

# GREY MATTERS

A GUIDE TO COLLABORATIVE RESEARCH WITH SENIORS

Nancy Marlett and Claudia Emes



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# Grey Matters: a guide to collaborative research with seniors

Marlett, Nancy; Emes, Claudia

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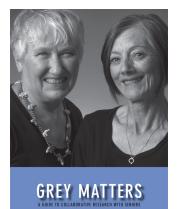
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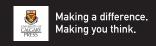
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# GREY MATTERS

Who would have thought that I could do research! I went to grade seven as a kid and I conducted a focus group! Not only was it fun, I think my kids are proud of me and I am pretty pleased with myself too.

(MW, 2004)

# GREY MATTERS

#### A GUIDE TO COLLABORATIVE RESEARCH WITH SENIORS

## Nancy Marlett and Claudia Emes

With contributions from
Penny Jennett, Bob Stebbins, Joan Ryan,
Dorothy Dooley, and Marianne Rogerson
and
Seniors and the Resilience Pilot Project Research Team,
Calgary, Alberta

Sponsored by the Canadian Institutes of Health Research (CIHR) and the Kerby Centre of Excellence (KCE)



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Experience shared builds togetherness and confidence.

Experience researched creates knowledge and action.

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This project grew from the vision of Pat Allen, founding CEO of the Kerby Centre in Calgary, Alberta, Canada, who developed the Kerby Centre of Excellence (KCE). Pat and two board presidents, Betty McCreight and Sheila Power, attended most of our workshops, training events, planning and evaluation sessions. Their input and guidance kept us on track and convinced us of the importance of the project for seniors.

The retired professors and team leaders were seniors, accomplished researchers, and the bridge between the senior researchers and the principal investigators. Their enthusiasm and wisdom kept the unruly project on target and on time. A special thank you to Dr. Mo Watanabe, Dr. Joan Ryan, Dr. Bob Stebbins, Dr. Ralph Miller, and Dr. Mary Sheridan. They came to help run a day-workshop on resilience and stayed for three years.

The senior researchers showed that, given the opportunity, they could stand with the best. They had to endure while we tried to sort out the processes; they bravely took on new and sometimes frightening roles; and they patiently negotiated with us for their power and gracefully took over the project. Their determination and talent was an inspiration. A special thank you to Anne Hartley, Margaret Harche, Shirley Atkinson, Pauline Gorton, Maureen Wills, Nancy Jensen, Fouad Henin, Noreen Mahoney, Ida Henin, Marilyn Akazawa, Dr. Jenifer Meynell, Winnifred Woodhouse, Geoff Elliott, Grant Allen, Sheila Power, Carroll Jonns, Julia Thorpe, Dr. Herb Breitkreutz, and Valerie Breitkreutz, who were the core of the senior researchers.

Our partner sites were the bedrock of the research. They welcomed us and opened their doors to a new model of negotiated partnerships. They were observed and interviewed and they hosted our focus groups. They encouraged their members to take part in the narrative interviews: Kerby Centre, Confederation Park Senior Citizen Centre, Japanese Canadian Seniors Club, Okotoks Seniors' Club, Cochrane Family and Community Support Services, and various churches. Through all of this they welcomed challenge and supported the seniors as they grew in their roles as researchers.

After the project was completed, two other sites offered to implement the research methods and these sites are included in this book. The Snowbirds Fellowship in Bragg Creek and their oral history project is highlighted in Chapter 3 and the Ogden House Housing Project is highlighted in Chapter 4. Okotoks Seniors' Club provides the basis for Chapter 5 and the experiences of the Kerby Centre in starting an Elder Abuse Shelter provides the basis for Chapters 7 and 8.

There are many at the University of Calgary and the Kerby Centre who should receive thanks but special thanks go to Dorothy Dooley, Coordinator of the KCE, who kept the finances on track, the schedules organized, the meals ready, and the reports written. She was always there when senior researchers were discouraged or angry, when the investigators or the university had impossible deadlines, and when the media demanded responses. She holds a vision of the KCE that will move seniors to the forefront of innovation and research.

Marianne Rogerson, the project staff person, brought calm and grace to the daily work of managing files, writing documents, analyzing data, and searching out materials and equipment. She worked with the team leaders, the team coordinators, the principal investigators and the Kerby Centre. Her organization and deep love of participatory research marked all of her interactions.

Finally, thanks to all the families and friends who supported us during the past three years of writing this manual through its various iterations: pamphlets, manual, and finally, a book written with seniors



This book is dedicated to the memory of Dr. Joan Ryan, a University of Calgary professor and one of Canada's pioneers in Participatory Action Research (PAR) with Aboriginal communities. She taught and enforced the principles of senior leadership with all of us. She gave seniors the confidence they needed to try something new and to be researchers with other seniors. Dr. Ryan will be remembered for her down-to-earth manner and her ability to teach through stories. Her passion about PAR kept us all on our toes.



Pat Allen

People do for us and that's very nice, but that's not what we need. We need to do for ourselves and be listened to before legislation is enacted. I wanted older people to do their own looking at what they need and to verify it in a way that would be recognized by the community and at a university level.

# The Kerby Centre of Excellence

The Kerby Centre of Excellence is a seniors-led organization dedicated to enhancing the ability of seniors to live healthy, creative, and productive lives within their community. Since it was established in 1973, the Centre has grown to become a dynamic, multifaceted organization, offering a wide range of social, recreational, educational, and wellness programs. It is Alberta's leading multi-service seniors centre, annually serving over 32,000 seniors and their families, more than 30 per cent of Calgary's senior population.

A social model of health has been developed by the Centre to meet seniors' intellectual, emotional, social, and physical needs and to improve their quality of life. To many seniors the Kerby Centre represents community. It is where they come for information, learning, advocacy, good meals, tax help, entertainment, socializing, exercise, and help, when needed.

The Kerby Centre of Excellence and Network in Applied Gerontology was established in 2002 to undertake research focusing on all aspects of aging successfully and to involve seniors in identifying and conducting research relevant to them and their peers. The Centre of Excellence is Canada's first community-based research centre to integrate research, education, and service delivery for seniors.

The goal of the centre is to conduct collaborative, multidisciplinary research into healthy and successful aging. One of the major thrusts will be to understand and promote resilience for seniors and their communities. This research will help to identify what makes seniors resilient, able to bounce back, and remain healthy and active

despite lifetime setbacks. The Centre of Excellence has a vision of involving seniors in all aspects of research: for seniors by seniors.

This manual is a product of the centre's first project titled *Seniors* and *Resilience: Sites and Sources*. It was a collaboration between the University of Calgary, the City of Calgary, and the Kerby Centre. It is hoped that this research manual will contribute to future research, programs, education, and services to improve seniors' quality of life today and in the future.

The funding for the research project was provided by the Canadian Institutes of Health Research, Institute of Aging. The one-year funding lead to a three-year project with other partners that turned the findings of the formal research into this book. We are grateful to them for their vision and willingness to start the process to a future where seniors are partners in setting the research agendas and are recognized as researchers in their own right.

# Prologue: Seniors' Collaborative Research Manual

This manual represents a major step in making collaboration between seniors, academic researchers, and community researchers a reality. It is of interest to:

- Aging adults who are interested in research and would like to understand research in their reading and everyday lives.
- Individuals who have a specific project they would like to undertake.
- Groups of aging adults who would like to engage in research as independent researchers doing their own projects such as collecting oral histories or conducting needs surveys.
- Researchers who would like to hire seniors as part of their research team.
- Researchers who are interested in forming collaborative partnerships in applying for research grants and conducting ongoing research projects.

- Policy-makers and planners who are concerned about hearing the authentic voice of seniors, as part of a planning process.
- Teachers in Gerontology and Aging Studies who are looking to train students in research methods appropriate to their field of study.

We began with an investigation into the methods best suited to collaborative, seniors-led research. We looked at four primary research categories: field-work, interviews and survey questionnaires, focus groups, and narrative interviews. All proved to be acceptable to seniors and appropriate for collaborative research. We asked seniors why they wanted to conduct research and where the research done by seniors might lead. We investigated how to train seniors to do research in an inquiry model that included formal training, mentoring, learning by doing, and reflecting. The results of this work far exceeded our initial expectations. Aging adults are capable and motivated. They have first-hand knowledge of the cultures of aging and their creativity will introduce new approaches to understanding emerging social problems.

We use the terms "seniors," "aging adults," and "elders" interchangeably, although our group preferred to use the term "seniors," despite the politically correct language of "aging adults." In general, we use the term "seniors" to denote our senior researchers and "older adults" to refer more generally to the sector of the population being studied.

The manual uses a mixture of lay and academic language. We have attempted to use technical terms sparingly and define these within the text. There is a glossary that provides a quick reference to technical words. We chose not to include formal references; however,

lists of good resources are to be found at the end of each chapter. The majority of these are available either online or at a local university.

**Section 1** provides the rationale and background for the book. Chapter 1 introduces the need for aging adults to be involved in research about seniors and what we have learned about the principles and practices of doing research in partnership. It is a useful guide for discussions among seniors, researchers, research funders, and policymakers as they explore the importance of collaboration. We hope that this chapter will encourage academic researchers to forge new alliances and prompt research funding bodies and policy analysts to increase their expectations of collaboration in funding criteria.

Chapter 2 is the story of our research project with goals, processes, and evaluations.

**Section 2** is a research manual; Chapter 3 considers Field-work and Participant Research; Chapter 4, Surveys and Interviews; Chapter 5, Focus Group Research, and Chapter 6, Narrative Research. Each chapter includes sections on: when to use the method, recruitment, and the relevant ethical issues to be considered; research roles; how to collect and analyze data; and, some hints about training seniors for that particular type of research. In some cases we challenge existing research practices or design new approaches based on the feedback of our senior researchers. In each chapter we consider a research project done by seniors as the example: the Elder Abuse Project at the Kerby Centre; the Snowbirds Seniors Fellowship of Bragg Creek; the Okotoks Seniors Club; and the Ogden House Seniors Housing project.

**Section 3** discusses how to create, implement, and share research in a partnership. Chapter 7 begins as a brief overview of the stages and steps of designing research, and what we have learned as the materials in the manual have been used by others. There are four major steps in Chapter 7, which begins with deciding on a research question and focusing your efforts.

Prologue xvii

Chapter 8 outlines the steps to developing a funding proposal. Chapter 9 then continues with conducting and evaluating research, sharing results, and taking action. The appendices include an article on resilience and older adults, a handout on the principles of PAR, an example of a research proposal, a template for recording the activities and observations, focus group workbooks, a narrative workbook, a narrative interview guide, a workbook for rural settings, and a glossary of terms.

# Section 1

# The Reason for the Book. How It Came to Be

The first two chapters discuss why, on the brink of an increase in the numbers of aging adults, it is important to prepare seniors to take on research roles.

Chapter 1 outlines the potential and essential roles seniors can play in creating new options in policy and services. It focuses on the importance of capturing the voice of seniors and how they contribute in ways that only a long life of experience can offer. It concludes by introducing the research approach that we adopted for our seniors'-led research project, Participatory Action Research (PAR).

Chapter 2 describes how a large group of seniors took on the challenge of becoming researchers and how to adapt research methods for seniors. It outlines four different methods that could be used in a participatory research project: field-work or observational research, interviews and questionnaires, focus groups, and narrative methods. It concludes with a discussion on evaluation of the research process.



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. Seniorsfrom 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 pretesting 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 through 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:

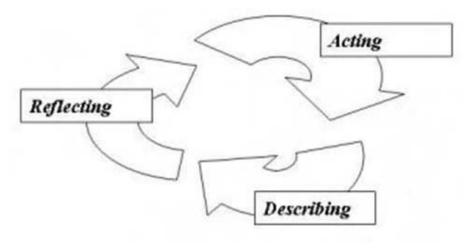


Figure 1: PAR cycle.

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 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 quides.

**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

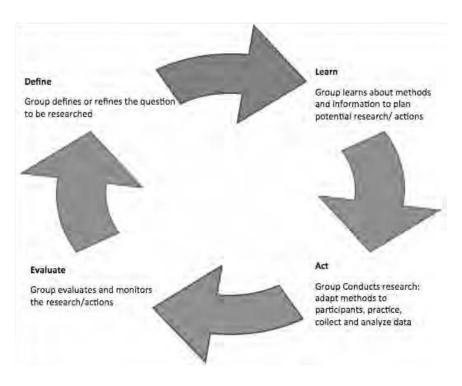


Figure 2: PAR-informed Inquiry-based Training.

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

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#### 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.



**Dorothy Dooley** 

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

2

# Resilience and Seniors: What We Did and What We Learned about Doing Research

This is the story of a large seniors' organization that decided it was time seniors had more say in research that could affect their lives. It is the story of 250 seniors who decided resilience was an important research topic because it spoke to their strengths, and it is about seventy seniors who took up the challenge to learn about research and conduct research about resilience. These were ordinary seniors, from 56 to 90 years old and from all walks of life, occupations, and education. They were salespeople, teachers, ranchers, politicians, managers, and homemakers. Over three years they paved the way for others to take up the challenge of using research as a tool for personal and social change.

When the Kerby Centre of Excellence was created, few understood the power waiting to be unleashed. While Kerby had encouraged researchers from the University of Calgary to conduct research at the Kerby Centre, few if any projects were done with seniors as full partners, nor did the research come back to Kerby in ways that could be used to improve the services Kerby provided for seniors. The biggest challenge was how to have seniors recognized by researchers as researchers. This chapter is an overview of the first few years in this journey.

While telling the story of the early stages of a shift from "seniors as subjects" to "seniors as researchers," we also introduce the rest of the manual. The process is shown in Table 1, starting with the introductory workshops that set the research agenda, through the four phases of collecting data on each of the four research methods, and finally to the evaluation and write-up phase.

Table 1. Flowchart of six steps of a research project.

| PHASE                                 | WHAT WAS DONE   | OUTCOMES   |
|---------------------------------------|---|--|
| Introductory<br>workshops             | Two workshops using focus group method at the Kerby Centre of Excellence Two workshops in the Town of Cochrane  | Resilience agenda approved Six resilience study groups started: health, leisure, learning, rural, ethno- cultural and spirituality Pilot proposal submitted and approved by CIHR |
| Field-work<br>training                | Training and practice sessions at the Kerby Centre Study groups became research groups Recruited partner sites for each of the six research teams Observed and recorded in partner site                     | Senior researchers seen as researchers within partner sites Seniors skilled at observing, recording, familiar with observer bias   |
| Interviews<br>and ques-<br>tionnaires | Review of field<br>observations to prepare<br>for interviews<br>Training at the Kerby<br>Centre of Excellence<br>Follow-up sessions<br>with research teams to<br>prepare questionnaires<br>for partner site | Developed, tested and evaluated questionnaires Senior researchers interviewed key people in partner sites Analyzed data from questionnaires and from taped interviews            |

| Focus<br>groups                | Review of interviews to prepare for focus groups Training at the Kerby Centre of Excellence in focus groups Negotiated with partner sites to develop the focus groups Senior researchers conducted focus groups in each of the partner sites | Senior researchers competent in focus group roles Analyzed data and wrote report for partner site  |
|--------------------------------|--|--|
| Narratives                     | Training at KCE for senior researchers alongside interviewees Interviews conducted same day with graduate student mentors Follow-up interviews and analysis  | Seniors competent at taping interview, compiling stories from tapes, and data analysis  Analysis of stories by PhD students and senior researchers (university course)   |
| Evaluation, reports and manual | Four group evaluation sessions by total research group – senior researchers, principal researchers and Kerby staff Ongoing group discussions with seniors.   | Developed evaluation methods as a group Final report written by principal researchers and project staff then shared with team leaders Manual drafted by principal researchers for future field testing Grey Matters written with seniors |

## A. Setting the Agenda

The KCE invited seniors from the Kerby Centre membership, a group of experienced researchers from local post-secondary institutions, representatives from the City of Calgary, and representatives from the Calgary Health Region to share their experience and help create a research plan for the Centre of Excellence. After much discussion, the seniors at the table suggested resilience as an important aspect of healthy aging.

A subcommittee of seniors and researchers then applied to the Canadian Institutes of Health Research (CIHR) for funding to run a workshop on resilience to test the interest in resilience as a research topic among seniors and to further develop specific research questions and methods about resilience and aging. A group of retired professors from the University of Calgary and Kerby seniors helped design and facilitate the day. They brought a love of research and their excitement about involving others in research.

I couldn't believe how much time we spent arguing about that first workshop – the right questions, how to get everyone involved, what to do with the information and how to reach our goal. After three planning sessions, I began to realize that this was really different from the kind of research I was familiar with where researchers are in charge. I hope all the planning and technology pays off. (BM, 2004)

We began the workshop by discussing people's experience of resilience because we wanted to start afresh and not be confined by definitions created by others.

I kept wondering why they wouldn't just tell us what resilience was, it was just a little vague guessing what everyone else thought. Eventually it became clear what we were doing. It was an interesting collection of people and I'm always pleased when people can come to their own understanding. (NM, 2005)

We had tablet computers that allowed recorders to write notes in longhand at the tables and transmit the notes to a central computer so that we could analyze what was happening. In the morning, workshop participants worked in small groups sharing their stories of resilience and thinking about what they had learned about resilience from their stories. Ongoing summaries were projected on a very large screen so that everyone could see their ideas take form. All felt part of the process and were intrigued to see their individual and small-group ideas on the large screens. Sharing ideas through technology meant that we didn't have to listen to each group present its findings. The feedback was immediate and easily led to consensus, as can be seen by the following quotes:

The recorders were extremely unobtrusive. Everyone was encouraged to speak and they were listened to. The recorders would check with us by asking if what they read from their recorded notes was what we said. (GQ, 2005)

It was stimulating! If someone was saying things that were similar to me it confirmed my thoughts. However if it was different, that's when I learn. Sometimes you shuddered when you heard what some people had been through. (NM, 2005)

In the afternoon, the focus shifted and groups were encouraged to think about the questions that were raised in their discussions. Each group came up with three to five questions that they wanted answers to. Again, with the rapid recording through the tablet computers and the ability to analyze group data, we were able to see themes or directions emerging.

Table 2. Questions and research themes from Kerby Focus Group, 2005.

| RESEARCH<br>THEMES            | HOW DO THESE ADD TO RESILIENCE?  |
|-------------------------------|--|
| Ethno-cultural uniqueness     | Is resilience affected by cultural values and traditions?                  |
| Spirituality                  | How do faith and belief impact on people's sense of resilience?            |
| Health of individuals         | How does health influence resilience?                                      |
| Learning                      | Does access to opportunities to learn and grow impact on resilience?       |
| Rural living                  | Do people in rural areas have a different way of understanding resilience? |
| Physical activity and leisure | How does activity and leisure support resilience?                          |

Although it was not part of the agenda, there seemed to be a great deal of enthusiasm in the group and people asked to form groups defined by the above areas. The retired professors, along with several others from the workshop, joined the groups to help refine research questions for a future pilot project.

## B. The Pilot Project Proposal

An application to the Canadian Institutes of Health Research – Institute of Aging (CIHR–IA) for the pilot project, Sites and Sources of Resilience, a study of how to engage seniors in doing research about seniors, came from the above groups (Appendix 3). We were also able

to clarify the research questions in two workshops that were conducted in Calgary and Cochrane, a small community west of Calgary. It was apparent that seniors wanted to be an integral part of the research so we made a concerted effort to use Participatory Action Research (PAR) principles to ensure full participation. We also capitalized on their interest in learning and working in groups: we transformed the study groups into research teams.

The research was developmental in that we began with basic research skills and each step in the project built on the accomplishments of the last:

- The results of observation phase were used to design the interview questionnaire phase.
- The results of the interview questionnaire phase led to the focus group phase.
- The focus group phase set the stage for narrative research.

### C. Organization of the Project

The project itself was complicated by the desire of the seniors to learn about research and to learn by doing research in the area that interested them. Each research group had a partner site related to their question. These sites worked with the seniors researchers in learning how to conduct research. This added a layer to the organization.

Figure 3 shows the research organization.

## D. Naming the Participants

We had some trouble deciding on the titles for the partners and finding a balance between everyday language and academic language to depict the various roles in Figure 3. Although we spent a great deal

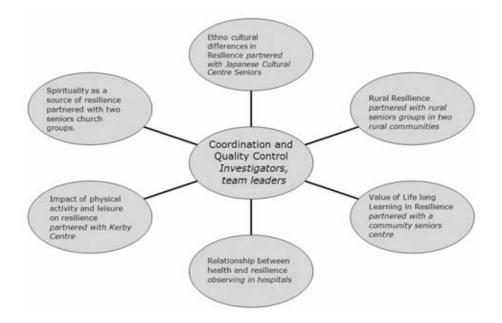


Figure 3: Organizational chart for pilot project.

of time debating terms before submitting the grant, the debates continued. The following titles were finally negotiated to describe those who were involved:

**Senior researchers.** These are the aging adults who participated in the research project. Senior researchers had three linked roles: to learn about research, to be studied as they conducted research, and to conduct research. There was confusion about these roles, especially since most had signed up following the introductory workshops on resilience to study the topic they had chosen.

**Group leaders.** Retired professors from the university, community researchers, or elected seniors. Each leader acted as a mentor, providing instruction, guidance, and supervision as needed to a group of three to seven senior researchers.

**Research group**. The three to seven senior researchers worked relatively independently, with the guidance of their group leader. Some groups met regularly outside of the required sessions and each developed its own style and roles. Most groups nominated a coordinator who worked with the project staff person to collect data and evaluations, organize notices, and schedule meetings with the partner sites.

**Partner sites.** These were the agencies, programs, or groups of seniors who were recruited as a research site for each group/topic. For example, seniors' programs in churches acted as research sites for the spirituality research group. The Japanese Cultural Centre was the primary research site for the ethno-cultural research group. The Seniors Centre in Okotoks was a site of the rural research group.

**Investigators.** University researchers named in the grant proposal worked closely with the director of the KCE and the project staff. Investigators handled the grant requirements as well as liaison with the university and the Kerby Centre. Along with the project staff and group leaders they oversaw both the planning and evaluation of the project.

**Advisory committee.** This consisted of representatives from the City of Calgary, the Calgary Health Region, post-secondary institutions, the Kerby Centre Board and the team leaders. They were responsible for keeping their constituents informed, advising on direction and results and arranging small funds when necessary.

**Total team.** Senior researchers, group leaders, principal investigators, and sponsors were involved in all policy changes, training events and evaluation sessions.

The following four sections tell the story of each of the research methods studied: field-work, interviews, four groups, and narratives.

### E. Field-work Observations and PAR

Always having been an inquisitive sort, I found the observation process interesting. I was struck by the seriousness of people and how briskly they moved around. (RM, 2005)

We chose field-work as the first research approach because we wanted to introduce research as part of everyday life. Here the "field" was a partner research site that represented the topic area. We adopted participant observation as the method because it provided a natural and practical introduction to research roles. In this method, seniors joined in with the activities of the site they had chosen.

As a researcher I was keen to observe everything about people's behaviour, the way they talk, laugh, walk and listen. I respect myself and have the self-confidence to do the observation, especially observing the body language. (AR, 2006)

The goals of the field-work/participant observer sessions were:

- Visit and learn about the chosen partner site.
- Explain and practice a research role.
- Learn observer roles while participating fully, partially or observing passively.
- Record observations of behaviour noting time, space, people present, activities and conversations.
- Compare recordings with other senior researchers and discuss sources of differences in their observations
- Discuss how to minimize bias in recording.
- Evaluate the field-work as a research method to be used by seniors.

The field-work workshop was conducted by Joan Ryan, a retired professor and anthropologist, who had trained communities in northern Canada to use research as a tool for social change and self-determination. She told stories about what communities were able to achieve. She taught that the foundation of good research is observation and recording. We were also visited by two disabled Aboriginal researchers who shared their research within their communities. They spoke about being marginalized within their communities and how this changed as they learned how to conduct research.

The research groups practised observing activities within the Kerby Centre. They then shared their findings and discussed how each person saw and recorded from his or her own perspective. They discussed how these perspectives were influenced by their values and experience. They also discussed how to hold their opinions in check while observing and recording.

The senior researchers decided that they needed an observation booklet and one was prepared after the session for the researchers to use in the field. This is included in Appendix 4. The following quote is from the summary of an observation of three hours:

As an observer, I just got a general feeling of comfort, people smiled at each other, they stopped to chat when they were getting materials, there didn't seem to be anyone who was more important than anyone else. There was one woman however who talked a lot and said a lot of negative things. (SR, 2006)

The senior researchers were now ready to observe at the partner sites. The process of obtaining agreements with partner sites reaffirmed how difficult it is to conduct partnership research in community settings. The opportunity to be involved in research, even when presented by seniors, was met with caution and concern about the agenda, how the information was going to be used, confidentiality, and the partner site's responsibility in the project. Once all of the negotiations and

release forms were signed, the seniors spent two to five hours "in the field," observing and participating at their partner site.

As first-time researchers, they were tentative and nervous. They felt they didn't have clear enough roles, and they felt awkward watching people or talking with people, but this changed for most observers.

I wasn't sure precisely what I was doing and what I should be looking for but I was surprised that I didn't find watching people or taking notes any way embarrassing. (RM, 2006)

The observation booklets worked well and the group leaders generally commented on the accuracy and thoroughness of the observations. Senior researchers recorded activities, interactions, hierarchies within the groups, and their perception of the mood of the group.

In Chapter 3, field-work methods are expanded to include oral histories and collections.

# F. Surveys and Questionnaires

Personally, I would have liked to have prepared questions and was a little concerned about where the open approach might lead us. I ended up being happy with the simple guide we had prepared of a few questions that I could refer to. I was able to feel that we were getting the info we wanted with our planned strategy. I felt good learning how to be a researcher using a method that was new to me. (SR, 2006)

At this stage the senior researchers used the information from their first visit to design a set of questions for the coordinator or president of the partner site and any others who were interested in being interviewed. The principles and goals of this session were to:

- Learn more about their partner site;
- Establish a working relationship with the leader of the program at the sites;
- Introduce the senior researchers to more structured research;
- Develop a questionnaire based on the observations of the group to gain information about the history and functioning of the partner sites;
- Interview and record answers to questions;
- Analyze the data gathered from the questionnaire; and
- Report back to partner site and research team.

Some of the groups developed open-ended questionnaires that ended up as conversations, whereas others developed very structured questions with prepared options for answers. We learned a lot about the advantages and disadvantages of the different strategies in the discussions that followed. The open-ended questions were easy to administer and difficult to analyze, whereas the closed questions produced somewhat boring and expected answers but were easy to analyze.

The session was conducted by Dr. Bob Stebbins, one of the research group leaders and a retired professor from the University of Calgary. He was able to provide an overview of more formal research expectations and focused on how to design questionnaires that would answer the questions people had. Chapter 4 looks at interviews and questionnaires in detail. It took relatively little time to teach the skills and the end results were easily analyzed in preparation for the next large step forward.

## G. Focus Groups

It is critical for the researcher to remain focused on the topic of the research. I had to learn to avoid injecting personal opinions or stories about resilience. Be ready to ask related questions if the participant's input lacks detail. Be alert to discomfort on the part of participants. Be a good listener. Be friendly but neutral during the break. Socializing, while important, should be done after the session is ended. I need more experience researching to be able to really do this well. (AH, 2006)

By this stage the senior researchers were anxious to move into researching the topic of resilience and move beyond getting to know their partner sites. The groups had become much more cohesive and wanted to work as a team. For the first time they were able to choose specific research roles as part of their teams. The focus group research had the following goals:

- Introduce the topic of resilience in the partner sites.
- Recruit focus group participants.
- Learn how to negotiate research agendas with the partner site participants.
- Take on specific roles within the overall research strategy.
- Practice and support each other in conducting the focus group.
- Design an evaluation and administer it.
- Analyze data from focus group research.
- Prepare reports for the partner site.

The introductory session on focus groups was conducted by one of the principal investigators, Nancy Marlett, who combined the lessons that had been learned to this point in the study. These lessons were: provide structure, use storytelling, build on group strengths, and enable groups to adapt methods to suit the needs of their topic and their partner site. The training workbook is included in Appendix 5.

During the training session, each group was encouraged to work through a structured workbook making suggestions to customize a research protocol that they could then take to the partner sites to negotiate and run their focus group. The following is a reaction to the experience:

As all participants had been mailed an invitation in advance outlining the purpose of the focus group, the topic of the day and the questions we would be exploring together, everyone felt comfortable and at ease in the setting. They expected to have their responses recorded and seemed unconcerned. As a result my recording felt comfortable, it was done as unobtrusively as possible. (AH, 2006)

Roles were well-defined, for example, who would make the room arrangements, who would greet the participants, who would do the recruiting, who would operate the flip chart, and who would provide comic relief. The details are included in Chapter 5: Focus groups and the workbooks and examples of reports are included in Appendices 7 and 8.

At this stage, the work of the senior researchers expanded as they took on more administrative duties. They recruited participants, negotiated the agenda, set up the focus groups, lead the group discussion, and recorded and analyzed the data. They also prepared reports to give to the participants. Each group worked in different ways, depending upon the team leader, the strengths within the group, and the nature of the focus group partners.

Without exception, this experience was the highlight of the research for the seniors. They felt that they had taken control of the research process, that they had learned a great deal about conducting research and that they were stronger not only as researchers but as people. As the groups met to analyze their data and write their reports, they began to understand the important contributions that they could make as researchers.

By this time, senior researchers and partner sites were familiar with each other; they had a base of trust that made recruiting participants relatively easy. The researchers felt competent and empowered and this made the seniors in the focus groups feel secure and open.

Everyone commented on the professional skill level of the senior researchers, their ability to structure and pace the day, their ability to engage participants, to honour the differences in the group, and to provide feedback about the direction of the research. The researchers themselves noted their surprise at how effective they were and how their earlier training was beginning to pay off. Most of all they enjoyed working with other seniors and conducting research.

### H. Narrative Research

The process of taping the interview gave me a "hands free" conversation. I tried my best to only listen, but found myself wanting to get in there with my own opinions. It was good not to have to take notes as well as interview. I would have missed a lot of the detail which was so interesting to hear, and later to analyze. (MW, 2006)

Buoyed by their success in the focus groups, the senior researchers looked forward to the challenge of conducting follow-up interviews with their chosen participants from the focus groups. Nancy Marlett, who had worked with many other marginalized groups

using narrative methods, relished the challenge of building on what had been effective in the focus group to develop a peer-based narrative interview process. Because the seniors were familiar with storytelling approaches, the senior researchers were able to move beyond basic narrative methods to create an in-depth interview process that introduced several new aspects to the research experience:

- Recruit a partner and prepare them for the interview experience;
- Interview using a peer-to-peer approach following a research script;
- Deepen their understanding of resilience with a knowledgeable participant;
- Learn specific skills related to in-depth interviewing, such as pacing, probing, synthesizing, and motivating;
- Manage tape recording and transcribing; and
- Analyze taped data and compile stories of resilience.

The senior researchers and the people they were interviewing were trained together to reinforce equality in peer-to-peer research. All participants were given manuals to work with during the training day. Once the protocol was explained, the peer pairs, along with a graduate student or other resource person, conducted the interviews.

The experiences of the narrative interview were not as positive as the focus group, partly because it was rushed and despite our attempts to provide materials beforehand, some participants did not get the materials in enough time to prepare. This emphasized the need for preparation beforehand. This was an advanced research technique and was unfamiliar to most. Many of the seniors felt unprepared to conduct these powerful interviews. Some felt nervous or frustrated with the equipment, others wanted more privacy in the interview process, and others found it difficult to engage seniors on a one-to-one basis. Nevertheless, the interviews produced very telling and provocative stories, which led to interesting information about resilience that would not have been achieved in any other way. Most senior researchers were quite amazed by their ability to extract stories and data from the interviews and the tapes.

I have enjoyed this experience but have a lot to learn about "picking up" on important points in the interview and getting the interviewee to elaborate. Also, I am not very good at expressing myself in writing, about putting down what I had experienced with the interviewee. (MW, 2006)

While some were shy about compiling stories and relied on other team members to assist in preparing their analysis, the stories were of very high quality. The method used was felt to hold promise within a larger research project where more time and support would be available. One senior researcher reported being a little tentative at first as this is a topic that asks people to dig into past experiences and often their innermost feelings, but said later:

Even though we hardly knew each other, we discovered we had experienced similar things in our lives. In other words there was already a kinship. Questions were handled easily and any problems were easy to clarify. (RM, 2006)

The research protocol has the potential of being adapted to research that requires in-depth narrative interviews about complex topics. In a follow-up session with seniors who wanted to learn more about narrative interviewing, it was clear that seniors were able to conduct interviews using the forms at an advanced level. Narrative interviews were then analyzed as part of a seminar course with seniors and PhD students on the topic of Resilience and Aging. The results are included in Chapter 6. The narrative interview guide and training material is included in Appendix 9.

## I. Evaluation and Follow-Up

The project itself was only a year long but the evaluation and followup discussions were still active two years later. The standardized evaluations designed as part of the project to assess the methods and the senior researchers' reactions to the methods did not begin to tap the profound changes that had occurred. There were a number of allday sessions where we reflected on what we had done and how to move ahead. The goals of the evaluation were:

- Identify challenges to teaching research with seniors;
- Adapt existing research methods;
- Identify which methods seniors like to use and which methods they excel at;
- Collect evaluations of the process by partner sites;
- Identify changes in seniors self-concept as a result of the training; and
- Decide on directions for future research

These sessions led to a number of presentations and articles about the findings. Most who heard about the project were surprised – surprised that seniors were interested in research, that we had taught

formal research methods and that a different view of resilience was emerging. The following are some suggestions about evaluation in this type of research:

**Don't wait to evaluate.** We had evaluation forms for senior researchers to fill out at the end of each method. These were not very effective because they seemed to be extraneous and not connected to the actual project. Very early in the process, we began to see the advantage of informal discussions about challenges and opportunities. Full team meetings that planned the next step were much more effective in evaluating the process. In these discussions, seniors had immediate feedback and saw their suggestions implemented.

Have some distance in evaluation. To save funds, the investigators and staff conducted the evaluation but it became apparent that, while the evaluator needed to be part of the project, he or she needed to focus on the evaluation, to record what was happening and to tailor the evaluation to the needs of the project. A participant observer/ evaluator would be more effective, especially if that person was a senior.

**Separate sharing from evaluation.** Research involving seniors needs to provide time to share ideas and feelings. When sharing and evaluation are combined, there was a tendency to see things as black and white. After the project was over and the formal evaluations were complete, we were able to achieve a much deeper understanding of the process because our discussions were not about good and bad, they were about changes in knowledge and self-concept.

This chapter has provided a general overview of the CIHR research that investigated the potential for seniors to be involved in research. Much of the manual has evolved as we applied what we learned to other projects. We recognize that without this opportunity to experiment, the dream of seniors-led research would still be at the concept stage.



**Penny Jennett** 

What fascinated me was the whole idea of seniors researching seniors, and being part of a project that provided seniors with some tools to provide input into how their stories are told.

# Section 2

## Research Methods Manual

For the next four chapters (3–6), we move to a manual format, a doit-yourself guide for inquiry and research. We use the terms "you" to denote that *you* are doing the work in each of the methods.

This book is designed as a course so that it can be used in sequence or you can use it as a reference manual using specific chapters of interest. Some groups or individuals may use the materials to guide independent inquiry or research, choosing the tools that best suits their needs. Others will invite a mentor, such as a retired academic, to work with them in designing a research project and learning the specific skills needed to carry out the project. Academics may use these chapters to train seniors to work alongside them in developing and carrying out research about seniors. Students may find these chapters very helpful in creating collaborative inquiry projects and research with seniors as part of their education. Several of these

chapters have already been adapted by other groups wanting to do collaborative research.

Each chapter follows the same format:

- Introduction and when to do this type of research,
- Recruitment of participants,
- Roles as a researcher
- Collecting data,
- Analysis,
- Interpreting and presenting your findings,
- Ethical issues and approval,
- Suggestions for training seniors as researchers,
- Summary, and
- References.

3

## Field Research

Chapter 3 introduces observing, recording, and collecting materials as the fundamental skills of all research. These are best learned in a natural or field situation. In field research the goal is to understand local knowledge and perspectives using organic methods so that the research unfolds naturally, without interference (although your presence is always felt).

For this chapter we visit the Snowbirds Fellowship in Bragg Creek, Alberta, and their oral history research.

The Snowbirds Fellowship of Bragg Creek, Alberta, was given a box of snapshots of the village and this led to many discussions about how the hamlet had changed over the years. The seniors felt it would be important to capture the history for the children and newcomers. The timing was right because their interest coincided with the Centennial of the province and there was money available for local history projects. They submitted a grant and contacted a local resident who had done biographical research to help them set up their project.

A group of volunteers held several training sessions to clarify the goals of the project, research methods that would work, and a process for documenting and saving the photos and recording the process.

They invited residents and those who had moved away to bring their photos to a photo collection day and, after obtaining consent, they recorded the details about the photos and scanned them. When they had collected the pictures they spent time discussing what they had found, sorting pictures into categories by date and figuring out what story the pictures told of Bragg Creek.

Once they had their research done and they had identified three historical periods and the reasons for transition, they contacted a local graphic artist who worked with them to present their work through computer-generated poster panels. The final product is a three-panel presentation, which travels between the schools, the Snowbirds Centre, and various events. The knowledge that the seniors held is now part of the story of Bragg Creek for all to share.

#### A. When Would You Do Field Research?

The ability to observe without bias, to record systematically and objectively, and to analyze what you have found enables you to understand what is happening around you. You then can make better decisions about programs, activities, and relationships. The following are examples of when you might use field-work methods:

**Oral history projects** are very popular and enable aging adults to research and record their shared past. Oral history shares many of the same features as writing a personal life history, but an oral history combines personal stories into a shared story.

**Participatory Action Research** with communities relies on the skills of observing, recording, and collecting to figure out how different people understand their situations from their unique perspectives. Field-work skills enable you to take part in events, ask questions, and

learn from what is happening in a natural way while meeting the requirements of research.

**Evaluation research** uses field-work skills to help you to note changes in the programs or policies you are assessing.

**Ecological research** looks at the impact that social environment (people, groups, networks, competitive situations) has on people's actions and beliefs. For example, the Bragg Creek Snowbirds could have studied the impact of cottagers and tourism on the ranching life of Bragg Creek.

**Lived experience research** attempts to document what life is like for people in particular circumstances. For example, if you are interested in what life is like in an Alzheimer's unit of a rural hospital, you might spend time on the unit with patients, observing what is happening, talking to them and carefully recording your findings.

Field-work consists of an extended period of study in a setting. We have organized the information on doing field-work according to the basic activities of all research and inquiry:

- Recruiting and orientating,
- Observing, collecting, and recording data,
- · Analyzing and interpreting your findings, and
- Presenting and disseminating your findings to others.

While these activities are presented as if they occur in an ordered sequence, in reality, the steps move backwards and sideways as well as forward. The process of collecting data deepens your understanding of the setting, and, as you organize and describe what you are finding, you discover other aspects to observe.

Field-work begins with the assumption that our environments and social experiences influence whom we become. For example, you will likely see Bragg Creek differently if you are a rancher, a summer cottager, or a business person or if you live in a large estate outside the hamlet.

## B. Recruiting Sites and Becoming Orientated

Finding and gaining access to situations and groups can take a great deal of time and effort. You may be lucky and be part of a group that is interested in doing field-work. You may be approached by a group that is interested in finding out more about a topic of interest to you. If not, find a contact within the group to act as your agent in arranging meetings to discuss research. If an informal contact cannot be made, you will need to approach someone in control with a formal proposal. Field-work often evolves; you start small and hope that sites will become interested.

Once you are in the setting, you will need to spend time taking in the physical setting and learning about the social environment. The following are some of the way that this happens.

**Develop relationships**. This may mean forming a research team or advisory group within an organization. The Snowbirds Fellowship is largely a social group that assists seniors and the community. The photo project attracted a small group of about twelve members who were interested in learning about research and producing a photodocumentary. This group was the working group for the project and shared all decisions.

**Negotiate the scope of the project.** The initial idea was to write a book about Bragg Creek history, but this was soon changed to focus on a photo exhibit. It was later decided to focus only on the built environment; the roads, buildings, oil wells, and fences. At each stage, the focus narrowed until the project was manageable.

Clarify roles of collaborators. Despite the fact that they knew each other, it was still important for the members to establish research relationships based on each person's skills and interests. The following segment was taken from minutes of one of the organizing meetings where each person identified how they might contribute to the project:

*Karen:* "I can be the bully to keep the project moving along and on track."

Hazel: "I've been here for fifty years; I have lots of energy and am willing to do most anything with guidance."

*Yolonde:* "I was the librarian and love to collect stories of the area."

George took the photos of the building of the Snowbirds Chalet.

*Brenda:* "I am comfortable organizing and working with maps and have a computer background."

*Terry:* "I know about computers and have the scanning software."

*Jacki:* "I was the postmistress when the post office was in my home and was a founding member of the Artisans. I know and will work with Sig who has the majority of pictures."

From these discussions, the following team functions were established: a. Contacting and recruiting people who had pictures, b. Interviewing people and filling out forms, c. Computer scanning of photos, and entering text materials onto computer forms. Everyone took part in the development of the data sheets, the organization of the collection of data, and the data analysis.

In field-work you meet people naturally. When you need to locate others to participate, you ask people in the group for suggestions. You can put up notices, and advertise in newsletters or local papers. In the photo project we prepared a description of the research and the

role of the senior researcher. We identified the time and involvement required and how the people might benefit from the field study.

The Snowbirds' photo documentary of Bragg Creek: We are collecting photos of our history that tracks changes in building, roads, bridges, and camps. We will scan your photos and return them, but would like to ask you a few questions about your photos. We hope to use the information we gather to produce a photo display. The photos may also be of interest to others researching Bragg Creek.

And the following is part of a script for doing phone recruitment:

I am a senior from the Snowbirds Fellowship in Bragg Creek. I am learning to collect information and will be involved in analyzing photographs. We have two researchers from the University of Calgary that are helping us conduct this research and if you have any research concerns they would be happy to meet with you. (phone recruitment 2007)

## C. Collecting and Recording Information

As a participant/observer you are involved in the activities of the group you are observing. You may have been a member previously or you may ask to join for a short time. While you may not know specifically what you might find, you must declare why you are there, what you are interested in, and what you are going to do with the information

As you participate, you become part of the group being studied. Your own reactions are part of the information you are expected to observe and record. You do this because you are a newcomer to the group and your reactions are as important as are people's reactions to you. You also do this so that you can study the impact you are having.

It will help you control your biases, your influence, and your desire to change things. While your presence may alter the established routines and interactions, you should not attempt to fix things.

As we started recording immediately on arrival, there wasn't really time to feel anything except busy. A few people made the odd friendly, basically meaningless, comment. No one seemed bothered by our activity. (NM, 2005)

When you become a participant in a group, you are working from an insider position of privilege. You have access to everyday life activities, expectations, reactions to change, and entrenched patterns of interaction and status. This information is not available to outsiders and you must honour the privilege you have.

There are many different ways to gather information. You may take minutes, collect hats, or take part in volunteer grandparent visits to a local day care. We begin this section with observation and recording, for no matter what else you are doing, it is important to record your process.

Recording that is done as part of field-work would be called "descriptive" because you are attempting to tell what is happening without opinion or judgment. Writing "everyone was interested" is a judgment not an observation. An observation might be "everyone was looking at the speaker and they were nodding silently to the presenter."

To learn how to write what you see, rather than what you think, practice recording with other seniors and compare notes. Compare and critique each other's notes to find examples of bias and judgment in order to separate your beliefs from what is happening. It is as if you are connecting your writing hand to your eyes and ears while bypassing your mind.

When observing a group, focus on each individual in the group, and notice who is not interacting. When observing individuals, try

to capture statements that seem to represent what you are observing. For example, one of the women declared in a loud voice, "why can't people let old buildings stand when they aren't in the way?" Make a record of statements that relate to your topic and be sure you have the date and the person's initials so that you can use it as a quote later on.

Having a consistent format at the top of your record sheets will help you keep track of your observations. Include the date, place, observer, and activity on each page. Most researchers divide the page in two when recording. They write what they are seeing on the left side of the page and use the right side for comments and notes. A sample of an observation form that has been filled in can be found in Appendix 4.

If you are familiar with the setting and activities and have an idea of what you are looking for, you can create a shorthand set of codes to make the recording easier. There are no standardized ways of creating shorthand codes so you must be sure to record what the codes mean alongside your data so people in the future can decipher what you were writing about.

You could choose to work with a commercial observation check-list that lists the behaviours you are looking for. For example, Rudolf H. Moos has created a series of Social Climate Scales (available online: http://www.mindgarden.com/products/scsug.htm) that have been created from years of observing social environments and summarizing important features. An example of this type of standardized observation form would be the Group Environment Scale that provides statements about relationships, system maintenance, and change. After observing within a group, you would respond to questions such as:

When members disagree with each other, they say so.

#### What can you observe?

In any situation, there is much more happening that you can realistically observe, let alone record. You could record whatever strikes you as interesting but this seldom leads to useable data. You will need some guidelines so that you can train yourself to focus your observations and recordings. The following is a sample of these guidelines:

**The setting** and how it is set up for activities. For example, if you were in the Snowbirds Centre, you might record:

The centre is a large log structure with high ceilings and a large fireplace. At the entrance door, several people are standing by a scanner on a reception desk. There are also three desks set up to record information about pictures posted at the far end of the room. On the wall there is a large area map where a person helps identify where on the map each photo was taken. There is a coffee area where people can sit and chat over coffee and cookies. When people enter they speak quietly and follow directions to work areas.

The people in the room and their interactions: Describe the people being observed; their age, gender, style of dress, and culture.

Volunteers smile and move about. There are 6 women and 2 men volunteering today, all appear to be between 65 and 80 years old. All are Caucasian and are wearing casual clothes. Those coming to donate pictures are also Caucasian, some come alone, others in couples or with family groups.

**Interaction patterns** and specific interactions that are relevant to the study.

While there is an easy rapport among the volunteers and donors, they go about their business without much socializing. Each person seems to know their job and they don't ask for instructions

**Activities and behaviours:** In addition to the actual activities, be sure to note who or what starts the action, who is involved, who is on the sidelines, what signals that activities are finished and how transitions are made.

I am sitting at the reception desk by the door and I am with a recorder and Terry, who is here to scan the selected photos. There is also a greeter at the door who opens the door for people and brings them to the reception desk. She also asks if they would like coffee or tea and thanks them for coming. She introduces the person to the recorder who then takes the person to one of a number of desks set up with two chairs, space to sort photos and a stack of scanning/photo information forms. They sort the pictures, choose the ones to be scanned and the rest are given back. The recorder then records the codes for the photos.

They then go to the map and place a pin where the picture was taken. There is a lot of interest in where the other pins are (noting where other photos were taken) and what the colours mean. There are still people from an earlier group and they talk about how their photos contribute to the overall picture and what else they should find pictures of. There are also some problems finding the exact location even though the map is very large.

There are several recorders waiting to take their person back to the reception desk where the photos are scanned and the originals returned. The person then is invited to chat with others or is seen to the door with thanks. Unexpected events and peripheral activity: Describe what is happening behind the scene, comments made about what is happening, or how language is used in particular ways. What is not happening that might be expected?

There is a bottleneck by the map, which is attracting people when they have finished the process. There is now an active group that is discussing where on the map a planned new bridge should go. It is difficult to get the new people processed.

Collect documents, artifacts, and quotes: The easy part is finding things to collect; the hard part is knowing what to select from all the items that are available.

We didn't want to offend people so we took more pictures than we needed.

The following computer format was created to collect data. The photo was scanned and the information was typed into the form while the contributor watched. They then signed the release at the bottom of the form and took a copy home with them.

The Snowbirds decided to use codes for most of the information they were collecting to make the recording process easier and to ensure that nothing was missed. The codes were entered onto the scanning sheet above. The codes related to:

- The year of initial construction;
- Map location co-ordinates;
- The function of the building's environment: ranches and farms, outbuildings and sheds, camps and cottages, churches and gathering places, etc.;
- Style of construction sod/tents/lean to/log/frame.

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Figure 4: Sample of photo information with codes: Snowbirds photo documentary.

# D. Analyze Observations: The More Structured Your Recording, the Easier the Analysis

Once you finish your recording, read over your observations and make comments on the right-hand side of the page about ideas that need to be clarified and your ideas about what might be happening. Write a short summary of what you learned at the end of each day of recording.

When you are doing descriptive recordings, read the summaries you have produced to get an idea of the general categories that are emerging. For example, you might become intrigued by the impact that large maps have on group behaviour. Read through your recording and highlight those sections about groups at the map with a highlighter pen. If you expect to have several different categories, use different colour highlighters and mark down what each colour means.

Once you have finished this, you could read each coloured section to find out the common descriptions. For example, you may find that groups are most likely to form when they are interacting with the map – placing pins where they live, locating bridges, etc. Whatever your findings, share them with people who were present to get their ideas about what you are learning from the data and ask for their input.

Cataloging and categorizing artifacts. If you are considering creating a collection of artifacts, it is always helpful to contact your local museum staff before you start. They are the experts in this type of research and would be happy to assist you. It is almost impossible to move ahead if you don't have a clearly defined path (called a provenance) for each item – where it originated, where it was found, who owns it, etc.

Once you have catalogued or categorized your items, look at all your information and try to **find similarities and differences** that can describe your collection. You will likely have to try out a number of categories and patterns as you sort your information.

All of the scanned photos were sorted first by year and then by the types of building. We then tried to figure out the story that the photos told.

**Locate quotes** that describe the visual and auditory materials you have found within the categories you have created.

As we sorted we decided that there were three main phases to Bragg Creek determined by the opening of roads. We selected pictures that best told the story and included quotes that people had given us.

These methods apply to any research project where you work systematically to collect, organize, and present collections of pottery, hats, letters, paintings, children's rhymes – the sky is the limit.

If you wish to do more interpretive field-work, you might use analysis sheets such as those produced by the Education Staff of the National Archives in Washington (http://www.archives.gov/education/lessons/worksheets).

The following form is an example of document cataloguing that can help you to start on your analysis. You could use the same approach for any items.

Table 3. Document analysis (adapted from the National Archives, Washington, D.C.)

#### 1. Type of document

Map

Telegram

Report

Advertisement

Government report

Census

Newspaper

Letter

Memo

#### 2. Unique physical qualities:

Interesting letterhead

Handwritten

Typed

Seals

**Notations** 

**Stamps** 

Other

Notes on qualities

- 3. Dates of document
- 4. Author and position
- 5. For what audience was the document written?
- 6. Document information:

List three things the author said that you think are important to your topic.

Why do you think this document was written?

What evidence in the document helps you know why it was written? (Quote from the document.)

List two things from the document that tell you about life at the time it was written.

What questions are raised about the document?

### E. Prepare Your Presentation

This is the creative phase of your work. Information needs to be presented so that others will be interested in what you did and can understand what you found and what it might mean. Many of the projects undertaken in field-work, oral history and Participatory Action Research invite presentation to an audience. You have a wonderful opportunity to move beyond the obligatory report to the funding body and to make your knowledge sing.

You may do a pamphlet, a poem, a poster session, a video documentary, a collection, a play. Many people run out of steam by this point in the research, but it may be the most important and the most fun. You have done the research to share your ideas with others so it is important to put all your creative energies into this stage. You may be lucky enough to find a new group to take on this aspect of the research – a local playwright interested in Readers Theatre, a muralist intrigued with how to capture the vision in your work, a poet, or a songwriter. Work outside the box in thinking about your potential audiences and how to get to them.

We were able to hire a local graphic artist who took the work we had done and created three panels that were that mounted on frames. This made a wonderful display that has been to local events, the school, and the municipal district offices.

Create a story about a critical incident or situation that speaks directly to your question. Whatever your chosen technique for getting your message out, frame your work within a story. Your audience will understand your research easily when they can relate to the story.

The story of Bragg Creek is a story of how bridges brought three distinct waves of settlers: first the ranchers, then the cottagers and finally the commuters.

## F. Ethical Issues and Ethics Approval

When using participant observation methods, it is likely that you are working with an inconsistent group of people. The person signing the consent form is representing the best interests of the site or program. This may cause concern within the university's ethics process, where the policies depend on individual protection and confidentiality. Most of our Kerby observation sites were concerned about why they were chosen and what information was going to be shared outside of the group.

In field-work situations, it may be impossible to keep the group's identity anonymous because the activities described are unique to the situation studied.

Ensure confidentially if people are concerned about not being identified. On the other hand, if you are collecting heritage items, families will want to be recognized and credited with the donation. Regardless, you will need informed consent to share the ideas and things that you collect. The original consent form followed archival procedures. The consent form stated:

Thank you for participating in the Snowbirds' photo legacy project. By signing the attached form you give your permission to use any photograph donated to this project. While the intent of the project is to produce a photo exhibit for Alberta's Centennial, the material may be of interest to public archives (museums, libraries). It will be available to researchers and the public for scholarly and educational purposes including publications and exhibitions. By giving your permission, you do not give up any copyright you may hold.

I agree to the uses of the materials described above.

Even though this type of form is commonly used, it proved confusing and difficult for those donating pictures and was subsequently revised. The final version is simple and to the point and was signed at the bottom of the computer-generated information sheet that describes each photograph that was collected:

| I understand that the photo and information I have offered will be scanned and may be used in presentations about the history of Bragg Creek. |
|---|
| Date:   |
| Signature:  |
| Witness:  |

Always test your consent form to make sure that you use plain English and strive for as short a version as possible. It is not uncommon for aging adults to refuse to participate if they do not understand what they are signing. When consent may become contentious, you will want to check the version you are using with a museum representative or lawyer.

### G. Outline for Training People To Do Field-work

Ideally, you would have three class times of about two hours each. Each class would include discussion and practice. Have people read Chapter 1 of the manual before starting.

#### Overview

Introduce the challenge of observation as a research skill and have the group watch a video clip to see if they can recount what they have seen. Discuss differences in what each person sees and how to separate what they see from what they expected to see.

Video clips of situations help in teaching seniors how to observe and record before moving into a practice situation. They can replay the action to observe as many times as necessary to describe what is happening. While it is difficult for the seniors to learn to watch and record simultaneously, practice with videos and data sheets will ease their anxiety.

### **Observing and Collecting**

Share thoughts and impressions about collections.

Introduce participant observation and have each person or small group decide what to observe and the forms they will use.

Forms are included in Appendix 4.

Have them practice their observation skills before the next class.

#### Analysis and planning research

Bring observations to class and share findings.

Discuss how they might use observations to further their own research ideas

Before moving to a real-life situation, make sure that the seniors have prepared, or are familiar with, a description of their role and the purpose of the study so that they can share it if asked.

Both the Kerby researchers and the Snowbirds felt that while it may have been confusing at first, learning good observation, organization, recording, and analysis skills paved the way for further research.

I felt relaxed and eager to record as much as possible. I was not questioned by any of the individuals that I was observing, but was able to share my observations with them. It was all so interesting when you see what you're really looking for.

### **Summary**

This chapter has attempted to introduce the reader to the importance of "true reckoning" when observing. It covered an introduction to field research and how to systematically collect and organize materials. It also introduced participant observation skills, why we use observation, the researchers' role, what to observe and how to record and analyze data. We finished with suggestions for training people to become good observers and recorders.

#### Resources

- Adler, Patricia, and Peter Adler. 1994. "Observational techniques." In *Handbook of Qualitative Research*, ed. Norman K. Denzin and Yvonna S. Lincoln, 377–92. Thousand Oaks, CA: Sage.
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- Patton, Michael. 2001. *How to Use Qualitative Methods in Evaluation*, 3rd ed. Thousand Oaks, CA: Sage.
- Spradley, James P. 1997. *Participant Observation*. New York: Holt, Rinehart and Winston.

4

# **Interviews and Questionnaires**

While it took time to compile the questions and do the interviews it was worth it. The older women who administered the questionnaires stood up to people at the town hall meeting. We were presenting a united front because we all knew where the information came from. (MW, 2007)

The seniors of Ogden were faced with a dilemma about how to support the needs of their community and at the same time find housing alternatives that they controlled. Ogden is like a small town surrounded by industrial areas and therefore isolated from the rest of Calgary. It was one of the original communities but had not been taken over by high-income housing like the rest of the inner city because of toxic waste. The housing prices and the income level are low but the percentage of people owning their own homes is very high compared to other communities.

As seniors they wrestled with the fact that many of the home owners were now aging and wanted to sell and downsize. They wanted to use their collective resources to support the community, by selling their homes to young families to rejuvenate the schools and the economic viability of their community. However, because it was a lower income area in the inner city, Ogden already had a number of charity or city-run housing projects. They did not want to be a project, looked after by others but wanted to be the masters of their own housing.

As they started to plan they were faced with bureaucratic red tape and entrenched beliefs that seniors were not capable of handling their own housing. These beliefs came from both sides, from the seniors themselves and from the officials they had to work with. Seniors felt: "How many seniors have ever had to deal with government? We've been raising families and keeping our heads above water. This all seemed so foreign to us. Talking to government is threatening; we don't even speak the same language" (MW, 2007).

As we talked about this chapter Marianne said, where was this book five years ago when we had to figure it all out for ourselves?

The same reluctance about seniors being able to see a development through to completion was apparent from officials as well. It seemed that at every stage, there was a need to prove that there was a need; each time the request seemed to mean a new piece of research but there was no money to learn how to do the work. Luckily, Ogden had practicum students and champions who had been part of the Kerby project.

If seniors are going to take control of their own destiny, they need to be able to counter prejudice with competent research. Ogden Millican seniors have agreed to share their experiences with us in finding questionnaires that worked for their planning process. We include not only questionnaires that were actually used but use their experience to design questionnaires that might prove helpful to others. The main

voice in the chapter is Marianne Wilkat, who was the president of Ogden House Senior Citizens' Club and is now the catalyst of the housing project.

Of all the research methods in this book, questionnaires and surveys are likely the most familiar. Most seniors have been involved in surveys, at least in answering survey questions at malls or on the phone. In this chapter we describe a range of survey research methods, when to use questionnaires, the role of the interviewer, what questions to ask, how to record answers and analyze results, and how to train seniors to become interviewers. In other words, we hope to prevent other groups from having to learn on the job, as did the seniors of Ogden House.

In the previous chapter, we explored what could be learned about people and groups by observing and participating in their activities. In this chapter, we move our attention to those aspects of research that are not readily observed – how a person's past experiences influence thoughts and feelings in the present. To tap into these aspects of people's lives we need to ask questions.

Interviews and questionnaires can be used in all forms of inquiry where you want to collect information from individuals about their thoughts and feelings. You might use a questionnaire in a newspaper mail-in asking if people support tax benefits for fixed income seniors, you could post a series of questions on your website to evaluate the website's effectiveness, or you could interview pioneers about what food they ate.

Surveys are large-scale investigations that use some sort of standardized oral or written questionnaire. When we call something standardized, it means that the questions have been tested to make sure that they are measuring what is intended and that the process used for administering the questionnaire is the same each time. Survey research is popular in consumer satisfaction and market research. Interviews can be conducted in person, by phone, by mail, or on the Internet. Administering questionnaires seems straightforward, but it takes practice to learn how to speak clearly, how to pace your questions, and how to clarify answers.

#### A. When and How to Use Questionnaires

The following is a quick overview of when you might use the different approaches. We have included both the Ogden Housing project and the Kerby Centre research project in our examples.

**Informal interviews.** Informal interviews are used when you want to explore a new idea. You should likely limit your interviews to fewer than twenty people and often three to ten are sufficient to understand the scope of the answers. You do not generally need ethics approval for this exploratory step because you are still setting your research directions.

The groups that designed this informal type of questionnaire in the Kerby research project found that informal interviews were much like a conversation and the questions emerged from the flow of the interview. They found that the person being interviewed was comfortable and open and that they could tailor the interview to the person. During the interview the information gathered seemed to be important but, once the interview was over, the senior researchers seemed unsure about what to do with the data other than to describe what they had covered.

The following quote from the Ogden House seniors' housing project is a good example of informal questions at the beginning of a project.

We started out asking people to make lists of their wishes, what they were looking for in a housing project. Because cost was a major concern in the first go round, we started looking at apartment complexes. We then spent some time talking to

people about what they were losing by leaving the community. Here we found a strong feeling that people feared losing a sense of community, the small town feeling you know. They were afraid of losing touch with family and friends, stores they knew, church and services. Both the positive and negative questions were important at the beginning to get the full picture at the beginning of the project. The questions helped focus our work. (MW, 2007)

**Interview guides.** Interview guides and semi-structured questionnaires are a common set of questions that are open-ended. These are good for involving a lot of researchers and for capturing people's experiences and stories. Generally ethics approval is not needed if you are using information to develop more formal research. If this is your chosen method in a formal study, you will need to consider consent forms that can be as simple as signing the questionnaire.

The Kerby group that used this method created a set of questions with space to enter answers. One of the researchers mentioned that she liked the blend of structure (knowing where she was going and what was coming next) and being able to ask the questions in a conversation. They felt confident that they had covered what they had wanted. In discussing the interview results, they used the outline and summarized the points covered under each question. They wondered if this was all there was to research. This type of questionnaire can be seen as intrusive in that you are controlling the questions but are asking participants to reply freely. As we see in the following quote from the Kerby research, asking questions can make some people uncomfortable because they don't know what is expected of them:

There seemed to be a sense of their privacy being invaded. They came to this club to get away from the pressure of every-day life. It's almost like a "safe-house" and they wanted it left that way. I had explained the process to them before we began

so they really didn't have any inquiries. They were all friendly and seemed happy to see me again but when the men realized why I was there, they began talking among themselves and shortly after, went for coffee. I was nervous to begin with but felt better as the interview progressed. The men had not returned before I finished the interview and left. (NW, 2004)

There is a variation of semi-structured questionnaires that provides very specific questions that are asked in a set order. In research, these are called "standardized open-ended interviews." A group in the Kerby project worked on the wording of their questions and were determined to use exact wording and to use the same order. The group was very secure in using their questionnaire because each senior researcher knew what to do and they felt that they were "scientific" because they felt their personal opinions and biases would not get in the way. They were confident that they would be able to combine their data after the session. However, they found that the interviews were somewhat awkward; the people answered only the questions and didn't offer much more. Their questions didn't seem to provide answers that were helpful.

The following example from Ogden House demonstrates how open-ended questions are used to guide discussions and planning.

Would you prefer to own your unit or rent it? Could you share the reasons for your answer?

The following summarizes the responses. While most people understood why an apartment complex was cost-effective, they were uneasy about renting.

They had worked all their life to own their own home and it was part of their family tradition. (MW, 2007)

This led the group to investigate life lease, a form of "ownership" that had the flexibility of leasing. Some of the questions they then asked included:

If you sold your present home, would you consider moving into a life lease? Life lease is taken to mean that the lease of the condo is paid up front, and you or your estate would receive the lease price back when you or your estate wanted to move. Please discuss your ideas and concerns about life lease.

Another example of open-ended questions was used when finding a location to build the housing complex. Originally the seniors asked, "What is needed in a location to build a housing complex?" They found answers: close to bus routes, shopping, children and seniors' centres. From there they located 13 green spaces and asked about each of the spaces in an open way. This led to an uproar over the one large empty green space and led to a heated community meeting. In the end the seniors chose a little-used baseball diamond beside Ogden House.

Closed questionnaires or surveys. Here the questions *and* the responses are fixed ahead of time. This type of questionnaire generally requires pre-testing to make sure that you have the questions that will provide the data you really need. Pre-testing also gives you a chance to ensure that you have covered most of the potential answers. Closed questionnaires are generally used when you want to reach a large number of people to prove a point to some authority. You generally need ethics approval to do large surveys and consent can be built into the survey format.

One of the research groups at Kerby chose to design a closed questionnaire with the questions and a list of answers attached to each question. While this type of structured survey is very useful with large numbers, it didn't work very well with our small samples. The list of answers didn't seem to fit very well and the questionnaire

seemed very impersonal and mechanical. The person being interviewed worked hard to fit her ideas into the answers provided but was frustrated. The senior researchers felt that if they were to collect information about a large population they would appreciate the careful construction of this type of survey.

The following section of a needs survey was crafted after much discussion and testing with groups of seniors at Ogden house. Two university students took a large number of open-ended questions that had been used; they recorded all the answers and created a set of answers from the responses. These were then tested with a small number of seniors and the questionnaire was formatted to make it easy to answer questions quickly. The survey had five parts but took only about five minutes to complete. It was administered by the seniors at the grocery store, the churches, and meetings. With seniors on hand, questions could be answered about why the survey was needed and what was going to be done with the information.

Table 4. Closed questions extracted from the Ogden House housing survey.

| What are the reasons you would consider moving from your present home?            |  |
|---|--|
| ☐ Sometimes I feel lonely and isolated.   |  |
| ☐ Upkeep of home seems a burden now.  |  |
| ☐ Stairs and accessibility.   |  |
| ☐ To reduce costs.  |  |
| ☐ Better location (closer to bus, walk to store, closer to family).               |  |
| ☐ Access to assistance and eventual care.   |  |
| ☐ Death in the family.  |  |
| ☐ Other.  |  |
| What services you like to see available in a seniors' affordable housing complex? |  |
| ☐ Seniors activities  |  |
| ☐ Shopping  |  |
| ☐ Health-related services.  |  |
| ☐ Meal services.  |  |
| ☐ Cleaning services.  |  |
| ☐ Maintenance.  |  |
| ☐ Parking.  |  |
| ☐ Small convenience store.  |  |
| ☐ Hairdresser.  |  |
| ☐ Other.  |  |
|   |  |

Ogden House also used closed survey questions in the newspaper and in a public canvass to gauge community support for their project. The questions were simple:

"Would you support an age in place complex in this area?" Yes or No.

"Would you support a complex that housed independent living and assisted living in Ogden?" Yes or No.

To each of these they received almost 100 per cent yes replies of the five hundred responses.

Whatever the style of interview or questionnaire, you need to know how many responses are enough responses to enable you to speak with authority about your findings. If there are only 200 seniors requiring social housing and you wanted to do a detailed needs analysis, you would need to aim at about 25 per cent of the potential population. When surveying a population over 500 you would want at least 100 surveys completed to be able to speak with confidence about the results. With numbers this large, you need to design a very short, precise survey.

You need to ensure that you represent the characteristics of the population you are surveying. For example, if you were looking at the need for affordable seniors' housing in Ogden and Millican, you would need to make sure that you surveyed people from each neighborhood, that you surveyed all age groups, and that both men and women answered the questions.

You need to include the important aspects you are studying (location, age, gender) in the questionnaire so that you can describe those that completed the survey to prove your sample represented the community.

#### In summary:

- Use open-ended informal questions to test the water.
   Use careful notes, flip charts and self-reports to gather as many different opinions as possible and to narrow your area of interest.
- Use semi-structured, standardized questions with space to record answers to test out your ideas and gather rich descriptions of your topic.

 Use closed questions for large formal studies to prove need, identify options, etc. These must be carefully constructed, pre-tested, and short.

## B. Ethics Approval

Closed questionnaires are widely used because the anonymity of the person is protected in the use of coded answers. However, individual personality is washed away with the protection. Informal in-depth interviews and open-ended questionnaires are more problematic from an ethics perspective because the personality of the person is more likely to be recognized in the quotes used.

The consent form should include:

**The purpose of the research.** This questionnaire will help us determine if there is a need for seniors' affordable housing in the Millican Ogden community.

Why the person was chosen. If you are 50 years old or above and live in Ogden or Millican, please answer the following questions. If not, we thank you for taking the time to answer the general questions.

The expected duration and style of the interview. This survey will take about 5 minutes to complete. You need not sign the survey and all information will be held in confidence; we will not be asking you for any personal contact information.

What will be done with the information they give. We will use this information in our negotiations with the provincial and federal governments and with the city for land-use permits. Potential investors and donors also need to know this information. Your ideas will guide the development of a senior affordable housing project in your community.

## C. Recruiting People to Answer Questions

If you are doing informal, guided, and open-ended interviews, select a small number of people, deliberately chosen so that they are different from each other while being knowledgeable about your topic. Recruiting is much easier when seniors know that other seniors are involved as researchers. They know that the research has been vetted by other seniors and is being done with them in mind.

If they know your face, you can talk to them; it's not just for me but for them as well. (MW, 2007)

The "look" of the questionnaire can be a factor in enlisting people. Seniors like to see what is being recorded or to record the answers themselves so that they know what is being attributed to them. This means that the questionnaire needs to be in large print with a minimum of writing. Don't try to save paper by crushing questions into a single page when you could make it easier to read and more understandable in two pages. Places to record answers need to be in a list, not strung out across the page.

People don't want to write a lot but we always leave space to add ideas. This lets them know we are interested in their ideas and it provides spaces between the questions. They feel they are getting somewhere when they have finished a page when there are lots of spaces. (MW, 2007)

Try taking questionnaires to a community meeting or a regular event but be sure to let people know ahead of time that you are coming and post the questionnaire beforehand so that people know what to expect. If the questionnaires can be completed when they are given out, you will have more returns, especially if there is someone there to answer questions. Natural meeting places include waiting areas, malls, the post office, the shopping mall, or grocery stores. You can use chat lines on the Internet if you know that the seniors you are targeting use the computer; chat lines have become the meeting places of today.

We found we got a much better response rate when we handed the surveys to people who were waiting anyway. For example, people are just sitting waiting to be called at our flu clinics and if it is a short questionnaire they can fill it in and hand it in when they go to get their shot. (MW, 2007)

If you want to recruit people to interview personally, it takes more time and care. Setting up appointments with seniors is best done through a trusted third party. Cold calls on the phone are particularly unsuccessful because of the high incidence of consumer fraud that begins with the pretence of conducting a telephone survey. Setting up interviews through a seniors' centre, a known program, or a community service works well. Meeting for coffee is likely the best way to set up face-to face interviews, especially if it is in the seniors' centre or a neighbourhood coffee shop. Meeting in a university office is not advised because these settings may make the person uneasy and shy. Conversely, suggesting meeting in the person's home can raise fears about invasion of personal space.

We found the best way to reach seniors in their home was to have pairs of a student and a senior. We were able to start with people from our group and then each person we interviewed was asked who else we should talk to. (This is called a "snowball effect" – like a snowball dance). This partnership between the student and the senior gave both sides credibility. The student from the university handled the recording and the senior described what we were doing. Most times people don't think seniors know how to do this work, but they do and do it well. (MW, 2007)

#### D. What Do You Do as an Interviewer?

Your role as a researcher will depend on the type of interview or questionnaire being administered. The more structured the questionnaire, the less flexibility you have. Highly structured interviews require less experience to administer because the process is set and you are expected to follow the protocol (the order, the wording, the answers, and your pacing). Even if these aspects are not stated, it is good to practice delivering the questions in research pairs so that you can be heard clearly and that you are comfortable waiting in silence for an answer.

In informal or conversational interviews, your role is one of a good conversationalist. You should be able to engage the aging adult being interviewed, guiding conversation and following up leads that arise in the interview. Depending on whether you are going to be interviewing people you know, doing phone interviews, mall interviews, or interviews on line, you need to practice so that you know the questions and how to get the answers.

Rules for asking questions:

- Use a conversational speed. If you read the questions you will start reading too fast. Reading too slowly irritates the listener who can easily lose touch of your meaning.
- Practice reading in front of a mirror. Learn to establish eye contact while you are reading.
- Pause between questions. Allow at least five seconds before you comment.
- Encourage sparingly. Do not say "good" after answers, for this implies that there are good and bad answers. If you must say something, say "thank you."

We found it better to do things in person. Seniors had trouble hearing on the phone and they were afraid of hackers on the Internet who could use their information for other purposes. Our seniors are afraid to let people know they live alone so we saw people at the Centre or arranged to meet them at home only after they were comfortable. (MW, 2007)

Work in pairs with one person recording or writing answers to openended questions while the other asks questions. Recording is a skill in its own right and sharing roles allows each person to concentrate on one aspect of the research at a time.

Seniors, both those answering the questions and those recording, didn't like to write very much. That may have been because they were not used to writing, they may have been embarrassed by their spelling or writing skills or they may have arthritis or shaky hands. Whatever the reason, we had to work to cut down writing and provide lots of practice so that people were more comfortable. (MW, 2007)

If you are administering questionnaires that people fill out independently, do not watch as they write their answers. Do not interrupt unless they ask a question, seem confused, or uneasy. On the other hand, if you are assisting a group of seniors who are filling out a questionnaire, it is wise to establish what you can answer in advance. For example, you may suggest that you can clarify the question but not tell them if an answer is what is expected.

Once, when we were doing questionnaires in a group, people would listen to the questions people asked about their answers and revise their own answers. We ended up with many people with the same responses. It was as if they used the other person's answer as their own since it had been discussed and was therefore acceptable. (MW, 2007)

#### E. What Questions Can Be Asked?

The simple answer is "any question." Questions emerge from thinking about your topic in light of existing information, and talking to other seniors and stake-holders.

When designing a survey it is helpful to start with very broad, open-ended questions and with more questions than you need. Reduce the number as the questions are tested and grouped. Seniors tend to appreciate questions that are similar being together, rather than randomly placed throughout the questionnaire as is done with many standardized questionnaires. The following are some of the questions that might be included in your questionnaire:

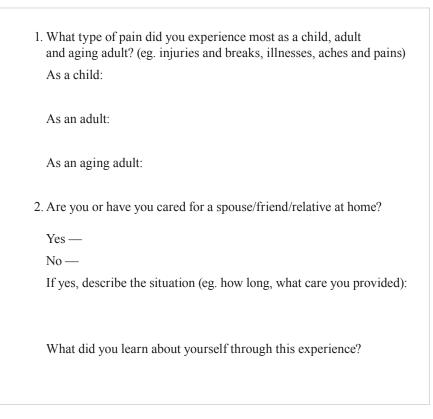
**Background questions.** These questions should always be part of a questionnaire because they provide a commonly accepted way of grouping your results. Questions generally tap age, gender, education, location, income level, transportation, and affiliations. Most research uses closed questions with fixed categories to ask these types of questions

Table 5. Standardized background questions.

| 1. | What is your age                        | 65 or under                | 66–75                      | Over 76                    |
|----|---|----------------------------|----------------------------|----------------------------|
| 2. | What is your gender                     | Male                       |                            | Female                     |
| 3. | Your education<br>and work his-<br>tory | Trades                     | Business                   | Professional               |
| 4. | Where do you live                       | Ogden                      | Millican                   | Outside of district        |
| 5. | Income level                            | CPP pension subsidy        | CPP and pension fund       | Pension plus investments   |
| 6. | How do you get around                   | Transit, Family or friends | Independent car            | Subsidized accessible pass |
| 7. | How long have you lived here            | All my adult life          | Most of my life on and off | Less than three years      |

**Experiences.** These questions ask people to think back and to remember what they have witnessed or lived through. Such questions might include examples of hardships they endured as a child, times when they had to manage pain, or moments of great joy in nature. These questions are generally framed in an informal way, although you might also be able to provide some answers to get people thinking. People appreciate the time to consider their answers and to compose their responses about their own experiences.

#### Table 6. Questions about experiences.



**Skills, interests, knowledge, and needs.** These questions can be addressed using closed formats that identify whether the skill, knowledge, or need is present, what kinds of support people would like, or how independent they are. These questions need to be developed with a group of seniors to make sure that the closed categories are respectful and relevant.

Table 7. Questions about skills, knowledge, and needs.

| What assistance do you take advantage of now? (Place checkmark where appropriate.) | Never | Occasional | Regular |
|--|-------|------------|---------|
| Yard work  |       |            |         |
| Snow removal   |       |            |         |
| Repairs around the house   |       |            |         |
| Chores/cleaning around the house   |       |            |         |
| Grocery shopping   |       |            |         |
| Other  |       |            |         |

**Opinions and feelings.** These questions are statements done with a standard response such as agree/disagree or a five-point or seven-point scale. These statements should address different perspectives and world-views, for a question that everyone answers the same way doesn't provide much information.

Table 8. Questions about opinions and feelings.

|   | Agree |   |   |   | Disagree |
|---|-------|---|---|---|----------|
|   | 1     | 2 | 3 | 4 | 5        |
| I look forward to moving into a smaller place.                      |       |   |   |   |          |
| My family are concerned about me being on my own in this big house. |       |   |   |   |          |
| I worry about what to do with all my "stuff" if I move.             |       |   |   |   |          |

## F. Recording Answers and Analyzing Data

Your analysis will only be as good as the questions you ask and your care in capturing the answer.

**Recording.** Recording of informal and open-ended interviews is usually done in one of three ways:

- You record the answer on the questionnaire or tape record the session for both in-person or telephone interviews
- You summarize the interview and answer the questions after the interview. You should record your answers immediately after the interview and enter answers in a structured guide. Recording an open-ended and unstructured interview after the fact can be risky as it is difficult to remember all that has happened unless you have some sort of structure.
- The participant records the answers with or without your assistance. It is much more effective to use a combination of closed questions and space for personal responses if the person is to record his or her own answers

**Analysis.** Researchers can develop many questions, spend a great deal of time getting responses and then be lost as to what to do with the data. There are several types of analysis you can employ.

- First impressions as you read the answers.
- Patterns and themes in open-ended questions.
- Responses that are counted and are reported as numbers, percentages, or graphs.

First impressions. Underline information or ideas that jump out while reading responses. Jot down ideas when first listening to the tape recording of the answers. You may notice that the person was uneasy about a question, that an answer raised a question for you, that it was a new way to answering the question. Always give yourself a chance just to read/listen the open-ended or semi-structured answers thoroughly before you do any formal analysis. Once you have spent the time reading/listening to all the responses, you will have a much better feel for the range of answers and where the problems or opportunities may lie.

**Patterns or themes.** Photocopy the questionnaire (put the originals away for safe-keeping) and cut the answers to each of the questions into strips so that you can look at everyone's answers to a question at the same time. You can then begin by sorting them into piles of similar responses.

For example, in the question about caring for someone at home, you got 30 responses. You might find that most people wrote in that they enjoyed being able to care for their relative or friend. Some answered that the person they were caring for was difficult to manage when they were in a strange environment and a few answered that the person wanted to die at home and they felt they had made a commitment to do this. You could then write about three themes (joys, challenges, and commitments) using quotes to back up your ideas.

Frequencies and descriptive statistics. In closed questionnaires you can calculate numbers and percentages to present a strong statement that will impress authorities. There are many easy-to-use software packages that produce tables, charts, frequency graphs, pie charts, etc. It is very important to know when it is possible to use these options to create the best presentation of your data. If you are using an

internet survey such as Survey Monkey, your data will be analyzed and presented for you

If you want to include number data, it is best to ensure that the recording for each of the questions you want to compare is the same. For example, in the needs study at Ogden House, you wouldn't want to have the questions about meals to refer to *how often* you prepare your own meals (never, sometime, often, always) and other questions ask about *how much* help they need (need full assistance, partial assistance, no assistance) and still others answer a yes or no. You may find that it is better to word all questions so that they are answered by a "yes" or "no," sometimes, so that you can present more than one question using the same type of chart or graph.

If you have fewer than a hundred responses, you can count the answers to each question by hand. Record the totals on a blank questionnaire. You can then add a marker at the end of the line as follows to look at what you have found. The following is based on a hundred hypothetical responses:

Table 9. The number of people who respond to questions about meal preparation.

| Question: When it comes to meals do you:              | Yes | Sometimes | No |
|---|-----|-----------|----|
| Like to cook and prepare good meals?                  | 48  | 44        | 8  |
| 2. Like to cook but find it expensive and worrisome?  | 38  | 60        | 2  |
| 3. Cook yourself but don't eat very well?             | 36  | 44        | 20 |
| 4. Have someone else in your home that makes meals?   | 46  | 7         | 47 |
| 5. Share some meals each week with friends or family? | 10  | 12        | 78 |
| 6. Use a meal service like Meals on Wheels?           | 15  | 1         | 84 |
| 7. Eat out more than 3 times a week?                  | 11  | 29        | 60 |
| 8. Have a friend or family who helps out?             | 8   | 2         | 90 |
| 9. Have a home maker to make meals?                   | 6   | 34        | 60 |

This chart was created from the earlier survey question on preparing meals. You will notice that there are more categories here to reflect write-in responses and the order has been changed to keep answers that were similar together.

This same questions could be used when asking people to think about what they might do in five years time. This type of data can be extremely helpful in thinking about how to arrange a housing project.

For example, only 48 per cent considered themselves well set when it came to meals (response to question 1), a good indicator of the current independence of those thinking of moving into a life-lease apartment. Over 35 per cent were coping but were not doing as well as they would like (questions 2 and 3). These are suggestions that they are already looking to some sort of support or sharing to handle meals (remaining questions). This would indicate that a housing project might want to include some type of voluntary meal-sharing, either a shared meal option several times a week or one meal a day, etc. By comparing this type of data to the five-year expectation, the group could much more accurately tackle the issue of meals in their planning.

Whatever method of analysis is used, it is helpful to do the analysis with a group so that ideas can be shared.

## G. Suggestions for Training People to Become Good Interviewers

It is possible to train aging adults to administer a standardized questionnaire without an understanding of the research methods as long as there is ample time for practice and feedback.

When questionnaires and survey research was taught to the Kerby group, we discussed how questionnaires could be part of qualitative research (describing experience) and quantitative or more scientific research

We found that developing a questionnaire was a wonderful learning tool. In the process, the seniors were able to make decisions about

the questions to ask and the type of questionnaire to develop. Administering their questionnaire and evaluating the results allowed them to learn about the advantages and disadvantages of their chosen method and the types of questions asked. By comparing notes with other groups, they learned about all approaches and could evaluate methods.

The following outline could be used to teach aging adults about survey research and questionnaires:

**Pre-reading (Chapters 1 and 3)** of the manual to provide a background on research in general. As a group, discuss the topic and the issues you might be interested in studying through questionnaires. (Discuss how to use questionnaires in other research and demonstrate related commercial questionnaires.)

**Set the topic.** Discuss how you might begin the process of identifying questions: make lists, brainstorm, ask open-ended questions. Take the ideas from the group discussion and create a set of open-ended questions that each person then administers to 2–5 other aging adults before the next class.

**Set the questions** from the open-ended or semi-structured questionnaires and decide upon a set of five questions, each with a range of answers. Pre-test the questionnaire with your research group and have each senior researcher pre-test them with up to five people to make sure that the questions and the answers are coherent before the next class.

Use the questions in pairs, practice the pacing of questions and the speed of delivery, pausing and prompting until comfortable. Bring the answers back to Day five to analyze your responses and write up a short summary. You are now ready to recruit a sample, gather your data, analyze what you have found. You can finish this section by reviewing what you have accomplished, how to share your feelings and use the data to guide what you are doing.

#### Resources

- For background reading on exploration as related to verification in the social sciences, see: R.A. Stebbins, *Exploratory Research in the Social Sciences* (Thousand Oaks, CA: Sage, 2001).
- For background reading on survey research, see: J. Converse and S. Presser, Survey Questions: Handcrafting the Standardized Questionnaire (Thousand Oaks, CA: Sage, 1986).
- For definitions of research terms, see: W.P. Vogt, *Dictionary of Statistics and Methodology: A Nontechnical Guide for the Social Sciences*, 3rd ed. (Thousand Oaks, CA: Sage, 1998).
- For specifics about design, see: W. Foddy, *Constructing Questions for Interviews and Questionnaires* (Cambridge: Cambridge University Press, 1994).
- For a more academic and historical approach, see: A.N. Oppenheim, Questionnaire Design and Attitude Measurement (London: Heinemann 1968).
- Questionnaire Design and Surveys Sampling: http://obelia.jde.aca.mmu.ac.uk/redesgn/arsham/opre330Surveys.htm
- Virtual Ethnography: Interactive Interviewing Online as Method: http://www.cjlt.ca/index.php/cjlt/article/view/40/37
- Summary of Survey Analysis Software: http://www.fas.harvard.edu/~stats/survey-soft/survey-soft.html

## 5

## Focus Group Research

Without a clear set of questions, there is no focus. (AH, 2005)

Okotoks is one of the fastest-growing small cities in Canada. It is located almost adjacent to Calgary. The seniors club has been a keen advocate and seniors are relatively well served because of their work. The seniors club was invited to be one of the research sites by the Cochrane senior researchers who were already part of the research project.

This chapter includes when to use focus groups, how to create an agenda, how to set up and organize a group, how to collect and analyze data, and how to train seniors to lead groups. Because focus group research was so effective, we have included a number of examples in the Appendices: 4,5,6 and 7.

Focus group methods were used throughout our resilience study. We learned how to make them work for seniors, and, in the process, challenged some of the established ways of doing focus group research. Focus groups were the most popular and effective of the methods studied, and focus group research seems particularly suited to the way that seniors think about and do research.

A focus group can refer to any group that wants to explore a specific and well-defined topic. A focus group is effective in gathering the opinions and insights of people without controlling their responses. This method originated in the 1940s as a reaction against survey research where questions and answers are largely predetermined by the researcher. Focus group participants are chosen because they have expertise or interest in the topic and they are expected to be willing to discuss the topic. Questions move from general ideas to a sharper (more focused) understanding. Focus groups are popular in marketing and strategic planning and, more recently, they have become more acceptable as research tools in medicine, education, and human services.

Many seniors had previous experience with focus groups and they had enjoyed talking to other seniors or service providers and giving their ideas. However, once the flip charts were taken down, they saw little of the results of their work. We were determined to train seniors to run focus groups in a way that would ensure full participation throughout the process.

Each of the partner sites hosted a focus group. The senior researchers negotiated the day and the agenda, conducted the focus group, analyzed the data, and wrote a report on the findings of the day. It helped to be familiar with the program and the participants. We had very few difficulties recruiting people when the partner site had been involved in planning the event. The following is an excerpt from a letter to the Okotoks seniors inviting them to be part of the focus group.

With the kind cooperation of many of your club members we successfully completed phases 1 and 2 of our research training and are now entering the 3rd phase, which is to conduct a focus group with about 10 of your members. Enclosed are some invitations you may wish to put before your members at your next meeting to explore the level of interest in the project. Date, time and location have been left to your discretion. (Excerpt from letter to the president of the Okotoks Seniors Association, 2005)

## A. When Should You Use Focus Group Research?

Focus groups can be used alone or along with other research methods. Group discussion brings a deep and rich understanding of your topic that is not readily available through other methods. Interaction is the key to the method because ideas can be confirmed, reinforced, or contradicted within the group discussion. Seniors might use focus groups to:

**Explore, define, or refine concepts** being proposed at the beginning stages of research.

The participants in our focus group (seniors themselves) had met to discuss the difficulties their elderly parents faced in accommodation and services once they lost their independence. Frustration and anger replaced the resilience they were once so proud of. These shared experiences helped enrich the discussion in the focus group.

The following is an excerpt from the focus group report that discussed the frustrations faced by older adults:

The focus group felt frustration and anger was often due to fear of the unknown, inability to cope with impending changes, loss of control and independence. This basic loss of control contributed to a loss of resilience and often resulted in deteriorating health.

**Explore and generate questions for research**. The following example from the report for the Okotoks Seniors explored the idea of stubbornness and resilience:

Stubbornness of seniors was noted when lifestyle changes were necessary. Dementia, fear of the unknown, depression, illness, withdrawal, inability to cope with impending changes, loss of control, and loss of independence were cited as some possible reasons behind stubbornness, which is often misinterpreted as being difficult or not motivated.

**But:** Does resilience promote stubbornness? Is stubbornness a lack of resilience? Or does resilience mimic stubbornness as a way to demand attention? (Focus group report)

This insight on the relationship between stubbornness and resilience might form questions for future research.

**Participatory Action Research.** The following shows how focus groups can help older adults become involved in their own services, as well as research and resource allocation:

The Okotoks seniors had identified the problems of seniors' organizations that provide volunteer support to other seniors but, as the senior volunteers age themselves, they cannot continue without support. As an organization they felt they needed access to government (health) agencies, corporate involvement, soliciting sustainable funding to help finance new facilities. (Focus group report)

This senior's centre not only provided the suggestions but carried through. They continued their involvement over several years. Their town now proudly boasts of a state-of-the-art Health and Wellness Centre for everyone, especially seniors.

**Provide seniors' input** into changes proposed by service providers, business, and government. Most governmental bodies now use focus groups to solicit input. We are suggesting that these governmental bodies either use independently trained seniors, or train and employ seniors to run focus groups. The major obstacle with this work is that seniors trained and employed by government may become absorbed by the culture of government. If government does employ seniors it may help to draw up a set of principles based on partnerships guidelines in Chapter 1.

**Evaluate products and services** from the perspective of seniors. **Explore common experiences** related to specific health, social, and economic aspects of aging.

In order to understand how to provide effective access to home care, bring volunteers and neighbours into a focus group. They know about other seniors and how to access services when failing seniors may not be able to figure it out. Go to the natural helpers that are identified by the person. (AH, 2006)

**Look for alternative perspectives** on topics and issues when existing approaches have become stale:

Needs surveys of seniors are particularly ineffective. Aging adults really aren't interested in taking the time to answer another questionnaire or be interviewed by a professional. The focus groups enabled seniors to discuss amongst themselves and offer their own solutions. The problem lies in making the results acceptable to those who only can think about surveys. (DD, 2006)

#### Create a shared understanding of everyday life and events.

We, as a research team, have come to believe that the role of seniors in setting the questions, facilitating the groups, and writing the reports is essential to good focus group research. If this is not done, the voices of seniors are easily used for the purposes of others who can take ideas out of context.

# B. Creating the Focus Group Questions and the Agenda for the Day

Of all the steps in focus group research, creating the agenda and the focus is the most time-consuming and the most important. While researchers should be flexible and willing to adjust the focus group process as it unfolds, without a clear set of questions and exercises, there is no focus, it becomes a group discussion. Plan from the desired outcome and work forward. You need to be clear about where you want to end up and why.

With our focus group in Okotoks we had several goals. We wanted to engage seniors in an open discussion about resilience so that individuals in the group might feel comfortable enough to be interviewed about their personal experience with resilience in the next phase of the research and we were interested in identifying some areas of resilience research that they might be interested in pursuing in the future. We realized that there were many ways to reach these ends but because we wanted to involve seniors, we began with personal stories of resilience and what was learned about resilience from these stories. From this foundation the groups identified research questions about resilience and seniors. (AH, 2004)

## Agenda for the Rural Resilience Day in Okotoks

Table 10. Focus group agenda for Okotoks Senior's Club.

10 a.m. Introductions (15 min.) Purpose of gathering,

explanation of process

11 a.m. Exploring personal resilience (60 min.).

The following questions might focus our discussion

around resilience and rural seniors:

 Think of someone you know in this area whom you consider to be resilient (it could be yourself) and think about an example of their resilience

- What do you think helped to make them/you resilient
- What factors in rural life can contribute to the development of this resilience? E.g. hardships of farming, isolation, farm friends.

Noon Lunch Break

1 p.m. Building senior resilience in small towns (60 min.)

- Do you think resilience in a small community like Okotoks is different than in large city?
- In what ways can small communities assist seniors to achieve resilience, particularly those with disadvantages such as: poverty, ill health or disability, loss of family connections?
- How can seniors assist other seniors develop resilience?

2 p.m. Wrap up/Evaluation of the session (20 min.)

- How comfortable did you feel?
- Were you pleased/dissatisfied with the session?
- What can be improved?
- What do you think about seniors being researchers about seniors?

While focus group literature recommends setting five to ten questions, we have found that two to five well-thought-out questions, each one focusing the issue more closely, worked better with seniors. Too many questions can leave people feeling confused and overwhelmed, especially if the questions are not clearly related and moving in the same direction. More than five questions can make it difficult to finish the agenda for the day and there is risk of people feeling frustrated or incompetent.

We found that sharing narratives or stories about the topic was a very important way to break the ice. The data from the stories was research in itself and so the stories serve two functions

#### Organizing the Focus Group Event

Preparing for the focus group session takes considerable advance planning. The structure of the day should take advantage of high energy time for group discussion mid morning and include some down time where people can relax, take a short walk, call home, or freshen up.

**Time.** Generally the best time for a focus group meeting for seniors is between 10:00 and 2:00 on weekdays. This avoids rush-hour traffic, includes a lunch break, and gives two defined work sessions.

**Meeting place.** Easy accessibility, good parking, and a central location are important factors for the participants. Breakout rooms are ideal for small group discussions.

The design of the room and the type of tables used is important. Everyone should be able to see one another during discussions; not being able to see or hear the speakers is a problem. Round tables are best. When using a long table, the

facilitator should not sit at the head of the table but rather one or two spaces to right or left where he or she can be seen but not be perceived as "the Leader." (BP, 2005)

**Introduction**. Before starting the focus group, arrange for fifteen minutes of introduction time with coffee, juice, etc.

**Refreshments.** If details like food, breaks and closure are well handled, focus group participants feel welcome and valued.

A break mid-morning or lunch takes the intensity level down and lets people chat with the leaders. (AH, 2006)

**Tasks and duties.** We developed a detailed list of responsibilities (Appendix 5) and the research team worked out their roles ahead of time

We had a good rapport within our research group so we chose our own duties, taking into account our individual strengths. We met several times, choosing roles carefully, capitalizing on the knowledge and expertise of each. This preparation time paid off in a smoother session. (AH, 2006)

An Ice-breaker was planned and a funny story or two connected with the participants and built that initial rapport so necessary for a successful focus group session. (AH, 2006)

**Feedback.** It is important that the participants know what will become of their input and have a chance to look at what was recorded. Occasionally a participant requested deletion or revision of some of their comments

At the end of the session the participants were advised that a draft report of the focus group session would be prepared, each was invited to meet with one of more of the researchers to discuss the report in general and their input specifically. (AH, 2007)

#### Recruiting Potential Participants

The partner sites hosted the focus groups and assisted the senior researchers to contact and talk to potential participants. Because the people in the partner sites knew the senior researchers, it was generally an easy sell. Personal phone calls to potential participants helped to secure commitment to attend and to answer any questions ahead of time.

Recruiting participants for focus groups can be difficult without personal contacts. The following guidelines should be useful.

- Sell the topic. Describe the topic in a short flyer/invitation so that it will attract those with expertise and interest.
- Co-sponsor the event. Host the focus group with a local seniors' club or organization, service provider, or community group.
- Negotiate the process and the day with the co-operating organization. Have the sponsor advertise to their members.
- Have a senior researcher talk about the project at lunch or general meeting to discuss what is involved and why it is important.
- Provide a phone contact. Be available to respond to phone calls about the day and follow up inquiries to ensure commitment.

## C. Ethical Issues in Focus Group Research

Ethical procedures in focus groups need to be carefully planned because participants may end up sharing more than they expect to in the comfort and stimulation of a group situation. Seniors need to know clearly what the topic is and what the process will be. In any group work, it is important not to pressure people to talk if they are uneasy. Ensure that everyone knows the signal for "pass by me this time." The facilitator needs to remind people during the session that people should share only those details that they are comfortable with. For example, participants might be asked, "Is there an experience that you would feel comfortable sharing with us about a time when you felt resilient?"

Consent forms must clearly outline the topic, the questions, and the process for not participating. When focus groups have been used in market research, the real purpose is sometimes clouded to get unbiased answers, and this has made many people uncomfortable with the ethics of focus groups. It is therefore very important to declare that this is not market research and that there is no hidden agenda. Be clear and truthful about your purpose in doing focus research.

Because this is a group process, you might consider a group consent form:

| Столи         | Data                | Dlaga                             |
|---------------|---------------------|-----------------------------------|
| Group         | Date                | Place                             |
| We, the und   | ersigned, understa  | and the purpose and process of    |
| *             | <b>O</b> ,          | e. In signing this we understand  |
| that our idea | s will be used as j | part of a report and also as part |
| of a study or | resilience.         |                                   |

Table 11. Group consent form.

| Name | Consent to participate (sign) | Consent to use<br>quotes with in-<br>itials (Yes, No) | Please send me<br>a copy of report.<br>(Yes, No) |
|------|-------------------------------|---|--|
|      |                               |   |  |
|      |                               |   |  |
|      |                               |   |  |
|      |                               |   |  |
|      |                               |   |  |

It is very clear that seniors are quite capable of knowing when to share and when not to share. In one focus group session in a different town, seniors began sharing stories of abuse and the facilitator tried to deflect the conversation until a senior declared:

It sure is good to talk about this; it's funny how great it feels to know you had the same experience. Don't try to stop us, we need to do this, we can handle it. (CP, 2004)

## D. Who Does What in Focus Group Research?

A focus group consists of a facilitator or leader, recorders, and participants. The leader presents a series of questions and or comments that guide the discussion on a defined topic. The recorders note the questions and comments and record the discussion of the participants. Participants provide the information and work to find meaning in their differences.

A workbook in Appendix 5 includes handouts of each of the following roles that can be photocopied and handed out during focus groups.

#### Role of the Facilitator

Facilitating a group is hard work; it helps to work as a team and plan to change facilitators about half way through the agenda. (AH, 2006)

The facilitator's personality counts! A good facilitator is enthusiastic about the topic, helps the group feel safe and secure in sharing their ideas, and ensures that no one will be embarrassed or criticized. The facilitator does this by engaging people in a discussion about a specific question or topic. He or she keeps the discussion focused and makes sure that everyone has the opportunity to be heard.

An issue, once opened, may stray off topic and generate a spirited discussion. A good facilitator allows the conversation to flow until an opening provides an opportunity to bring the group back on track. (CE, 2006)

A senior as facilitator has much in common with the participants and he or she has an advantage over younger facilitators in understanding how to engage participants. Any facilitator faces the challenge of remaining neutral and of keeping in mind that he or she is not there to sell a particular point of view. If biases are apparent, a facilitator loses effectiveness, even to the point of silencing some participants who disagree. At worst, a group may join in trying to prove the facilitator is wrong. One leader commented:

I enjoyed this focus group experience but have a lot to learn about collecting objective data and, generally, about being involved in research instead of talking a lot. I will increase my effectiveness by pushing harder to keep the focus in mind. (MW, 2006)

The following are some of the tools that facilitators can use to provide a positive experience for the participants. Focus groups are about group interaction, not a series of questions put to a number of individuals who happen to be sitting in the same space.

**Post ideas** from other groups on the wall as people come in. Some facilitators used inspirational sayings. Participants can also be encouraged to jot down their own ideas on the posted sheets as they come in

**Share.** Seniors appreciate a chance to introduce themselves and talk about their background at the beginning of the session. We heard from our researchers that people need time to get warmed up and get to know each other.

**Rules.** Start by sharing some rules. For example, you might write on the flip chart: "Respect everyone's ideas, listen and don't interrupt, be creative in trying out new ways of thinking, speak up if you are unsure, uncomfortable or lost."

**Post the agenda** so that everyone can see, or give everyone an agenda or a workbook to follow. Refer to the agenda or workbook each time you move to a new question, linking what has been done with the next topic to be discussed.

**Promote diversity** of opinion and debate by asking open questions and asking for alternate views. For example, "Has anyone had experiences that would be just the opposite?" Celebrate difference and be accepting of all opinions: a facilitator is not a judge. As one researcher put it, "It can be difficult to get information from some people but it helps that participants can 'play-off' one another."

**Probe for details and depth.** You might ask such questions as: "What led you to think that? Can you tell us a little more about that?"

Be careful not to give the impression that you do not believe what has been said. Frame your questions so that it is clear that you are interested in more detail and not in challenging the truth of the statement.

Control air space. Make sure that everyone has a chance to contribute. If there is someone who tends to talk too much, you need to help them wrap up their ideas and focus on others. Some seniors liked to know when their turn was coming up and appreciated a quick "go round the circle" to start a topic. This allowed them to say something quickly and then they could enter into the discussion more fully after everyone had declared their position. For example, you might say, "Let's start this question with a quick response from every one about who first taught you about resilience?" You could then follow up with ideas people suggested. Other prompts that would work include: "Could we hear from this side of the room? Does anyone have a different idea? Does Bob's experience trigger something in your past?"

**Change direction.** Search for questions that open the discussion in new directions: "How might things be different if ...? What else might explain this?"

**Switch with a partner** before you become tired or frustrated. This is hard work and you need to be aware of your energy in the process.

**Build consensus** and team spirit in the group as you wrap up. Ask people what they learned during the session, what they appreciated about the discussion, or was there anything that they might like to follow up on.

**Summarize** what has been discussed and what contributions have been made to understanding the topic or question at hand. If you record the summary on the flip chart, the group needs to agree that the summary reflects what was said. Some facilitators have the participants sign the summary.

**Evaluate the process.** Senior researchers interviewed each participant personally at the end of the day. At the very least, the facilitator should discuss what people were pleased with and what they would suggest changing. Leave plenty of time for this evaluation so that you honour the input of the group. Evaluating the session as people are putting on their coats is disrespectful.

### Roles of the Recorders

Recorders recognize and preserve personal ideas and group consensus. While some focus group facilitators prefer to do their own recording, the seniors in our project found it helpful to separate the various functions so that it was a team process. We eventually used two recorders. One recorder worked with the facilitator to capture the ideas of the group so that every one could see. A second recorder used the techniques learned in Chapter 3 (Field-work) to record the process, who spoke, what was happening, alliances and areas of concern and agreement. Having two recorders provided a backup and a way to ensure that all the data were recorded. Specific suggestions for how to record are included under the next section, Recording in Focus Groups.

One of our senior focus group leaders commented that the focus group required concentration, good writing skills, and alertness. I was feeling anxious about getting everything down but was prepared and eventually started to feel quite relaxed. (OP, 2006)

The flip chart recorder works with the leader in conducting the focus group. Discuss ahead of time how the leader likes to work and how to ensure that you can keep up with the ideas, how to check the recordings for accuracy, and how to summarize at the end of each question. You will also need to have an agreement with the leader on

how to ask for assistance if the pace is too fast or if you are confused about what is expected.

The recorder is the keeper of the discussion because they capture each person's ideas. The role of the recorder can be challenging when several people are making the same point but in slightly different ways. As one researcher commented: "Attempting to consolidate ideas into a list left out much data in my view. Some areas were not recorded at all."

Flip chart recorders should practice summarizing ideas on a flip chart with the research team until they find a method that is comfortable to them. Much valuable information is lost if poorly recorded. Some participants may feel ignored if their input is not recorded properly.

You will develop a comfort recording and interacting with the leader and the group, but this will take practice. Each group and each leader will demand a slightly different style. This task requires balance. One recorder commented:

I learned that I talk too much – that I don't record well. Two tasks – thinking and writing – are one too many for me when there is a good conversation going on!

**Process recorder.** In most focus groups there is no need for a process recorder, but if you are collecting data and using more than one focus group, this role is very helpful. The process recorder does not interact except to clarify what is happening. This role is similar to that of a participant observer who sits as part of the group but their primary role is observer. This person tracks the interaction, identifying alliances, leaders, those who are silent. They also record the flow of the conservation as much as possible. These records are helpful as a backup to the flip charts. They assist the research team to debrief after the group session and to hone their skills.

#### Role of the Participant

Participants in focus group research have an obligation to participate. But what does participation mean? The following is an affirmation of participation, based on comments from our research. You may find it helpful to give participants this list before they start their focus group. This is written in the first person, as a participant, so that you can use it with your focus group members.

I have been invited because I have expertise and interest. This is a chance for me to step up and be part of the process, to contribute and to learn

My ideas help the group create new knowledge that none of us have on our own.

I must really listen to what other people say. When I spend all my time preparing what I want to say, or what I think about other people, I miss the best parts.

We are all here because we represent different perspectives. If everyone had the same opinions and ideas there would be no need for a group.

I must give everyone a chance to contribute. If I take up too much time, others who are shy can become intimidated. I need to encourage others to speak.

It is important to be polite. As a participant I don't talk on the cell phone, hold side conversations or talk directly to the facilitator or recorder about other topics. This interrupts the conversation and the ability of the group to focus. I contribute when I have an idea. If I wait until I see if someone else has a similar comment, I will likely have forgotten what it was I wanted to say.

If I think about other perspectives on the question I should offer them even if I don't agree with them. It is all about trying to find as many different ideas as possible.

## E. Recording in Focus Groups

Groups also use a number of data collection techniques: flip chart notes, tape recordings, continuous reporting of the process using a laptop computer, or workbooks that participants fill out during the session. The techniques and their advantages and disadvantages are presented below.

Flip chart recorders must paraphrase to get the information down quickly. Read what's been written and check with the participant to ensure that the intent has not been changed in shortening their ideas. Flip chart operators need to be able to think on their feet, consolidate ideas, ask for clarification and write clearly. Participants see an entry on the flip as recognition that the idea is worthy.

Before the session begins, prepare all flip chart pages with a code that identifies: the recorder (e.g.NM), the date of the presentation (04/02/04), the topic of the focus group (e.g. Sex and Resilience), and page numbers (e.g. 5). e.g. NM, 04/02/04, Sex and Resilience, pg 5. This information should be entered in a small box in one corner. Flip chart sheets get jumbled during analysis, and without identifying information the data can become confused. Put the name or number of the question on the top of each page, so that it is clear what the notes are referring to.

Use coloured pens when doing flip chart recordings. For example, you could use black to record ideas that come from individuals, red to summarize group ideas that come from discussion, and green for ideas that you need to come back to because they relate to the recommendations but are not part of the question being covered.

There are symbols and drawing techniques that capture how a group is thinking about a topic. You could explore them once you are familiar with recording for a focus group.

**Tape recording.** Tape recordings should only be used as a backup to ensure accuracy of the discussion. Often a tape recorder distracts the group and members are diverted into thinking about what they should say. Participants must be able to offer ideas "off the record." When you are learning how to run a focus group, you can justify using a tape recorder as a learning device. If there are a number of focus groups in your study, tape recordings done with a digital recorder can provide a way to transcribe and analyze data, but this requires additional consent.

Continuous recording on a laptop computer. In the first resilience workshop, we had the luxury of a trained recorder with each of the groups. The recorder not only recorded but transmitted the data to a central computer where two of the researchers were gathering and analyzing the data as it was transmitted. While this is expensive, it is worth the effort when launching a project because it adds a layer of fun and science to the project. It kept the process moving along and alive. People liked seeing their group ideas projected on the screen for everyone to see.

Written record of the process. A recorder sits with the group as observers, providing backup for the facilitator and the flip chart recorder. These recordings are very useful when analyzing data; they present a perspective on what happened from a more detached perspective.

Individual workbooks. An individual workbook adds a new variation on focus group recording. We discovered this by accident during a large focus group session. In developing a guide for the day, we provided space so that people could add personal ideas. When coffee or lunch occurred after the completion of a particularly interesting question, the seniors used some of their break time to enter their thoughts.

The first time this happened we were surprised by the care given to the individual records, and we were intrigued with the data. We had to negotiate with the participants to give us their workbooks and had to promise to return them. They didn't want to lose their record of the day because they wanted to keep their ideas for future use.

We have adopted this workbook process as particularly useful for seniors. Although we do not expect people to record their personal thoughts, if they wish to share their personal reflections it can be a powerful addition to the data. It is a way of capturing thoughtful ideas that may not have been part of the group discussion or a reaction to ideas

### F. Data Analysis in Focus Groups

Participants in focus groups are more than data providers or collectors. Participants in focus groups analyze their own information as a group. They prioritize and categorize ideas, create abstractions, and look at implications. This would normally be called analysis. Senior researchers led these discussions and were responsible for completing the analysis of the data collected. The following steps were followed after the focus groups had completed their work:

**Compile data**. The researchers gathered all the flip chart sheets, the recorders' notes, and any individual submissions. They transcribed these into one summary document according to questions or general categories.

At the rural workshop in Cochrane we collected all the sheets and notes. A group of researchers and participants spent a day cutting up ideas and sorting these into categories. We tried many groupings but came up with a set of strategies/experiences that helped people understand the complexity of resilience. These ideas were prepared into another workbook and were presented back to a second focus group for verification and correction. We were able to develop an analysis that suited the data because we worked with the group of seniors. (Refer to Appendix 6 for a copy of this analysis workbook from Cochrane.)

**Verify information**. Because decisions are made based on the data, it is important to check the data for accuracy. Researchers take a common idea and look for examples of support for the idea within the flip charts and notes. This process is continued until there is a sense of confidence that the pertinent information has been accurately identified and expressed in the analysis.

Use computer analysis. In the large initial workshops (where we had over a hundred participants), we transmitted the data into a common computer while the groups were in process. Several of us were able to read the incoming data and identify emerging themes and these were then checked by the people who were at the session. You can use computer programs to analyze large data sets but you need to input the data. If you use digital recording, it is possible to use transcription programs but these are still in the early stages and take a lot of time.

Whatever the method of analysis, the results need to be written up for those who participated. It is also important to send reports to those who would be interested in your findings. Sharing findings will increase the likelihood that your group will be contacted when new topics or issues arise. If the focus group is a part of a larger research study, it is helpful to invite participants to attend follow-up sessions to learn about the progress of the project and how their information added to the knowledge being created. The techniques in the final section of this book draw heavily on maintaining contact with participants.

There are more formal ways of analyzing data once you begin using focus groups to explore specific questions. The analysis you use will depend on the question and the purpose of the study. (Refer to the references at the end of the chapter for more ideas about analysis.)

#### G. Suggestions for Training Seniors to Conduct Focus Groups

The following suggestions were offered by participants in focus groups:

Seniors liked to "make a day of it." We found that most seniors liked to come at 10:00, have a lunch break, and leave at 2:00. They also preferred to work primarily in small groups. They found large group reporting to each other hard to hear, repetitive, and time-consuming.

Noise is a major factor in large groups. Seniors felt exhausted and frustrated by noise interference when several small groups worked in a large room. In another large workshop, groups were able to work in separate rooms and this was much more successful.

Seniors appreciate the open interaction among participants. When they sensed a mutual support that came from listening carefully to each other's ideas and comments, they were open to debate their own ideas. A respectful, frank and open discussion usually brought a mutually satisfactory conclusion.

The actual size of the small group did not seem to matter to seniors, although the facilitators seemed to like groups under ten because they were easier to manage.

They felt their ideas were recognized when they were written on a flip chart. They felt consensus needed to be clearly written and discussed at the completion of the session. The following outline can be used to train aging adults about focus group research:

**Pre-reading.** Read this chapter of the manual ahead of time along with an example of research developed from a focus group process. (A focus group report available in Appendix 8 and Cochrane follow-up is available in Appendix 7.) If the group has not studied Chapter 3 (Field-work), have them read this as well.

Each of the following sessions should be one to three hours in length.

**Overview.** Discuss the pre-reading and decide on a topic for a practice focus group. Follow the training workbook to prepare an agenda.

**Preparation.** Decide on roles and discuss what is not expected. Prepare materials.

**Conduct** the focus group.

**Debrief** and analyze findings.

Write report.

#### Resources

- For a sound introduction to all sorts of focus groups, see: R.A. Kreuger, *Focus Groups: A Practical Guide for Applied Research* (Thousand Oaks, CA: Sage, 1994).
- To extend the above resource in how to design questions, see Richard Kreuger, *Developing Questions for Focus Groups* (a Focus Group Kit). (Thousand Oaks, CA, Sage, 1997).
- David Morgan has an excellent introductory book and a Focus Group kit in six volumes. Morgan, D. *Focus Group Guidebook* (Thousand Oaks, CA: Sage: 1997).
- For those who want to use focus groups to explore people's lives and experiences, try Jean Bystedt's, *Moderating to the Max: A Full-Tilt Guide to Creative*
- You might also try Gloria Bader and Cathy Rossi's, *Focus Groups: A Step-by-Step Guide* (San Diego, CA: Bader Group, 1998).
- For a reference that talks about focus groups in the larger international context, see Holly Edmunds, *Focus Group Research Handbook* (Whitby, ON: McGraw-Hill, 2000).
- You might also find Bonnie Goebert's *Beyond Listening: Learning the Secret Language of Focus Groups* interesting if you want to pursue the technique (Somerset, NJ: Wiley).
- For researchers interested in focus groups for traditional and non-traditional research, see Edward Fern, *Advanced Focus Group Research* (Newbury Park, CA: Sage, 2001).



Mary Ann Wilkat

Just because we're 65 doesn't mean we don't care anymore, can't do anymore. That's an important lesson.

6

#### Narrative Research

In Chapter 6 you will learn how to conduct in-depth interviews with other seniors, using a narrative technique that was designed especially for you. We spend more time in this chapter talking about truth and meaning than we did in earlier chapters. This is because personal stories capture a personal truth that may be at odds with historical truth.

This chapter looks at the occasions when you might use narrative methods in research. It also covers some of the principles that guide the use of narrative as research; techniques for collecting and analyzing data, samples of narratives, and evaluation of the methodology as a tool for seniors.

The method is a combination of peer interviewing and a storied research model developed by Nancy Marlett, one of the principal investigators. Narrative celebrates stories as a way of sharing personal experiences, and in this method, the story itself becomes the unit of data collection and analysis.

In the first resilience research workshops, seniors told stories of resilience in their lives. Most of the focus groups began by sharing stories, for example, the spirituality group began with a question: "Could you share a time when your faith made you resilient?"

While the senior researchers were well-versed in the power of stories, it was a challenge to design a structured process that was also natural and comfortable. We didn't want to get in the way of the rich exchanges that occur naturally when seniors talk to each other about their lives. We didn't want to limit interaction with a questionnaire, nor did we want to encourage open conversations that would prove difficult to analyze. The method chosen uses a structured workbook approach introduced in the focus group chapter (Chapter 5). This provides a sequence for data collection, an interview guide, and a series of prompts for eliciting stories about resilience. The entire structured narrative interview guide is included in Appendix 9.

#### A. When Do You Do Narrative Research?

Narrative research has become very popular in most of the health and social sciences because it provides a natural way for people to share and explore meaning. Most of what we know is held in stories and we share our ideas and feelings through stories. Stories can be shared and adapted to suit the reason for the telling. There are many current sources on narrative but we are still in the early stages of understanding how to use stories in a research context. Most often the term narrative is used when people are encouraged to recount their experiences and thoughts in their own way and the analysis then reverts to more traditional qualitative techniques of identifying themes and patterns without attention to the story structure itself. The following are some of the more common uses of narratives:

**Personal life stories (autobiographies).** As seniors look back and celebrate their lives, many are moved to write their personal story

as a way to make sense of their lives. Writing the story captures the lessons learned for family and friends to share. Desktop publishing places autobiography within most people's reach.

**Representations of memory.** The use of story is not limited to written stories. Story-boards, scrap books and memory boxes support seniors who are losing their memories. Stories captured in pictures, video, songs, and poems help people hold and celebrate their memories and connections. There is a large body of research about the use of narrative to maintain memory and cognitive functioning.

**Oral history** research, as described in Chapter 3, captures the traditional cultures of a region or specific group. Seniors have a long history as amateur scientists who collect materials and record their stories for museums, historical societies, universities, and archives. This informal research is often called "folk life research." Researchers collect a wide range of artifacts, pictures, and stories about: material cultures (houses, transportation, food, crafts, commerce, the arts, and folk medicine); oral traditions and performance (legends, humour, proverbs, songs, dance, games, and play); and family life, traditions, and customs. The ability to collect and record stories is central to this work, for all collections tell the story of the past.

**Stories as text** can be collected and analyzed as qualitative research. In this work, themes and common ideas are extracted from people's stories. We will see an example of this later in this chapter.

**Stories as structures** – the types of stories people tell, the story-telling methods, stories as examples of the scripts people live by. By looking at the various elements of stories, we have a way to study what precipitated the action of the story, the normal plot or script of the stories being told, and what were the expected outcomes. This approach is also the foundation for the research method developed for seniors.

#### B. Stories in Research

Stories are used in research because meaning is created in conversation as stories are told and explored. There is no established truth that we are trying to find, no theory about what is right. For example, we did not have a theory of resilience or a hypothesis to prove. In our research we were trying to find out what people thought about resilience. We expected that knowledge and meaning would evolve and change and that resilience would mean something different for different age groups. The meaning of resilience for older adults is no more "true" than the meaning teens find in resilience, for both are meaningful within the context of the experiences of the story-tellers.

Meaning, in a narrative approach, is contained in stories about events, relationships, emotions, and thoughts. In narrative research, we look for stories to provide information, just as we looked to observations and artifacts in field-work, answers to questions in the interviews, and thoughts around a topic in the focus groups. Each method has a different way to create data.

While narrative research can be very unstructured, with stories loosely embedded within the stream of conversation, we are suggesting a method whereby stories can be elicited and studied as discrete units. Even with this structure, a story is not a clean, direct line from beginning to end. Most stories have a tendency to be messy and rich in detail that may seem irrelevant at the time. These diversions are often important when looking back at your data to find meaning or lessons in the story. However, as stories are recorded, they take on more direction and form.

We can think about the structure of stories as containing:

The title of the story. The title captures the essence of the story and creates a shorthand reference to it. You may have time to create a title with the person during the interview, but it is more likely that you will think of a title as you read your notes or listen to the tape. If you

have made arrangements to follow up with the person after you have recorded the stories, you might ask for input about what titles work best for them as well.

The context of the story – setting the stage or the backdrop to the story. The context creates a "frame" for the story: where it takes place, what is happening at that time in the community and the world, and who is involved. Others reading the story connect through common contexts

That was like me even though we come from very different backgrounds, that story speaks to me because I knew poverty from the war too. (SP, 2005)

The plot or script of the story. Events fit together in order from the beginning to the end of the story. It may be effective to guide the conversation by asking the question, "And then what happened?" to ensure that you have a chronologically sound story.

The lesson or meaning of the story, why the person told the story and what they found out in telling it.

The person's reaction to the process of telling the story.

Your reactions to hearing the story and the meaning you found for the topic being studied. You were a part of the creation of the story; you were the listener and were active in the creation of meaning. Your insights at the time of the telling are considered to be of particular importance in this method.

#### C. Recruiting and Ethical Approval in Narrative

Recruiting participants in narrative research is seldom a problem, but there are some particular ethical issues when it comes to people's stories. Stories are personal property and hold particular meaning and importance to most people. In most other research one can figure out ways to maintain people's anonymity, but how do we hide the details

of a person's unique story? There has been a long and vocal history of groups objecting to researchers coming to record their stories. In many situations this has been seen as stealing, using people's stories in ways that the owners of the stories have not sanctioned or understood. While there has not been much concern among seniors' groups yet, it is well to learn from minority groups, indigenous people, people with disabilities and alternate lifestyles. They claim that it is their right to be named in their own stories. Thus, when deciding to use narrative as a means of collecting and presenting research, think carefully about ownership and how to share these stories with honour.

Seniors have a wealth of stories and limited opportunities to share them, and this is both an advantage and a challenge. People are willing to share their stories, not only because it validates their lives and knowledge, but because it gives them a chance to put things in order and to celebrate their accomplishments and hardships.

Telling life stories is therapeutic in a fundamental sense, for it is what humans do to make sense of their lives. Because of the benefits, telling stories can also make people very vulnerable. People generally want and need to tell stories to those who can bear witness to their struggles and accomplishments. However, in the process, they may encounter old fears, pain, and trauma. There is a fear in research communities that these old experiences need to be guarded. Some feel that painful stories are best left alone. The dilemma is captured in the following field note:

In our first rural resilience workshop, 3 of the 4 focus groups independently began sharing stories of what we would today call child abuse. As a trained researcher I tried to control this sharing because of the hurt it could bring to those sharing their stories. I assumed that these stories were too dangerous to be shared with other seniors without a professional present to "deal with the emotions." Luckily my colleague

was a long-time researcher in the north and reminded me of what I knew with other groups – people are strong and share what they want to.

These sessions, from my perspective, were deeply personal and therapeutic. From the perspectives of those doing the sharing, they were stories that they had not had a chance to tell. Their experience made sense when they heard other people's stories.

Life in earlier, remote and harsh environments could not be compared to urban life today with our values and expectations. Yes, they were treated harshly, as were others. In context, the experiences were not traumatic; it made them strong and they didn't know anything different. To pathologize their experience would have been a disservice. We had come to learn about resilience, and harsh punishment had been part of their path. We had not come to learn about abuse. If it had been framed as abuse, I doubt if they would have been willing to share their stories. (NJM, 2005)

We see from this that it is important to be clear about the purpose of your research and how stories will be used. People choosing to take part in research need to be aware of the potential dangers and advantages. Research around difficult topics should not be avoided because of professional sensitivities if seniors feel it should be done. However, we need to be transparent and honest about what is expected and what safeguards are in place for everyone. Seniors are able make decisions about what to share. They just need the information and the safety to do so.

Ethics approval should allow the option for seniors to maintain ownership of their stories and that they will retain decision-making power over how their stories are told and distributed. This may cause concern within many university research traditions where seniors are seen as subjects, and where committees make the decisions about what is in seniors' best interest. It will be rough ride for those seniors' groups who take on the academy in its role as protector of seniors as a vulnerable population.

#### D. Role of the Interviewer

A good narrative researcher is an attentive listener who follows up on ideas, explores the details, and shares short reflections from his own experience. The researcher is considered a peer, for both listener and story-teller have come to learn and to listen, to contribute and to create. While the interviewer brings experience and knowledge to this process, his or her primary goal is to make it possible for the person being interviewed to tell his or her story.

The skills and knowledge from the chapter on interviewing and the responsibilities of a group facilitator in the chapter on focus group research are all part of becoming a good narrative interviewer. The narrative research guide in Appendix 9 outlines the specific roles of the interviewer at each stage of the interview.

In addition to natural interpersonal skills, there are several skills and talents that are particular to narrative interviewing:

Listen for stories. It helps to begin with prompts that encourage stories such as "Could you tell me about a time when ...? Do you remember a story about ...?" Listen for the entrance into a story, for example, the person may begin with "I remember when ...," "When I was a little girl ...," or "When we came to Canada..." All of these are indicators that a story is being readied for the telling. It is as if the person were setting the stage for the story to be told. We are taught as children through fairy tales that each story begins with "Once upon a time there was someone, somewhere doing something." When the

person announces a story, listen carefully and encourage the story to unfold

Listen for plots. When the story begins, most people are shy about expanding upon the details until the listener shows interest. You can prompt, "And then what happened? How did that happen?" In northern countries, most stories follow a specific format: a beginning where something happens to disrupt the status quo, a middle that describes what happens after the disruption, and an ending that re-establishes some semblance of balance or normalcy. Listen carefully for these indicators. Do not assume that other cultures follow the same structure. Some cultures tell stories that are open-ended explorations of thoughts and events combined.

Share your own stories as prompts. It is natural for you to share your own experiences since you are a peer in this process. When this happens, attempt to share your experiences as a story to let the person know that it is all right to talk in stories. Many seniors don't see stories as real research and may need to see story-telling modelled. They may feel that you really want opinions and facts. You may want to practice telling a short personal story related to your topic so that you are prepared. As the person being interviewed listens to your story, they can then be comfortable that an everyday story, told in a natural manner, is acceptable.

Explore the impact of stories as a way to extend the story. When you hear a story, use the opportunity to comment. Do not use "good" as a descriptor; it implies that you are in a position to judge the quality and usefulness of the story. Instead, comment on how the story affects you — that the story is interesting, disturbing, moving, lovely, powerful, etc. In this way you are a witness and convey to the person how hearing the story has had an impact on you. This enables you to explore what the story meant to the narrator and what that person learned by thinking about the story again. Connect the story to the topic by sharing what you have learned by hearing the story in

the context of the topic you are studying, i.e., hearing your story really brings home how important rural teachers were as examples of resilience. Reinforce the idea that stories hold meaning and that meaning is made when stories are shared and discussed.

#### E. What Kinds of Stories Can Be Collected?

The following are the types of stories that were most commonly told by seniors in our research. These are presented in a sequence that emerged from listening to seniors tell stories in the focus groups. All types of stories may not be relevant for your particular research project. We found that progression assisted the participants to feeling at ease.

**Topical life story.** If your research is about the person's life story, this section will be the entire research project. However, in narrative research, the life story is generally tailored by the teller to fit with the topic of the research. Out of the thousands of events and markers that could be included, people will select those stories that they think have most relevance to the topic they have been asked about. The selection of stories is interesting in itself. In the following example, Bea is being interviewed about resilience and rural life. Her story about her grandmother is tailored to this topic. It is written by the interviewer.

Bea talked about how their family fled from Eastern Europe with only their clothes and photographs. They settled in the west where she had three brothers, two died in childhood in accidents on the farm. Bea went to school and eventually became a teacher in a small town. Her father died in an accident and her mother continued on the farm where she died alone and wasn't discovered until a week later. Bea married and had four children. She lost her husband and eventually moved in with her remaining sister in the city where she has now joined a seniors club and helps out with baking for events. (Bea's life story, 2007)

**Stories in the third person related to the topic**. Most of our work seemed to begin with stories about family. While this may be due to the topic of study, resilience, telling stories of other people seems to break the ice and overcomes shyness about telling personal stories.

Bea talks about how her mother was feisty and resilient. She loved to care for sick animals, and took hurt animals into the farm house when her husband was away. Her mom was a wonderful baker and made extra money baking for the hotel in town. She also made due with cast offs and made things nice in spite of hardships and isolation. In the end, she felt her mother lost her will to continue and died of the grief of losing her two sons and husband. (Narrative data summary, 2007)

**Personal stories.** Once people are comfortable and have practised telling stories about other people, they are able to call up personal stories about the topic.

Bea tells the story of the death of her older brother and how she felt it was her fault, how she finally told her Sunday school teacher who was very kind and helped her understand that accidents in farming are a part of life. She tells how she spent many hours in the fields that took her brother away and how, in learning to love the fields through the seasons, she found some peace. She likens the passage of the seasons to life and resilience. (Narrative data summary, 2007)

**Topic-related stories.** If your narrative interview follows a focus group or workshop, you may be able to relate to the focus group results to trigger specific stories. The following story was told as part of being raised in a rural setting and resilience. Bea thinks back over her other stories, and the interviewer reports:

In thinking of resilience among her children and what she could pass on to them, she muses on the importance of a connection to something bigger than oneself in being able to find meaning and move on. For her, it was connecting to the land, but her sons live in the city now and her grandchildren know little of her past. She thinks that she may invite the youngsters to visit the farm and spend time in nature with her. That way she could help them find something that might be meaningful for them. (Narrative data summary, 2007)

#### F. Data Collection: Gathering Stories

While it is easy to listen to stories, it is much harder to record them. Sharing stories includes not only the words, but body language and shared meanings acknowledged but not spoken out loud. There are several methods for capturing stories told in conversation.

Written stories. Collecting stories can be done by asking people to write or record their own stories about a topic. It is helpful to share examples with them so that they understand that you are looking for full stories. We found that an effective way to encourage written stories was to introduce a topic for discussion and model story-telling then invite people to write their own stories at their own pace. You need to be sensitive to the discomfort of some seniors when asked to write, so include a secondary activity, such as a coffee break, so that those who are reluctant can ask for help without feeling singled out.

Write up the stories after the conversation. You can engage in a conversation where you take brief notes and write up what you remember. You tend to remember the first and the last part of any story and the stories that resonate with your own experience. This means that, if you are like most people, you will remember only parts of the story.

Recorded and transcribed stories. This was the method chosen for the Kerby study because it enabled the interviewer to focus on the questions and the flow of the interview. This meant that a good-quality tape recorder had to be found and mastered. Some seniors preferred to have someone else handle the equipment. At Kerby we had students who were there to help out with the initial training sessions and handled the tape recorders.

**Group interviews.** Narrative work can also be done in groups where the group can ask questions and make comments as a person tells his or her story. This method was very popular and is effective in making seniors comfortable with sharing their stories. People tend to remember more when interested listeners ask questions and respond. We used this method of sharing stories to start focus groups and workshops. The trick is to sort out each persons story since they become mingled. It may mean piecing the bits together with each person.

#### G. A Method for Recording Stories

The particular method presented in this chapter was created specifically for seniors. It is a structured interview with a specific topic as the focus. The interview is taped and stories are composed as the interviewer listens to the tape and records stories following the structure in a workbook. The questions facilitate the telling of stories and the researcher uses the same format to record. This consistency in method simplifies the data-collection process and leads directly to analysis and interpretation.

Table 12. Sample of story form used in composing stories from transcripts.

| Title of the story:  |
|--|
| Context: the setting, what is happening before the story starts, the characters, |
| The trigger: what happens to start the story action.                             |
| The plot: sequence of events that occur.   |
| Consequence: what is the outcome of the story, the lessons learned.              |
| The storyteller's reaction to the story when told.                               |
| Your reaction to hearing the story and links to the topic.                       |
|  |
| Signed (recorder) Date   |
| Was this version shared with the person? Yes/No                                  |
| Permission to share the story  |
| Datesigned   |
|  |

#### Composing Stories from a Taped Interview

This manual does not include information about full transcription. In full transcription you attempt to turn an oral experience into a grammatically correct written form. This is an extremely time-consuming process (about six hours per hour of tape), and it involves translating sentence fragments into a coherent written document. If not done well, people are embarrassed when they see their thoughts transcribed into written form and may avoid working with their own story.

An alternate form of narrative transcription creates a script based on speech rhythm, writing each phrase (marked by a pause or breath) on a separate line. The transcript looks like the example below:

Well
I really got caught up
With everyone else you know

In the bigness of the thing

Little did we ever think

That once we were into the storm that the sucker would not let up

This method was developed by Nancy Marlett and allows you to type everything that was said but in a form that looks like a poem of the spoken word. This method of transcription takes about 1.5 hours per hour of tape once you have learned to listen for the pauses. People are intrigued with how it sounds when they read their words on the page. They are more willing to maintain ownership of their words and thoughts with this method. It is relatively easy to analyze this style of text. Ideas seem stand out even though they are often short fragments.

The method created for seniors in this manual involves listening for stories and writing coherent stories using the person's own words whenever possible. In listening to the tape, you are asked not to transcribe the conversation word for word, but to listen and take notes about events and thoughts until you can piece together a summary of each of the stories. Most of the seniors liked this process, although it was very time-consuming in the early stages. Some found it helpful to listen with a friend or co-researcher. One even invited the person interviewed to help write the stories.

When composing stories, use as many of the person's own words as possible, but do not feel shy about adding materials or leaving other parts out to make sense of the story.

Remember that stories as told, wander, perhaps not as far as that shaggy dog, but wander they do. It is your task to bring the parts back together again and to write a coherent story with a beginning, middle and end, using the elements in the above format – title, context, plot, and lessons learned.

The following story is taken from the tape:

Title: Mom's Version of Bouncing Back

**Setting the stage (context):** Mother and three children (in elementary school) living on 20 acres when father is away at war.

The plot: As children we had little money and mom went to work cleaning houses for neighbours. We children did most of the work at home and looked after the animals and gardens, as well as our schoolwork. We had summer jobs picking berries for extra cash. We often missed the first few months of school because we were working, and then we had to study extra hard to catch up in school. Many friends and neighbours visited, brought food, and stayed to play.

The lessons of the story for resilience: Mother taught us children to work and play hard together. We learned many skills early and had an attitude that there was nothing that we couldn't do – if something doesn't work try another way or do something else. We learned the importance of other people coming to help and play. They learned to enjoy working hard to overcome difficulties and to love others.

The person's reaction to telling their life story: I realized how important my upbringing was to me, how much my mother's attitude to work and play has become my own. I really appreciate my mother and understand more about why she was away so much.

What I learned about resilience from this story: I realized the importance of a consistently loving upbringing where the mother's attitude is adopted by the children. They learned to be accountable and to have fun as well as to work hard. The children were not embarrassed by the gifts of others and accepted food and help with a natural appreciation.

#### H. Story Analysis

Collecting and presenting stories may be the goal of your research project, but in this chapter we are exploring how stories may provide data for studying a research topic. Analysis begins as you listen to the tape and check to make sure each of the story elements is present. You continue as you discover new knowledge and establish patterns from working with a number of stories on the same topic.

Recording the story in the format is the first stage of data analysis.

- The contexts and what they teach about the conditions that led to the telling of stories. You will see later in the chapter how the contexts led us to explore the conditions that created the need to become or to be resilient.
- The plots and what they teach us about the underlying scripts or strategies to deal with challenges.
- The endings and what they teach us about what people expect as outcomes.
- Personal meaning. Thinking about the meaning is the second stage of analysis for both the story-teller and for you. This may be a simple emotional reaction:
- Themes and patterns. You can also use the structure of the stories to perform more sophisticated analysis.

Look for metaphors in the stories, for common themes within stories, and search for relationships between themes. There is no limit to the work that can be done with stories as data

#### I. Interpreting Stories

The following interpretations emerged from a PhD seminar on resilience and seniors. The seminar was an opportunity for students studying resilience at the doctoral level to study in partnership with senior researchers who had just completed the resilience project. During a portion of the seminar, we studied the stories that the seniors had collected about resilience and together we analyzed the data.

The contexts of fifty stories were studied to identify common themes related to the conditions that either taught people to be resilient or signalled the need to respond in a resilient manner. For each of the stories we looked at the plots of the stories to identify the strategies people used to become resilient. We then grouped stories. This work is in the very early stages but eventually others will hopefully share the excitement we felt at finding a new way to think about resilience.

**Disaster/war.** A shared experience that threatens loss of a way of life and status. People expect that a disaster will be time-limited. People are not chosen to experience the disaster, it is beyond people's control. Personal loss is seen as chance. There is no blame attached.

The strategies or scripts of resilience were all based on a temporary setback and the loss of fathers. Strategies included: taking on nontraditional roles (mothers working outside the home, children taking on adult roles); sharing labour and resources with others (friends and family and neighbours); doing with less; working extra-hard and giving without expectation of receiving in return.

Loss of loved ones, of a way of life, or of competence (disappointments of aging). These challenges were spoken of as a

never-ending sadness, a dragging down, a loss of interest or a depression. The notion of burden was also mentioned (a dying parent, a disabled child, etc.). Sometimes, the burden seems to be the source of personal meaning.

Resilience scripts in a situation of loss include becoming absorbed in ways to find meaning, focusing on relationships with others, finding a way to contribute, or finding a reason to go on.

Illness, disability, and chronic pain. While illness seems to be more time-limited, it still invokes the need to be resilient and to adjust to changed lifestyles and relationships. Persistent pain generates worry – the anticipation of pain can be more damaging to resilience than the pain itself. Resilience strategies and scripts included distraction, acceptance or finding meaning in pain, and making pain a companion.

We end this section with a story that emerged from a focus group; it begins as the group discusses the topic and then shifts to a story told by one of the group participants. The voice is of the recorder for the group.

#### Story Analysis: A Balancing Act of Caring

**Setting the stage (context).** The health focus group was interested in why women who were caregivers seemed resilient. They thought that resilient people were those who took the time to care for and help others. The group thought that people (women) who were expected to be, and were trained to be, caregivers had an advantage over men who were not taught to care for people. This is the starting point for a follow-up story with one of the focus group members.

An individual contribution. In talking about men, Mary tells of her husband who had been a widower, and when his wife died he was pretty helpless; he had been waited on for years. She told of his mother who had done everything when he was a child and as an

adult he was not self-sufficient but found a willing wife. When Mary started dating, it was apparent that she was to be the next in line as a caregiver. She made it clear that he had to learn to look after himself before they married and that she expected to be looked after too. There was much laughter and talking about similar situations.

**Lessons learned.** We talked about whether seniors can be taught to become more resilient and everyone agreed that it could happen but it would take persistence.

The person's reaction to telling their life story. Mary felt strongly that many people do not want to learn to be self-sufficient; they don't want to put the effort in when someone has always been there to help. If people show that they can do things they will be expected to do them on their own.

What I learned about resilience from this story. I believe that children should become more self-sufficient and that everyone should learn to take care of others as a way of learning to take better care of themselves. This story also raises issues about caregiving as a contribution to others and the important link between caring and resilience. This also begs the question of learning resilience through socialization, and this could be one of the reasons why people see women as more resilient and likely to outlive their male counterparts.

#### J. Suggestions for Training Narrative Researchers

We decided to introduce a relatively sophisticated interview process when we completed the focus group research because we knew that the senior researchers were both competent and eager. We created this narrative method to take advantage of their skills and abilities.

The experience taught us that it is possible for seniors to conduct in-depth narrative interviews with relatively little training. We only had time to introduce this new method and to provide some experience in conducting in-depth interviews during the funded project. However, there was so much interest that we conducted a follow-up session focusing on narrative. We were able to complete the analysis with the PhD class that began after the project was completed. The following outline reflects the steps we took:

**Pre-reading.** Read relevant sections on interviewing and facilitating focus groups. Have participants bring a autobiography or personal story to the first class.

**Listening for stories.** Practice finding stories within autobiographies. This leads to a discussion of the elements of a story and practice in working with the story-analysis forms.

**Narrative in research.** Review this chapter and discuss the various types of research that can be done. Discuss the ethical and clinical implications of this type of research. Practice telling stories to each other about a topic. Create your own workbook based on the narrative interview guide in Appendix 9.

**Technical aspects.** Practice tape recording. Practice listening to tapes and extracting information.

**Conduct interviews.** Work in pairs (one doing the taping and the other the interviewing). Bring the taped stories back to the group. It is important that the group be able to work with stories prior to the actual research. It is only as stories are analyzed and interpreted that the reasons behind this method become apparent.

The seniors' evaluations made it very clear that this is a powerful method, but it is difficult to master without time and practice.

#### **Summary**

This chapter has introduced a new method of narrative interviewing. It was the culmination of the previous methods, and it has great potential as a method in research done by seniors about seniors. The stories that were collected yielded rich understandings of resilience that could not be obtained from any of the other methods. A senior

researcher noted that "the interviewee's story had so much power and sincerity that, at times, it was overwhelming."

#### Resources

- The foundations of the storied method used is contained in an unpublished manuscript called "Empowering stories; a topic and a method," available from the author, Nancy Marlett (marlett@ucalgary.ca).
- Dan McAdams, *The Stories We Live By: Personal Myths and the Making of the Self* (New York: Guilford Press, 1993) introduces the reader to the rationale for using narratives.
- Jerome Bruener's *Making Stories: Law, Literature and Life* (Boston: Harvard University Press, 2003) is a classic on how narrative underlies all our understandings.
- For the more academic, Donald Polkinghorne's *Narrative Knowing and the Human Sciences* (Albany: State University of New York Press, 1988) is well worth the read.
- Jean Clandinin. provides a personal exploration of how to work in a narrative way in conducting field research in *Narrative Inquiry: Experience and Story in Qualitative Research* San Francisco: Jossey Bass, 2000)
- A recent book on narrative, *Narrative Analysis* (qualitative research method) by Catherine Reissman, (Newbury Park, CA: Sage, 1993) marks the movement of narrative into more formal research designs.
- Web-based searches on narrative will put you in touch with narrative research conferences, listservs, and web sites devoted to narrative methods and research

## Section 3

### Conducting Inquiries and Research

This section includes three chapters about how to do your own inquiry and research. It helps you to put the specific research skills (observing, interviewing, focus groups, and peer-narrative interviewing), learned in chapters 3–6, to work. It is constructed as a series of steps, and each step includes a general description, key material, and links to resources. You can use this section as a course outline, a guide to the manual, or a framework when you are beginning a research project.

In this section we introduce a variation on collaborative inquiry to ensure that seniors are directly and authentically involved in research that affects them. This method arose during the writing of the book as we struggled to live up to the high standards that were proposed at the end of Chapter 1. We trust that you will find that this design helps you to appreciate the power of seniors-led research.

The three chapters draw on the experience of the Kerby Centre over a ten-year period, in taking up the cause of elder abuse. It is an example of how to create a program based on research. It also includes recent applications on elder self-neglect (an emerging aspect of elder abuse). Seniors who were involved in the project from the beginning provided the input.

We first saw a need to do something about elder abuse because of the persistent phone calls we received at Kerby Centre. Distressed seniors and their friends and family were desperate for help. We searched the community to see what was being done by others and in doing this we realized that there were few if any existing services and resources. We had a feeling that it was up to seniors to bring this problem to light. (CPA, 2007)

We have used the metaphor of a race in introducing this section for modern-day research has become very competitive. Each chapter depicts one stage in the race to research:

**READY** (Chapter 7) refers to the stage of gathering interest and focus, thinking about entering the research race, preparing for a race, getting the team together. We have included three activities in this first step: engaging other seniors, or building a base of interest; clarifying the problem or opportunity; and attracting other members. This stage ensures that the supports – the coaches, trainers, and equipment – are there for the race.

**SET** (Chapter 8) documents four activities that lead up to the writing of a research proposal: becoming recognized or qualifying as a race participant; surveying and selecting funding possibilities, which is like selecting the particular race to take part in; choosing a method or working out the race plan; and, writing a proposal, which is like registering to be a competitor for the race.

This chapter introduces a new research design, a collaborative inquiry method based on three distinct steps (SET, COLLECT, and REFLECT) that ensures that seniors are invested and involved in the process and outcomes.

**GO** (Chapter 9) refers to conducting the research or running the race. There are three activities here: creating the infrastructure; recruiting and training seniors as researchers; and, collecting and analyzing your data. Here we build on the values of partnered research (Chapter 1) and inquiry and the structures of SET, COLLECT, and REFLECT (Chapter 8).

At the **FINISH LINE** you have reached your destination and are savouring the results, preparing to let others know of your accomplishments. You are likely also preparing for the next race, reviewing your performance and planning to do better the next time. Here we discuss evaluating what you have done, sharing results, and taking action.



**Grant Allen** 

Finally, I feel that I can play a role in credible research that can give seniors access to the decision-makers in matters specific to older people. 7

# READY: Setting the Agenda for Your Research

Take your time getting ready for inquiry and research, for this is your foundation. Shoddy or rushed preparation may get you to the starting line faster but may get you to the wrong race altogether. Community-based research is inundated with "hurry up and wait" research, conceived to meet the needs of a funding body. This process is generally called RFP or requests for proposals, which are initiated when a funder has a particular issue they need input on. The proposals can languish in the in box until funding is approved or guidelines are finalized.

The following steps will help you sort out what you are interested in so that you can respond to requests for proposals with confidence or start your own inquiry process without formal funds. The steps are: A. engage with your topic and other seniors, B. clarify the issue or opportunity, C. attract other partners.

#### A. Engage with Your Topic and Other Seniors

I was really upset and didn't know if I was the only one who was concerned. Then I found out that it was worse than I thought from my neighbour and I went and talked to the manager of another building who confirmed that it was a problem. She told me to get more information and more people involved. (CJ, 2006)

If you feel alone with a concern you may give up in the face of the enormity of the problem. Before you do anything, talk with other seniors. The following are some of the ways that you can connect with them:

**Form an informal network of concern.** Find a friend or two to start an informal network by word of mouth. Spend time thinking together about what is bothering you and what you hope to achieve. If you decide to proceed, talk to people in charge at a centre, club, or group that could provide a place to meet, sponsorship, and perhaps even the use of official letterhead.

Contact retired professors. Most universities and colleges have an association of retired professors that sometimes are called emeritus professors to denote that they have made a significant contribution to the university. We found this group to be a wonderful source of seniors with a love of research and a willingness to help others get involved in research.

I was pleased to be invited to join the Kerby Centre of Excellence. You can look at research that isn't restricted by the university; you can be wider in scope. The biggest part is having the time to enjoy the research itself, and to touch things that you haven't done before. (HB, 2006)

**Hold information meetings.** Advertise to find people who share your ideas so that you can get together and discuss ideas. It is helpful to have someone prepare a talk about your concerns from a senior's perspective. The following quote is from a related project in Cochrane.

We had a small group of us interested in elder abuse in Cochrane, so we got someone from Kerby to come out to talk about abuse with our seniors. From these meetings, we saw that our seniors were also being abused. We got the institutions involved, some of the seniors were interested particularly in bullying and then the council and the local government got involved. It was no longer just a few of us. (MW, 2005)

**Organize your inquiries:** The following are some of the ways that you can create a record of your work so that when it comes to writing proposals or reports, you can find your ideas and contacts.

Take minutes. Set up a notebook or computer folder and take notes as if you were a secretary taking notes at a meeting. Have someone in the group designated as the scribe so that you can trace your ideas, referring back to what was happening when decisions were made and who was involved when topics were discussed. One effective way to take notes is to send e-mails to the group about what you did and invite them to reply. You can then save e-mails at each stage and print them out if you want to keep track of what is happening in hard copy.

**Create Files.** As you begin to gather information, start a file box. Separate personal stories, articles (by topic), and policy statements (by level of government) from notes taken on events. It is very useful to have the files in a common area where everyone can see what is happening.

#### B. Clarify Your Shared Concerns

Once you have a better idea of your concerns or opportunities, you are ready to test out your ideas. This includes collecting short narratives, looking at your concerns as a social problem, systematically collecting information and contacts, and finally testing your motivation for conducting research. This is likely the most interesting but most time-consuming aspect of conducting research, but it will move you from "a token senior at the table" to "a partner with information to share".

#### Observe, listen and document personal stories.

Listen carefully to the stories of people who live your topic (elder abuse, lack of access to transportation, loneliness, training for a marathon) and begin to collect these stories using the methods described in Chapter 6 (Narrative Interviewing). The following quote shows how a personal story calls out to research and action about elder abuse:

There were all these calls from seniors that really bothered us. One old fellow had his nephew visit and take his bank card. The nephew was stealing from the old guy. He called us because his nephew hit him when he tried to get his bank card back. So many of these old folk are afraid because they have no one to help them out so they take the abuse. (CJ, 2006)

Personal stories define the problem you are seeking to understand, illustrate issues, and can be used in reports and proposals. By connecting to the stories of seniors, you stand with them and this is what distinguishes senior researchers from other researchers. The following is an example of a vignette – a very short story about elder abuse.

Granny Joe, as she was known in the community had been a keen supporter of children in need her whole life. She moved in with her son when he moved back home after a failed business in the city. She looked after their three children until the children grew up and she grew frailer. She seemed to withdraw from her community friends and when Betty, the eldest daughter, returned home for a visit, she was shocked at the fear she saw in her gran's eyes. Granny Joe went to live with Betty and much later Granny Joe confided that she had been frightened for years by her son, both emotionally and physically. Betty decided not to intervene but stopped visiting her brother.

As volunteers and staff at Kerby were collecting stories, the federal government, through Health Canada, was looking to research elder abuse. Kerby was invited to become part of the national initiative because of their earlier work on identifying the stories of abused elders. Kerby was able to interview another 100 abused seniors because of its reputation in the field.

From these interviews Kerby developed a report on the 100 cases and wrote a manual called *Golden Years: Hidden Fears* for frontline helpers (available through the Kerby Centre for a nominal sum). The purpose was to define abuse and supply a list of resources in Southern Alberta. It also declared that Kerby was at the table in setting policy and program agendas about elder abuse.

It is hard to collect stories on topics such as abuse and isolation because people often hide when they are embarrassed or frightened. You may have to use other seniors or a local service such as Meals on Wheels to find people that might be abused or isolated. Chapter 4 (on doing field-work) will help you think about the ways that you might observe and listen, to identify what the problem or opportunity is and how to define it.

### Frame your issue or question as a social problem.

We knew from pulling the records of calls made to Kerby that many old people were afraid of their relatives and we made a decision to pursue this further. The small group of us knew we had to follow this lead even if no one else was concerned. (NM, 2007)

A social problem is an issue that is likely to attract attention and resources. Before you invest a great deal of time and effort into turning a concern into a more formal inquiry or research project, it is wise to step back and think politically. There are thousands of issues that are important and only a few get recognized. This work can be painful for it requires that you temporarily shelve your passion and look at your issue through the eyes of politician and potential funders.

An excellent resource is Donileen Loseke's short book *Thinking about Social Problems: An Introduction to Constructionist Perspectives.* It is available through the online bookstores. The first part of the introductory chapter is reprinted as Appendix 10 of this book. It will help you separate the personal anguish you feel from the external forces that cause the problem to be ignored or addressed. This is not to suggest that you drop your concern if it is not currently or potentially a social problem. Many personal or local concerns need to be honoured and may in the future become social problems, but you may need to make other inquiries and take action to bring the problem to the fore.

There are four questions to ask yourself in deciding if your issue can be seen as a social problem worthy of being funded in your current political climate.

Does the condition you are concerned about create harm; is it wrong? One need only look at international differences related

to weight, institutional care for the elderly, marijuana use, spanking children, and same sex marriage to understand how cultural values impact social problems.

**Is the problem widespread?** This helps you separate a social problem (one that affects a large number of people) from a personal problem that may be very upsetting but is limited to a small number of people. You can often form alliances with others who share a similar problem to create a critical mass of concern. For example, elevator access to rail transportation is a concern for seniors, persons in wheelchairs, and mothers pushing strollers. Together they can claim that access is a widespread problem.

Can the problem be solved? Many serious issues (e.g., death, taxes, incurable disease, and natural disasters) are not social problems because there is no way to fix them. Unsolvable problems can often be broken into smaller elements and reframed, for example, premature death because seniors can't get health care, unfair taxes for seniors living in inner cities, etc. You need to think carefully how your issue might be stated and defined as a social problem that might be solved.

**Should the problem be solved?** There are many social issues that irritate us or seem to be important to a small group, but if the general public are not concerned, it will likely not be addressed. For example, spanking children has become a problem only in recent years and the new term "elder self-neglect" has moved frail, fearful, and confused seniors into the limelight as self-abusers. Problems are constantly being redefined to create a reason to act.

As you complete your analysis, you will have a much clearer understanding of how to frame your concern in preparation of building a more formal information base.

### Collect related information.

You will likely have already found some literature related to your topic. Now is the time to conduct a thorough review of information available

Search the Internet by topic. You are lucky to be starting a research career in the era of the Internet. There are many sources of information available. With tools such as www.google.com and www. Copernic.com you can easily browse the literature on your chosen topic or issue. The trick to using the Internet is to frame your search so that you don't come up with thousands of hits (potential sources of information). Most search engines provide guidelines to figure out how best to search. After a while, you will locate online journals that seem to address your topic and you may want to subscribe to one or two to stay connected to developments.

Connect with Consumer websites. Seniors, disabled people, aboriginals, and poverty coalitions host advocacy discussions that provide leads to good literature sources that are relevant to your search. Don't rely only on sites about seniors, as other groups have a longer history of advocacy that you can take advantage of. The following is a list of websites you can try:

- National Seniors Council (Canadian), www.seniorscouncil.gc.ca
- Seniors and Community Supports (Province of Alberta), www.seniors.gov.ab.ca/contact us
- Canadian Pensioners Concerned Inc., www.canpension.ca
- Canadian Association of Retired Persons, www.carp.ca

- Older Women's Network; e-mail info@olderwomensnetwork.org (they have an active research and education department)
- Canadian Network on Third Age Learning, www.catalist.ca
- National Council on Aging; American Association of Retired Persons, www.aarp.org; American Society on Aging, www.asaging.org
- National Institute on Aging Information Center, www.nia.nih.gov
- Canadian Centre for Disability Studies, www.ccds.ca

Don't overlook the national and provincial (or state) websites related to your topic. They provide an excellent source of current policy directions. Locate the national seniors advisory councils for their yearly report cards that provide a quick overview of what is happening to and with seniors

**Shop at booksellers' websites.** A current book on your topic often helps provide a structure for the rest of your work. Websites like www.chapters.ca or www.amazon.com are good places to start.

**Search university libraries**. A subject librarian can help you with a library search. You may have to take out a community membership but a library card is a good investment.

You should now have a good idea as to who is currently doing the type of research you want to do. You may not agree with their findings or their approach, but it is important to know who could be your allies and your challengers. Summarize your findings under the following

headings: names, references, contact numbers, and a quick summary of their findings.

- Researchers at your local or regional (state) university
- Researchers who support your perspective in journals
- Researchers who challenge your perspective in journals
- Government policy and research allies and detractors
- Local professionals and groups that are allies and detractors.

### Consider your motivation for doing this research.

This next section has been included, with some modifications, with the kind permission of Ronald J. Chenail of *The Qualitative Report*. He introduces you to how your motivation to conduct research will guide what type of research you may want to do.

With this in mind he introduces us to seven methodological families or approaches to doing research. These he calls the Seven C's: curiosity, confirmation, comparison, changing, collaborating, critiquing, and combinations. The entire article is included in the Appendix 11 if you wish to use it to facilitate group discussion. You may also want to read Chapter 1 of *Doing Qualitative Research: Multiple Strategies*, by B.F. Crabtree and W.L. Miller; it also outlines the questions of research in an easily followed manner that will help you work with academic and health researchers.

**Curious:** If you are curious about an intriguing topic, you might be interested in conducting an informal inquiry and you will likely approach your ideas from a qualitative research perspective that emphasizes open-mindedness and flexibility. Some of the questions

you might be asking if you are at this early exploratory stage might be:

- What is it? For example, what is elder abuse, what sorts of abuse are elders exposed to?
- Who is affected? Which seniors are most at risk of being abused?
- What is important here? What protects seniors from being abused?

**Confirm:** If you want to prove a theory or make predictions, you will want to use quantitative methods and control the conditions such as age, gender, and income. Some of the questions you might find yourself asking include:

- Does this theory apply to seniors? Do theories of spousal abuse apply to seniors?
- If abusers were charged, would this help seniors or put them at greater risk?

This type of research is not included in this book, but there are many ways to become involved as a partner in more formal research through your local university.

**Compare:** If you want to compare one group or approach with another, you would generally evaluate the differences between the two conditions you want to study. Some of the questions might include:

• What are the differences between two groups of people? What are the differences between men and women who are abused as seniors (background, lived experiences, supports, income)?

• What might account for the differences? Why are there more urban seniors in abuse shelters than rural seniors?

**Change:** If you want to change actions, policies, and practices that reinforce the status quo, you would approach your project from a Participatory Action Research perspective (PAR) perspective. Some of the questions you might ask:

- How might police procedures be changed to ensure that abused seniors are not left in an abusive situation?
- How can funding for women's shelters be expanded to include abused seniors?

There are excellent resources written on action research that are written for community members and are easy to understand. One of the best is *Participatory Action Research with older people: A source book* is available on the Internet at <a href="https://www.helpage.org">www.helpage.org</a>.

**Collaborate:** If your primary purpose is to form relationships and through those partnerships understand each other's perspectives, then your research method should be a collaborative inquiry. One question you could ask is:

 How can we get seniors associations and services to work together to improve services to abused seniors?

This manual is written to promote collaborative research where the initiative comes from seniors or researchers with a deep commitment to partnership.

**Critique:** If you want to critique (challenge) those in power, you would chose to look at critical research methods such as discourse analysis, which emphasizes a particular stance related to values and power. Some of the questions you might ask are:

- What aspects of aging (loss of income, status and/or physical appearance) create the excess of discrimination?
- What beliefs, attitudes, or policies maintain abuse and discrimination?
- What practices create dependencies and devalued roles for seniors?

Feminist research and disability studies have created critical research frameworks that are very useful for senior's research. You might refer to *Disability Is Not Measles*, edited by Marcia Rioux and Michael Bach as an example. Over time, seniors will develop their own brand of critical analysis as aging studies becomes recognized.

**Combination:** One type of combination research occurs when different disciplines contribute their perspectives and methods to a common issue. Our interest in aging studies comes from our belief that it is not realistic to look at aging through one set of disciplinary glasses. We hope to encourage research that crosses disciplines while including the perspectives of seniors.

### C. Attract Other Research Partners

We paired up with the Calgary Crisis Centre to set up a dedicated seniors help line. This became a 24/7 telephone line for calls requiring an outreach worker. This would allow us to gather specific information about what abuse was happening and how frequent it was. The line was jointly manned by the Calgary Crisis Centre and the social workers at the Kerby Centre. We used this pilot project to determine if this approach might work and to identify and define the need for elder abuse service. (NM, 2006)

Once seniors are engaged, it is possible to invite others who share your concern. You may not need people from each of the following categories but you should consider these resources and, if appropriate, include them early in your process. You do not need a long-term commitment at this point. You need one or two sessions to explore your thoughts and to find out what others have to offer. Some of these partners might be:

Academics and students are some of the most useful resources since they represent committed and enthusiastic labour. Students can do literature searches and community surveys or write proposals, often for course credit. An academic who is interested in your topic can bring networks and the use of university resources as well as help in writing and doing research.

Contact the community relations department at your college or university for a list of people who might be interested in your topic. Contact them early in the process because it often takes a while to set up practica where students work with you for credit.

Students often provide a new perspective on things; very often they have unbounded enthusiasm and work very hard when they are considered part of the team. Students tend to identify with seniors, through their grandparents and this tends to be a more personal endeavour. It is a great opportunity for students to value what seniors have to offer society and that seniors contribute a lot. (HB, 2006)

**Professionals.** There are many sources for professionals. In the case of the elder abuse project, Kerby looked at social workers, lawyers, doctors, law enforcement groups, and educators as potential resource people.

Each project will require its own partners. Try to find professionals outside of aging. They will balance the tendency of professionals

to take the lead and will often ask the probing questions that move you forward because they are unfamiliar with the issues of seniors.

**Advocates.** Groups and agencies that address similar issues and problems. These might be other seniors associations, service providers, or advocacy groups. Reach out beyond your network to groups with proven track records in the work you are contemplating. Look to unions, poverty coalitions, or cultural groups who are innovators.

**Service providers.** An outside group can bring attention to seniors' issues. In the case of elder abuse, the distress centre was concerned with abuse but had not considered the needs of seniors, and by working together each gained.

I was a volunteer on the social work committee when the calls about abuse were coming in. We had a meeting to talk about the calls and from that meeting we selected people from Kerby to meet with the Calgary Distress Centre. We first set up a pilot project to get more information; we were then able to add others as we learned more. (NM, 2006)

**Politicians and bureaucrats.** It is helpful to find someone inside the system that you are targeting for support. Cultivate the contact early so that it isn't considered an attempt to curry favour. You need to know the culture of the government departments that are most relevant to your topic. For example, abuse is most often considered to be an issue related to women and children but the Kerby Abuse Centre did not exclude older men who had been abused and this caused conflicts within the funding routes.

Someone close to retirement is ideal. They have little to lose in exploring new ideas, and they have a long history of what works and what won't work. They will also relate well to your group as they are aware of the issues of retirement and aging.

You will likely have to go to the head of the government department and ask them to recommend someone to work with. If you can,

have them recommend two or three options so that you can interview to find someone with similar values.

**Community groups.** While community seniors associations may be decreasing in size and influence, large retirement homes are fast becoming communities on their own. The seniors in these settings are well-organized, and management may be willing to support research by providing space and facilities.

I met a senior from a large residence and he went around asking if people needed anything, he wasn't even on the residence council but kept everyone informed about what was happening. (HB, 2006)

#### Resources

An excellent resource is Donilee Loseke's *Thinking about Social Problems: An Introduction to Constructionist Perspectives* (New Brunswick, NJ, Adline Transaction, 2003).

HelpAge International: www.helpage.org/

Disability Is Not Measles: New Research Paradigms in Disability, ed. Marcia Rioux and Michael Bach (North York, ON: Roeher Institute, 1994), examines attitudes toward disability, rights of people with disability, and the perspective of disability as socially constructed. It further examines disability research questions through the lens of human rights and ethics.

Ronald J. Chenail, *The Qualitative Report*.

8

# SET: Creating Your Research Proposal

Once you have an idea of what you want to achieve and of your general approach, you shift your efforts to gathering your resources, sharpening your focus, and preparing research proposals. At this stage you will want to gather a group made up of seniors, your agency, members of your first advisory group, people from the university or college, and representatives of local government departments of elected officials.

This chapter covers how to survey and select potential funding opportunities and how to choose a methodology that fits with your beliefs, values, and motivations. With this knowledge, the writing of the proposal will stay in your control.

### A. Survey Possible Funding Sources

Begin by identifying potential funders from the list below. Most people are much too narrow in finding research funding options.

**Service clubs.** Service clubs like the Lions, Rotary, and Jr. League are ideally suited to support early research and inquiry. Many service clubs are looking for activities that their retired members can participate in and will give preference to these projects over cash donations. Arrange to meet their funding coordinator and find out what they are currently funding, what their priorities are, and what types of grants or donations they generally provide. Be sure to ask if they would consider small research partnerships.

As the needs of elders who were being abused became clear, we formed a partnership with Rotary International. They were instrumental in knowing how to get resources marshalled long before elder abuse was recognized by service providers. However, ongoing funding continues to be a problem. (PA, 2006)

Local initiatives funding. Every community has funding sources to enable citizens to investigate issues, identify needs, and sort out options to meet their needs. The names will be different and the funding priorities will change. Be careful not to use these funds to create expectations or start a pilot project since these funds tend to be timelimited. Look up the following sources on the Internet or contact your local representatives.

- Community sources: United Way
- Municipal sources: City seniors division or the division that looks at your topic (housing, abuse)
- Local health authority

- Provincial (state) social programs division
- Provincial seniors division or division looking at your topic (for example, environment, housing, shelters)

**Development grants.** These grants generally target pilot projects to test out a market, service, or need. Development grants may be available through the same sources as above with the following additions.

- New Horizons Seniors grants (In Canada, provincial programs are funded through a federal government program).
- Lottery grants. In Alberta these are part of the Wild Rose Foundation.
- Provincial/state innovation funds
- Federal small project funding or special initiatives grants through Health, Human Resources, etc.
- Private foundations and donations

**Formal research grants.** These tend to be routed through universities or university partnerships. Provincial (state) grants and federal grants may be available. Currently in Canada the following formal grants may apply:

 Social Sciences and Humanities Research Council (SSHRC). These grants are organized according to discipline and generally need to be submitted by a university.

- Community University Research Alliances (CURA) under SSHRC. These grants are ideal for communities and associations, but they are very limited in number.
- Canadian Institutes of Health Research (CIHR). These grants are organized by topic area e.g. Aging, Social Policy
- Provincial (state) grants such as Alberta Innovates

It is unwise to spend a great deal of time designing a research proposal until you have an idea of who you are going to submit your proposal to. At this stage you might compile a short list of potential funders and test out their interest in your topic and approach. The following letter of intent might be sent to several potential funders.

The Research Aging

Dear Sirs

We have chosen your foundation from your description on the Internet as a possible source of support. We represent a partnership of seniors, academics, and service providers and are deeply concerned with finding ways for seniors to provide natural peer support to frail seniors.

We are looking to evaluate the impact of training seniors to offer instrumental support (shopping, cleaning, paying bills) to fragile older adults. We would like to compare this to an existing professional home care program already in existence. We believe that peers will be effective and accepted more readily by seniors as confidents and friends.

If you have a funding opportunity that we can apply for, please let us know the details and limitations of application.

Yours truly,

List of partners.

### B. Program Logic Model

One of the most effective strategies for depicting the relationship between goals, objectives, and outcomes is called a "program logic model." We have simplified this as a chart for Goals and Objectives for Collaborative Research. See Appendix 12 for a full example of a program logic model.

Table 13. Collaborative Research Goals and Objectives

| The situation which led to this proposal (rationale) Write as a social problem  |   |  |  |  |  |  |  |
|---|---|--|--|--|--|--|--|
| Short term objectived of doing the reserch.  • knowledge generation  •increased research capacity  •knowledge transefer | Collabor-<br>ators and<br>beneficiaries | Practical,<br>theoretical<br>and policy<br>outcomes as<br>a result of<br>the reserch | Collaborators and beneficiaries of the results | Long term<br>goals and<br>anticipated<br>impact in 10<br>years |  |  |  |
| Possible obstacles to doing this research  practice  citizenship policy  Who is involved                                |   |  |  |  |  |  |  |

Many funders now require a logic model that reflects the principles underlying the grant. It must lay out the goals and objectives in a clear, concise framework.

**The situation** (the box at the top) defines what brings you to your research. It could be considered a statement of the social problem (Loseke). It should identify why the funder should be concerned about the issues you propose, how widespread the problem is, and what you intend to do about it

**Short-term outcomes** (objectives) are listed in the first column. These objectives are what you intend to do to collect and analyze data. It is divided into the principles that are listed in the request for funding. In this example, the principles were knowledge generation (the data or information you hope to gather), capacity building (how you intend to increase the abilities of researchers, students, aging people, etc.), and knowledge transfer (what you intend to do with your results).

Immediate beneficiaries (the second column) identifies who will be involved in using the data collected. This is a marked deviation from former processes of establishing goals, objectives, and outcomes. It allows you to discuss who are the participants in the project and who will work with the data collected at the first level. In this example, with CIHR and researchers in healthy aging to create a Canadian research agenda. The project also directly involves support and service providers in collecting and interpreting information.

**Mid-range objectives** (the third column) is again a new feature in that it invites the research team to think about the changes that are expected to occur at the behavioural or personal level, first at the practice level and then at the policy level. This moves the development of goals to a more abstract level.

Intended beneficiaries of personal, practice and policy change are clearly defined.

The long-term outcomes (goals) look to future impacts of the study in a ten-year span. These long-term outcomes are actually more far-reaching than most goals used in traditional frameworks and enable the funder to think about social impact of the study. These outcomes identify the larger social groups that might be impacted, e.g., the Canadian public, the health care system, etc.

**The context** (the box across the bottom) depicts the factors that will impact the research – the social, political, and environmental forces that need to be accounted for.

The level of detail involved in writing goals, objectives, and outcomes will depend on your funding route. For example, it would not be reasonable to do a project logic model for a grant funded by the Lions club to research volunteers to help in hospice care.

## C. SET: COLLECT: REFLECT — A Collaborative Inquiry and Research Framework

This section marks a new approach to inquiry and research that is based on the principles and practices of partnership research (Chapter 1) utilizing the research skills (Chapters 3–6). The principles in brief are:

- · Equal but different
- Trust
- Shared power
- Shared work

In brief, seniors and their partners SET the direction and goals for the study. Then the team COLLECTs the data. You end with a process to REFLECT with seniors what was done, what the results might

mean, and how to use the information gained. This technique applies the participatory action research principles and processes that are the foundation of this book to a broader range of questions. Each of the following methods imply that action will be the result of the research.

**SET** the research agenda, topic, method, etc., in collaboration with seniors. This generally will involve a focus group/workshop where the topic is presented along with the options to be discussed. This might include: the working definition of the topic, the scope of the study (who is to be included), what will be done, how to establish working groups, etc.

**COLLECT:** "Collecting" refers to the inquiry processes that will bring information together in a form that it can be used to make judgments, decisions, or ask more questions. Depending on the nature and scope of the project, "collect" may mean: additional informal inquiry, design and use of questionnaires, establishing working groups, conducting observations or collecting materials, reviewing policy, creating media packages, etc.

**REFLECT:** In collaborative research, seniors have been included in setting the research question and collecting data, but their involvement is sidelined while the data is analyzed and prepared for reaction. In this model, we have reclaimed this important analytic aspect of research, as seniors are expected to reflect on the information collected or the initial analysis of questionnaires. This last stage also includes how to use the data, what to present, and how to make the presentations meaningful to other seniors.

Table 14 outlines six examples of collaborative inquiry/research that may be of interest to seniors. From this you can extrapolate for your own research ideas by following the same process: set; collect; reflect.

**Awareness raising research** brings an unfamiliar issue or discovery to the attention of seniors. Elder abuse, new income tax policies, health breakthroughs, and the impact of weight training are

some examples. This research is considered to be knowledge translation, for it encourages seniors to study new knowledge and find ways to increase its uptake. Funding for this type of research may come from governmental bodies interested in disseminating new policies and programs, from formal researchers who want to involve seniors in disseminating their research findings, etc.

**Setting a research agenda** is becoming a more popular research process, and it can be called pilot or catalyst research. Funding for agenda-based research is time-limited and is often intended to provide incentives for researchers to enter new fields of study. This type of research can be used to attract new partners and to clarify terms and related research traditions. Refer to the elder self-neglect example as a research agenda research project.

**Needs analysis** is a popular research approach. Needs-based research allows you to define as well as measure needs: needs for service, funding, planning. Funding is generally time-limited and can be linked to other opportunities to follow up in addressing needs.

**Evaluation of programs, services, and policies** provides opportunities for senior's to evaluate not only seniors-led programs but programs run by other's for the benefit of seniors. There are many models for evaluative research: some are outcome-based, others are process-based, but all will require that the voices of those being served is recognized.

**Descriptive research,** is, as it implies, an exploration of a topic that captures your interest. Almost any topic can be researched, and funding is most likely to come from sources who share an interest in the topic – self-funding, local or national foundations, business. If your interest coincides with an emerging area of interest such as the accessibility of local public parks as a factor in heart health, there may be more formal funding avenues. The sky is the limit – Internet travel options, communication among pigeons, blood pressure tests at pharmacies, hopes or fears related to pain, housing, vitamin D.

In-depth research of lived experience such as that described in Chapter 6 is a more formal research process that involves trained interviewers; thus, you may want to undertake this research in partnership with academics. This peer-based interview method enables you to explore almost any aspect of aging by taping memories, experiences, hopes for the future. Funding for this type of research could come from many sources, depending upon the stated interests of partners or funding agencies.

Table 14. Collaborative inquiry models for seniors' research.

| PURPOSE                       | SET   | COLLECT   | REFLECT   |
|-------------------------------|---|---|---|
| Awareness<br>Raising          | Focus group to introduce issue/ topic.  Recruit seniors to work on materials related to the topic | Create materials based on input from Focus group, literature and seniors' experience (film, pamphlets, murals, etc.)  Work in teams with professional input. For example, pamphlet group, video group, etc. | Focus groups<br>to test materials<br>and recommend<br>ongoing evaluation<br>of how seniors<br>are using the<br>information. |
| Research<br>Agenda<br>Setting | Observations, recording, interviews with those who live the experience being studied.             | Focus group with stakeholders (seniors, professionals, academics) using the previous step to set priorities and negotiate how each group might engage in the research  Prepare funding or work proposals    | Bring representa-<br>tives of earlier<br>groups together to<br>plan action based<br>on needs.                               |

| Needs<br>Analysis   | Focus group to raise awareness and provide input into categories of need and strategies for gathering data. In new areas, use in-depth interviews to identify complex needs. | Design survey<br>research and train<br>seniors to collect<br>data by phone,<br>personal interviews<br>or online  | Focus group response to survey   |
|---|--|--|--|
| Evaluation  | Focus group to<br>establish evaluation<br>goals and choose<br>methods (process,<br>outcomes, impact)   | Working groups<br>to carry out the<br>evaluation plan<br>using interviews,<br>surveys, document<br>review etc.   | Focus group to review results and make recommendations   |
| General<br>descriptive<br>research<br>related to<br>specific<br>topic | Focus group to set<br>scope, purpose,<br>and strategies<br>around topic to be<br>explored  | Focus group exploring topic by category (age, gender, location, etc.) Survey methods to reach broad section of those affected by topic and a small number of in-depth interviews to deepen the description | Focus group's reaction to results by groups impacted by topic                                  |
| In-depth<br>research<br>of lived<br>experience                        | Focus group to introduce topic and recruit participants for in-depth narratives  | Narrative peer<br>interviews or group<br>interviews where<br>appropriate   | Reflection on findings. React to formal reports. Create interactive presentations for seniors. |

The research design may be as simple as a study of the uptake of an exercise video that seniors have expressed concerns about. The process might be:

**set**: focus group to raise awareness to discuss the implications (advantages and risks for self-monitoring cholesterol levels) and recruit participants to work on the project,

**collect**: develop an open-ended questionnaire and administer it to a large sample of seniors,

**reflect:** focus group to evaluate the advantages and risks that emerged from the interviews.

### D. Write the Research Proposal

Each funding source has a different process for writing a proposal. You may have graduate students and university faculty on your working group who would help in writing proposals until you are comfortable with the language and expectations.

There are a number of fairly consistent questions you will encounter in writing any research proposal. Even if you are not going to do the actual writing of the proposal, seniors should be engaged in answering the following questions:

What questions you are interested in? Be very specific. It takes a great deal of time to refine a statement from your initial interest (as evidenced in the number of steps in Chapter 7). Government funding bodies and foundations tend to use terms such as "expected outcomes," "goals," and "objectives." Goals and objectives are the observable results you hope to achieve. Goals are long-term outcomes and objectives are the detailed instrumental steps necessary to reach your goals.

Both can be written using the SMART system that is a set of principles for writing goals and objectives.

- **S** is for **specific.** The activity, behaviour or change must be clearly described so that there can be no confusion.
- **M** is for **measurable**. The specific behaviour or activity should be observed, described, or counted.
- A is for **achievable**. The project is do-able within its resources and constraints. It is much wiser to identify modest goals than to inflate your hopes.
- **R** is for **results-oriented**. This refers to outcomes of your goals and objectives.
- T is for **time.** This is the estimated date for achieving the goal.

List two to five long-term goals and, beneath each of these, list the short-term instrumental objectives that will lead to these goals. Depending on the funding route, you can also include the timelines. Why do you think the research needs to be done? Formal research will link the need to a literature review. We have not dealt directly with formal literature reviews, although you will have become familiar with literature in Chapter 7 when trying to identify your question. For many projects, you can ask for funding to hire someone to write a formal literature review. If you want to write your own literature review, ask to see literature reviews from approved proposals.

Development funding and service clubs want to know why the question or topic has come to your attention.

How do you intend to address your questions? This is generally called your methodology, and this combines your general approach (the seven Cs) along with your work on research design in Set: Collect: Reflect. Refer to each of the chapters in Section 2 when writing out your description of the methods you intend to employ in your research design.

Who will take part in the research? Call seniors "research participants" to denote that they are considered partners in the project. Be sure to identify who your participants will be:

This study will tell the stories of 100 seniors who called the Kerby Centre to find support in an abusive situation. All seniors will be included without regard to age, sex, or cultural background.

When and how will you conduct the research? Timelines and management structures are usually connected to the key questions you want to ask. It may take some time to figure out, but a good rule of thumb is to double the time you think it will take.

Timelines allow you to estimate and plan how long the various tasks will take to accomplish and to organize your tasks into a logical sequence. If you intend to become part of a large project, look into project management software. It involves determining how to achieve specified objectives within time, personnel, and resource constraints.

Thinking about projects – especially group projects – in terms of project management can help you determine what is possible and where your energies should go. Do not try to create project management processes on your own, it is a discipline in it's own right and it is wise to contact a project management department at your local college or university to learn about the many options.

What will it cost and who will share in the costs? This format is usually determined by the funder. They will identify how much they are willing to grant and you need to stay within their guidelines. The following are guidelines for determining expenses:

 Hire a qualified project co-ordinator on flex time so that you can respond to the variable demands. Always apply for the maximum possible as this position will be on call for volunteers, senior researchers, funders, agencies, and academics.

- For in-kind contributions, estimate how much time volunteers and committee members will put into the project and multiply that time by minimum wage plus 20 per cent. Be sure to include agency and academic contributions as well
- Expenses for senior researchers, participants and volunteers. Most volunteer associations can help you with this. Cover a minimum of bus, accessible transit fare, or parking costs, along with meals and coffee. A set fee of \$30.00 per day is likely the best way to cover these costs.
- Costs for senior researchers should be equivalent to research assistants once they are trained.

Now that you have your research proposal written and submitted, call in the shaman, the prayers, and whatever else you can access. Remember research proposals are very difficult to secure. Few are successful the first time but a submitted grant helps build a track record. Do not become discouraged if you are not successful. Once you have a grant application written, it is easier to rewrite it and resubmit it to other sources of support.

### Resources

- Philanthropic Foundations Canada. A full service website about resources and processes, www.pfc.ca/cms en/page1111.cfm
- Project management software is widely available commercially or through free software on sites such as tudogs.com or tucows.com
- Writing a funding proposal: There are many resources online but be careful not to be drawn into resources for writing a research proposal that are targeted to graduate students. The following resource is a handy source for writing practical funding grants. www.learnerassociates.net/proposal/



Herb Breitkreutz

Watching seniors' participation as researchers was a pleasant new experience. The results showed the unique views of their latter years.

### GO: Conducting Research and Sharing Results

Once your funding is approved, you generally need to move quickly to set up the structures and processes to conduct your research. It is as if the gun has fired and you are off, running as fast as you can.

We are using the principles and standards for good partnered research to guide the implementation of your research project along with the SET: COLLECT: REFLECT model of organizing research. In all stages of implementation, the following indicators of good collaborative inquiry and research are essential. Whether you are creating committees, hiring and training staff, working with agencies and participants, or sharing results, the following indicators should be apparent:

**Plain language.** Proposals, interactions, meetings with stakeholders and media, research methods and protocols, and reports

should demonstrate language that is understood by all. Where technical terms are needed, meanings are negotiated, clearly defined, and understood by all.

**Representation.** The various voices in your project 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 process and results should signal a change in the practices of research.

Begin by reviewing the following principles of collaborative research with each person who joins your team. These set the expectations of how all researchers and participants will be included in the process:

**Equal but different:** The thoughts and beliefs of all participants about the shared questions and issues are equally valid. Everyone from the grant holders, project coordinators, senior researchers, participants, and volunteers need to accept that everyone will have a say. Regular meetings attended by all parties are the cornerstone of this, but it is also important to have mixed committees to encourage people to speak in smaller task-oriented groups. The committee leaders may need coaching in how to conduct meetings when seniors and academics are involved. It is sometimes necessary to meet with the different parties (seniors, academics, students) to practice speaking up and preparing for the group. Academics have a tendency to take over and use academic jargon, and it can be difficult to break these habits.

**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. Here again, the role of the coordinator is key to ensuring that the accomplishments and contributions of all members are acknowledged as part of the project. The concept of taking e-mail minutes and sharing these among all project team members works here for team members feel valued and recognized.

Shared power: Nobody decides for somebody else. Sharing power starts with the expectation to listen and the freedom to express opinion. Each person learns from others and grows in his or her own confidence and capacity. The coordinator and committees need to ensure that there is a consensus process in place for meetings and a process to make decisions between meetings. It is not feasible to make all decisions in committee, but it is also not acceptable to make decisions without consultation. This requires a strong coordinator that summarizes information and data for discussion, sets meetings, writes minutes and e-mails and maintains open logs of progress. If the participants are going to own the results, they must feel they own the process.

**Shared work:** To share expertise there needs to be a willingness to use common language, to model and mentor unfamiliar activities. Learning to share requires time for reflection on the process and joint ownership of successes and failures. Working together includes the glamorous tasks of planning and committee work but also the tasks of clearing up, making tea, and taking the heat for missing deadlines. It may be just as hard for an academic to learn to chat with a potential participant over tea as it is for a senior to analyze data. Neither task is exclusive in collaborative research

This chapter is about doing the research: creating the committees, recruiting and training volunteers or paid senior researchers, and

collecting and analyzing data. Also included is a section on evaluating the information that has been collected and analyzed.

The chapter ends with one of the most critical stages of conducting research – sharing the results. Although information can be shared using a variety of methods, the most important consideration is to target the likely consumers of the newly developed knowledge and find ways to engage them in discussion.

### A. Creating Research Committees

Careful organization is required to ensure that everything is running smoothly, and this is especially true in collaborative ventures. Although you may feel that one good organizer is enough, you need to include others in the process so that there is good communication and liaison with those who can support your research. The following are the types of committees or groups you may need:

**Advisory Committee.** By now you can select those people who you can go to for guidance and direction. Key to every research investigation is creating clarity around the purpose of the research. An advisory committee plays an important role in translating the questions for the group they represent.

The advisory committee can be as large as makes sense but most advisory committees consist of five to twelve stakeholders. While they are advising you they are learning about what you are doing and linking you to the resources they have. Meet on a regular basis every two or three months. Take minutes to create a paper trail.

**Management Committee.** The management committee holds the authority to plan, oversee, and implement the research project with the input of the committees. The size will be dependent upon the size and complexity of the research. You will need a minimum of the research coordinator, the named investigator, a member of the advisory committee, and team leaders from the research.

**Liaison Committee.** If you are working with a university department, a government body, seniors association, etc., you may need a liaison committee to ensure that everyone is in the loop. Some find that they can combine the advisory committee and the liaison committee.

**Research Teams.** It is essential that there be a clear organizational structure of the project. We found that seniors liked to work in small teams (see Chapter 3), but there are many structures that you can use. Whatever structure you adopt, it is important for the researchers to meet on a regular basis to maintain motivation and common direction.

### B. Recruit and Train Seniors as Researchers

Please refer to Chapter 2, on how to train seniors, and Appendix 1 (Resilience as Social Capital) when recruiting seniors as researchers. Chapters 4 through 7 each have a section on recruiting and training seniors to conduct specific types of research. If you have been doing this section of the book with a group of seniors, you already have a group of informed, motivated seniors ready to receive specific training for your project. Senior researchers put forward the following suggestions and these were used in the later stages of the pilot to refine the training. You may find these helpful reminders in implementing your training sessions.

- Recruit and train about a third more seniors than needed to ensure that you can allow flexibility in scheduling their time.
- The training sessions should be no longer than four hours in length (10:30 to 2:30) with a chance to take breaks.

- Training seems to work best with workbooks, where guidelines are included along with clear steps in the process
- When working in a group of fifteen or more, ensure that there is opportunity to discuss what is being learned in small groups.
- Provide opportunities to practice the skills with feedback and support.
- Share ideas and results from practice.

If you are moving directly from training to data collection, use the training time to finalize the research protocols and instructions. You can also use this training time to practice with data collection strategies and analyze data collected during training to familiarize senior researchers with analysis and interpretation.

### C. Collect and Analyze Information

Data collection and analysis are two sides of the same coin. The data you collect determines the range of analysis you can use. We are not covering statistical processes of analysis in this manual because these tend to be associated with quantitative studies, which collect numbers. The four techniques chosen for this book are particularly useful in collabotative projects. These techniques have been incorporated into the SET: COLLECT: REFLECT research design for partnership research. The specific methods are:

**Field-work:** Here you are collecting data by observing, talking to people, looking at documents and materials. Chapter 3 outlines field-work where seniors conduct research while participating in the activities of the group.

**Surveys and questionnaires:** The strategy here is to construct specific questions about your area of interest. The questions can be written as a questionnaire and given to people to fill out in person, by mail, or on the Internet. The questions may also guide interviews. Chapter 4 is devoted to the many ways to ask specific questions.

**Focus groups:** Focus groups were chosen specifically for inclusion as a strategy for collecting data with seniors because it combines a number of techniques into a recognizable format. Chapter 6 was designed and is devoted to the use of focus groups with seniors.

**In-depth narrative interviewing:** While there are a number of techniques for conducting open-ended and discursive interviews, narrative interviewing was selected as particularly useful with seniors. The technique presented has been created specifically for seniors and combines the use of structured formats, guided questions to elicit stories, and analysis techniques. Chapter 7 presents this material.

The **SET: COLLECT: REFLECT** model provides a set of steps to ensure that seniors are central to the partnership and that they are included in all stages. If you are using a structured research design, you might want to read Marlett (1998) on Partnership research. It provides guidelines for negotiating research roles.

### D. Evaluate What You Have Accomplished

As you are ready to implement your study, take time to think about how to evaluate your research process apart from the knowledge you gain. While you need to complete the required research report, you will also want to evaluate how you conducted the inquiry and what you have learned about collaboration in order to plan the next steps, share your results with other seniors, and take the action suggested in your findings.

Evaluating what you have accomplished is very important from a number of perspectives beyond the actual completion of your research. Some of the evaluation approaches that might prove useful include:

**Process evaluation** of what you are doing and the changes you make during the research. You will want to evaluate progress automatically at monthly meetings of your management committee or regular meetings with your advisory committee. Having a process evaluation format included in regular meetings will help keep you on track. We found that evaluation meetings of the entire team after each step in the resilience research provided the most effective input to the research and ensured that everyone had a say in evaluation and the direct implementation of ideas.

Negotiate the markers you will track as you conduct your research. These markers might include:

Timelines for achieving the goals and objectives. Are we on track or what is holding us back? How do we modify either the work plan or the expectations? This might best be accomplished by reviewing and modifying the timelines that are part of the research project.

Budget and resources. Are we on track with our expenditures? Are the resources we allocated working effectively, do we need to modify, add or reduce aspects of our infrastructure, personnel, or equipment? What are the implications for short falls and over expenditures for the next time period.

*Partnership effectiveness*. Is the project meeting the indicators of good partnered research? You might regularly review plain language achievements and obstacles using specific examples.

Does each group in the collaboration feel represented and respected? Regular process evaluations should uncover and address inequalities that will lead to loss of trust and ultimately the failure of your collaboration. Some of the indicators you might want to track include: who is speaking on behalf of the project? What negotiations have taken place about roles and expectations? What strengths are emerging that can be celebrated and what problems need attention?

*Next step.* This may be the most important of the process evaluation. It asks 'Okay, now what?' as milestones are reached. The questions to include in this section challenge everyone to see the current research not as an end but as a stepping stone. What new questions have arisen in this time period? What research might come of this? Who has come onto the scene who might become a new collaborator and finally, What can we do to encourage other seniors to take up the challenge of this research?

**Summary evaluation** of what you have accomplished. If you were able to use a Collaborative Project Logic Model or equivalent you would refer to your success in the short term, intermediate and long range objectives. In chapter eight we focused on how to write what the research project hoped to achieve. These are the objectives that you will include in the summary evaluation.

Short term objectives. These are the objectives related to conducting your study: what you are able to do and how it impacts those conducting the research. You are able to gather the information as proposed and make changes when collecting and analyzing data? What you find out (knowledge generation)? You are able to increase research abilities of seniors and students; you are able to impact the capacity of seniors and collaborators (capacity building). You are able

to share your results through the work of seniors. What methods you are able to explore and use as part of this knowledge sharing—media, fine arts presentations, reports, newsletters.

Practical and Policy outcomes. These are the intermediate goals for the project and are based how the results of the study might impact the lives of seniors, the practices of professionals, and the policies of organizations and governments. What outcomes hold promise for implementation, what suggestions arose for changes to practice and policy?

Long term goals. How has the research influenced the possibilities for change in the long term? What new alliances are possible, what next steps emerge from the project?

#### E. Sharing Results

You will find that the media are interested in the research that seniors do so it is important to plan ahead and be prepared. In our project, the university notified the media of our project as part of their community partnerships. The following are some of the ways to get your information out:

**Newsletters from your sponsoring agency.** It is most helpful to write short pieces about your research as it progresses and then a larger piece once your research is complete. Keep the tone personal; highlight researchers contributions and interesting findings.

**Website information.** If you can afford a website developer to set up a project site, you will find that it allows you to recruit participants, find allies in your work, share results, and find other avenues for research

**Regular media.** You might host a news briefing when you receive approval of your funding. Be sure to invite local or neighbourhood

newspapers, television, and radio stations. Set a time for media to come back at regular intervals and at the end of the project.

**Pamphlets or reports.** The elder abuse project produced a powerful booklet that is still in demand about their research project. These materials can be available online, through other seniors groups or government agencies.

**Theatre presentations.** Data can be translated into a story line or readers theatre where seniors are involved in creating the presentation and performing for many different groups. If you are interested in this exciting work, contact ACT II Studio at Ryerson University.

**Visual presentations.** There is considerable scope in mural presentations of research outcomes, posters, and visual art forms. Contact your local Fine Arts department at your college or university to find out more about this exciting way to place your research findings in public spaces.

**Film and documentaries.** The National Film Board has made a commitment to assisting groups with research messages to use film to communicate their message. A term used for this endeavour is popular theatre. With the advent of YouTube, the world is your audience.

#### F. Take Action

With results in hand now comes the hard question: "So what?" There is always a lot of enthusiasm when your research proves that there is a need for action. However, be careful not to assume that, because the results are important to you, anyone else cares enough to take up the challenge. Your work is just beginning.

The call to take action generally begins as results come in, but it is wise to keep research and action separate unless you are engaged in ongoing PAR research.

A committee that is separate from your research group should be convened to look at action steps. You may also find that your advisory committee may be willing to explore potential actions.

Action is generally aimed at changes to existing social structures and processes. For example, in our research we changed the perspective of Kerby members so that they are confident that they can conduct research that is meaningful to the membership. Rather than contracting external resources, the organization can now validate its positions and services in various areas using collaborative inquiry and research.

In this chapter we have attempted to provide a step-by-step guide to build the capacity of seniors to become researchers. We have introduced examples from the elder abuse experience at the Kerby Centre as a way for you to think about your own topic.

If you have read this through on your own you are likely feeling overwhelmed but take heart, it is meant to take ten to twenty sessions of discussion to understand fully. If you are using this as a checklist, we hope that you find the resources and references helpful. If you are contemplating inviting seniors to work with you in a research project, we hope you find ideas to make your collaboration one of equal partners.

### Further Readings and Resources

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### **Appendices**

# Appendix 1 Resilience as Social Capital: Lessons from Older Adults

Nancy Marlett, Claudia Emes, Kimberley Petersen, Lynn Meadows, and Ralph Miller

**Abstract:** This paper explores data collected by older adults while setting a research agenda about resilience. Focus group data from 120 older adults generated group consensus research questions, a computer-aided content analysis, and interpretive discussions with

older adults as researchers. The results reflected by socialization and cultural differences prompted us to explore a possible convergence between resilience and the literature on social capital. The data suggest that this particular cohort of older adults considered resilience to be learned, strengthened, shared, and passed on during times of challenge and struggle, and thus resilience acts as a social currency.

Key Words: social capital, resilience, older adults, healthy aging

**Note:** This paper represents an attempt to recognize the voice of seniors by weaving their quotes into the text.

#### 1. Introduction

"Are you going to take resilience and make it into something I have to feel bad about not having enough of?" Maureen asked as I walked into a large gymnasium where we were hosting a workshop on resilience. The purpose of the workshop was to discuss an understanding and interpretation of resilience from the perspective of seniors. She called "resilience" a good word, and went on to tell us about how the wars made children resilient and how young people today have it too easy and she worries about them becoming resilient. This was our introduction to resilience through the eyes of older adults, and it captures the spirit and commitment to the meaning of resilience for a generation that shared the common threats of war and the great depression.

The workshop on resilience, sponsored by the Canadian Institutes of Health Research, was held at the Kerby Centre of Excellence, and it was the first initiative to increase the voice of older adults in research about resilience and healthy aging (Emes et al., 2008). The Kerby Centre, is a large, seniors-led organization of older adults supporting older adults, and it has fought for thirty-five years to have seniors' voices heard. In the early stages most literature about seniors came from medical specialists and geriatricians. It was dominated by

problems, loss, and physical and mental degeneration that was represented by a "steady trajectory of decline." Later gerontology was established as a multidisciplinary field about the psychosocial aspects of aging that take into account both the gains and losses associated with aging (for a more complete review, refer to Heckhausen et al., 1989); still focused primarily on how older people adjust to loss<sup>2</sup> (Carstensen and Freund, 1994) or unexpected change due to life's circumstances. More recently aging dominates much of the health literature, including resilience and aging.

#### 1.1. Resilience

Resilience as a recurrent theme within gerontology (e.g., Lavretsky and Irwin, 2007; Staudinger et al., 1993, 1995) is commonly referenced to overcoming trauma or adversity. Dependent variables include personality characteristics or internal resources, social support (e.g., family and community support or external resources), and neuronal and cellular integrity (Marji and Dutman, 2001). Research on older adults demonstrates their resilience (Bergeman and Wallace, 1999; Garmezy, 1985; and Rutter, 1987). Various definitions have emerged from resilience literature. For example, the ability to maintain or regain active or latent coping and adaptation capacities through various individual and interpersonal mechanisms (Foster, 1997). An alternative definition reflects the voice of seniors: resilience is "about moving beyond adversity to strength, about turning hardships into insights and about skills and character that lead people to anticipate and believe that they can handle future challenges" (Emes et al., 2008).

In a historical review article, Tusaie and Dyer (2004) described the evolution of the construct of resilience. They identify the roots of resilience within psychological and physiological literature. It emerges in research that examines human responses to adverse events as a dynamic process, when an imbalance occurs between risk and protective factors. It was the notion of a person improving in response to an adverse event that laid the groundwork for the construct of resilience. Resilience focuses on positive outcomes. Definitions also focus on both intrapersonal and environmental factors. But most important is the understanding that resilience does not function uniformly and automatically but is unpredictable in response to contextual variables. Further, the domains of resilience are appropriate according to different life stages (Tusaie and Dyer, 2004).

As interest in resilience in older and very old people increases (e.g., Nyrgen et al., 2005), the definition of resilience in aging shifts dramatically from characteristics to exploring the connections between resilience, a sense of coherence, and purpose in life.

#### 1.2. Social Capital

The other construct that frames this article is social capital, a term used to recognize the non-monetary contributions people make to a society so that it can be productive. It is a difficult concept to define and measure because it resides in relations between and among people (Coleman, 1990). What may constitute social capital in one context may be regarded as useless or even harmful in another (Krishna and Shrader, 2002). Nevertheless, measures of social capital have included: trust (e.g., in others and in institutions); reciprocity reflected in social cohesion (e.g., respect for diversity, values) and social support and networks (e.g., frequency of contacts, quality of relationships); civic participation and social engagement (e.g., sense of belonging to the local community, membership in community groups or associative activities, volunteerism, civic participation); income distribution; and health (e.g., self-rated health status, Van Kemenade, 2003). Social capital is therefore not a single entity but is multi-dimensional;

it is a function of the value assigned by individuals, families, and the communities in which they reside (Coleman, 1990).

For purposes of this paper, we chose to rely on Cahn's (2002) framework of social capital as a "non-monetary infrastructure of trust, reciprocity, civic engagement." In this respect we have combined social cohesion, social support, networks and social engagement within the category of reciprocity as they reflect "connectedness." Included in civic engagement are social awareness and activism, membership in community groups and volunteerism, as these features are about contribution.

The subject of social capital is prominent in current health literature (for example, Lomas, 1998; Pootinga, 2005). Studies focus on successful aging and approaches that offer reliable measures of social capital. In a review of thirty-one articles, Kawachi et al. (2004) identified a complex pattern of associations between social capital and individual health thereby concluding that social capital is "a true contextual construct."

Social capital literature on community and individual health has recognized the potential contributions of older adults (Fried et al., 1997). It also appreciates that most seniors (59%) have a desire to stay active and productive, therefore offering a growing source of human or social capital (Fried, 1996). A relatively new program that taps into the aging adult population is Experience Corps®, a volunteer service program designed to connect and improve the lives of urban school children while at the same time improving health for older adults (Glass et al., 2004). The program targets schools where committed long-term volunteers can enhance teacher and student experiences. This is a relatively sophisticated initiative that respects the needs of both the school, its teachers and students, and the older adult volunteers. Short-term evidence of increased social capital as a result of the Experience Corps® is reported in Rebok et al. (2004). Research by Pollack and Von dem Knesebeck (2004) also showed that social

capital indicators at an individual level are associated with various health indicators in the elderly. Despite the evidence that of the importance of social capital to health at both an individual and community level, social capital appears to be on the decline (Cannuscio et al., 2003; Putnam, 2001). This is particularly critical to older adults because they are at greater risk for losing social ties as they age and consequently face increased risks of dependency.

This study reinforces a new voice in research literature about older adults, a voice that challenges the dominant discourse of both geriatric and gerontological research. It also represents social capital that comes from the lived experience and the rich cultures of aging adults. Most importantly, it was retrieved by their older adult peers.

#### 1.3. Purpose

The purpose of this article is to explore the parallels between resilience and social capital as an individual and community currency. The study also proposes a model of social capital that is informed by the outcomes of a workshop on resilience for older adults.

#### 2. Method

The principles of Participatory Action Research were instrumental in the development of the resilience workshop (Green et al., 1995), and this study is an opportunistic analysis of data collected by a group of academics advisors involved in the workshop. This paper, therefore, while taking advantage of the data collected within a PAR-informed process, does not claim to have been written with participants because there was no way to involve all those who had attended. We did consult older adult researchers who had participated in the workshop and who were later part of subsequent research that was based on a research agenda set by workshop participants.

#### 2.1. Participants

Members and non-members of the community-based Kerby Centre were invited participants. Inclusion criteria were sixty years or over, registration, participation in the entire workshop, and willingness to have their comments recorded. Announcements about the workshop were posted in the Centre and e-mailed to members, and a notice of invitation was printed in the *Kerby News*, a monthly newspaper published for seniors that has a circulation of 250,000 readers (Emes et al., 2008).

#### 2.2. Design and Procedure

The Kerby Centre of Excellence invited older adults to attend a workshop on resilience. Participants registered upon arrival and signed consent forms. The topic of resilience was introduced and then followed by a presentation on resilience by a researcher from a neighbouring province. Her study involved rural participants whose background was similar to many of the workshop participants. After a coffee break participants were divided into discussion groups that were led by retired professors. Each group also included a volunteer student scribe. They used networked tablet computers to hand-write their notes and this new interactive technology made it possible to collect and synthesize data as it was recorded. Two main questions guided their discussion: (a) "can you think about a time when you were struck by your ability to cope or the resilience of someone else," and (b) "as a group, what would you consider the three most important aspects of resilience that need to be looked at further?" Participants worked in small groups, sharing their stories of resilience and thinking about what they had learned about resilience from these stories. The results were projected on a large screen so that there was a feeling among the participants that their ideas were turning into research directions as they watched. In the afternoon, research questions were identified by the focus groups through a group consensus process.

#### 2.3. Analysis

After the workshop, the rich data gathered was subjected to extensive qualitative analysis. During the many discussions about the findings, one of the researchers noted that the results seemed to reflect a socialization process that resulted in learned ways of responding to challenges. The parallels we recognized between resilience and social capital as we worked with the data intrigued us. As such we wondered if the data might address our understanding of social capital in relation to older adults and aging. The challenge was to determine if resilience is a distinct form, or a process, or a structure within social capital.

Data were then analyzed for evidence of the parallels between resilience and social capital. As the evidence was coded, we began to explore the fit for a model of social capital.

#### 3. Results and Discussion

Participants in the workshop (n = 120) were 88 females, 15 males, and 17 others who failed to provide age and gender information during registration. They were aged 60 and older; 35 from 60 to 69, 59 from 70 to 79, and 26 over 80 years. They represented a broad range of socio-economic and ethnic cultures (e.g., European, Indian, Japanese, and Ismaili), and service personnel (n = 5).

The pivotal outcome of the workshop was a definition of resilience that was crafted through the interpretation of the stories that participants shared when they were answering the two questions regarding their personal experience with resilience. It is "about moving beyond adversity to strength, about turning hardships into insights and about skills and character that lead people to anticipate and believe that they can handle future challenges."

This definition reflects the process of responding to challenges; however, the conversations that were the basis for this understanding suggested a broad scope that includes social groups and communities. One women described to struggle after her divorce from a marriage of forty-three years, "support groups have helped for abused women. They encouraged me to go on despite my age and stage of life." Another talked about her volunteering experiences as "using [the] rich resource of people" and "serving to be served." The ability to cope effectively with change does not diminish with age, provided that support is available, nor is it limited by changes in circumstance.

In summary, resilience in these older adults was considered less a trait and more historically situated within a shared socio-cultural context (Jarvis, 1987). Kolb (1984, 38) defines learning as "the process whereby knowledge is created through the transformation of experience" and involves active participation or emotional involvement (Jarvis, 1987). This would appear to capture the culture of resilience we witnessed.

The perception of resilience as a fluid acquisition led authors to note the unmistakable alignment of resilience with social capital. In the following sections those variables that constitute and influence social capital are examined through the lens of resilience. Social capital is based on the degree to which society cooperates and collaborates through such mechanisms as shared trust, reciprocity, and civic engagement.

#### 3.1. A Model of Resilience as Social Capital

Social capital generally addresses non-monetary economic value that contributes to a society's capacity to be productive; indeed, Alder and Kwon (2002) identified important benefits of social capital. First,

social capital facilitates access to broader source of information, thereby improving quality relevance and timeliness of data and ideas. Power, influence, and control constitute a second benefit that leads to achieving goals and getting things done. Lastly, social capital is solidarity that creates social norms and beliefs associated with social networks. We suggest that social capital has two outcomes: productive function and resilience. We further suggest the following model of social capital as a process whereby the capacities of individuals (human capital) as part of social groups create productive function and resilience (social capital) through opportunities for building trust, reciprocity, and civic engagements. Whereas human capital refers to individual ability, social capital refers to opportunity; it is a quality created between people.

Productive functioning is the capacity of individuals and social groups to work effectively within collaborative structures to create and sustain needed goods and services. Resilience, using the definition developed in the initial workshop, is then the capacity of individuals and social groups to move beyond adversity to strength, to turn hardships into insights, and about a history of resilience that leads people to anticipate and believe that they can handle future challenges. In short, it is the social history and capacity that enables a society to respond to and overcome the challenges that threaten its ability to be productive.

Resilience in this light is a reserve, or a legacy to be drawn upon in times of challenge. An example of resilience as a non-monetary reserve becomes clear when confronted with the escalating health care costs associated with aging. The capacity of seniors to maintain functional autonomy and contribute to their health and the health of others through natural supports will make it possible for society to continue to care for the health needs of all members.

This particular age cohort has a strong sense of resilience, and it may be opportune to call on them as experts of resilience to understand the how to manage health care for an aging population. It is time to see aging adults not as a threat to economic stability because of their potential problems, not as sidelined and discriminated against, but as a source of social capital, capable of finding new solutions to the challenges that society faces.

According to Brehm and Rahn (1997), civic engagement and interpersonal trust are in a tight reciprocal relationship, where the connection from participation to trust is strong. We witnessed the sharing of life experiences during the workshop develop into a cohesive factor in their understanding of resilience and a solidarity in their agreement on the meaning of resilience.

It might be suggested that the way to mobilize social capital is to understand the operation of trust, reciprocity, and civic engagement in creating social capital. It would seem that trust enables people to enter reciprocal relationships, and experience in reciprocal activities promotes civic engagement.

#### 3.1.1. Shared Trust

Shared trust can be defined as the attitude, spirit, and willingness of people to engage in cooperative and collaborative activities. It refers to the belief that people and or groups will honour their commitments and that obligations will be enforced by social groups such as families, communities, and society as a whole. This trust is shared between individuals and between individuals within social networks. Trust begins in connections among individuals and families, while the broader community foster norms of trustworthiness (Van Kemenade, 2003).

Trust consists of webs of personal beliefs and expectations that enable people to engage in social behaviour. These webs of mutual beliefs and expectations create trust and safety, a sense of stability and order. Trust can be as ephemeral as a phone call every day at ten o'clock, or watching out to make sure the home care nurse comes to the home of a friend across the street. Trust and resilience are deeply connected for one cannot risk trying again, "bouncing back" without trust in a social contract.

Although the word "trust" was seldom used in the focus groups, there were narratives of trust within families and about obligation and mutual expectations found in later life when family ties diminished. This age cohort shared powerful stories of families surviving in the face of violence, hunger, poverty, displacement, and harsh environments. Close bonds were built on the belief that family members could be relied on, members were accepted because they were family and everyone worked to protect and help the family survive and prosper. This almost instinctual reliance on each other led to trust that enabled the family to hold on (and onto each other) in the face of unpredictable and often hostile environments. The trust and safety found within families tamed the fears that existed outside these families where the outside was marked by stangeness, unpredictability, and the potential for harm

Later in life the basic foundation of trust tends to break down as family ties unravel and there is a rise in fear and feelings of alienation, loneliness, and hostility. Without trust, society needs "constraints, supports, leaders, managers, teachers, intervenors and we surrender ourselves and our lives to them for guidance, management and manipulation" (Gib, 1978, 14). In other words, as trust bonds break, people are more likely to enter into a cycle of reliance on paid staff for guidance and support which in turn further reduces natural trust bonds.

The participants spoke of the loss of family or intimate ties that led to feelings of being alienated and fearful. They countered with suggestions about connecting with others seniors. Examples of this were found in the stories of senior's groups that were formed in the 1980s in Canada with the Secretary of State programs. They spoke

of the vitality of these groups, how they provided a site of friendship, mutual support, and a sense of identity. These associations developed the same trust bonds that were evident in families, once families and work ties were no longer viable.

Participants also acknowledged that these seniors groups were being threatened by declining membership. These groups are "becoming soulless, lacking in sensitivity and connectedness." If communities are to maintain the needed social capital resources of seniors, they will need to attend to this loss of shared trust and build ways to increase the power inherent in natural seniors communities.

We can begin by addressing those practices that undermine trust. One example of this is the current enthusiasm of community developers and community health staff to strengthen and support seniors clubs and associations by placing social workers and community health workers in these centres. As paid staff, they are responsible to the funding body, not the association, and many of the natural functions done by seniors are assumed by young professionals. As social clubs are turned into resource centres, the obligations, narratives, sanctions, and supports are undermined, and this further reduces the social capital that was the hallmark of seniors' centres. Professionals and planners need to be careful lest they trample on natural support networks that cannot be replaced. Our data can only speak to an older cohort for seniors clubs and associations do not attract younger seniors. It is up to others to create a model to maintain and build trust for the next generation of seniors.

#### 3.1.2. Reciprocity

Reciprocity is "a combination of short term altruism and long term self interest" (Taylor, 1982). People act for the benefit of others at a personal cost. They do this in the general expectation that this kindness will be returned at some undefined time in the future when

they might need it themselves. Portes (1998) describes reciprocity as providing access to resources with an expectation of repayment in the future. This creates obligations that are repaid in ways that may differ from the way they were incurred and timing of repayment is not specified. Reciprocity exchanges occur between individuals, the individual and the community, and between communities. In a community where reciprocity is strong, people care for each other (http://www.mapl.com.au/socialcapital/soccapl.htm). Social supports, networks, social cohesion, and social engagement are also included in this section.

Reciprocity was a strong theme among participants, demonstrated by comments such as, "You can't stay the victim when your family and others around you push you to go on." Reciprocity depends upon meaningful and positive relationships. Most meaningful relationships begin with family.

Participants discussed learning about resilience by "sharing stories of personal strengths that celebrated where we came from and the obstacles overcome," e.g., "my grandparents were very creative ... they came with nothing but learned how to make do with what they had." Thus, many older adults discussed "mentoring as a way of teaching and encouraging resilience" in others; "linking the younger generation to how things used to be." Older adults who immigrated to Canada in their youth felt a loss of meaningful relationships because they left behind extended family, neighbours, and familiar communities. In these cases, informal networks came to replace the role that family would normally play. These informal networks allowed individuals to cope effectively with unexpected change. "You need to stay busy, giving and receiving in the community, meet new people regardless of the barriers."

With aging, this loss of meaningful relationships accelerates. For many older adults, the community centre provides opportunities to connect with others. This reduces feelings of being excluded from society, especially "when family has stopped coming around," "I feel more isolated now ... my friends are dying, and making friends is harder as you get older."

The participants had good suggestions for building connections again:

- "When people lose their abilities and their friends they get angry and they really need to find a good friend to listen."
- "Reach out to others and look for younger friends."
- "Find a friend that helps you feel good about yourself, keeps your dignity and expects you to help in return."
- "Stick to the optimistic people for friends, stay away from the basement people."

Meeting people is hampered by fixed incomes and accessibility. Affordable and accessible transportation provides opportunities to meet people with similar interests; for example, "one man is known to go to Canadian Tire because he is acknowledged there in a man's world," another explains, "My bus pass is a great thing, I get out [and] roam around the city and meet new people."

Once people are able to connect with others, it is possible to move to mutual support and reciprocity. The following are examples of this reciprocity:

• "Two years after coming here my husband died. None of my children are here. I am alone. I have health issues. I find it hard to meet friends.... I started going out of my mind; I looked in the phone book and called Kerby. The people at Kerby helped, I feel more open and brave. They hired me as a volunteer and now my life is getting better."

- "I was working for the school board and the stress was too much so I had to take early retirement (due to a heart attack) at one point I realized I needed to get back to things again. I needed something to do. I spoke to others with health problems and realized I needed to try and help others."
- "I am a volunteer teacher and through reading to children I have come to appreciate my ability to be a good volunteer for over 40 years. I am useful and that helps me a lot; it keeps me going."

Another example of the progression from reaching out and connecting, to helping others and finding a source of reciprocal support, was told by one participant who lost a grandson to suicide and through sharing her experience has provided emotional support to others, "I have been able to talk people out of committing suicide ... this has helped."

Reciprocity builds on trust within social relationships, it creates social capital through shared help, support, and encouragement, activities that validate who we are and what we contribute "by helping others, you build your own reserves of worth and feelings of competence." Reciprocal activities also give people something to look forward to, to plan for, and in the process it focuses on the potential of the future rather than the problems of the past.

If we hope to capitalize on the potential of resilience as social capital we must understand the how to mobilize the opportunities for seniors to contribute to others and to build personal resilience.

#### 3.1.3 Civic Engagement

Civic engagement relates to the active interest and participation in community interest groups such as neighbourhood and senior centres, sports clubs, and political parties. The denser the civic engagement networks, the more likely that communities will be able to work together for mutual benefit. Also included in this section are notions of volunteerism, social awareness and activism, and membership in community groups.

Volunteerism is basically a reciprocal activity whereby older adults become engaged in service towards others and thus give back to family and the community. In "volunteering – you get more than you give." Through volunteering, older adults spoke about being much more aware of issues such as poverty, housing, and transportation but spoke most about: those who fall through the cracks, low-income seniors, older adults who don't speak English, shut-ins, those who can't get around, men who have lost a loved one, and the forgotten.

Civic engagement goes beyond awareness of social issues and many felt that they had an obligation to respond to larger societal need: "the community is changing" and the "Governments' priorities are not meeting the needs of today's older adults." "In the old days life expectancy was shorter and people were worn out." "Nowadays, we aren't sitting out on the porch, we are living longer and have the energy to do more, we just have to learn to harness this energy."

Committed to their community, these older adults wanted to take an active approach towards "planning for aging communities"; in their words, "We need to feel a challenge again, we need challenges to keep us going. "We must build our community and lobby for senior advocacy groups."

The results of our analysis support the rising concern that volunteerism is tied to the current older adult population. The older adults in our sample were engaged in volunteering and eager to be at the table of social change. However, they expressed deep concern about the lack of younger seniors to take their place. Putnam identified the immediate determinant of the decreasing national stock of social capital in the mid-nineties (Putnam, 1995). Our sample of older seniors despaired at the loss of civic engagement and responsibility as a way

of life that generally passes down from one generation to the next. They felt that this heritage was being lost.

#### 3.2. Recommendations for Future Research and Action

This was not a formal study; it represents interpretations about powerful data collected by seniors with seniors on the topic of resilience. Further research will hopefully be conducted with other groups of seniors and with younger seniors since there may be dramatic generational differences in the culture of resilience, volunteering, and civic engagement.

Given the limitations, these finding would seem to warrant further research to investigate the connections between resilience and social capital. The current paper suggests that the social capital reserve of seniors is being ignored and devalued. And yet, seniors may hold the key to the major social problem facing societies today — an escalating aging population. As researchers we need to recognize and pay close attention to aging adults for they know best the resilience culture of their age cohort.

In the end, we, as authors have realized that it is not realistic or effective to expect professionals who see the world through their own resilience culture to apply their culturally sanctioned strategies to older adults. We believe that the cultures of those over seventy are very different from those in their sixties. Each age cohort experiences challenges and create socially sanctioned methods of handling these challenges. If we are to address the needs of older seniors we must do so within their own culture of resilience, society needs to draw on the social capital reserves of seniors to meet their future challenges and those of society. As seniors, they in all likelihood hold the key to creating a culture of resilience for healthy seniors.

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## Appendix 2 Handout of Basic Principles of PAR

Prepared by Dr. Joan Ryan from Doing Things the Right Way

Participatory Action Research is a methodology that has two basic goals. The first is that it is community-based and that it draws participants from that group to actually do the research (after a modicum of training) and, secondly, that the research can enable communities to initiate change. The changes can include different ways of doing things, new forms of communication, education within the community, and also initiatives for policy changes at various government levels (health, education, resources, paring of youth and seniors, etc.).

While each research community can evolve its own criteria and ways of working, some basic principles are the following:

• The community requests that the research be done.

- The community and external resource facilitators/researchers develop consensual research expectations, processes, and outcomes.
- The community establishes a Community Advisory Committee (CAC) or similar body to oversee the project, keep it on track and on budget.
- The research process remains flexible and adaptable within a consistent framework
- Local researchers receive (comprehensive) training.
- The researchers, resource persons, and CAC work together on evolving the interview guide and informed consent form and on data analysis.
- The interpretive analysis is verified by the whole community.
- The report is written in a language that most community members can understand.
- The report is made available to all interviewees and community members.
- The CAC does an evaluation of the project.
- The community takes steps to implement actions arising from the project and desired by the community.

#### Key Terms in PAR

**Equitable partnerships.** The community partners with a resource person or team in ways that ensure the balance of power is equit-

able. There is no "boss." People build on strengths of each participant, which will vary so that the whole becomes greater than the sum of its parts.

**Enhancement.** Some practitioners call this "empowerment," which is a term to be avoided since it implies that one party has "power" to give the other. Not so. The PAR process allows each participant to gain new skills and perspectives and thus enhance their own abilities; as well, the group as a whole gains knowledge and capacity.

**Community Control.** As noted elsewhere, the community (however defined) takes the initiative and maintains control of the research process throughout the project. The results belong to the community, as does the end product.

**Different Ways of Knowing.** People bring much diversity to any project and there are many ways of knowing. PAR projects respect all ways of knowing and thus many new perspectives can be developed on any given topic or process. People also are diverse in expressing what they know; one may tell a story that seems irrelevant but on reflection caries an important message.

**Communication.** In PAR projects, communication needs to be continuous so that participants know what is going on, what it means, where the process is taking them, and what actions might flow from the information. Sometimes, "unintended consequences" occur as a result of understanding the communications and these can be quite exciting. Communication also determines what forms can be used when telling others of project results; print materials may be appropriate but so might a video or a play.

**Action.** Action is the end result of any PAR project. What actions take place and to what end is determined by participants as a result of the research. One of the characteristics of PAR projects is that people begin to see what actions might be reasonable; they sometimes tend to move ahead of the project completion. This makes life exciting but also means that participants may need to back up and reflect a bit.



Marilyn Akazawa

It is really important when you're researching seniors to have seniors do it, because you're looking in a mirror.

# Appendix 3 Sites and Sources: Seniors and Resilience Research Proposal

By N. J. Marlett and C. G. Emes

Relevance/Responsiveness to the RFA: Today the seniors' point of view is commonly absent in policy and everyday decisions that deeply affect them. The result is to underestimate the capacity of seniors to manage their own affairs while marshalling effort and resources that are unnecessary and possibly counterproductive in the mistaken belief that they are thereby being helped. Given this, and within the priority research area of healthy and successful aging, this innovative pilot study engages seniors as leaders and participants in: 1) setting research directions, 2) developing research skills and building senior research capacity, 3) promoting and advocating research about seniors by seniors, and 4) translating findings into future related research and

policy. The results from the pilot research were used as the foundation for a full operating research proposal in 2004/2005. The purpose was to study resilience as an interactive process between individuals, their social groups, and communities, as one aspect of healthy aging. The team's vision is to establish the Kerby Centre as a community-based Centre of Excellence that attracts students and new researchers to work with seniors in pioneering new research directions about successful aging.

**Background:** In preparation for this pilot, funding from CIHR, the City of Calgary, and private funders was used to run a series of workshops and to support a research steering committee. The steering committee includes retired academics (professors emeriti), current university professors and community researchers (seniors, affiliated professionals and policy-makers) interested in the social construction of resilience in relation to health and successful aging. The initial workshop attracted close to 200 seniors (age 60 and over). Eight research working-groups involving approximately fifty seniors, were established as a result (Table A1).

Table A3.1. Summary of existing research groups and the research leadership: Pilot Project CIHR–IA.

| RESEARCH<br>DOMAIN            | TEAM<br>LEADER                   | EXPERTISE  |
|-------------------------------|----------------------------------|--|
| Gender                        | Dr. Joan<br>Ryan                 | Anthropologist, PAR with women, aboriginal peoples, and immigrants |
| Physical activity and leisure | Dr. Bob<br>Stebbins              | Sociologist, grounded theory of leisure and work                   |
| Ethnocultural                 | Dr. Mo<br>Watanabe               | Medicine, interest in cultural foundations of health               |
| Spirituality                  | John<br>Pentland                 | Minister and Community Development with Seniors                    |
| Intergenerational             | Dr. Greg<br>Fouts                | Psychologist, resilience research with children and adults         |
| Health                        | Dr. Jean<br>Miller               | Nursing, health care models for seniors                            |
| Education                     | Dr. Ralph<br>Miller              | Education and growth   |
| Rural                         | Dr. Geoff<br>Elliott<br>Al Hagan | Kinesiology, Public policy   |

In anticipation of approval of the pilot study, the City of Calgary funded two workshops for the fall of 2003. The first introduced Participatory Action Research practices and principles and used current research on gender to teach senior participants to conduct interviews. Seniors were also asked to nominate community locations as sites where resilience is fostered and maintained.

In November 2004, a second workshop introduced research field-work, participant observation, and community mapping methods. The participants were invited to visit one of the sites recommended in the first workshop and to contribute to the community maps of the city and the health authority.

#### Literature Review

Grotberg (1996, 2) defines resiliency as "the human capacity to face, overcome, and even be strengthened by experiences of adversity." Health Canada (1997) defines it as "the capability of individuals and systems (families, groups and communities) to cope successfully with significant adversity or risk." While further studies relating health and resilience with seniors have yet to be done, there is a strong research tradition surrounding resilience in nursing, psychology, and social work. The majority of studies focused on individual traits and characteristics (Quinney and Fouts, 2003; Fraser, M.W., Richman, J.M., & Galinsky, M.J. (1999), on adolescents and children (Jacelon, 1997; Felton, 2002), on response to adversity (Zimmerman, 1999; Greene, 2002) on strategies for coping with adversity (Ramsey and Blieszner, 1999; Gerrard, 2003; Kulig, 2003) or on community resilience (Brown and Kulig, 1996/7; Stehlik, 2003). For this study, we have adopted the definition by seniors at the workshop who saw resilience to be "about moving beyond adversity to strength, about turning hardships into insights and about skills and character that lead people to anticipate that they can handle future challenges." This definition reflects the process of responding to challenge and broadens the scope to include social groups and communities.

Seniors have been found to be reliable and insightful researchers (Good and LaGrow, 2000; Prager, 1995) and various Participatory Action Research methods based on constructivist theory have been found to be effective with seniors (Hurd, 1999; Smith et al., 1997;

Leonard and Nichols, 1994). Four methods used in participatory research have been selected for this pilot (see Table A2): 1) participant observation and community mapping (Elliott et al., 2001; Parks and Stoker, 1996; Witten et al., 2003; Stringer, 1996; Monette et al., 1986; Hurd, 1999; Aleman, 2001),

2) survey methods (Stringer, 1996; Monette et al., 1986), 3) focus groups (Morgan, 1993; Stringer, 1996; Lingafelter, 2002) and 4) narrative interviewing (Tate et al., 2000; Rubin and Rubin, 1995; Herzog and Rodgers, 2001).

Table A3.2. Research methods chosen for evaluation. Pilot Project CIHR–IA.

| RESEARCH<br>METHOD  | ASPECTS<br>COVERED   | FOCUS OF RESEARCH<br>TRAINING   |
|---------------------|--|---|
| Field-work          | Participant observation, ethnography, community mapping                              | Observation, recording, transcriptions, descriptive analysis, inter-rater reliability   |
| Survey              | Structured and open-<br>ended questionnaires:<br>face to face, telephone,<br>written | Standardized interviewing protocols, overcoming bias in recording open-ended responses, descriptive statistics on data, coding open-ended responses |
| Focus groups        | Popular education<br>and PAR methods for<br>groups                                   | Facilitating research groups, audio tape records, group methods of prioritizing ideas, movement from knowledge to plans for action and follow-up    |
| Narrative<br>method | Narrative interviewing, stories, scripts, meta-phors                                 | In-depth individual interviews, use of case examples as triggers for narratives, transcription, and content analysis                                |

#### **Purpose**

This pilot explores innovative ways of involving seniors in research about successful aging. Specifically, the pilot will investigate, test, and evaluate methods of engaging twenty to forty seniors as researchers, in eight areas (Table A3.1) related to resilience in preparation for submission of a CIHR operations grant.

#### **Objectives**

- To investigate methods of engaging seniors as researchers.
- To train groups of volunteer seniors to do and evaluate Participatory Action Research.
- To develop and test research methods and tools appropriate for use by seniors with seniors.

#### **Research Questions**

- 1. What are effective and non-effective ways of engaging seniors as researchers? What are the enablers, challenges, and lessons learned in such activities?
- 2. What are the elements of a successful/unsuccessful research training process for volunteer seniors? What constitutes appropriate, valid, and feasible quality control for such training?
- 3. What are valid and feasible research tools and approaches that can be used by seniors when seniors are conducting research on healthy aging?

**Method:** The research structure (Figure 1) reflects current working relationships established after the workshop.



Figure 1: Research domain structure: Pilot Project CIHR-IA.

The structure builds praxis between the steering committee, senior researchers, students, and interested professionals within the research groups, enabling a strong forum for generating ideas, overseeing the implementation of the research agenda, and problem-solving. It is guided by PAR principles and practices (Marlett, 1998; Smith et al.,1997) and incorporates four major research methods: field-work, survey methods, focus groups, and narrative research as outlined in Table A3.2.

*Field-work* (participant observation) provides opportunities to gain a clear picture of the research context by observing the activities and interactions within the chosen sites. This will encourage researchers to separate their observational role from that of participant (Stringer, 1996; Monette et al., 1986; Hurd, 1999; Aleman, 2001). Recordings of observations provide the detail for descriptive research

and an opportunity to explore inter-rater reliability. The observational protocols will include categories for community mapping (Elliott et al., 2001; Parks and Stoker, 1996; Witten et al., 2003).

Survey research, structured interviews, and open-ended questions will involve spokespersons nominated by the chosen sites to explore quantitative and qualitative data collection and analysis. Standardized questions will introduce descriptive statistics. Open-ended questions will explore the history and operations of the site and how the activities of the site contribute to the resilience of seniors. Open-ended questions symbolically recognize the legitimacy of the interviewee's point of view (Stringer, 1997; Monette et al., 1986).

Focus group methods build on the principles of PAR (Stringer, 1997; Berg, 1995; Morgan, 1993). Focus group participants will be recruited from the research sites. The team leaders will supervise the sessions. The protocols for each of the focus groups will tap the role of friendship, sense of common purpose, and the status associated with being part of the site.

Narrative research is emerging as central to understanding personal meaning at the deeper context of threats to personal identity (Gergen and Gergen, 1988; Josselson and Lieblich, 1993). The methods involve exploration of life stories, narrative accounts, scripts, and metaphor as theory. This technique would seem to be particularly suited to seniors as researchers since they come as peers to the experiences.

Each of the methods will be evaluated through the PAR sequence of: *engaging* seniors as participants in each of the sites; *training* the "senior" researchers in the method; *deploying* the method in the sites; *analyzing and synthesizing* the results from the perspective of each research group and then sharing results across each of the domains. The results will be then summarized and developed as a pamphlet by a communications group for *dissemination* on the Internet and in a

print form. The timelines and details of the research are presented in Table A3.3.

Quality Control specific to the research process, tools, content, and evaluation of outcomes will be the responsibility of the emeriti and the research steering committee. Validity will first be assessed by triangulating the data through multiple methods and sources of information. Construct validity of the concept of resilience is achieved through the reflexivity inherent in the structure that critically questions actions and practice. Face validity is fostered by the ongoing feedback from the larger working groups, who will also be engaged in the analysis and interpretation of the data.

The tools (measures, instruments, protocols) will be tested in the pilot and adjusted based on feedback by all involved in the PAR process.

#### **Outcomes**

- (1) A partnered new variation of action research that other researchers working with seniors will be invited to adapt and use.
- (2) A resource of trained "senior" researchers to further the research agendas of Kerby and other researchers interested in research on aging.
- (3) Tested methods, tools, and adaptations that foster research about seniors by seniors.
- (4) New field connections.
- (5) New knowledge that informs future research directions related to resilience of individuals in their social groups and communities

(6) Evaluated community mapping categories and processes and a list of potential sites and sources of resilience for future study.

Innovation and Originality: This pilot is original and innovative in the depth of involvement of seniors, both emeriti and community volunteers. Further, the project bridges individualist and collective PAR research approaches. Outcomes are not only methodological, the process will build a research infrastructure in the community, strengthen existing inter-sectoral partnerships and shared use of data, and empower seniors as researchers of their own lived experiences. We anticipate that the momentum generated in Calgary will encourage other communities to collaborate with us in extending the methods to create a national study of resilience.

Value of the Partnership: The strength of the partnership begins with the contributions of the stakeholders: seniors, the investigators, Kerby Centre, the emeritus professors, and the service/policy sector. Volunteer seniors who are part of the project have already made a significant commitment to deepening their research expertise and knowledge of resilience. The investigators represent a number of disciplines (Medicine, Kinesiology, Social Work, Community Rehabilitation) and research expertise (health science research, PAR, narrative research, and field-work). They come with extensive experience working with communities, consumers, and public policy. Kerby Centre of Excellence, established in 2001, is Alberta's first community-based initiative to focus on the integration of research, education, and service delivery with an overriding goal of keeping seniors healthy and aging successfully. The emeriti represent a bold innovation in research about aging. Each retired professor comes with strong academic credentials in their own disciplines (Table A3.1), research networks in Canada and abroad, and extensive research expertise. They are able to authentically animate discussions about aging from both experiential and research perspectives to the project.

**Ethics:** The pilot proposal is being submitted to the University of Calgary, Faculty of Medicine, Conjoint Health Research Ethics Board, and the Kerby Research Ethics Review Committee to ensure that informed consent, confidentiality, privacy, and security processes are in line with required health information policies and standards.

**Conclusion:** This research challenges traditional research practices that often separate seniors from those decisions that affect them by involving seniors to become skilled researchers and to play an active role in designing and disseminating research findings, exploring research opportunities for other seniors, and recruiting research students and new researchers to the field of aging.

Table A3.3. Timeline: Pilot Project CIHR–IA.

| BACK-<br>GROUND                  |                                    |   | PILOT<br>PROJECT  |  |   |
|----------------------------------|------------------------------------|---|---|--|---|
| SepDec.                          | Jan.–Feb.<br>04                    | Mar.–Apr.<br>04   | May–Jun.<br>04  | JulSep.<br>04  | Oct.–Dec.<br>04                                 |
| Pre-pilot<br>preparation         | Field-<br>work<br>methods          | Survey<br>methods   | Focus<br>group<br>methods                                 | Narrative<br>methods                                       | Write up<br>and dis-<br>seminate                |
| Formalize<br>model<br>(Figure 1) | Negotiate<br>site in-<br>volvement | Review<br>literature<br>on sur-<br>veys                                 | Conduct<br>training on<br>PAR                             | Conduct<br>training  | Prepare<br>prelimin-<br>ary report              |
| Recruit potential sites          | Meet with<br>research<br>groups    | Select<br>spokes-<br>persons to<br>interview<br>in each of<br>the sites | Recruit<br>focus<br>group par-<br>ticipants<br>from sites | Recruit<br>partici-<br>pants for<br>narrative<br>interview | Pamphlets<br>re: seniors<br>research<br>methods |

| Workshop<br>on PAR<br>and inter-<br>viewing | Finalize<br>field-work<br>protocols  | Finalize<br>interview/<br>survey<br>protocols                                  | Finalize protocols  | Finalize protocols   | City-<br>sponsored<br>confer-<br>ence<br>on pilot<br>results   |
|---|--|--|---|--|--|
| Workshop<br>on field-<br>work/<br>mapping   | Each<br>group col-<br>lects data<br>in two<br>sites                              | Collect<br>data in<br>person,<br>telephone<br>or written<br>format             | Conduct<br>focus<br>groups<br>within sites                      | Conduct<br>narrative<br>interviews                                       | Recruit<br>other<br>research<br>partners<br>in other<br>cities |
| Select<br>"senior"<br>researchers           | Groups<br>analyze<br>data and<br>the ef-<br>ficacy of<br>the meth-<br>ods used   | Groups<br>anlayze<br>data and<br>the ef-<br>ficacy of<br>the meth-<br>ods used | Record,<br>transcribe,<br>and ana-<br>lyse results<br>in groups | Record<br>and<br>analyze<br>results<br>individ-<br>ually and<br>by group |  |
| Groups select sites                         | Com-<br>mittee<br>synthesis  | Com-<br>mittee<br>synthesis  | Committee synthesis   | Com-<br>mittee<br>synthesis  |  |
|   | Prepare<br>pamphlet<br>on inter-<br>viewing/<br>surveys<br>for and by<br>seniors | Prepare<br>pamphlet<br>on inter-<br>viewing/<br>surveys                        | Prepare<br>pamphlet<br>on focus<br>groups                       | Prepare<br>pamphlet<br>on nar-<br>rative<br>methods                      |  |

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Marianne Rogerson

It seems so obvious — of course seniors should contribute to the issues and research that affect them!

### Appendix 4 Observation Workbook for Field-Work

| Name:  | <br> |
|--------|------|
| Phone: |      |
| Team:  |      |

Going into the 'field,' to settings where seniors gather, to observe what is happening there. Record what you see, not what you think is happening!

#### A. Description of the Site

| Name and address of site:                     |
|---|
| Dates of observations/collections             |
| Relationship of observer to site/collection   |
| What is generally done here?                  |
| Who is being observed and why?                |
| What is the role of the seniors/staff/others? |

#### **B.** Observations and Recordings

General description of activity:

Repeat page for each observation.

On each page, do one recording. If you need more pages, duplicate these pages. You have been allotted one page for each recording; please feel free to use the back of the page if you need more space. You may want to take notes on sheets in a binder and transfer them to this page.

Space: (describe the size, furniture and décor of the space.)

| General description of activity.      |          |  |  |  |
|---------------------------------------|----------|--|--|--|
| Time of observation:                  |          |  |  |  |
|                                       |          |  |  |  |
| Recording of activity and interaction | Comments |  |  |  |
|                                       |          |  |  |  |
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|                                       |          |  |  |  |

#### Evaluation of Your Observation Experience

- How did you feel recording and what were people's reactions to you? How did you handle inquiries, etc.?
- What were the major challenges to getting good data in this process?
- What do you think you learned about healthy aging from doing this observation?
- What did you learn about yourself as a researcher from doing this observation?
- How might this work for other seniors, what might have to be changed to make it more enjoyable and productive as a research process?

It sure is good to talk about this; it's funny how great it feels to know you had the same experience. Don't try to stop us; we need to do this, we can handle it.

(CP 2004)



Janice Kinch

This project was learning in action – for all of us. The importance of community collaboration and participation are key to health, health care, and justice for all. The learning from the project has stayed with me and found a way into my life as an educator and as an aging woman every day.

## Appendix 5 Focus Group Training Notes

Nancy Marlett, with team leaders Prepared for the Centre of Excellence

A focus group can refer to any group that meets with the purpose of exploring a specific and well-defined topic. There is usually a facilitator who ensures that everyone has input. There are many tasks to perform and everyone will have a specific role.

#### **Setting the Stage**

What have you learned about the possibilities of doing research with your site?

For example, do the group members know each other well? What brings them together? How might this lead you to use their common interests as a starting point for your study?

How many people would likely make a good focus group? (Focus groups tend to range between six and fifteen members.) How would you select and invite those that might be interested or those you would like to select?

Where and when should the meeting take place? Focus groups tend to be engaging, so people want to spend some time. You could meet for one or two hours or you could meet for an entire day if you feel the group is able to sustain energy that long.

Is your group likely to want to discuss and share ideas in general or would they want to have some concrete product at the end of the day? What kind of product would they be interested in?

#### The Invitation for the Day

| An invitation to (your site group)  |
|---|
| Date, time, location, and parking   |
| Hosted by the and sponsored by  |
| The topic of the day will be  |
| By the end of the day you will have   |
| Your facilitators for the day are: list each researcher with a brief description. |
| Please let us know if you are interested by phoning                               |
|   |
|   |
|   |

#### Tasks for the Day

There are a large number of tasks involved in running a focus group. You will need to decide who is to do each task and practice the tasks you have:

- Sending out invitations and following up with prospective participants to explain what the project is and what your role is in the research. This will also include the consent to take part in the focus group forms (see attached).
- Getting the refreshments and the room set up.
- Welcoming people, making sure that they are introduced to each of the researchers
- Recording the discussion of the group on flip charts. (Needs to have good handwriting and be able to summarize information, this also entails providing feedback to the group if requested.)
- Recording the process of the group (as in observation research). This will involve using a notebook and recording interest, emotions, consensus, key points of interest, etc.
- Assisting with the facilitation. You may choose to divide the process of the focus group into sections so that you can share facilitation.
- Completing an evaluation with each of the participants at the end of the session. This can be done with the group, comments on how comfortable people felt, what they were pleased with and what could be improved. You may also wish to invite individuals to take part in future research.

- Writing up the results of the flip charts and the materials from the recordings of the group process. This will likely be done by the people who are doing the recordings.
- You may wish to do a follow-up to thank people and send them a copy of the materials that have come from the focus group.

#### Setting the Tone

A focus group is only as good as the 'goodwill' of those participating. It is important that the group feel safe and secure in sharing their ideas, that they will not be embarrassed or criticized. This can be done by sharing some 'rules' to start with. For example, you might write on the flip chart: Respect everyone's ideas, listen and don't interrupt, be creative in trying out new ways of thinking, speak up if you are unsure, are uncomfortable, or are lost. You can also begin with some "ice breakers" if the group does not know each other.

You might post ideas from other groups on the wall as people come in. Celebrating their ideas might set the tone. You can use ideas from the workshops that have been run to date. You can also post inspirational sayings that you think might appeal. You could have people jot down their own ideas on the posted sheets.

During the session, it is very important to stay in touch with the group and each individual. It may be that the person is shy or he or she may be very reluctant to say something that presents a very different way of thinking. You may need to use prompts such as: could we hear from this side of the room? Does anyone have a really different idea here? How is everyone feeling about what we've done so far?

**Appendices** 

#### **Group Processes**

There are several general processes that you can choose from, once you have your question. These are presented below, from open-ended PAR processes to those that are more highly structured.

**PAR-based processes.** With PAR, participants have input into the questions and processes so the first task of the facilitator is to run through several possibilities while also soliciting ideas from the group. The goal is to end up with a list of topics people want to discuss.

**Structured questions.** The questions we used in the first workshops at Kerby were: Do you remember a time when you realized that you or someone you were close to was resilient. How did you know it was resilience when you look back on it? These questions engage the person in creating their own definitions.

**Brainstorming.** Participants offer the first ideas that come to their head. All ideas must be recorded. Then the group or the facilitator takes the time to look at relationships between the ideas. This requires that the flip chart recorder is quick and accurate, always checking to make sure that they have recorded the idea accurately.

These ideas can be analyzed and presented in booklet form for follow-up focus groups. Appendix 7 and 8 is the most recent rural workbook that summarizes the knowledge that they generated in their previous workshop

**Delphi techniques.** These techniques are often used when people want to provide a sharper focus to discussion. In Delphi (Linstone &Turoff, 1975), participants think about a question on their own (usually this involves writing ideas down) for a short time period (usually about five minutes). The person chooses one or two ideas to share that they are most committed to and these are written on the flip chart.

The group prioritizes ideas to take to the next stage. Currently a popular method is to give everyone sticky dots (three to five, depending upon the size of the group) and each person can 'vote' for the ideas they are most committed to.

Once the top three to five ideas are voted on, the next step might be to think about barriers to achieving each of the ideas. You might also look at how groups might support the ideas. You might also bridge to research ideas from the ideas chosen.



**Bob Stebbins** 

Working on this project was a natural fit for us as retired researchers. It was fun to work on research without the politics of university grants and it was good to work with other seniors. It would be wonderful to build a network of trained senior researchers across Canada, able to work in partnership with non-academic seniors and policy makers.

# Appendix 6 An Example of a Structured Workbook Approach to Focus Groups

#### Resilience and Seniors in Rural Communities

"Resilience is like living on a bungee cord, bouncing back from adversity"

Your facilitators for the day: Dr. Joan Ryan (emeritus professor from the University of Calgary) Dr. Nancy Marlett, and seniors research facilitators from the Kerby Centre of Excellence.

- An invitation to explore resilience in everyday life and research
- Sponsored by the Town of Cochrane, Kerby Centre of Excellence, Canadian Institutes of Health

Feel free to write a resilience story in each of the boxes.

When and where did you first learn about resilience?

School and sports stories about resilience

Family Members

Personal stories responding to adversity.

Community/group stories of resilience

What strengthens resilience?

What weakens resilience?

# Appendix 7 Follow-Up Focus Group to Discuss Rural Resilience Findings

Cochrane, 2004 Sponsored by Family and Community Support Services (Cochrane), Town of Cochrane, Kerby Centre

This follow up workshop provides an opportunity to learn about the ideas generated in the first research workshop. In Participatory Action Research, you, the participants, are the active ingredient – like the yeast in baking. You ideas lead to new ways of thinking about resilience. In the group sessions, we invite you to react to the themes that emerged from your earlier work, to think about whether the theme holds true to your experience and to add your own stories about how this theme makes sense in your own life.

#### Five factors were identified:

- Personal strengths
- Opportunities that adversity provides to learning about identity
- Resilience roles learning from others
- Purpose and contributions
- Natural cycles
- Quotes are included

#### **Personal Strengths**

Personal strengths seem to include characteristics or skills that have come from your experiences and family background. Please add personal examples to the following categories:

• Ability to live with change and that you can be flexible.

I moved so much; I just learned to be resilient.

Family relationships change dramatically; you always have to regroup.

The war separated us; we had to learn to do things differently.

• Finding balance in your life and interests.

Exercise, entertainment, volunteering, a little bit of everything.

I'm happy my family helped me find peace and balance.

• Learning to focus and to plan.

Chores, children's responsibilities. Work was so hard, you had to stay organized and focused to get the chores done.

Chores build resilience; you couldn't not do the chores.

Keep your things in order so that others don't have to clean up your mess.

Live your own life; let other's mind their own business; don't meddle in your children's lives and let them live their own problems and solve them.

When families are in trouble, the little ones are expected to take their roles and be responsible.

Accept responsibility and act accordingly.

#### Sense of humour.

Black humour to see you through.

Just see the funny side of tragedy.

Try to see the funny side; talk your troubles out by laughing.

#### Self-esteem.

Belief in oneself; self-confidence and self-esteem will build resilience.

Family and friends build self-confidence; they care about your struggles and successes.

### Opportunities that Adversity Provides to Learn about Identity

Stress and struggle helps you learn about strength and resilience, tempering the steel of your personality.

Please add personal examples to the following categories:

• Shared grief and loss. You develop identity based on common struggle; you all can survive and grow.

Kids died young; you became a new kind of family and formed bonds with other families who shared the same experience.

My father died early, my mother ran the farm, and we all pitched in.

• Learning to accept suffering, situations that couldn't be changed.

Family violence was a source of resilience, isolation made it easy to hide the violence; we didn't know it was not that way.

Times were just tough, violent to wife, kids, animals and sons learned to be the same.

• Doing without. We were the lucky ones, we know the hard times.

This generation is resilient because we survived without comforts.

Living through the depression, everyone had to live through it.

The war brought us together; no one had much.

#### **Purpose and Contributions**

Having a purpose keeps you going with a reason to try again and a reason to live. Please add personal examples to the following categories:

• Make the world a better place, keeps you focused.

Leave your footprint behind,

Make the world a more beautiful place, garden, be kind.

Stand up for someone.

• Appreciate the small things.

I look forward to each new day, new season, hot tea.

A pet means a lot.

Cocoa at the end of a walk home.

The things we did without made us appreciate the little things.

Good music, going to church.

Today I enjoy making something out of nothing.

• Power of vision: Involvement beyond yourself.

Belonging to church.

Knowing there is a purpose to my life.

Giving without expecting.

Helping people just comes naturally when you all had to help to survive.

Standing up for someone should be natural.

BSE, farmers helped each other.

Everyone helped with the haying.

#### Roles and Resilience

How being connected and in relationship teaches you about resilience and what is expected to be resilient. Please add personal examples to the following categories:

• Childhood freedom to experience life without adult control.

Children were able to be active and independent, not like today.

When we were young, my brother and I would ride to Vernon on the train that delivered mail, rode on the mail bags.

Had to learn how to get along with each other, on our own.

You could fight your own battles.

Go off on your own.

• Gain strength from being with others like me, knowing that I can be strong.

Getting to know others who have survived grief and illness helps me to know that it is possible to get on with life.

You feel less isolated, you see yourself in others when you belong to a group of people like you.

Cooking together really helps, get together with friends.

• Family members were role models, especially mothers and women relatives

Grandmas cared for children, taught us what it was like for them.

Mothers were left raising the family in war and on the farm. They became our models for resourcefulness.

When my wife died, I thought I had lost everything; I found another partner who has taught me resilience.

Large families teach children about hard life and finding joy.

• Teachers were a window to the world.

When things were bad, the teacher was there to demonstrate strength and build self-confidence.

Teachers were very young, just like us, and they were on their own.

Showed us you could get off the farm, to become a teacher and see the world.

The scoutmaster was my model when I was in my teens.

Teachers gave us strength and ideas to help us cope.

#### The Role of Natural Cycles in Understanding Resilience

Living in isolated, harsh, and marginal farms, children were part of harsh treatment that had to be made sense of. Without extended family or neighbours, many turned to nature and the promise of spring and regeneration to give them a sense of meaning. Whatever happened, things would get better.

This theme seems to reflect a particular rural theme. Could you expand?

| Would you be interested in continuing this resilience project? Yes No        |  |  |  |  |  |  |
|--|--|--|--|--|--|--|
| If yes, would you like to help with other rural workshops?                   |  |  |  |  |  |  |
| If yes, would you like to help design research projects?                     |  |  |  |  |  |  |
| If yes, would you like to join the research teams studying resilience?       |  |  |  |  |  |  |
| Would you be interested in developing other options for seniors?             |  |  |  |  |  |  |
| Comments on the process or the information.                                  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |
| Thank you for your assistance and we look forward to working with you again. |  |  |  |  |  |  |
|  |  |  |  |  |  |  |



**Noreen Mahoney** 

It's amazing to see the energy that comes from being involved in research that can make a difference.

# Appendix 8 Report of the Focus Group Meeting with CJCA Seniors Club

August 1, 2004; Location: Japanese Cultural Association

This is an example of a summary of focus group research, prepared for the participants.

Ethnocultural Research Team and their responsibilities:
Marilyn Akazawa, flip-chart recorder
Fouad Henin, process observer
Aida Henin, timekeeper
Anne Hartley, observer
Mo Watanabe, facilitator

The facilitator opened the meeting with welcoming remarks, an overview of the Kerby Centre of Excellence/University of Calgary Seniors Resilience Project and the specific goals of the Ethnocultural Research Team. An invitation and consent form was circulated and each participant was requested to read and sign the consent form, and all did so. The agenda and time commitment for each question was included in the invitation.

#### **Definition of resilience:**

To begin the discussion from a common base of understanding, the group was asked, in general, for definitions, and, in particular, for examples of resilience. The participants offered many views and perspectives of resilience including:

- Ability to spring back from traumatic life's events
- A new beginning or the ability to move and look forward despite some traumatic event
- Not only to spring back but to end up stronger than before the traumatic event
- Emotional strength and growth resulting from traumatic events
- Perseverance through difficult periods a Japanese word "gambari" describes it well
- To accept, come to terms with, adapt to loss or the situation, as opposed to rejecting or fighting Japanese words that describe the sense are "shikataga nai" (nothing can be done), "akirame" (to accept)

Some members amplified the definition by telling their own stories and providing examples of resilience. The participants shared some emotional, heart-breaking tales from their own lives including:

- Surviving through world war
- Surviving death of a child, spouse
- Separation from families
- Crossing language and cultural boundaries

The group identified reasons why resilience is important to them, such as:

- Health
- To cope with life's event
- To move forward
- To reconnect with the world
- To accept, come to terms with loss
- Survival strength to live
- To assist with the spiritual healing of the heart
- To become more sympathetic of others suffering traumatic events

The group identified the following factors that make people more or less resilient:

- Role model, teaching of parents
- Family support, marital support
- Support of friends
- Cultural heritage
- Societal and/or cultural expectations
- Unconditional love from friends, strangers
- Surviving major trauma

- Awareness of not being alone
- Perseverance
- Happy events
- Pride in children
- Childhood memories
- Desire to live vs. wanting to die no fear to live a new life
- Hope to continue living
- Healthy community community support associations, organizations
- Associations such as CJCA
- More groups (like this focus group) sharing experiences is good for resilience
- Physical health and fitness, nutrition, spiritual and mental well-being

The group felt that it was important to recognize those who are less resilient, especially if help is to be provided. Some characteristics of less resilient people were considered to be:

- Often are loners, unhappy, complainers, and negative thinkers
- How can you teach people how to become resilient?

The group felt that resilience is something that can be taught or transferred but felt that people need to come to their own realization that they need help. Do they know they are negative or do they even care? Some suggestions for assisting:

- Reach out to those who need help support groups
- Encouragement from family and friends

- Force them to re-join the world of the living
- Give them lots of unconditional love and support
- General education and raising awareness of the concept of resilience
- Set example
- Exercise mentally and physically
- Take their hand and show them the way
- Circle of friends
- Sharing information
- Need to raise awareness with medical community
- Meeting for tea, or just 'dropping in'
- Talk to elders of community
- Reconnect to the traditions
- Storytelling

#### **Characteristics of resilience:**

The group was asked to comment on whether there are things, such as gender, ethnicity, and cultural heritage that affect resilience:

#### Gender

 Women seek support from friends; their resilience and strength comes from sharing and support of one another.
 Women find it easy to connect to others. Men are less likely to seek help and support from others. It may be viewed as a weakness

#### Intergenerational

- Will be different for children, for each generation as the "trauma" and adaptation issue may differ.
- External environment is different for each generation TV, computer, and computer games changes the focus and priority of social interaction.
- The social structures and institutions of our parents' time are disappearing it might be important to preserve, resurrect those that promote resilience.
- Loss of traditional culture is growing each generation loses more.

#### Cultural Traditions, Ethnicity

• Cultures help you to understand and prepare you to deal and cope with life's situations. You learn how to be resilient.

#### Communication

- Technical society takes away from talking to each other.
- Storytelling is important to learn the mistakes and lessons of the past.
- Family album a good way to tell a story about each person in the family. Keep a journal of grandchild their comments at a young age things they notice.

#### **Future Research Questions**

The following research questions are derived from the discussion and answers that were offered in the focus group. They form the research questions that should be addressed in a broader project.

- a. Differences between different cultural/ethnic groups and coping strategies
- b. How cultural traditions/understandings create community and individual resilience
- How community associations such as CJCA assist individuals in becoming and/or maintaining their resilience
- Record and document stories of resilience in day-today living in addition to examples of resilience under extraordinary circumstances
- e. How to recognize people who are not resilient
- f Is resilience teachable? How?
- g. Are there intergenerational issues amongst ethnic/ cultural groups that increase our understanding of resilience?

#### Participant's Evaluation of the Focus Group

#### General Comments:

• Everyone found the day's purpose and discussion enlightening.

One commented that she had not thought about resilience as an important characteristic of people's lives. One commented that she had not related resilience to ethnicity and cultural traditions before this but now realizes how important the relationships are. Almost everyone would appreciate feedback on what we learn of resilience in seniors.

#### Specific comments:

- Resilience has a new meaning for me.
- Very enjoyable and enlightening listening to people's lives.
- Never thought club was important to our well being. Some members thank you for attending community activities when in fact we are reaping benefits.
- Good to use brain to learn new things.
- Music and learning are good tools to keep brain active.
- Didn't think resilience was connected to culture hardship builds resilience
- Requirement of resilience is a good sense of humour.

# Appendix 9 Narrative Interview Guide

This protocol provides a step-by-step guide to conducting research based on the collection of stories by seniors with seniors. Details about why you might want to use stories in research, the theory behind this research, examples of stories collected by seniors, and how to analyze and use stories in reports are included in Chapter 8 of the seniors' manual.

Narrative interviewing needs to be paced and structured to promote a safe space for peer-to-peer interaction. This protocol includes background information, a structured workbook, and conversational prompts.

It is intended that you tape your interview, and this workbook can be copied or scanned. You can use the same form to take notes while interviewing and to record the data later as you listen to the tapes.

Narrative research captures people's experiences and thoughts through their stories. The skill of the researcher lies in soliciting stories and writing about the topic through the stories so that others can understand what you have learned. Through careful documentation and thinking, you come to understand the meaning of events.

Meaning is created in conversation as stories are told and explored. There is no hidden truth that you are trying to find. There is no theory or definition to prove. Knowledge and meaning evolve and change through the process of talking, documenting, and analyzing the stories you create together.

Meaning is contained in stories – stories about events, relationships, emotions, and thoughts. You need to use great care and skill in locating and documenting stories, just as you look for behaviours while observing, answers to questions when using questionnaires and ideas about issues and topics in focus groups.

#### A. Stories in Research

While you can do narrative research to find interesting stories about a person's life experiences, this particular method has been developed to collect stories to add to our knowledge about the topic you are researching. In order to achieve this goal, you need to set an expectation that thaws out stories about your topic.

A story is seldom told from beginning to end. Most stories have a tendency to be messy and rich in detail that may seem irrelevant at the time. These diversions are often important when looking back at your data to understand the meaning or lessons of the story.

We will be using a narrative framework that has come from the study of literature and has been adapted to serve research purposes. We will be asking you to pay particular attention to the following parts of each of the stories.

**The title of the story.** The title captures the essence of the story and creates a shorthand reference to the story. You may have time to do this with the person during the interview, but it is more likely that

you will think of a title as you listen to the tape. If you have made arrangements to follow up with the person after you have recorded the stories, you might ask for input about what titles work best. For example: *Playing the piano while the kitchen burned*.

**The context of the story** – setting the stage or the backdrop to the story. The context creates a frame of reference for the story: where the story takes place, what is happening at that time in the community and the world, who is involved. A context sounds like the beginning of a fairy tale. *Once upon a time*. The context provides very important information about what precipitated the story.

The plot of the story as you piece it together – from the beginning to the end. It may be effective to lead the conversation by asking the question, "... and then what happened?" To ensure that you have a chronologically sound story – in order over time.

**The lessons of the story**, why the person told the story and what lessons they felt were there to be discovered. For example, "Looking back on his experience, Tom comes to see that being injured on the farm kept him from going to war and made it possible for him to go to university so he could support the family."

The person's reaction to the process of telling the story. For example, "Jill seemed very sad at the beginning of the story as she spoke of the hardships when she was young, but became very proud of what she and her brother had accomplished. She felt strong in her achievements."

Your reactions to the story and the meaning you found for the topic. For example, "I really learned that loneliness can lead people to do things that are harmful to themselves; they turn inside and that makes it more difficult to meet people and they become afraid of new people."

#### B. Conducting the Interview

A good researcher in narrative research is an avid listener, or fan, of the person's story, following up on ideas, exploring the detail and sharing short reflections from their own experience.

You are considered a peer because both of you have come to learn and to listen, to contribute, and to create.

Before you sit down with the person, make sure that your tape recorder is working by taping the date and the topic with your name and the other person's name, rewinding, and listening for volume. For example, "This is my first narrative interview. My name is Angel Star and it is November 8, 2009. We are in the volunteer office of the Kerby Centre, and Jam interviewing Betsy Bim."

As you begin the interview be sure to offer a cup of tea or coffee, and ask if there is anything that you should know before you start, such as which side to talk on, is the person likely to tire quickly, or would they like to stand and stretch or even walk as you talk?

Reinforce your status, you are helping to collect data for a seniors' group, for a doctor's study, or that you are learning how to be an interviewer (there may also be a helper with you taking notes for you as you go, so introduce that person). Be sure that the following are done before you start:

The consent form and identifying information.

Go over the workbook ahead of time (or give them a copy), and show them what you are following so they know what is going to take place. Explain any questions but do not go into great detail.

Reinforce that, at any time, if the person is feeling uneasy or confused about what is happening, they should let you know. They are free to stop the interview at any time.

Your role in the interview is to be the guide, following the workbook process but not enforcing it. You do not have to follow a specific order in the interview because you will be able to collect the bits and pieces of the story on tape and enter the whole story together in the workbook later on. Keep an open mind when listening for links to your topic and to follow-up ideas. You do not have to ask direct questions but allow for a conversation to emerge. Be careful not to judge what is being said but be an active listener.

The following sequence has arisen from listening to the natural way that seniors tell stories. You do not have to follow this particular order and may find that you need several pages for one or more sections. These are merely suggested frameworks for a storied research process.

Brief story of the person's life: People will feel more comfortable, and also be validated, if the researcher takes the time to listen to the person's life story. If you do not honour their personal story, the more targeted stories may be told in a manner that includes their life story.

Tell the person being interviewed that you would like to begin with a brief story about the person's life so that the rest of the stories can be understood better. Begin by asking the person to tell you a little about where they were raised and their family, their schooling, marriage and family, work life, creative gifts, and retirement. This is not the focus of the interview but a way to establish the context for the stories to come. You may find that the person becomes very detailed about aspects of their story. If that happens, suggest that you may want to return to that time in more detail later on. You may want to share some examples of people's stories to help them get started. Examples are included in Chapter 8 of the manual.

**A family topic story.** Begin this section by referring to the short story of the person's life and ask:

In looking back at your family, do you think you learned about "your research topic" from them? Is there one particular person that seemed to stand out as representing the topic? Could you tell me about a time that you remember as being a good

example of "your topic"? Would you tell me a story that you would feel comfortable sharing about that person and what they taught you about "your topic"?

If the person can't think of a family example or if it is inappropriate to ask, suggest:

Is there someone in your life that taught you about the topic and could you select a story that you would feel comfortable sharing about that person and how they taught you about the topic? Be sure to include the relationship to the person and the context of this story.

**A personal story about the topic.** You may find that you can bridge from family to personal stories as follows:

Could you select a story that you would feel comfortable sharing about a time when you were most aware of the topic being discussed? Encourage the person to tell one story in detail.

**Topic-related stories.** At this point we are shifting the focus of the interview from general stories to stories that come from your previous work or directly from the topic at hand. You may wish to take a small break here and note that you are now going to carry on with stories directly related to the topic. After a brief chat about the topic, negotiate the questions that you would like to follow up on. For example: "Having had some time to think about the role of culture in understanding resilience, do you have some examples about being a woman in your culture and how this affects your resilience? Would you select a story you would feel comfortable relating about a time when this became clear to you?"

Completion and other stories that the person may wish to share. Thank the person for their stories and contribution to the

research. Ask, "Are there other stories about loneliness and aging that you would like to share?"

As you complete the interview, offer to give them a copy of the stories you create from the interview, and you may wish to ask if they would be interested in seeing the stories when they are written to make sure that they are clear and correct. You may also invite them to contribute to the analysis that you have been able to complete. Set a rough time for this and exchange contact information.

Ask if they would like to learn more about research or to help with the next project.

## C. Listening to the Stories from the Interview and Recording Stories

Once you have completed the interview, you will have the tape of the interview and any notes you have been able to make. In listening to the tape, you are asked not to transcribe the conversation word for word, but to listen and take notes about events and thoughts until you can piece together a representation of each of the stories.

This listening and note-taking is the first stage of data analysis because you are extracting the essential elements of the tape to create the stories in the form of a story about your topic. Record each story in the boxes of the workbook. Be sure to record the title and context separately.

The second stage of analysis and interpretation occurs as you explore what the story meant to the person interviewed and to you. This may be a simple emotional reaction: "She seemed pleased to have recalled this story after all these years and she felt warm about her memories of her mother despite the hardships they all endured." You will likely find that the moral of the story was included in the telling of the story, but that it was possible to separate this.

Please return to your work after you have recorded your first impressions and re-read the stories and the reactions to see if you think of other ideas and themes. You may also feel that you want to link the stories together and note what was the overall impression of what you learned and how the stories were connected.

Once you have recorded your stories and impressions you will likely want to get together with the other members of your team to share ideas about what you have discovered as a group.

#### D. Storied Research Workbook

Based on information from senior researchers from the Kerby Centre of Excellence

| Name of interviewer:                                       |
|--|
| Date and place:  |
| Identifying code for tape                                  |
| Name of person being interviewed and relationship to topic |

Topic of the research being conducted and stage of research:

Consent to be interviewed as part of the study

Name:

I have read the summary of the research project and understand that they information gathered will be shared with me prior to any use of my stories or any publication.

| Turne.                               |  |  |  |  |  |
|--------------------------------------|--|--|--|--|--|
| Date:                                |  |  |  |  |  |
| Place:                               |  |  |  |  |  |
| Comments or qualifications:          |  |  |  |  |  |
| Short overview of the person's life: |  |  |  |  |  |
|                                      |  |  |  |  |  |
|                                      |  |  |  |  |  |
| Family story: Title                  |  |  |  |  |  |

If we waited for other people to do research on things we really cared about, we might be waiting forever... and we have the ability.

(PA 2010)

# Appendix 10 Examining Social Problems

(From Chapter 1 of Donilee Loseke's Thinking about Social Problems: An Introduction to Constructionist Perspectives)

It's 8:45 a.m., September 11, 2001. I'm thinking about examples of social problems to use in my class today while drinking coffee and watching the Today Show. This program is loaded with possibilities. Al talked about a tropical storm heading for my home in Tampa. Matt talked with a scientist about the health problems of elderly people who can't afford their prescription medications. Katie talked with a representative of a group trying to stop the government from opening up huge areas in Alaska for oil drilling. I've seen a commercial for an

upcoming *Dateline* challenging the effectiveness of school vouchers in giving students better education. So many possible examples of social problems. But in the middle of a sentence quizzing Congressman Condit's lawyer about a missing congressional intern, Matt stops. The picture changes: a burning World Trade Center is on the screen. What are we watching? No one knows. I forget my thoughts about the social problems of hurricanes, medical insurance, environment, schools, unethical politicians. Horrified, I watch and by 11:00 a.m. I can't think. I feel only horror, panic, fear. We can't think about it until we make sense of what is happening.

Loseke's book is about social problems so I will begin simply with a question for you, the reader of these lines: What do you think are the ten most important social problems in the United States today?

Most certainly, since September 11, 2001, your list probably includes the multiple problems of war and terrorism. Your list also might include AIDS, crime, credit card theft, identity theft, child abuse, wife abuse, sexual abuse, alcohol abuse, drug abuse, animal abuse, homosexual rights, ability-impaired people's rights, laboratory animal rights, racism, sexism, ageism, anti-Semitism, homophobia, unemployment, poverty, increasing college tuition, welfare, affirmative action, global warming, acid rain, toxic landfills, sport utility vehicles that use too much gasoline, tires that fall apart when driven at high speeds, illegal campaign contributions, voting machines that don't work, corrupt politicians, divorce, men who don't pay child support, single mothers, teenage pregnancy, schools that don't teach, schools that don't have money to hire teachers or buy computers, a lack of affordable child care, housing or medical care, medical malpractice, smoking, drinking, Satanic cults, obesity, teens who gun down classmates.

There are four important lessons in this small exercise in naming social problems. First, what we call "social problems" is *not* a stable category. In my newspaper delivered early in the morning on

September 11, 2001, there were many articles and opinion pieces about problems with the social security system, too costly medical prescriptions for the elderly, voting machines that don't work, crime, and school failure. My paper on the next day included nothing about any of these. The social problems of one day simply disappeared the next as all attention was riveted on terrorism, national security and war. It is likely that by the time you read these lines the list of things we worry about will have changed. Today's worries are not necessarily tomorrow's worries.

Second, there seemingly is no end to conditions in America that might be called social problems. Granted, crime and poverty tend to remain on the public's and policymakers' lists of problems, and racial inequality often is called this country's most enduring social problem. But after these, the list is all but endless. Given time, you could think of more than ten problems confronting the United States today, and if you compared your list with those made by others, the number of items would grow. What we call social problems range from conditions isolated within one or another community (there tend to be large forest fires each year in Malibu, California; moose from the Adirondacks in Northern New York sometimes wander into small towns creating much havoc), to those affecting particular states (the budget problems in Florida because the state's economy depends on tourists who stopped traveling after the terrorist attacks), to those in particular regions of the country (flooding in the Midwest, migrant workers in California, Texas, and Florida), to problems found throughout the entire nation (AIDS, inequalities, lack of low-cost day care for children), to those crossing international borders (human rights, world hunger, refugees without homes, overpopulation). The list is seemingly endless, ever changing.

A third lesson from this simple exercise in naming social problems is that social problems are about *disagreements*. You might believe that some of the problems I offered are not social problems at all, or that I failed to mention others that are far more important. Or, you and I might be thinking about very different things even if we did agree to include something on a list of important problems. If there is a problem called "homosexual rights," for example, is this a problem of too many rights or too few? Is the problem of school prayer a problem of too much prayer or too little? Or, we might disagree on what, particularly, should be included in the problem. So, for example, we hear about the problem of "teenage pregnancy." A married nineteenyear-old college student is a "pregnant teen," but do we include such a woman in our worry? Or we might agree or not agree that something is a problem, we might agree on what should be included in this problem, but still not agree about what causes it and therefore, what should be done to resolve it. Is the problem of teens who gun down their classmates a problem of schools? Parents? Mentally unbalanced teens? Peer pressure? A mass media saturated with violence? Guns? Social problems are about disagreements.

A fourth lesson from this simple exercise of naming social problems is that social problems are about conditions *and* they are about people in those conditions. A social problem called crime is about criminals and victims of crime. A social problem called poverty is about poor people. Terrorism involves terrorists. Whether explicit and obvious (the condition of unemployment and unemployed people) or implicit and subtle (the deindustrialization of America, which implies unemployed or underemployed workers), social problems are about conditions (some*thing*) and they are about people (some*body*).

Another important lesson about social problems is not obvious from this exercise because I started by asking you to list important problems in the *United States now*. A critical characteristic of social problems is that each is located in a particular time and place. Social problems in the United States change: People in the late 1600s worried a great deal about the problem of "witchcraft." We no longer have that problem but we worry about the problem of "mental

illness." Likewise, social problems are located in particular cultures. For example, although the United States and Japan both are industrialized, urbanized countries, social problems in these places are not the same. Consider how children who refuse to go to school in the United States are believed to have a personal problem. This same condition, children refusing to go to school, is called "school refusal" in Japan and people believe it is the consequence of bad schools and bad teachers. Likewise, while the federal government in the United States has taken a major role in combating child pornography, the Japanese government has not taken on such a role.

As another example, consider the behaviours of "uncivil and aggressive behavior in workplaces." We certainly have such behaviour in the United States, but it is not generally accorded the status of a social problem. Yet in Great Britain such behaviours receive considerable attention and "bullying" is an important social problem. In brief, what is – and what is not – a social problem, and how the problem is responded to, depends on when and where the condition happens.

Let me ask another question. Think of your list of the top ten American social problems. What do all of these conditions have in common? What do conditions as diverse as illegal drugs, unemployment, child abuse, and environmental ruin share? Stated otherwise, what *is* a social problem?

#### What Is a Social Problem?

While we rarely ask in our daily life what the term *social problem* means, studies conclude that Americans in general do have somewhat specific notions about the characteristics of conditions that should be categorized as social problems. There are four parts to this common public definition.

First, we use the term *social problem* to indicate that something is *wrong*. In popular understanding, a social problem is not

something like happy families, physically fit people, or schools that teach children to read. This is common sense: The name is social *problem* so it obviously refers to conditions evaluated as wrong because they create harm.

The second part of the definition of social problem sounds harsh and uncaring: To be given the status of a social problem the condition must be evaluated as widespread, which means that it must hurt more than a few people. If I lose my job, that is a personal trouble. It is a problem for me but it is not necessarily a problem for you or for anyone else. But if something causes many of us to lose our jobs, then it is a social problem. I think Jeffrey Dahmer can illustrate how we use the term *social problem* to categorize conditions we think are widespread. Jeffrey Dahmer was a man who killed – and then ate - young boys. Certainly we all would agree that killing and cannibalism are wrong. But Americans never mention the problem of cannibalism when polled about the country's problems; cannibalism never is mentioned in social problems texts, it is not debated in the halls of Congress, we do not have social services to reform cannibals, we are not asked to donate money for the cause of stopping cannibalism. Why not? Because as hideous as it was that Jeffrey Dahmer killed and ate young boys, one cannibal among us is not enough to make cannibalism a social problem. Social problems are troublesome conditions we believe affect a *significant number of people*.

Third, the definition of social problem contains a dose of optimism. *Social problem* is a name we give to conditions we think can be *changed* by humans. Consider the condition of death. This certainly is a troublesome and widespread condition. But humans will die and that cannot be changed. Death is not a social problem. At the same time, there are many conditions associated with death that *could* be changed and therefore can be talked about as social problems: We could change *when* people die (disagreements about using medical technology to extend life or assisted suicide to end life) and

how people die (the problems of care in nursing homes for elderly people, the problems of automobile and airplane crashes that cause early death). Likewise, earthquakes, hurricanes, and tornadoes are not social problems because nothing can be done to stop them. But there are many actual and potential social problems surrounding natural disasters such as the cost of insurance, failures of early-warning systems for disasters, and the response of officials to such disasters. Social problems is a term we use when we believe the troublesome condition *can be fixed*.

A social problem is a condition evaluated as wrong, widespread, and changeable. The fourth and final component of the definition is that social problem is a category for conditions we believe *should* be changed. This is very logical: If the condition is evaluated as wrong, if it occurs frequently, and if it can be changed, then it follows it should be changed. To say that something is a social problem is to take a stand that *something needs to be done*.

In our daily lives, we tend to use the term *social problem* to categorize conditions that we believe are troublesome, prevalent, can be changed, and should be changed. When I write *social problem* from now on this is what I mean.

With this basic definition, we can go on to the next question: What should we *study* about social problems? This question does not have a simple answer because social problems are about *objective* conditions and people (things and people that exist in the physical world) *and* they are about *subjective* definitions (how we understand the world and the people in it). Because it is not immediately apparent why the objective and subjective aspects of social problems can be separated, I will discuss each of them. I begin with the commonsense framework of a type of person I will call a *practical actor*, a term I will use throughout this book to refer to a type of person like you or me in our daily lives. As practical actors, we go to school or work, we take care of our children (if we have them), and pay our bills (the best

we can). Unlike scientists and other academics who study the world, we live in the world. While we might not have the education or intellect of a nuclear physicist we are logical and try to make sense of our world. Practical actors most often are concerned with social problems as objective conditions.

#### Social Problems as Objective Conditions

When members of the American public use the term *social problems*, we most frequently are interested in these as objective characteristics of the environment. "Objective" means real, tangible, measurable. Within this *objectivist* perspective, social problems are about things we can see; they are about measurable and widespread conditions in the environment and they are about the living, breathing people who are hurt by these conditions (people we evaluate as victims) or who create these conditions (social structures, social forces, or people we evaluate as villains). Within this perspective, poverty is a condition where people do not have enough money to live a decent life, while poor people are people living in this condition; drunk driving is a condition where people with a high blood alcohol count drive, and drunk drivers are the people who do this. A series of practical questions emerge when we think about social problems as real conditions and real people: Who or what causes the condition? Who is harmed by it? What harm do they suffer? What can be done to stop this harm?

When experts study social problems in this way, they rely on *objective indicators*. These indicators include statistics about the condition (such as the number of school children who cannot read, the number of crimes committed, unemployment rates) and the people in it (measures such as the age, ethnicity, or gender of people causing social problems or harmed by social problems). At times, objective characteristics of people appear as complex psychological profiles: people who commit crimes are given various psychological tests and

a profile of "criminals" is constructed; tests are given to heterosexuals to measure their "homophobia"; women victims of "wife abuse" are given tests and, from this, psychological profiles of "battered women" are constructed, and so on.

Such objective indicators are the basis of discussions in most social problems textbooks. Such texts most often are arranged in a series of chapters with titles such as problems in the economy, problems in government, problems of inequality (poverty, ethnicity, age, gender), and problems of deviance (sexual behavior, drug use, crime). Each chapter in these texts tends to contain a more or less standardized treatment of the problem at hand. Readers see objective indicators describing the extent of the problem (how widespread it is), what types of people are victims or villains, and the consequences of the problem for the victims. Various theories are used to explain the causes of the problem and this leads to statements about what can be done to resolve it

While it makes sense to examine social problems as objective conditions involving flesh and blood people, we cannot stop there because it is not enough. Social problems are about things and people we *worry* about, and when we talk about "worry" we go beyond objectivity into *subjective definitions*. But you might ask, so what? Don't Americans worry about things we should worry about? To answer this question we must leave the concerns of the commonsense practical actor in order to examine the confusions in this thing called social problems.

#### **Objective Characteristics and Subjective Worry**

We cannot simply assume that we worry about things we should worry about, because there is no *necessary relationship* between any objective indicators (statistics, results of tests) of social problem conditions and what Americans worry about, what politicians focus on, or what

television, newspapers or magazines tell us about. This means there is no necessary relationship between the measurable characteristics of any given condition or the people in it and a definition of that condition as troublesome. For example, there can be *objective conditions* without subjective worry. Earthquake experts, for example, often talk about the potential damage of earthquakes throughout the United States. Yet the condition of earthquakes typically receives notice by the public or social policymakers only for a brief time after there has been an earthquake, people continue to live in areas prone to earthquakes, and they often fail to even buy earthquake insurance. In this case, there are objective indicators that a condition exists, but there is little public worry. People's *ideas* about risk matter more than the actual risk measured by objective indicators.

Conditions creating harm can exist without public worry. Americans also can start to worry about a condition when objective indicators seem to show that the *condition is not new*. For example, the historical record (an objective indicator) shows that what we now call child abuse always has been part of human existence. Indeed, the historical record can be used to argue that what we now call child abuse was much more common in the past than in the present. Yet the term *child abuse* did not appear in the United States until the 1960s. In this case, the behaviors now called child abuse are *not* new, the worry *is* new. Or, how long did slavery exist before it was called a social problem? In these examples, objective indicators about the troublesome nature of conditions were available long before there was any worry about them.

Likewise, Americans can begin to worry about something when objective indicators seem to show that the condition is actually *getting better*. For example, there was much public and political concern about poverty in the 1960s, but this was a time when objective indicators were showing rates of poverty were declining. Concern about poverty began as the objective condition of poverty was getting

better. Or, we can begin to worry about something where there is *no objective indicator* pointing to the presence of a prevalent condition. For example, fear about the safety of children trick-or-treating on Halloween was based on very few incidents. Yet these few incidents led to a generalized fear that many children all over the United States were being victimized by Halloween sadism. In the same way, the condition of "crack cocaine" received incredible attention in the United States beginning in 1986. Yet at that time there were no objective indicators that the use crack cocaine was widespread, nor did objective indicators support the image that this drug was "instantly addicting."

In brief, it is not possible to argue that Americans worry about what we should worry about. It is not enough to examine social problems as objective conditions because there is no necessary relationship between what we worry about and what exists in the objective environment

Note: This chapter does not include the full set of notes as published. Please refer to the full text in D.R. Loseke, *Thinking about Social Problems: Introduction to Constructionist Perspectives*, 2nd ed., 3–24 (Piscataway, NJ: Transaction Publishers, 2007) for full details.

### Appendix 11

### Navigating the "Seven C's": Curiosity, Confirmation, Comparison, Changing, Collaborating, Critiquing, and Combinations

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www.nova.edu/ssss/QR/QR4-3/sevencs.html

#### **Abstract**

It is important for researchers to establish a research posture (i.e., the relationship a researcher wants to have with his or her subject or other) (Wolcott, 1992) and making subsequent methodological choices in which all cohere and are consistent with the ascribed posture. By keeping things plumb in this manner, researchers can greatly increase the chances that their projects will be internally coherent and imminently more do-able than those studies which grow out-of-alignment. A method for assessing research posture, the "Seven C's," is presented and a series of questions are introduced to help researchers match their postures with particular research methodologies.

#### Introduction

In an earlier essay (Chenail, 1997) I wrote about the challenges which can arise in qualitative research projects when the methodological choices made by researchers do not stay plumb. The discussion in that paper centered around the importance of establishing a research posture (i.e., the relationship a researcher wants to have with his or her subject or other) (Wolcott, 1992) and making subsequent methodological choices which all cohere and are consistent with the ascribed posture. By keeping things plumb in this manner, researchers can greatly increase the chances that their projects will be internally coherent and immanently more do-able than those studies which grow out-of-alignment.

In this essay, I want to focus on one part of this interactional process, posture, and how it relates to basic families of methods for systematic inquiries. The way in which I will do this is to concentrate on

seven different relationships researchers can have with the other and how researchers can assess which relationship is indeed the one which characterizes their posture in a particular study. I call these relationships the "Seven C's" and being aware of them will certainly help researchers navigate a straight course in their studies. Conversely, researchers who ignore the Seven C's are most likely facing a stormy future in their research projects.

#### Relationship with the Other and Oneself

Although researchers may not be overt about it, their relationships with the other in their studies is governed by a particular posture. Some researchers posture themselves as "curious investigators" who wish to address gaps in the literature and discover that which previously had been unknown (Mahrer, 1988). Some want to fulfill a reflective posture and desire to be reflective practitioners who shed new light on the nuances of their work or the implications of their actions (Schön, 1983). Still others assume a critical posture and conduct their inquiries to raise issues and to produce cultural critiques (Marcus and Fischer, 1986).

Each of these postures carries with it a particular relationship with the other and reveals a certain notion of the self of the researcher. To be curious about an other or the self is different than being critical of an other or oneself, It is very important for researchers to be aware of these postures and to carry out a research method which is fitting with such a stance. Of course, it is not always the case that posture and method live in simple harmony. Also, it is often the case that the posture of a researcher is left a bit covert in a study. Without such an awareness, problems of coherence and consistency arise.

To have a clue into this sometimes unarticulated posture, consider what researchers call the other in their studies. Some use the term "subjects." Others are called "interviewees." Some are termed

"research participants." Still others are called "stakeholders." Each of these terms is a metaphor. It tells the reader something about the relationship the researcher is having with the other. It gives away the posture of the researcher. It can also lead the reader to see certain inconsistencies in a particular study. For instance, a researcher who stresses a collaborative, non-hierarchical relationship in their work with others and who also refers to these others as "subjects" is not being very consistent. Are these others considered to be "subjective" or are they being "subjected" to a particular methodological protocol? Depending on the researchers desired relationship, the use of the term "subjects" may be very misleading or quite fitting. The confusion arises with the lack of an overtly articulated posture. In order to express their posture, researchers need to conduct some self-evaluation to assess their research postures. One way to shed light on their stance is to "navigate the Seven C's."

# The Seven C's

In surveying the current array of methodological families, I have broken them down into seven broad categories based upon the relationship with the other invoked by each method. These categories, dubbed the "Seven C's," are Curiosity, Confirmation, Comparison, Changing, Collaborating, Critiquing, and Combinations. Each of the "C's" stands for the tenor of the relationship between researchers and the other in a project and each one is connected with a particular method:

# The Seven C's and Their Associated Research Methods

- Curiosity and Qualitative Methods
- Confirmation and Quantitative Methods
- Comparison and Comparative Methods
- Changing and Action Methods
- Collaborating and Collaborative Methods
- Critiquing and Critical Methods
- Combinations and Mixed Methods

In the next section, I want to present these Seven C's in terms of the questions researchers can ask themselves in order to determine their research postures, and maybe, to clarify their relationships with their research subject or subjects.

# The Seven C's

# 1. Do you want to be curious about the subject?

If curiosity is the tenor of your relationship, if you want to know more about the particulars of the subject (i.e., what you already know about the subject is limited), then you should most likely approach your project from a qualitative research perspective (e.g., Crabtree and Miller, 1992; Denzin and Lincoln, 1994). A hallmark of the qualitative approaches is their emphasis on open-mindedness and curiosity.

# 2. Do you want to confirm what you already know about the subject?

If confirmation is the tenor of your relationship, if you want to control the conditions around the subject so you can confirm certain relationships or patterns (i.e., what you already think you know about the subject), then you should most likely approach your project from a quantitative research approach (e.g., Babbie, 1998; Robson, 1993). A hallmark of the quantitative approaches is their emphasis on experimentation and prediction.

# 3. Do you want to compare your subject with another?

If comparison is the tenor of your relationship, if you want to examine the configuration of conditions of cases so you can compare the logic of one configuration with another (i.e., similarities and differences across a limited number of cases), then you should approach your project from a comparative research approach (e.g., Ragin, 1987, 1994). A hallmark of the comparative approaches is their emphasis on contrasts and diversities.

# 4. Do you want to change the other?

If change is the tenor of your relationship, if you want to examine the actions an organization takes to change (i.e., the cycle of assessing the situation, developing a plan, implementing the plan, and evaluating the success of the plan), then you should approach your project from an action research approach (e.g., McNiff, 1992; Stringer, 1996). A hallmark of the action research approaches is their emphasis on participation and community.

# 5. Do you want to collaborate with the other?

If collaboration is the tenor of your relationship, if you want to examine the community's needs by involving the perspective of non-researchers in all aspects of the inquiry (i.e., building collaborative systems with the purpose of joint problem-solving and positive social change), then you should approach your project from a collaborative action research or collaborative inquiry approach (e.g., Catelli, 1995; Oja, 1989; Schensul and Schensul, 1992; Stull and Schensul, 1987). A hallmark of the collaborative action research or collaborative inquiry approaches is their emphasis on building networks and utilization.

# 6. Do you want to critique the other?

If critique is the tenor of your relationship, if you want to examine the world from a critical perspective (i.e., the systematic deconstruction of a privileged description, explanation, or interpretation from a feminist, cross-cultural, Marxist, post-modern, or post-structuralist point-of-view), then you should approach your project from a critical research approach (e.g., Carspecken, 1996; Reinharz, 1992; Lather, 1991). A hallmark of the critical research approaches is their emphasis on values and power.

# 7. Do you want to have a combination of these relationships?

If combination is the tenor of your relationship, if you want to examine the subject from multiple perspectives and/or paradigms (i.e., the triangulation of theory, participants, observations, data, and/or analyses to produce developmental, expansive, and/or convergent descriptions, explanations, and/or interpretations), then you should approach your project from a combined or mixed method research approach (e.g., Creswell, 1994; Sells et al., 1995; Tashakkori and Teddlie, 1998).

A hallmark of the combined or mixed method research approaches is their emphasis on integration and contradictions.

## Conclusion

These distinctions are meant only as basic guidelines or suggested starting points and not as hard and fast rules. For instance, researchers have used qualitative methods for confirmation purposes and quantitative approaches to discover new relationships in social phenomenon.

The Seven C's can also be used throughout the research endeavor. They can serve as "posture reminders" or "relationship checks" to help researchers "to stay the course" in a project. For example, if the tenor of the relationship is collaboration, researchers can keep check of every methodological choice being made to evaluate just how collaborative they are being with the other, or as they progress in their study, researchers can constantly be rechecking in order to build more collaboration into their research processes.

The purpose of the Seven C's is to help you to make your relationship with the other or others in the study clear and to select a method which has a coherent fit with your posture. Of course, you can select different postures in a particular study, but I would recommend trying one at a time. You have to try to build simplicity somewhere into the research process because the phenomenon being studied is quite complex. It is very difficult to study a complex phenomenon with a complex method. You are better off keeping the method simple and let the complexity lie in the other.

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# Appendix 12 Elder Self-Neglect: Project Description

# Nancy Marlett

This is an example of a formal research proposal written with an aging studies orientation. It was not funded and so can be used for discussion purposes.

Elder Self-Neglect (ESN) has been called by many names: Diogenes syndrome, hoarding syndrome, social breakdown, or even squalor or messy house syndrome. ESN is defined as "the inability or unwillingness to provide for oneself the goods and services needed to live safely and independently" (Murphy, 1994). It occurs in vulnerable older adults who have multiple deficits in various social, functional and physical domains, and who often live in extreme conditions such as squalor (Pavlou and Lachs, 2006). They are socially isolated with poor health, disheveled or unkempt appearance. "These persons habitually hoard.... Yet, alarmingly, these persons are often comfortable in their

surroundings, refuse intervention, and believe nothing is wrong (italics added)." (Dyer and Prati, 2006) Only 30–50 per cent of reported cases in the United States are associated with mental illness or cognitive impairment (Burnett et al., 2006). Under all the descriptions is a fundamental failure to care for one's self.

As a "syndrome," ESN collects many of the problems faced by very old, poor, isolated, and fearful seniors losing physical capacities and without adequate access to primary care or in-home support. But as a medical syndrome, pathology is accentuated, and most research looks at those who have been institutionalized due to medical and psychiatric crises (Burnett et al., 2006). However, Interviewing persons prior to a crisis presents a serious challenge. Researchers can unintentionally pose a threat to a person's self control (Heisler and Bolton, 2006). How the condition manifests or why it occurs is complex, and understanding this failure to maintain functional autonomy is indeed a priority for Canada as our population ages and our service infrastructures fail.

The language used to describe health problems affects how professionals see themselves in relation to those who are labelled. Most of the professional language about ESN has been held by nurses and homecare workers and has had little influence in the public sphere. However, this situation is changing. There has been a move, primarily in the United States, to link elder self-neglect with elder abuse. This transforms ESN from a private or professional issue to a public concern (Pavlou and Lachs, 2006) and this, in turn, brings into play protective and legal systems. Claims have been made in USA that ESN as the most commonly reported form of elder abuse (Dyer and Pati 2006). This leads to fear among seniors that this trend is bound to affect Canadian thought and our commitment to values of tolerance and support in contrast to protection and control. The exclusive use of medical frameworks may be too narrow (Lauder, 1999b) and there is a pressing need for a fresh look at ESN in the context of prevention and health promotion (Lauder, (1999a)

# What We Want to Accomplish: The Questions and Objectives

The study is presented in a logic model (Figure 1), with the goals represented by intermediate outcomes and objectives as short-term outcomes. In the interest of space, these will not be discussed here. The overall goal is to take a new look at the language, concerns, research trends, and priorities through the eyes of seniors who befriend and support other seniors who are not looking after themselves. This information, along with reports on research trends related to ESN, will be taken to public guardians, health care professionals, and service providers to add their input. All data and reports will be compiled as study material for a two-day forum to discuss priorities, strategies, and partnerships for a Canadian ESN research agenda with strategies on how to manage the ethics involved in proposed research directions.

In the long term we hope that this fresh, open, and grounded look at ESN will contribute to research that will increase the quality of life for seniors who struggle to care for themselves and remain independent. Equally important is the opportunity to make a place at the Canadian research table for seniors as full and capable partners.

# Why Is This a Reasonable Thing to Do: The Rationale

There is considerable confusion and concern about ESN among professional, academics, and seniors (Lauder, 1999a Lauder et al., 2002). The voices of the seniors have been profoundly silent, and yet, this topic is very relevant to seniors because most seniors fear losing their ability to look after themselves. The treatment of those labelled ESN influences everyone who could lose their independence. All seniors will, to some extent, bear the stigma of the discourse of self-neglect as abuse, and seniors and service providers share concerns that this emerging discourse will impact service options and debates about intergenerational conflict.

ESN might more effectively be located within the CIHR–IA priority area of maintaining functional autonomy.

To one side are the hopes of seniors that they will continue to thrive and be resilient in the face of the challenges of aging. On the other side there is the fear that they will lose autonomy because they are seen as incapable of looking after themselves. Previous research work on resilience conducted by seniors has provided insights into the nature of resilience from the seniors' perspectives (see Appendix 1 in this book). Seniors locate resilience as social capital to be earned and shared, in stark contrast to medical and psychological theories, and we would hope that their input would provide an opportunity to take a fresh look at ESN. The following four aspects of health discourse will frame our initial investigations into related research trends (Marlett and Shklarov, 2008) and will guide our focus groups and interviews:

**Biomedical:** health risks that come with advanced age, disability, health and mental health conditions, and pain;

**Functioning:** daily living and health routines and habits that interfere with functional autonomy;

**Social and societal aspects** including social and economic determinants of health; and

**Personal autonomy:** motivation and the strategies that enhance control and choice.

The following represents a snapshot of the current literature on Elder Self-Neglect in the above four perspectives:

**Biomedical.** Most of the literature on Elder Self-Neglect to date deals with untreated medical and psychiatric conditions: depression and post-traumatic stress disorder from previous or current mistreatment or abuse (Burnett et al., 2006; Dyer and Pati 2006); cognitive impairments, including memory loss, decreased brain activity, stroke, heart attacks, dementia, Alzheimer's disease, psychiatric illnesses such as schizophrenia, psychosis, alcohol abuse (Aung et al., 2006), Vitamin D deficiency, nutritional deficiency, and defective food intake (Poythress et al., 2006) and general pain or physical decline (e.g., arthritis, hearing loss, loss of eyesight) (Paylou and Lachs, 2006; Naik et al., 2006)

Coping (functioning). A number of studies addressed the impact of health conditions (e.g., falls, stroke, apathy resulting from depression, frailty, incontinence) (Burnett et al., 2006; Naik et al., 2006) on the ability to fulfill daily routines at a general level. There is a need to investigate mechanisms, strategies, and supports that could reframe the diagnosis of ESN and bring a clearer focus to behaviors such as hoarding (Heisler and Bolton, 2006; Poythress et al., 2006).

**Social and societal aspects.** Research on social aspects of ESN in the United States indicates that those at particular risk are older males living alone on low incomes (Burnett et al., 2006a). Also at risk are those who have fewer contacts with family or neighbours, participate less in religious activities, and in general have less adequate social resources (Burnett et al., 2006a).

**Autonomy.** Autonomy touches research related to personality, hope, and motivation. The impact of the loss of control on health and mortality is startling (Poythress et al., 2006), with the estimated rate of death after intervention above 50 per cent. Autonomy decreases when power figures intervene (Heisler and Bolton, 2006) and increases with the availability of peers (other seniors) who offer assistance, friendship, and guidance (Lauder, 2001).

Table 10.1. Logic model of Catalyst grant proposal: Elder Self Neglect: A Canadian Agenda

Situation: the concern surrounding the concept of Elder Self-Neglect (ESN) syndrome as abuse calls Canadian researchers to rethink "maintaining functional autonomy" and to do so in partnership with seniors.

#### Short Term Outcome Arenas

#### Research and development

- -Describe research trends in biomedical, functional, social, and, personal autonomy perspectives that may be relevant to ESN
- Describe the lived realities of a small representative sample of those who are at risk of losing functional autonomy.
- Describe what seniors providing friendship and support and professionals in home care, public guardians, mental health specialists, and physicians understand about losing functional autonomy and the potential impact of the term ESN.
- Negotiate conceptual maps, definitions, language, priorities, partners, and strategies based on above information to create a Canadian research agenda.

#### **Capacity Building**

- Attract early career researchers in aging (Doctoral and post Doctoral students) to work with senior researchers and provide support for their research interests.
- Train seniors as researchers in setting research agendas.
- -Provide an opportunity for seniors, academics, and professionals to learn about seniors as researchers.
- -Create a collaborative Canadian research network related to maintaining functional autonomy.

#### **Knowledge and Translation**

- New knowledge related to the socially constructed nature of functional autonomy through the lens of ESN.
- Compilation of research trends in plain English to be available for the research participants, on line, as pamphlets and as articles.
- A Canadian research agenda and strategy related to the loss of functional autonomy in relation to the construct of ESN syndrome.
- -Articles on the process of creating a partnered research agenda in academic and lay platforms.

#### Intermediate Beneficiaries

- CIHR-IA and Canadian Researchers in Aging.
- Natural and informal supports and service providers for at risk seniors.
- Seniors at risk of being "diagnosed with ESN syndrome".
- Health and Guardianship systems.

**Contextual Factors:** Canadian history of entitlement to health and autonomy, Canadian voluntary and formal health systems, systemic barriers that may arise from re-conceptualizing loss of functional autonomy as elder self neglect.

#### Intermediate Outcomes

#### Policy

- Integration of priorities into Canadian research agendas.
- Understanding of how the label 'ESN syndrome' might effect access to community supports and services
- Clarify the use of the medical terminology in Guardianship processes for at risk seniors.

#### Practice

- Facilitate the role of seniors in negotiating Canadian research agendas.
- Promote the potential roles for seniors in collaborative research methods.
- Promote the need for ethical procedures and strategies when engaging high risk seniors in situations where harm may be a factor in the research intervention.

#### Behaviours

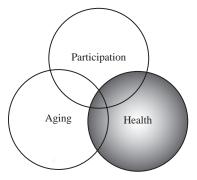
 Seniors will become more active partners in setting collaborative research agendas. Their perspectives will be heard and their skills acknowledged.

#### Intended Beneficiaries

- Canadian public.
  - Seniors at risk of losing functional autonomy.
- Support and service providers,
- Health care providers.
- Public Guardians.

#### Long Term Outcome Arenas

- Maximize the potential for seniors to maintain functional autonomy.
- Promote public awareness of the obstacles faced by seniors in maintaining their independence.
- Promote awareness of the importance of seniors as research partners.



# Appendices

#### Major Life Domains

# Why Is This Important?

The rapid increase of numbers of very old seniors, the diminishing access to primary care for seniors, and inadequate funding in home care create an incubator for the development of conditions understood as ESN. In order to prepare a proactive Canadian response, we need to review research trends and offer new ways of thinking about functional autonomy and ESN, ground our understanding in survivors, establish new partnerships and directions in research, build the capacity of seniors to be involved in this research, and find ways to involve seniors as participants.

# How Do We Plan to Accomplish This?

The purpose of this research is to establish a first Canadian ESN research agenda. The study will follow the "READY: Setting the Agenda for Your Research" chapter of *Grey Matters* (Marlett and Emes, Chapter 7 in this book). Seniors will be trained in facilitating focus groups and interviewing. We will:

- **1. Gather interest and awareness** through a workshop where we will recruit eight to ten seniors willing to be trained as researchers. Others may join working groups related to the topic.
- **2. Clarify the problem.** We intend to accomplish this by: (a) providing awards to PhD and postdoctoral students to look at research trends in biomedical, functional, social, and personal (autonomy) research that could open new lines of inquiry; and (b) interviewing seniors who help and befriend those with ESN to describe lived experiences and create sample vignettes. Note: there will be no direct contact or identifying information gathered during this grant.
- **3. Attract other players** though focus groups with those providing in-home support (Meals on Wheels, shoppers, elder abuse shelter), Public Guardian representatives, and seniors' health professionals

(mental health, homecare professionals, and physicians). We will explore the topic and language used. For example, "What impact would the term 'elder self-neglect' have on your work and communications with other groups and families?" "What research would you like to see done to clarify the issues and challenges you face?"

- **4. Negotiate a Canadian research agenda.** Materials from the above steps will be sent to forty invitees (senior researchers, award winners, representatives from focus groups, stakeholders, and experts identified in the process) to a two-day research forum sponsored by the Kerby Centre of Excellence, the Office of the Public Guardian, and the Community Health Sciences department. Participants will discuss the materials and make recommendations on priorities, partners, and strategies to include seniors as researchers and participants.
- **5. Prepare research reports** and plan submissions to CIHR and related funding sources and facilitate a collaborative grant.

Before commencing any activities, the project will be approved by the appropriate university ethics committees. The project will consider ethical issues related to this type of research.

# Why Should We, Seniors and Academics, Do This Research?

The Kerby Centre of Excellence and the University of Calgary have established a good working relationship and KCE holds a unique knowledge and skill set related to seniors as researchers, which has been used in three research projects to date. Kerby staff and volunteers supporting isolated seniors have assisted in the preparation of this proposal and will continue to be involved. The investigators have ongoing and direct contact with health care providers, the Office of the Public Guardian, and Jewish Family Service Calgary.

A Canadian Institutes of Health Research funded project investigated the potential of seniors as researchers this informs the methodology of the current project. The KCE hosted the first National Senior's Assembly in collaboration with CATALIST (http://dev.www.uregina.ca/catalist/), a network of over fifty seniors-led third age learning agencies to discuss seniors-led supports and services, education, research, and policy development. An agreement was reached to create a Canadian network of trained senior researchers to take up issues important to seniors. This research committee will advise the next steps in the creation of a national research proposal.

Seniors and seniors-led services are increasingly providing support and guidance to vulnerable seniors and, as peers, they have the advantage of being trusted and able to promote autonomy. We have chosen to begin the study by listening to elderly volunteers (most in their 70s and 80s) who visit isolated and frail seniors, because they bring an insider perspective to what counts as functional autonomy for the very old. The principle investigator, herself a senior, comes to health research from Community Rehabilitation and Disability Studies. Her research includes: the development of an Adaptive Functioning Index (Marlett, 1971), which is a measure of functional abilities, problem-solving, and cognitive abilities; training of marginalized populations in the use of research; narrative in achieving personal autonomy; and the determination of the need for guardianship.

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# **Glossary of Terms**

**Advisory committee** – group of individuals who provide guidance and direction

**Advocate** – resources such as seniors associations, service providers, who work for social causes

**Aging** – process that happens to everyone, is not an illness or disability and is not a problem

**Bias** – influence in an unfair way

**Changing** – process of challenging beliefs and actions with an emphasis on participation and community

CIHR – Canadian Institutes of Health Research

**Collaborating** – process of building networks to improve outcomes and planning

**Collaboration** – form relationships to understand each other's priorities

Combination – mixed method research that enables you to combine data and information gathered in different ways

Community groups – organized citizens of various size and function

**Comparison** – process where the emphasis is on contrasts and diversity

**Consent form** – form listing the most common and worst possible risks of a procedure

**Confirmation** – process of what you will want to control in order to confirm relationships and patterns

**Credibility** – technique of good research believed to result from the perspective of the participants in the research

**Critiquing** – critical research that examines a particular stance related to values and power

CURA – Community University Research Alliances

**Curiosity** – process of discovering what has previously been unknown

Data – collection of facts

**Data analysis** – identification of themes or information through methods such as field-work, surveys, focus groups, and Participatory Action Research

**Dependability** – declaration of how carefully the research was conducted, problems that arose, and how any changes affected the study and the result

**Development grant** – money provided by a funding body to gain insight into specific social issues

**Direct observation** – occurs when the researcher sets time aside to deliberately observe and record what he or she sees

Ethics review – process to ensure that participants in the study meet all of the requirements of traditional research

**Exploratory stage** – stage of investigation

**Facilitator** – individual who engages people in a discussion about a specific question or topic while keeping the discussion focused

**Field-work** – short period of study that usually takes place away from a university setting

**Focus group** – form of qualitative research in which a group of people are asked to explore a specific and well-defined topic

**Group leader** – individual acting as mentor, instructor, guide, or supervisor to senior researchers

**Informal networks** – friends, acquaintances sharing information

**Liaison committee** – committee that works in partnership with another group

**Management committee** – oversees and implements the research project

Narrative research – captures people's experiences and thoughts through their stories

Narrative interviewing – process where the researcher listens to stories

**Negotiation of process** – method of data collection

**Objectivity** – an attempt to keep your own values and opinions out of data collection, data analysis, and presentation of findings **Observation** – general term that includes options from direct observation to reflecting on past participation; part of all other types of research

**Participation** – full participation in all phases of research no matter which research approach is used; collaboration of equals

**Participant observation** – data collection where the researcher is part of the community under study

Participatory Action Research (PAR) – technique to mobilize communities to take control of the problems that oppress them

Partnered research – research that draws on both quantitative and qualitative methods

**Partner sites** – agencies, programs, or groups of seniors recruited as research sites for particular research groups

**Peer counselling** – seniors guiding other seniors

**Peer-to-peer research** – research where individuals have equal status

**Personal life stories** – narratives provided and collected by senior researchers and study participants

**Pilot project** – a small cast study designed to test a research question

**Principle investigators** – academic researchers named in the grant proposal

**Process evaluation** – analysis of what is being done and change that should be made

**Professors emeritus** – retired university professors

**Project staff** – individuals who worked with project participants

**Protocol** – step by step guide to conducting research

Qualitative research – research that seeks to uncover how people make meaning of their lives and how their ideas influence their action and relationships

Quantitative research – research that seeks to uncover the truth (the natural laws and theories) through careful and controlled observation and experimentation

**Questionnaire** –a form containing a series of questions

**Recorder** – individual who preserves the ideas during a focus group

Research – a thoughtful and careful process of asking and answering questions so that you have some confidence in what you find out and present to others

**Research group** – groups created around a specific topic suggested by the seniors

**Resilience** – a dynamic concept that manifests in different ways through life. "Resilience is about moving beyond adversity to strength, about turning hardships into insights, skills

and character that lead people to anticipate that they can handle future hardship" (Resilience workshop report, 2003). This view of resilience reinforces the value and the need to learn from seniors and to have them directly involved in the research process.

**Service clubs** – clubs that provide support in areas of funding, support, and information

**Service providers** – people who share certain expertise

**Seven C's of research** – curiosity, confirmation, changing, collaborating, critiquing, combinations

**Senior researcher** – those who agreed to participate in the research project to learn about research and be studied as they conducted research

**SSHRC** – Social Sciences and Humanities Research Council

**Storied research protocol** – step by step guide to conducting research based on the collection of stories

Story – a narrative

**Summary evaluation** – identified achievements

**Survey** – a method of collecting data

**Team building** – process that includes leader/mentor and senior researchers

**Transferability** – relates to the findings of the project, not only similar situations

**Vignette** – short written story

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Many aging adults are motivated to undertake research projects in later life or even return to university after retirement. *Grey Matters* is the result of a pilot project developed to study the effectiveness of collaborative re search involving seniors and marks a major step in making collaboration between seniors, academic researchers, and community researchers a reality. Due to the success of the project, the authors were encouraged to make their model available both to seniors interested in undertaking their own research and to those hoping to involve seniors in collaborative research. This guide provides a helpful framework for making the most of research projects by and with seniors, including sections on such techniques as narrative interviews, focus groups, and surveys.

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