

Participatory Action Research:

*An educational tool for citizen-users of
community mental health services*



Getting started on your journey to create change

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How the Project Started

If you are reading this manual, you are probably interested in finding out more about Participatory Action Research (PAR). First, we want to introduce ourselves and provide a context as to why this educational tool was developed. At the time of development of the tool, the first two authors were Master of Occupational Therapy students at the University of Manitoba. With their advisor, Gayle Restall, they selected and completed an in-depth study on a topic relevant to occupational therapy practice. Community partners, Ruth-Anne Craig and Gerry Duguay, contributed valuable ideas about the direction and focus of the project.

At the beginning of the project, we completed literature reviews to gain knowledge in the topic area. One review focused on PAR theory and its application to community mental health. The other focused on different adult learning theories and learning styles, and the most efficient and effective ways to communicate information. The information was used to create an educational tool about PAR for community mental health citizen-users. The tool is an interactive web-based module with this supplementary manual. Along with the literature reviews, the content and formatting of the tool was developed by consulting with two community mental health participatory action researchers, Ruth-Anne Craig and Gerry Duguay. In addition, Gerry Duguay provided personal experience video clips for the module.

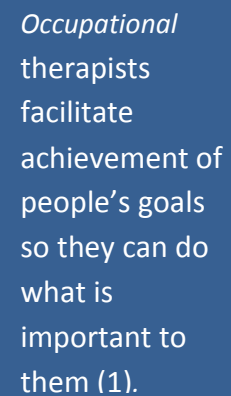
What is Occupational Therapy?

Occupational therapists are health professionals who enable people to engage in meaningful day to day activities. Occupational therapists are concerned with people's abilities to take care of themselves, participate in paid work or volunteering, and enjoy their leisure

time. In other words, occupational therapists facilitate achievement of people's goals so they can do what is important to them (1).

Mental health is one area of practice for occupational therapists. For example, an occupational therapist may work with people who have mental illnesses by helping them achieve their recovery goals in some of the following ways:

- Developing coping skills, self-esteem, stress and relaxation techniques
- Providing education regarding their mental illness
- Assisting people in regaining skills for meaningful employment
- Connecting with community resources



Occupational therapists facilitate achievement of people's goals so they can do what is important to them (1).

Working with people to develop skills enables the client to re-engage in meaningful activities that are important for their journey to recovery (2).

Occupational therapy and PAR have many commonalities. Client-centredness is a fundamental aspect of both PAR and occupational therapy. A client-centred approach emphasizes the active participation and collaboration of the client. Client's experiences, knowledge and strengths are valued. Clients are treated as partners in the therapy process (3). Occupational therapy is a client-centred profession because clients direct their own treatment goals. PAR also demonstrates client-centred values through citizen-users selecting areas of research they are interested in pursuing (4,5). Including the lived experiences of citizen-users is an important method of equalizing power amongst PAR researchers (6).

Overall Purpose

The overall purpose of this educational tool is to act as a resource for community mental health citizen-users to increase their knowledge of and involvement in PAR. The educational tool is designed for people who have limited knowledge of PAR as a tool for change and are interested in making a difference within their communities. The manual will supplement the information in the module. We hope the manual and module will accomplish the following:

1. Identify the main differences between general research processes and PAR
2. Gain an understanding of how PAR can benefit you as an individual and the impact it can have on society
3. Understand the stages of the PAR process
4. Gain an understanding of the roles within the research team

Knowledge Transfer

This section of the manual speaks to why an educational interactive web-based tool was chosen as the communication method. The method was chosen based on the findings in the literature. There are several advantages for using web-based educational tools. One advantage is accessibility (7-9). Not everyone has access to, or owns computers. However, many public facilities, such as libraries, offer access to computers and the internet at no cost. One goal of this project is to widely distribute this tool to ensure it is accessible to people who are interested. Thus, using a web-based tool allows us to achieve this goal. As well, adults have diverse learning styles, for example, some people learn better through listening to others or

through visual means (diagram, charts, etc.). Having a web-based tool allows us to accommodate the various learning styles by adding different applications to the tool (10,11). Another component of the web-based tool is its interactive format. Presenting information in an interactive manner influences one's motivation to learn about a subject (12). We want to present our information about PAR in an interesting and fun way.

What is Research?

There are several characteristics of research. First, it is systematic and structured, meaning there is a step-by-step process that is followed while conducting research. Second, research is a process of exploring literature and obtaining new evidence to generate knowledge that can challenge or support existing evidence. Third, research serves to study issues and provide solutions for a specific dilemma (13).

Within the typical research process there are two types of roles: participants and researchers. Participants are recruited to provide information about their specific experiences. They are limited to being research subjects and do not contribute to the overall research process. Their involvement with the study is complete when the data and information has been collected. Researchers are regarded as the experts and, therefore, shape and inform the research process. They are responsible for interpreting and communicating the results of the study (14).

What is Participatory Action Research?

Participatory action research (PAR) is a type of research that combines two different approaches: participatory research and action research (15). Participatory research encourages equal involvement from researchers and participants in the research process. When participants and researchers are equal partners, the research focus and results can be more relevant to a specific community (16). Participatory research typically involves selecting research issues related to dependence, oppression, and other inequities in need of evaluation (15). In contrast, action research uses findings to reveal strategies that can address community issues. Community needs are evaluated and action is taken with the purpose of social change through development of services and organizations (14,16).

The concepts from participatory research and action research are combined

PAR is unique because participants are regarded as experts due to their lived experiences related to the research topic, ensuring that relevant issues are being studied (16,17).

to give rise to PAR. PAR is a research method involving both participants and researchers throughout the process from the initial stages to gathering and communicating final results. The method is unique because participants are regarded as experts due to their lived experiences related to the research topic, ensuring that relevant issues are being studied (17,18). By involving participants of the study in the research process, PAR promotes changes desired by the group in the form of policy, program, or research developments (14,18). The overall goal of PAR is to use research findings to influence social change.

PAR is a unique approach to research because power is shared between all team members. Power sharing eliminates the inequality that traditionally occurs with researchers

and participants in a typical research design. All team members participate in making collaborative decisions. Everyone has unique and equally important contributions that create mutual learning.

Another characteristic of PAR is mutual respect among all team members regarding their unique areas of expertise. Community mental health citizen-users have unique perspectives because of their lived experiences with mental illness, in addition to their other knowledge and skills. Researchers have knowledge and expertise regarding how to do research. Working as a team allows the opportunity for informal learning to occur by both parties. For example, citizen-users will learn more about specific research processes and researchers will gain insight into the experiences of living with a mental illness (14).

Participatory Action Research and Community Mental Health

Within community mental health services there is a growing trend for citizen-users to take charge of their own services and focus on independent living (5,6,16,18-22). Historically, citizen-users have not been involved in the development of the services they receive creating a power imbalance between citizen-users and mental health professionals. PAR creates the opportunity for citizen-users to be more involved in influencing the types of services and resources that are needed. Many researchers believe that citizen-users' participation is a useful tool for creating equality. Citizen-user run organizations have emerged to provide support to individuals and promote social change within the community (23). The growing self-help movement in mental health is providing citizen-users with the opportunity to question traditional treatments and system organizations that historically have been a source of

oppression and control (20). Increasing citizen-user participation in research is another means to influence positive change in program, services and systems.

Why Should You Become Involved in Participatory Action Research?

Getting involved in research may seem overwhelming. At this point, you may not think you have the skills to offer a research team. Many individuals who become involved in PAR speak about how it has benefited their life. There is a broad range of personal and societal benefits that you may experience by becoming involved in PAR.

Personal Benefits

Many people who become involved in PAR talk specifically about the individual benefits gained and the significant changes that can occur within their lives as a result.

- **Research skills** – involvement with PAR may provide you with the opportunity to develop your knowledge and awareness of the research process. PAR teams usually have expert researcher involvement which provides the opportunity for non-researchers to learn about the research process. Depending on your skills and interests, you can take on roles that you want to learn more about. Learning research skills through PAR can be self-empowering (24). Through participating in the research process you may increase your comfort, knowledge of the research process and develop your critical thinking skills. In turn, this allows you to challenge the information sources around you and make more informed decisions (Gerry Duguay, April 12, 2010).

- **Gives you a voice** – PAR is a way for people to gain support from others facing similar issues and challenges. The issues raised by individuals, combined with the supportive network of a research team, increases the likelihood of your voice being heard. For example, if a lack of resources exist for individuals with a mental illness in your community, and voicing your concerns does not make a difference, becoming involved in a PAR project with others who face similar issues gives you a ‘louder collective voice’. Power exists within numbers; more public awareness can be raised with an entire team advocating for a similar purpose (Gerry Duguay, April 12, 2010).

- **Social supports** – Often, when faced with a difficult issue, you may feel isolated and

Gerry described one advantage that he experienced while being involved in PAR “I found out I wasn’t alone...we spoke the same language, we all had similar experiences and that was validating.”

- Gerry Duguay

alone because no apparent changes are being made. Becoming involved in PAR provides the opportunity to meet and learn from individuals who have lived experiences with similar issues to your own. Members not only feel connected to the topic area but to the people who form the team as well. A

sense of community and the opportunity to form relationships is commonly reported among people involved in PAR. One of the key principles of PAR is the equal power distribution amongst members, which facilitates an environment that promotes the

development of team peer support and friendships through honest and respectful interactions (19-21,25).

- Networking** – Networking with others is a skill that can be acquired and refined through your involvement with PAR. Throughout the PAR process there are many opportunities to communicate with research colleagues, a variety of professionals, government officials and community organizations. Gaining experience in communicating with a variety of people allows you to build your professionalism and confidence in your ability to interact as experts in the research process. As well, networking with a variety of people gives you the opportunity to learn more about the specific issue being researched (26, Gerry Duguay, April 12, 2010).

“There are individuals out there that can see the bigger picture...you need to find them. “

- Gerry Duguay

““Enter into partnerships with organizations that have similar viewpoints and through them you can get your point across....to politicians. I’ve presented to politicians and I would have never had the opportunity before.”

- Gerry Duguay

- Advocacy** – Throughout the process you are aiming to influence and create more awareness of the issues being studied so there will be many opportunities for you to advocate for your beliefs. You will learn to advocate individually within your research team, for example, through the decision-making process. The team will also advocate as they support change based on their research findings. Advocacy skills you develop

from the PAR process will translate into advocating for yourself in your everyday life (Gerry Duguay, April 12, 2010).

- Personal empowerment** – Acquiring the personal skills mentioned above can lead to growth and development as a person. You will find that the PAR process is intrinsically empowering in that you are directly involved in a process that impacts the quality of life of others through social change. Being involved in your community can foster a sense of empowerment. Similarly, PAR gives you the opportunity to be involved in your community and make positive changes within, which can lead to feelings of empowerment. PAR allows everyone on the team to have power and control over the research process and the findings. Within the process of PAR, you will have the opportunity to share your opinions and positions on certain issues and be involved in the decision making on the team (16,19,21). You will take an issue that you and others may feel helpless about and bring more awareness to the situation in order to create social change for the betterment of society. Experiencing personal empowerment can lead to the development of increased feelings of confidence, self-efficacy and self-esteem (22,26). Feelings of empowerment may influence your quality of life and allow you to become more involved and proficient with your contributions to the PAR process.

“I’ve grown in a number of ways...I know who I am. I am more confident, I know who I am and I know where I want to go. I’ve never had that before.”

- Gerry Duguay

Societal Benefits

- ***United as a community*** – The beginning stages of PAR involve individuals or groups coming together around a common issue. Gathering information and seeking to improve current issues within a community leads to greater understanding and knowledge of that community. Having communities involved in the process to make change can lead to more cohesion and collaboration amongst members. A community that faces challenges together can become more united to advocate for the needs of the community. A united community is more organized and efficient at voicing their concerns. For example, if the mental health community is aware of a lack of resources and use a PAR initiative, the commonality of the issue will bring this community together to advocate for more accessible resources (20,21).
- ***Social Change*** – An ultimate goal of conducting PAR is using the results and findings of the project to take action towards making improvements within society. Social change can be an intimidating term to confront; however the scale of involvement to promote change is broad and varies. For example, one end of the spectrum could include speaking at a community centre to create awareness, while at the other end of the spectrum you can lobby large governmental organizations towards action. Any involvement can have an impact to benefit society. Social change can occur in some of the following ways (20,26):

- **Awareness** – Awareness is drawn to a specific issue by presenting and educating others on project findings. You can choose to target and educate a specific audience depending on the issue.
- **Creating or improving resources** – Results from a study can highlight needs not currently being met within the community. Emphasizing these needs provides the opportunity for new programs and resources to be created or improved.
- **Policy and program development** – The results of the research study can be used to lobby key government officials to advocate for policy changes or demonstrate the need for new programs.

Stages of Participatory Action Research

The stages of PAR are represented in eight different stages sequenced from the beginning of the process to the end (26). In reality, both typical research and PAR do not always follow this format. For the purpose of this manual, the stages are presented in this particular order to demonstrate the differences between each step. However, each research process will be different depending on the methods used.

Stage 1: Choosing an Issue - What is the goal?

The beginning stage of the PAR process consists of individuals or groups identifying an issue of concern. It is important that issues are chosen by individuals who have expertise and have lived experienced with the specific topic. Once an issue has been chosen to explore further, a research question must be formulated and clearly stated. It is important that the question is

clearly articulated because it will direct and guide your research process with the end goal of generating knowledge and implementing change. Having people with lived experience participate in choosing the issue and research question ensures the relevance and reflection of a specific community. The research question should reflect the group's goal of change they want to occur (26,27).

Stage 2: Choose Participants and Identify the Research Team: Who will be involved?

The individuals or group of individuals who identified a relevant issue must now decide whether they have the knowledge and skills needed to conduct the research, or whether they want to recruit 'outside' researchers to be a part of the team. They can also choose to recruit others who experience and face similar circumstances. In this stage, it is important to consider the option of partnering with others, such as community organizations. Partnerships are beneficial because these organizations may provide funds to conduct your research or they can support your project by advocating for change in the action stage. As part of the initial planning process the roles of the team members are also identified. Experienced researchers will be beneficial to have on the team because they will have knowledge and familiarity with the research process. Researchers generally take on the role of sharing their expertise in research methods, develop data systems, and conduct data collection and analysis. Within this stage it may be helpful for the team to decide on how decisions will be made or how conflicts will be resolved. The team will be composed of many people who have strong ideas and opinions. Therefore, it is important to plan ahead and be prepared to deal with issues that arise so the project can move forward (26,27).

Stage 3: Find funding

Depending on the project, conducting research can have high costs. For example, honorariums should be provided to participants and there are many administrative costs such as printing and distributing. It is common for a research team to apply for funding to assist with these costs. To obtain funding, a team can submit a proposal to an organization that offers grants specifically relating to the topic being researched. A funding proposal usually includes a description of the research project, why the topic is relevant to the organization that you are requesting funds from, a budget outlining the project's expenses and a timeline of when you are going to conduct the research. It is important that a team tailors the funding proposal to the eligibility criteria and guidelines of the funding agency. In doing this, your funding proposal will more likely be considered amongst all the other proposals that were submitted. It is helpful to have an experienced researcher on the team who is knowledgeable regarding organizations that offer research grants (26,27).

Stage 4: Methodology: How will the team collect information they need to know?

This stage refers to how the team is going to collect their information. Common methods of obtaining data are through interviews, focus groups, surveys, questionnaires and many more. The research team will need to decide the best way to collect information to answer the research question. For example, conducting interviews with participants may be more useful when you want to acquire in-depth information about people's history or perspective on an issue. However, a survey will allow you to get less detailed information but from a more people. Also, the team should consider how they are going to organize the information they collect and

who will perform that task. It is important that information is kept well-organized to avoid confusion later in the project (26,27).

Stage 5: Data analysis and interpretation: How will the collected information be interpreted?

After selecting the method you are going to use to collect the information, the interpretation of the data needs to be completed. You and the team will decide the most appropriate method of analyzing and interpreting the data collected (25). If your team has decided to recruit an outside researcher, both parties are equally involved in analyzing the data. It is very important that citizen-users are involved in this stage because they play an important role in determining what conclusions will be drawn from the study (13). When analyzing the information, often times you are searching for patterns and commonalities between what participants are reporting. In doing this, you can identify common factors that are problematic for this particular group of people and recommend solutions (25).

Stage 6: Presentation of results: How will your team present the results of the study?

Once your team has analyzed and interpreted the findings of the study you must then decide how you are going to present your results. Depending on your targeted audience, findings can be summarized and presented in many different ways. Depending on the targeted audience, your team must decide which method of communication will have the greatest impact. For example, findings can be summarized and presented in a report which can be distributed to a variety of organizations and other target groups (27).

Stage 7: Take Action: How will your team act on the results of the study?

Taking action with the findings of your research is a key element of PAR. Taking action refers to taking your study's conclusions and using them to take steps towards changing the existing issue or situation. An important part of this stage is deciding how and what action you are going to take. For example, what method(s) will be used as an avenue to communicate your results? Depending on the issue or situation that your team wants to change, you should consider what method is most effective. For example, perhaps using the media to bring awareness to a specific situation is the best method or, perhaps making speeches at political committee meetings is the most effective way. As well, it is important to have the target audience in mind because they will influence what method is most appropriate. Your target audience will differ depending on the goal you want to achieve as an end result. For example, targeting the public and policy-makers may require different methods of communicating the results (25,26).

Stage 8: Evaluate: How will your team if your team's action was successful?

The final stage involves evaluating the project. This stage can also be viewed as reflecting upon the whole process of the project from the initial stages. For example, the team may reflect on whether the goal was achieved or look at aspects of the process that were or were not successful. Evaluation is a process rather than a stage in itself. The team can constantly evaluate each stage. Decisions made during the preliminary stages impact the later stages of the process. For example, deciding on what methods will be used to collect data (stage 4) will impact the type of information and results that will be obtained. By reflecting on the outcomes of the project, the team may decide to re-visit a previous stage. For example, if a team

originally chose to collect data by distributing surveys and their results were limited, they may decide to use a different method to collect information. Overall, PAR is a cyclical and dynamic process where each stage impacts the subsequent stages, and each stage can be re-visited as a result of constantly evaluating the process to ensure you achieve your goals (13,26,27).

Examples of Participatory Action Research Projects

There are many situations in which PAR can be used within community mental health. Here are three examples of how a PAR approach was used with the goal of influencing how health services are delivered. :

Dissatisfied with previous evaluations of mental health services, a team of eight citizen-user researchers interviewed 80 people who had experienced mental illness. The researchers asked participants about their experiences living with mental illness, their life goals and the influence of mental health service on their lives. The researchers presented their findings as a live performance and an academic report (28).

A group of people with schizophrenia conducted interviews with each other to study the experiences that people with schizophrenia have with medical professionals. The group created a readers' theatre presentation to communicate their results and recommendations (29).

A PAR project was undertaken to seek the perspectives of mental health service recipients and service providers about their definitions and understandings of recovery. Findings were documented and shared to encourage greater collaboration among service recipients and providers and to promote recovery as a basis for action in the mental health system (24).

Researcher Roles

Throughout the research process, tasks and duties will be divided into a variety of roles, all of which are equally important in contributing to the PAR process. Some of the reasons for creating specific roles within PAR include:

- It helps facilitate the development of partnerships by dispersing power and responsibility among team members.
- Setting specific roles, rules, and procedures facilitates success in implementation and maintenance of the project by providing structure in the organization of the team members and processes.
- Assigning roles encourages accountability for all members to each other and minimizes confusion regarding who is responsible for what tasks.
- Defined roles and rules help minimize any potential confusion in the decision making process.

PAR can be a time consuming process, and having full participation in all areas of the PAR process is not realistic for one individual and thus, it is natural to split up the process. You may select roles depending on your knowledge, skills, interests and experiences. This process is usually completed during the earlier stages of PAR to avoid any confusion on individual's responsibilities.

Researchers generally take the role of sharing their expertise in research methods, developing data systems, and conducting data collection and analysis. Citizen users tend to identify their concerns, needs, and priorities for research, and provide technical support for data collection and analysis according to skills and interests. Collaboratively, researchers and

citizen users develop research questions and decide on research design and data collection methods, and ways to disseminate information. All parties are involved in developing action steps for future study (14).

Here are examples of some roles you may occupy within the team:

Role	What you do	Skills you use
Principal Investigator	<ul style="list-style-type: none"> • Supervise research activities • Assume responsibility for the project budget • Allocate money to cover project expenses according to the project budget • Provide input about methods and tools to be used for data collection and analysis • Facilitate decision making 	<ul style="list-style-type: none"> • Organizational • Interpersonal • Supervisory • Delegation (of tasks) • Facilitation • Research expertise or lived experiences
Research Coordinator	<ul style="list-style-type: none"> • Oversee day-to-day operations of the project • Guide, support, facilitate and train team members to implement the project • Ensure PAR methods are being used appropriately 	<ul style="list-style-type: none"> • Organizational • Delegation (of tasks) • Research expertise, including knowledge of PAR, research methods and

	<ul style="list-style-type: none"> • Organize team meetings • Provide expertise about methods and tools to be used for data collection and analysis 	<p>measurement tools</p> <ul style="list-style-type: none"> • Interpersonal • Facilitation
Research Team Members	<ul style="list-style-type: none"> • Participate in project decisions by providing input into how the project is designed, developed, implemented and evaluated 	<ul style="list-style-type: none"> • Lived experiences • Interest in research • Interest in advocacy
Research Assistant	<ul style="list-style-type: none"> • Provide technical support to the project by helping to collect and analyze data 	<ul style="list-style-type: none"> • Organizational • Interview • Computer
Data Manager	<ul style="list-style-type: none"> • Ensure all data is gathered and recorded appropriately 	<ul style="list-style-type: none"> • Organizational • Computer skills
PAR Organizer	<ul style="list-style-type: none"> • Facilitate communication among team members, schedule team meetings, record minutes of meetings, identify interests and training needs of researchers 	<ul style="list-style-type: none"> • Organization • Interpersonal skills
Other Expertise	<ul style="list-style-type: none"> • Conduct tasks that require specific expertise such as data analysis 	<ul style="list-style-type: none"> • Research expertise

Adapted from (14)

What are the Next Steps?

Now that you have an idea of what PAR is, we hope that you have a better understanding of the following: you recognize some of the main differences between general research processes and PAR, you can identify the stages of the PAR process and the roles within the research team, and most importantly you realize how PAR can benefit you as an individual and the impact it can have on society.

At this point, you may be wondering: *Where do you go from here? Where do you get more information regarding PAR?* This section will answer some of these questions.

- You can find out more about PAR through additional literature and websites that you can access from your local library or university. The educational tool is meant to provide citizen-users with a brief overview of PAR. If you are interested in learning more about PAR, you should seek out more resources.
- Aside from reading more literature, you can find organizations that support PAR. Organizations that support PAR may have additional resources available for you. As well, you may be able to speak with others who have been involved in PAR projects and learn about their experiences.

If you have sought out more information regarding PAR and you are interested in becoming part of a PAR project, begin at the first stage:

- Identify an issue that requires further exploration within your community.
- Collaborate and connect with others who face similar issues and want to take action.
- Contact local community organizations that provide support regarding the specific issue.

- Seek out more information regarding the issue you would like to change. For example, if you recognize there is a lack of resources available to mental health citizen-users. You may want to know more statistics regarding this population and research related to the consequences of not having available resources. The Government of Canada or Statistics Canada websites may be valuable resources to learn more about population demographics.

Participating in PAR can be, at times, tedious and frustrating. It can also be an exciting and rewarding experience that can have benefits to individuals and society. We hope this module and manual has given you some insight into what is involved in being a PAR researcher for social change.

"I have to encourage people, if you appreciate a challenge and want to grow, and you want to learn, take up PAR research, you won't regret it... it's needed now more than ever. I think it's time that individuals started stepping forward and not be ashamed of who they are. Their opinion is valid, their experience is valid and I think that society in general needs to start recognizing that"

- Gerry Duguay

Message from the Authors

We hope this tool has been useful and has sparked your interest in wanting to learn more about Participatory Action Research. Through the experience of completing this project, we have had the opportunity to meet with community members who are involved in the mental health system and in PAR. Upon listening to these individuals, it is evident that more resources are necessary for citizen-users. We hope this tool will become one of many, in allowing citizen-users to learn more about PAR and the power it has for change.

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