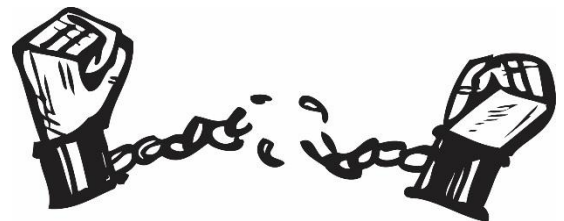
Involving Peers on research teams helps consumer/survivor voices to be heard.

Peer Leadership and Advocacy

People diagnosed with mental illness have historically been thought of as only the *objects* of research, rather than as *leaders* or *agents of change* (Tomes, 2006). Advocacy can be defined as the act of addressing an infringement of rights, or working to remove barriers to accessing a service. Mental health advocacy has been defined as individuals living with mental illness to have more control over the “design, delivery and evaluation of services and to influence policy to improve conditions for, and uphold the rights of” individuals living with mental illness (Gee, McGarty, & Banfield, 2017, p. 231). See *Handout for Mental Health Consumers in Action handout, Consumer/Survivor Advocacy* (Vezina, 2002).

Upstream Leadership and Advocacy

Peer leadership at the systemic level can involve promoting a welcoming environment that fosters the values of Peer support (i.e., autonomy, diversity, and empowerment) (Cyr et al., 2016). Examples of Peer leadership at this level may include: governance, management, service delivery, training, research and evaluation (O’Hagan, 2009). Sometimes an individual may need to advocate for themselves, or for a client, because the mental health professionals in the clients’ life may have failed to provide them with the appropriate services or referrals. Social and policy change are not always achieved solely through research, and many partnerships are typically needed.



Midstream Leadership and Advocacy

Community-level leadership is often shared, collaborative, and transparent. A knowledge and understanding of the business skills required to run an organization are also important for leaders in Peer-run initiatives (Cyr, McKee, O'Hagan, and Priest, 2016).

An individual, a group of people, or an organization may speak out on behalf of a group of marginalized people.

Downstream Leadership and Advocacy

Leadership in one's own recovery may include: accessing Peer support; learning about the principles of recovery; engaging in strengths-based person-centred care with mental health professionals (O'Hagan, 2009).

Peers may advocate for changes at the institutional (e.g., health care system) or legislative level (e.g., government policies) that serve the needs of marginalized populations (Vezina, 2002).

Why it's *Awesome* to be a Peer Researcher



While the consumer/survivor movement has had many successes in promoting self-determination, diversity, and empowerment, there is still much progress to be made, and you now have some basic research skills to help forge a new landscape in the lives of your Peers.

Grant Writing



When applying for grants, you must convince the funder that a particular problem or need exists, and that the individuals that make up your organization have the means and ability to address it (Vezina, 2003). As a Peer, you have first-hand knowledge of needs and/or gaps in the mental health system.



Sample Questions for Writing Funding Grants and Proposals

Answer the following questions in 750 characters or less:

1. How does this project/program align with your organization's mission and mandate?
2. Describe the capacity of your organization/staff/volunteers to follow through with project/program. Please note special knowledge, skills and qualifications embodied by staff and volunteers.
3. Are other organizations doing something similar? If so, how would your project make a difference?
4. Are there any organizations you will be partnering with? If so, in what capacity?

-  tip Emphasize the needs of the target population. Describe the nature of the need you are proposing to address, evidence that the need does indeed exist and how your proposed project plans on addressing this need.
-  tip Make a thorough assessment of the various kinds of capital possessed by your organization (e.g., knowledge, skills, qualifications, other resources), and how they combine to make your organization the most capable of conducting such a project (Vezina, 2003).

Working as a "Peer" on a Research Team

One of the biggest challenges as a Peer on a research team can be having your voice listened to in an equal capacity as the voices of your colleagues. Peers may be stigmatized by their colleagues and seen as “not qualified” if they do not have academic, research, or professional experience. It is, unfortunately, common for Peers to feel isolated on a research team and feel dismissed when their opinions are not truly heard and validated. Peers can be seen by their colleagues as less knowledgeable about certain topics because they might not have specific training or education. There can be various levels of discrimination towards Peers in professional settings; while many people and companies embrace the inclusion of Peers, others may feel as though Peers are biased, or that their views are invalid. Peers might have to work harder than those around them to gain the trust and respect of their colleagues; however, with the right education and training, there is absolutely no reason why Peers cannot be a vital and valued member of a team (Mayes, 2009).



“Knowledge-making cannot be neutral and disinterested, but is a political process in the service of particular purposes” (Reason & Bradbury, 2006).

Self-Care

Self-care is the act of doing things that personally benefit and/or enhance your life. It is especially important for anyone who is working with others, as Peer researchers do. As a Peer researcher, you should be aware of your internal and external resources, inner strengths and personal tools in maintaining overall wellness (Open Door Group, 2016).

Wellness is more than just physical health, exercise or nutrition. Wellness is about balancing and enhancing various domains of life: mental, physical, social, emotional, and spiritual. Taking care of yourself within each of these domains increases your overall wellbeing and ability to motivate your Peers to maintain appropriate self-care (Open Door Group, 2016).



Individuals operate daily out of their personal space. Depending on the levels of intimacy and trust between people, insertions into one’s physical or emotional space will be accepted or rejected. Although, as Peers, we want to help others, we also need to take care of ourselves. Part of self-care involves setting boundaries that serve to protect us against burnout, feeling obligated to do things we don’t want to do, or feeling disrespected (Open Door Group, 2016).

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