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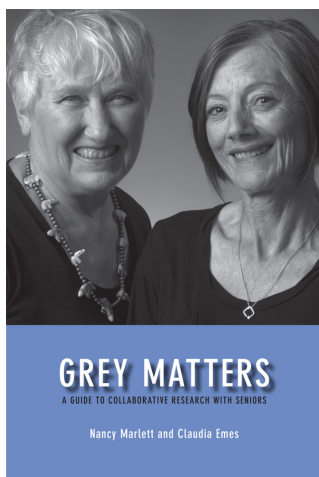
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GREY MATTERS

A Guide to Collaborative Research with Seniors

Nancy Marlett and Claudia Emes

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Sheila Power

The seniors involved wanted their children and grandchildren to understand what resilience meant so they could be resilient themselves.

1

Make Room for Seniors: Research with, for, and by Aging Adults

Do you ever get angry when you read in the newspaper about yet another study that talks about the problems of being old? (BM, 2006)

Not another focus group! They always ask us to come and give our ideas and then they pack up their flip charts and go home. We never hear from them again.(PA, 2004)

To older adults, it becomes frustrating when the only research news about seniors is negative. When seniors have been asked for their ideas, their ideas seem to be taken and used by others with little credit or recognition. Many aging adults have been involved with focus groups and know about research through this experience. While they

appreciate the chance to get together and talk about issues, they feel used and ignored when the sessions lead nowhere. One said, “being involved after the research has been designed is like being invited to comment on the menu after the meal has been prepared.”

And yet, things don't have to be negative, there is another way. I always thought that if the professor said it was “this” way, it was. Now with us working together, I know there are options and appreciate being listened to. There can be more meaningful science when we build on personal trust. (JL, 2006)

A. Historical Approaches to Research about Seniors

Research is a systematic inquiry into a topic, or a method of checking information. Research is about being thoughtful and careful in asking and answering questions so that you have some confidence in what you discover and share with others. Research comes in many sizes and styles, from massive projects such as the census for Statistics Canada to a gardener researching the best soil for her prized roses. Each type of research has its own methods of inquiring and making sense of information gathered. These methods are tools that anyone can learn about and use to solve problems or explore something you care about.

There are two established traditions in research about aging. One looks at problems of aging, and, the other, ways to fix the problems of aging.

The first tradition sees aging as a biological decline to be slowed or reversed. The researchers generally work at a university in a faculty of medicine or science. People working in health research are often called geriatric researchers. Geriatrics is a branch of medicine that deals with the diagnosis and treatment of diseases and problems specific to the aged. This type of research is recognized by the public

and is well funded. Seniors from the perspective of Geriatrics are considered to be losing health and competence.

For example, if research in this tradition were to investigate resilience, it might look for resilience genes, or how people who are resilient are different from those who are not according to some characteristic like adrenal functioning, health status, or depression.

Medical research is generally quantitative in that researchers pose questions that turn events and characteristics into numbers so that information can be subjected to statistical analysis. The methods used are generally experimental in nature. The researcher sets out to see what happens when a condition or situation is repeated in controlled situations to assess the impact. The most widely understood method is the controlled trials method used in testing an intervention, be that a drug or treatment. Here the people who are receiving the intervention do not know what they are receiving and the people who are conducting the study do not know either. This is called a double blind (both parties don't know) study and is considered the standard to ensure that the drug or intervention is indeed having an effect. It controls the expectation or hope that something may be helping. There are common statistical standards (tables of numbers representing the possibility of an event occurring by chance) that are used by all scientists to judge their work.

Your input in this type of research might be requested in pre-testing the language and structure of questionnaires, administering the questionnaires to other seniors, and looking at the implications of the results. You would likely not have a role in deciding the research questions or interpreting the results since this is the researcher's responsibility as part of ongoing scientific studies.

The other research tradition is not about aging *per se* but about "fixing the problems of aging" and tends to be found mostly in professions such as social work, nursing, rehabilitation, psychology, and sociology. Gerontology is the scientific study of the biological, psychological, and

social (the bio-psycho-social) phenomena associated with old age and aging. A wide range of professions bring their disciplinary skills to look at the life experiences of those who are aging so that professionals and policy-makers can be more effective in providing services. For example, the Calgary Health Region is developing a questionnaire to measure resilience so that they can identify people who are not resilient in order to offer programs to help them.

Gerontology research may use the experimental methods outlined above but are more likely to use qualitative methods, which take a more natural look at what, how, when, and where things happen. This type of research uses words to tease out meanings, concepts, definitions, characteristics, and descriptions of events and ideas. It uses methods such as observing, interviewing, documenting, and collecting objects in natural and unobtrusive ways. More recently, this type of analysis is aided by computer analysis, which organizes information, looks for patterns, and calculates the number of times that ideas occur together.

You might be invited to take part in this type of research by working to define problems and needs, to provide input into where best to study the problems, who to contact, how to do the research, and you may be invited to collect information and help with the analysis and interpretation.

A new perspective or third way of doing research looks at aging, not as a problem, but as a culture and opportunity. While there is not a readily accepted term for this type of research, the concept is taking shape within Aging Studies, an emerging field of study related to healthy aging. Here the focus shifts to the cultures of aging (history, values, beliefs, language, media) and the politics of aging. In many ways this new area is like Women's Studies and Disability Studies, although the academic roles of seniors have yet to be widely accepted in universities.

This research is closest to the interests of most seniors. It clearly states that aging is not an illness or disability nor is it a problem. Aging happens to every one and, like any other stage of life, becoming older has advantages as well as challenges. Aging studies would place the “problem” not with individuals but with society that tends to use age as an excuse to marginalize older people because they are seen as being less productive once they reach “a certain age.” With the loss of status and place in their communities, seniors often lose connections, struggle on fixed incomes, and become overwhelmed with the illnesses of idleness.

For example, when seniors set the research agenda for resilience, they looked at resilience as a legacy that seniors had worked hard to learn and accumulate and as such resilience is a resource for future generations. From a seniors-led perspective, they did not want to research the loss of resilience as a biological function nor as a service problem, they wanted to understand how they were recruited into being resilient in childhood and how they could make sure that their grandchildren became resilient (Appendix 1).

The methods used in this type of research look to the relationships between groups of aging adults within the broad segments of society, why decisions are made, how to impact stigma and policy, how seniors can help each other avoid being marginalized and made dependent. Many methods can be used but methods such as focus groups, interviewing, collecting, and documenting seem most common.

In this research seniors are more likely to lead the research, identify an issue that needs to be addressed, attract other seniors and researchers, and set the agenda. They would be partners in deciding on the methods and analyzing the data. They would present results to other seniors, professionals, and academics and take action based on what has been found. It is research about seniors, by seniors, and for seniors.

B. Research about Seniors and Research by Seniors

This section begins with a vignette that illustrates the differences between research done by a professional about seniors and research done by seniors about seniors. It is an attempt to clarify some of the issues that arise when research about seniors does not include them and what can happen when seniors attempt to do research without having research training.

A young male cancer doctor decides to conduct research on older women with cervical cancer because he is considering hiring a social worker to provide more holistic service to his older patients. In his office he interviews older women who have had cervical cancer, using a standardized questionnaire on body image and cancer. Based on the responses he received he concludes that the women being studied are ill-informed about their bodies and seem not to care about the impact of the treatment.

The same research topic is taken up by three older women who are part of a self-help cancer support group when they became interested in some of their shared ideas about their bodies and the impact that their ideas about their bodies had on their relationships. During a series of support meetings, the three women observed and raised questions about the treatment of cervical cancer. They took careful notes and shared these with the women in the support group. They came to a consensus about their shared findings and wrote about their shared deep feelings of violation, shame, and embarrassment that interfered with intimacy. They also wrote about how to overcome these feelings and how to move to a healing process. They then wrote an article in a newsletter about their findings to share with women in other support groups.

The young doctor wrote a review of their article and claimed that, based on his research, their findings were biased and not valid because they did not use proper research methods.

The above example describes two approaches to doing research, one from a professional or problem base and the other from an aging studies perspective by seniors. The topic of the research in both cases was personal and body image related to cervical cancer in older women and the impact of cancer on relationships.

This short example puts forth the value and potential of collaborative research. It identifies some of the barriers that may face professionals and academics working with seniors. It also highlights some of the conflicts that seniors may face.

- What would be the result if seniors were trained to conduct research so the results were taken seriously by professionals?
- What would happen if the young doctor worked with seniors in designing and carrying out research?

The women who took on the responsibility of collecting ideas as part of the support group represent the audience for this manual; seniors who are drawn to know more about how and why things are the way they are. They are also clearly working within an Aging Studies understanding of culture and a qualitative research tradition. They were interested in research as “insiders,” working from within the group. As such they were trusted to represent the ideas of the group. They did not have their own agenda but noticed and recorded ideas that arose from general conversation in the group. They were then able to bring the recorded ideas back to the group for clarification and consensus. As the concerns were identified, it was a natural next step

to think about how to overcome the negative feelings that they shared and understood.

They were using research to understand their personal and shared experiences and used that learning to take action to improve their lives (Chapter 1). They could have used observation techniques (Chapter 3) and focus group methods to clarify their ideas (Chapter 5) so that their wisdom would have been considered knowledge and their efforts would have fostered action to change the way that cervical cancer is managed.

The young male doctor, on the other hand, was an outsider because of his age, his gender, and his position of power and authority. He was trusted to be a caring and interested professional but not someone you would naturally share feelings and personal experiences with. The answers to the questions in the questionnaire were influenced by his power position and the women's uncertainty as to why he was asking the questions.

His use of a standardized body image questionnaire gave him a feeling of security that he was doing research that would be accepted by his peers and that he would be able to relate his findings to a theory of body image and cancer. What he lacked was a bridge to the older women he chose to interview to ensure that they felt safe in sharing their feelings.

Had he been alert to the potential of doing research in partnership, he could have pre-tested his design with a focus group (Chapter 5), he could have trained older women to administer the questionnaire (Chapter 4), and he could have discussed the results with these women to help make the interpretations meaningful to other women with cancer.

C. Why Should Seniors Get Involved in Research?

In one of our sessions we were reviewing an unpublished article (Resilience as Social Capital, Appendix 1) that had been written about our resilience project and we were talking about how important seniors' ideas looked when they represented many people's experience. We came up with the following way of capturing what this meant to us:

Experience shared, builds togetherness and confidence.

Experience researched, creates knowledge and action.

The following ideas came from our discussions over a three-year period as we discussed why seniors might want to get involved in research and where their involvement might lead research about aging.

Capture the wisdom of seniors. Research provides a way to make the knowledge/shared experiences of seniors available to other seniors and those they want to impact – the general public, service providers, academics, and politicians. Unfortunately seniors' experience and wisdom has often been overlooked. Through this manual we are looking at ways to transform shared experiences into public knowledge and action.

Make a difference. Most seniors care about the things that affect their lives, families, and communities. They worry about issues that affect everyone: health, housing, environmental warming, family histories, violence, and economics. When older adults know how to evaluate research and conduct their own research, they are more likely to change the conditions they care about. To own accurate and revealing information and research is to have power and to make a difference.

Document the cultures of aging. There are many distinct groupings or cultures within “the Senior Years” – master athletes, church helpers, veterans – and most are hidden, not valued or misunderstood. What people know about seniors is often limited to caricatures in the

media and movies and the hero/horror family stories of older relatives.

When the richness and diversity of aging becomes public knowledge, society will be less likely to see all seniors as the same or to propose one solution for all circumstances.

Influence research agendas. The larger research community needs stronger seniors' voices to bring a practical and positive reality to the dominant problem-focused academic and professional debates. While the questions asked by seniors may prove uncomfortable, their ideas about what research needs to be done and how to do it will broaden research perspectives and options.

Seniors need to sit with researchers as they conceive proposals, to be present at the table when funding choices are made, and, to be in the trenches, working alongside academic and professional researchers. They need to be the "knowledge translators" for other seniors.

Manage research more effectively. Many of the logistical problems that lurk in a complex study such as ours were minimized because seniors took control. They set up the arrangements with other seniors in ways that were natural and comfortable for both the researchers and the participants. They knew how to recruit, explain the research, and welcome potential participants. Many of the recruiting and orientation problems that haunt research were minimized when it was designed by seniors to be "senior friendly."

Rather than go to the seniors' church group as researchers we decided to go to their monthly lunch where they did the birthdays. We were able to observe and interact quite easily. We each sat at a different table and had more chances to interact. (SA, 2005)

Change the role of seniors in policy, development, and service provision. While there is a growing fear of aging adults using up resources, seniors can be involved in creating new policies and services

that will increase the capacities of seniors to be healthy and to help each other.

Build confidence and competence of seniors. When the training began, many felt shy or uncomfortable. One of the seniors remembered:

When the Kerby news advertised the chance to learn about research I thought “why not.” I got into it because I thought it would be nice to meet new people. Although I had no idea what research was, I decided to take a risk and jump in with both feet not knowing what I was getting into. (SA, 2005)

By the end of the training most seniors were negotiating with research sites, collecting and analyzing data, and writing research reports. The same senior states:

I enjoyed coming to the sessions and learning about the research and I really liked our group. It got easier as we got into it and I think that I learned a lot and could discuss it with other people. Most of all I had fun. (SA, 2006)

Explore a new career. Research is an ideal second career, a way to learn new skills, meet new people, and get involved in the community. Research can be stimulating, engaging, and future-oriented. You can do your own research, volunteer to collect materials and information, sit on advisory groups, or train to be a paid researcher – all are possible.

D. Challenges of Involving Seniors as Full Partners

While we believe that research about seniors will become more powerful with seniors as partners, it is wise to think about some of the challenges to be overcome.

Team building. We chose to use groups in training, each with a leader/mentor and three to seven senior researchers. In the early stages people felt very uncertain and the team provided security and support. However, we learned that teams need extra time and attention to form and be effective. Many of the senior researchers did not know each other at the beginning. SA states:

I was comfortable with everyone; they made me feel like part of the team even though I didn't have the same vocabulary. Some of them used big words but it didn't get in the way, I got the general idea and we went on together. Even the people with education were learning new things so we were all in the same boat. (SA, 2005)

It was up to the team leaders, who initially were retired professors or trained researchers, to create a strong cohesive team. Three of the six teams worked as planned; they had strong, caring, and creative leaders that guided and completed the process roughly as anticipated. They guided the group in the training and practice sessions, met outside of the planned times to review the material, organized their research, and worked with their research sites.

Three groups made their own way – either because the leader could not commit the time required or because conflicts arose. Rather than intervene to solve the problems, the investigators decided to trust the seniors and learn from their solutions. The trust was well placed and some of the strongest research was produced by these “reconfigured teams.”

The leader we had was not very interested so we elected Jane and she just stepped in and took over. She got us organized and we decided who would do what. We met a lot to figure out how to learn on our own and keep up with the rest of the

groups. We really worked as a great team and I think we all learned from it because it was really ours. (MW, 2005)

We learned that there was no best way to organize research teams, the challenge was to trust the process and the seniors to find the team approach that worked best for them. It takes an enormous amount of time and commitment to build ongoing research teams but the effort pays off in quality and retention.

Scheduling. We tended to schedule meetings when speakers or researchers were available but most of the senior researchers would have preferred to have regular consistent meetings and more opportunities to be involved in the process.

When I get involved I like to stay involved, I often didn't have the chance to read all the materials before the next meeting, so it would have been good to meet more often to talk about the readings before the next training session. (MW, 2005)

We recommend sessions every two weeks to create consistency and to build a sense of identity with the project. Regular times to connect would dramatically improve communication and a sense of belonging. The group also suggested regular Internet contact and more sessions with the principal investigators.

Funding. Collaborative research needs to acknowledge the skills and work of senior researchers and team leaders. While we were able to cover small honoraria for team leaders and travel costs and meals for all senior researchers, these expenses are seldom seen as legitimate research expenses.

It was okay for me as a senior because I have a yearly senior's bus pass, but it may have been different for those who had to drive any distance. It was nice to have the meals because it gave us a chance to talk to each other and we didn't have to

pack our lunches. At least we knew we were important when they fed us and some may have left at lunch if there was no food. (SA, 2005)

Increasingly research projects pay the involved participants. Funding bodies should expect to introduce codes and methods to recognize participant travel and meals as legitimate expenses. Funding for projects involving seniors as researchers should include money for training, staff to ensure communication, stipends for researchers, and expenses of participants. Once seniors are trained, they should be paid like any other researcher.

Now that we have trained researchers, other groups want our seniors to do interviews for them but they assume that they will volunteer, we think the seniors should be paid just like any other researcher once they are trained. (DD, 2006)

The seniors who have been involved in the project are in demand and many seniors have been co-opted onto advisory committees because they have an understanding of research.

All levels of government expect seniors to volunteer because they are getting pensions; they don't see the need to pay seniors for their work. That has to change; we are on the poverty line and senior volunteer hours exceed any other age group. We should be recognized for our work and not treated as if they were doing us a favour by keeping us busy. We have busy lives and would appreciate a little extra money to cover the costs of working for the community. (CG, 2006)

Cultural sensitivity. While we were cautious not to adopt a Western, middle-class approach, we found that there were distinct cultures within the various age groups in our researchers. It almost seemed that the decades defined cultures, those in their 60s, those in their 70s,

and those in their 80s; they were not a unified group. They present a stratified set of cultures defined by their shared experiences (e.g., the War group distinct from those born after the War), where they lived and live now, cultural affiliation, and economic status.

Last night I had a sixty-year-old over to play scrabble, and she was complaining that her 101-year-old father was fiercely independent and he wouldn't take any help. She felt that since he emigrated as a child he had to do things on his own and now he couldn't change, whereas she believed that services were available and he should use them. I, as a seventy-year-old, could understand both because I lived both realities. (HB, 2006)

Research ethics and ethics reviews. Research ethics have become formidable obstacles to the democratization of research. Academic research ethics standards protect subjects from being identified or explored and in the process remove the identity of the participants. Qualitative research also struggles with how to represent and acknowledge those who contribute their ideas.

The Canadian Tri-council Policy on Ethical Conduct (<http://www.pre.ethics.gc.ca>) is an excellent resource for any group considering research within an academic partnership for it clearly describes the culture of ethics.

Collaborative research has been spoken of in academic research for many years, but collaborative research still is expected to meet all of the ethics requirements of more traditional research. Ethics processes such as signed consent forms are expected. Despite our best efforts, consent was an intimidating and legalistic barrier to participation:

Just recently I came across some of the ethics forms I had signed and couldn't figure out what they were for. When I

signed them originally I thought, am I signing my life away, what is this all about. I still wonder why we had to do all that when I was just a volunteer researcher. I felt I had to sign to be part of the group but it made me wish I could wait until I knew more and could understand it. (SA, 2006)

We were able to design consent forms for each of the steps in the research and were therefore able to adapt and change as we progressed and even with this, consent forms were an obstacle. When starting a research project, senior researchers should meet with others doing collaborative research and with their university's legal departments to design a workable solution. We found it helpful to include a simple consent as part of an information session about the project. It would also be more helpful to have one general consent form with options to remove consent if required.

The approval of the groups or agencies who are part of your project is just as important as formal ethics approval through a university or professional/governmental organization. Procedures for ensuring ethics approval by seniors' organizations need to be honoured. Seniors could refer to disability research, culture-based research and aboriginal research for ideas on how to set up their own ethics approval processes. The last section of this chapter provides some guidelines to use in creating your own research approval process.

E. Participatory Action Research (PAR) in Collaborative Research

PAR originated in South America as a technique to mobilize communities to take more control over their lives and the problems that oppressed them. Literally, PAR states that people take control of their research and use the research to take action to better their lives.

PAR increases participation, builds capacity, vests ownership of knowledge with the participants, and empowers people through research. Many research techniques can be used within PAR: focus groups, questionnaires, observations, review of documents. There is primarily a commitment to the autonomy of the group: The group decides what it wants to work on, what information to gather, and the action to take. The PAR cycle can be drawn as follows:

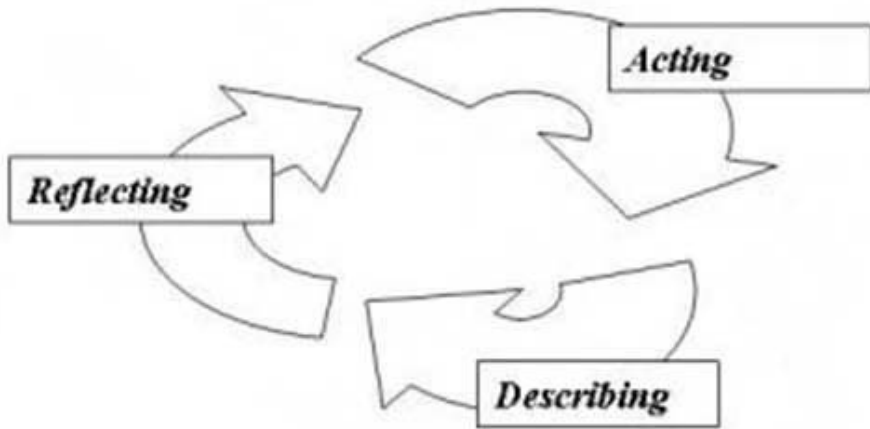


Figure 1: PAR cycle.

While the PAR cycle is about mobilizing groups to take effective action, the principles of PAR can guide any collaborative research endeavour. Most collaborative research recognizes expertise – methodological expertise of academics and lived expertise of the participants. However the direction and interpretation of the research tends to be in the hands of the academic researcher with seniors in the roles of advisors or data collectors.

Our resilience research project developed from a decidedly different assumption. Seniors initiated the partnership while the academic

researchers were there to assist them to learn about research. All partners agreed that the goal was to move to a collaboration where seniors were full partners in conceiving, implementing, and disseminating research.

Principles of PAR in Collaborative Research

We recommend that any group wishing to begin a research project or training program should become familiar with the principles of Participatory Action Research as outlined in Appendix 2: Handout on Basic Principles of PAR.

Other terms such as emancipatory research, action research, discovery research, and participatory research are often used to denote that the beneficiaries of the research, in this case seniors, are included at all stages of the research.

We considered research to follow PAR principles when seniors:

- choose the topics for research as relevant to seniors;
- are active at all stages of the research;
- determine how the results are used to promote positive change; and
- take on research as a skill to be used in new situations.

The following example from the resilience project shows how PAR evolves:

Five people from rural areas west of Calgary attended the first resilience workshop. At the end of the event they offered to host a follow-up workshop in Cochrane, a small town west of the city. These rural seniors became part of the rural

workshop team and were involved in planning and running the Cochrane focus groups.

There was an interest in exploring services for seniors after the workshops and some of the participants became part of a new service board. Part of their work included training more seniors to run focus groups and they conducted 12 rural focus groups that identified housing as a key issue.

From this they trained a group of seniors to use focus group techniques to conduct community focus groups to mobilize a housing project. This initiative is now lobbying for zoning to construct housing options based on community input.

Inquiry-Based Learning as Participatory Action Research

The project is an example of inquiry as a method of learning through research, activity, and reflection. This method was adapted from a collaborative inquiry method for teaching that was developed at the Community Rehabilitation and Disability Studies program at the University of Calgary. Throughout this manual, the terms “inquiry” and “research” are used in parallel since the methods presented here are applicable to both the open and creative process of inquiry and the more structured process of research.

The major actions in inquiry are:

Define: Each of the four methods/tools were chosen by a committee of researchers and seniors as part of the research proposal. The definition of the method was reviewed and adapted at the beginning of the project and again as each method was presented.

The definitions of the method changed as the project evolved. For example, observing and PAR became Field-work.

Learn: A day-long workshop was held to introduce each method, its background, and scope and practice. The teaching was done by researchers with the input of seniors. By the last two workshops, seniors were involved in developing the teaching materials and the teaching process. Workbooks, guides, and research tools were prepared and distributed in advance.

Act: Four steps make up this phase:

Apply and adapt techniques: During the workshops, senior researchers sat with their team leader so that they could ask questions and “role play” new skills and roles. This allowed them to become comfortable with research techniques and theory. Each group adapted the teachings to their particular research topic and site. For example, in the survey interviews, each research group designed a questionnaire for their partner site based on what they had learned from their previous visits and observations. Some used formal questions, others used very open conversational guides.

Practice: Time was allocated during the formal training for participants to practice the skills being taught. Most groups also met after the formal session to refine their skills in preparation for conducting their research with their community partner site.

Collect data in partner sites: The following are samples of the processes used in the four methods: During the methods of observation and field-work, the leisure and physical activity group observed a bridge club in a seniors centre. As part of the interviewing session, the rural group interviewed the

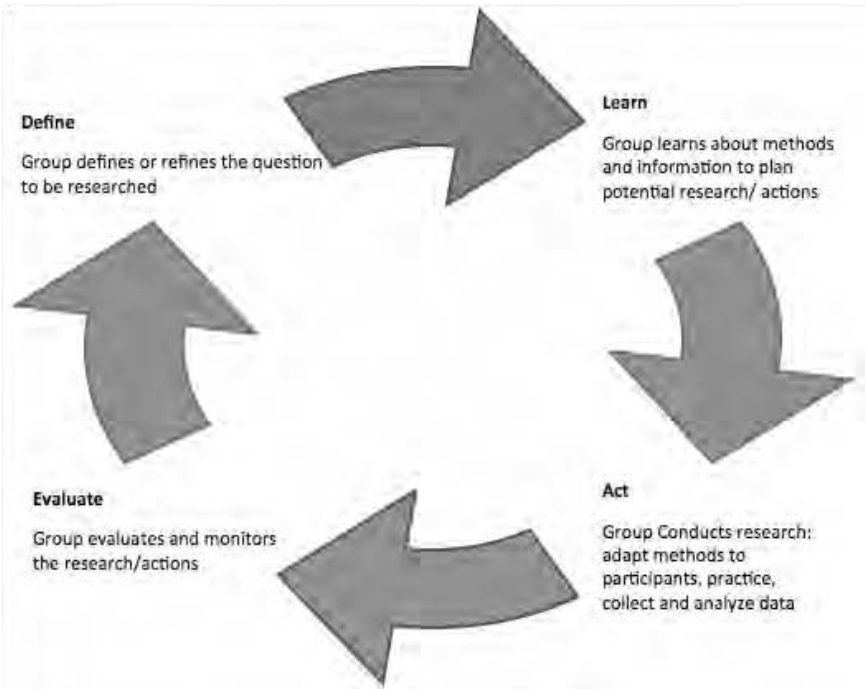


Figure 2: PAR-informed Inquiry-based Training.

director and key members of a rural seniors association. For the focus group sessions, the ethno-cultural group conducted a focus group with seniors from the Japanese cultural centre about a Japanese understanding of resilience. As part of the final session related to narrative research, the health group conducted narrative interviews with seniors about how their health impacted their understanding of resilience.

Analyze the data and write a report: After the data were collected, the research groups met to analyze their finding and report back to the larger group and to the partner site. Examples of reports for focus groups are included in Appendix 7 and 8.

Evaluate the methods used: At the end of each phase, the senior researchers recorded impressions on standardized evaluation forms. These were compiled by the research coordinator and were reviewed by everyone. At the end of each method, we discussed what we had learned and how to apply that learning to the next session.

Exit interviews were conducted with team leaders and senior researchers and four months after the project was finished, everyone was invited to reflect on the process and make recommendations for future research proposals and publications.

The usefulness and integrity of the inquiry model was achieved through constantly reflecting and thinking about what was being done and learned. In inquiry learning this is referred to as critically questioning actions and practices. Ongoing feedback from the larger working group became more animated as the project proceeded with seniors offering to assume more control of the research teaching and data collection.

While some of the original academics chose not to be engaged, those remaining felt that their capacity to do authentic research was increased by this full partnership. They felt that they gained power by sharing skills and co-owning the results.

Such a dramatic shift in the balance of power in research will not be an easy transition but seniors are taking on more control of their lives. Seniors have taken up the call to form policy coalitions, run their own services, and create their own insider knowledge. While a shift of this magnitude will take a generation or two, it will not even begin without knowledgeable seniors who are willing and able to collaborate with professionals and academics in forging a new balance of power in research.

F. Indicators of Quality in Research

It may be easy to learn how to do the research but how do we know if we are doing it right or if it is any good? (JW, 2005)

JW has a good point, wanting to do research isn't enough, it is necessary to know the standards used to judge good research so that there is confidence in the quality of the work. The standards for judging quantitative or experimental research (experiments with numbers) are widely accepted. Reliability means that the findings can be replicated by others who use the same procedures. Validity is about the extent to which the results reflect the topic being studied. If you are involved in experimental research, be sure to look up how reliability and validity are defined for the research you are conducting. The following are commonly accepted standards for qualitative (describing life experiences) research.

Credibility. Are the results believable from the perspective of the participants in the research? Would a senior cruising the Internet have faith in what you are presenting? This includes faith in the question, the methods, and the findings. This is where seniors have the edge over most academic researchers. If the research is designed and conducted by seniors, the results should speak to seniors.

In the example of the seniors researching the impact of cervical cancer, we can see this standard of credibility in play. The desire to do research arose from a curiosity about shared experiences and the results emerged from the discussions of the cancer support group. The results should therefore resonate with or speak to others in the same situation. The study reporting the standardized questionnaire results may not have as much credibility among seniors (women, cancer survivors) since the language and the categories in the test speak to a theory constructed by academic or professional researchers. Seniors need to capitalize on the standard of credibility and they must be

careful not to lose touch with their participants lest their results lose credibility.

Transferability. When a researcher talks about findings or writes an article, can other people relate the findings to their own situation? To accomplish transferability, the researcher starts by carefully describing the “who, where, how, what, and when” of the research so that the reader can understand the research and relate it to his or her own experience. In the cancer situation the young doctor may assume that the findings apply to all older women with cervical cancer experience because he used a standardized questionnaire, but it may only be relevant to women willing to answer questions posed by a young doctor.

The observations made by researchers who were part of a women’s support group might transfer well to other support groups, older women who are alone in their healing, other women with different types of cancer and illness, and even younger men with prostate cancer. Because the research evolved from the lived experience of women with cancer, there are many points of connection or transfer.

Dependability. This is a confirmation of how carefully the research was done, what problems arose, and how the changes made affected the study and the results. Dependable research is transparent, meaning that nothing is hidden. In the example with the cancer support group, the senior researchers took careful notes and they tested out their ideas with the group. They might be criticized by other researchers because they were not using accepted ways of recording and they might also have been criticized because they were not trained observers. However, they were intuitively “dependable” in that they recorded what they did and what they found.

The male doctor assumed that his method was more dependable because he used a questionnaire in the same way with all participants. His measure of dependability lay in the fact that he used a consistent set of questions, a consistent way of asking questions and recording

answers, and a standard way of analyzing the answers. Sometimes standardizing the process increases dependability but can decrease credibility. As one of our researchers commented when administering their standardized questions:

We felt good that we had a standardized questionnaire and that we were doing the questionnaire the right way but the answers were boring and left a lot of questions unanswered.
(DW, 2004)

Objectivity. It is necessary that researchers keep their own values and opinions out of the way when collecting, analyzing data, and presenting findings. While it is difficult to be completely objective, it is important for researchers to declare their biases and how they tried to hold their biases in check. Academics are most likely to use this objectivity standard against research done by seniors. They may feel that seniors are biased and tempted to distort the information to reflect what they want to find. Research should not be about proving the researchers' thoughts and knowledge, rather it should be about looking at every event or piece of information as if it were happening for the first time. Objectivity means that every observation is open to question. Every researcher, regardless of age, has to struggle to avoid having their biases affect their observations. Chapter 4 discusses how to stand aside when observing and how to challenge first impressions.

In the cancer support example, the senior researchers were open to charges of bias because they were cancer survivors and were part of the support group. While they did check their observations with the women in the group and wrote about what they had done, they needed to demonstrate that they were aware of the need for objectivity and how they had worked to identify and control their biases.

Research can range from a very simple observation to a very complex investigation, but regardless of the size or complexity, all research is a process of discovery. As human beings we share a curiosity about

the world around us and curiosity is not bound by age. In this chapter we have attempted not only to provide a broad overview of research but also to present it in a way that will encourage the reader to become engaged in a partnered research process, for both seniors and academics have a lot to learn. The following quote is from two of the authors of this book as part of their field notes.

It was so easy to take the data and to write it up as an academic, the data spoke to the theories that we were interested in. It was a hard decision. In the end perhaps there is a place for both, research that speaks to theory and research that speaks to everyday life. The ideal would be to have both goals possible in the same method; at least it's something to work toward. (NJM and CE, 2006)

G. Quality in Partnership Research

We end this chapter with a challenge couched in a statement of intent about the values and indicators of good partnership research. This extends the accepted indicators of quality research previously discussed and can be used in a number of ways:

- Seniors organizations can use it to guide their research committee's negotiations with interested researchers.
- Academics can use it to guide their teaching of partnership research and to judge partnered projects with students.
- Funders and policy-makers can use it to encourage meaningful partnerships in research and policy development.

- Readers of this book can use it as the motivation for the rest of the book.

Values of Partnered Research

These values only come with openness, hard work, trust and practice.

Equal but different. The thoughts and beliefs of all participants about the shared questions and issues are equally valid. For example, a retired farmer and a scholar studying rural seniors have different perspectives about what research needs to be done, how to do it, and what can be done with the results. Each needs the other's experience and knowledge to reach his or her own goals.

Trust. Trust is hard to earn and is quickly lost. Actively acknowledging the contributions of every participant leads to greater understanding and an openness to hear and learn from the voice of others. With familiarity and appreciation comes trust.

Shared power. Nobody decides for somebody else. Sharing power starts with the expectation to listen and the freedom to express opinions. Each person learns from others and grows in his or her own confidence and capacity.

Shared work. To share expertise there needs to be a willingness to use common language, model and mentor expertise. Learning to share means time for reflection on the process and joint ownership of successes and failures.

Indicators of Good Partnered Research

Plain language. Proposals, interactions, meetings with stakeholders and media, research methods, protocols, and reports should be written in language that is understood by all. Where technical terms are needed, meanings are negotiated, clearly defined, and only used when understood by all.

Representation. The various voices are clearly recognized and documented. Changes in voice and conflicts in voice are noted and addressed.

Negotiated process. The methods for achieving partnership at each stage of the research – from creating the research agenda to presenting findings – are negotiated through a process of mutual agreement.

Relevance. The results should impact the lives of seniors.

Shared ownership of results. The format and content of the results honour the contributions of the partners. Findings are accessible to seniors and other stakeholders.

Resources

- Jones, W. Paul, and Jeffrey A. Kottler. 2006. *Understanding Research: Becoming a Competent and Critical Consumer*. Columbus, OH: Pearson, Merrill, Prentice Hall.
- Marlett, N.J. 1998. “Partnership Research in Health Promotion” in W.E. Thurston, J.D. Sieppert, V.J. Weibe (ed) *Doing Health Promotion Research in the Science of Action*. Calgary, AB: Health Promotions Research Group.
- Krueger, Richard A., and Marianne Casey. 2000. *Focus Groups: A Practical Guide for Applied Research*. Thousand Oaks, CA: Sage.
- Leedy, Paul D., and Jean E. Ormrod. 2005. *Practical Research: Planning and Design*. Columbus, OH: Pearson, Merrill, Prentice Hall.

Maureen Wills

Until I became involved in the research regarding the resiliency of seniors – the word resiliency was simply a word in the dictionary. For three years I belonged to a group of like-minded seniors that traveled the rural areas surrounding Calgary. We learned how to do research and facilitate groups. What I learned from the seniors was that the most important persons in their lives were their teachers.

Those teachers taught in one-room schools and focused on reading which opened a world wider for the students, showing them for that there was a life beyond theirs. This truly was the combined effort of seniors helping seniors. The research, interviewing and facilitation skills I learned helped me in other projects that I have worked on. The resiliency project was intense – we spent many hours gathering the data and reporting our findings back to the research team. Hearing the stories of seniors was representative of time where neighbours helped neighbours and friends came to a person's aid without being asked. The stories have left their print forever with me.