HOW ARE HEALTH REFORMS AFFECTING SENIORS?

A PARTICIPATORY EVALUATION GUIDE

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FOREWORD

This Participatory Evaluation Guide is the end product of three years of research and analysis undertaken by the National Advisory Council on Aging (NACA) to develop a tool to assist seniors' groups, service providers and others in evaluating the impact of health reforms on the availability, the accessibility and the quality of health care for seniors and their families. To accomplish this goal, NACA members first interviewed seniors receiving health services and their caregivers to discover what they expected of the services they received. The values expressed by seniors and their caregivers lie at the heart of this evaluation tool. To complement the exploration of seniors' values regarding health care, NACA reviewed the health reforms undertaken in all provinces and territories and reflected on the potential impact of these reforms on the care of seniors. As well, an evaluation framework was developed, which provided the basis for a series of evaluation questions, success indicators and information sources. The final step was the production of a practical evaluation guide, to which have been incorporated key elements of NACA's research on seniors' values, health reforms and the evaluation framework.

The Council hopes that these reports will encourage provincial and local health and social planners and administrators to give at least the same weight to the values and concerns of service clients as to system demands. Service agencies in many jurisdictions are increasingly called upon to demonstrate to public funders that they offer quality services at competitive rates. This Guide provides an approachable and easy-to-use evaluation tool to help them respond to funders and adapt to the needs and wishes of their clients. For seniors and their caregivers, the Guide provides information that can assist them in participating meaningfully in service evaluations. Finally, and perhaps most importantly, the document is a first attempt to articulate clearly what matters most to seniors and their caregivers regarding health and home care and to apply these expectations in developing outcome measures. NACA hopes that many planners, service agencies and seniors' organizations will adopt this approach to evaluation.

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CHAPTER 1: INTRODUCTION

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Purpose of the Guide

This Guide is intended as a practical resource to help evaluate how well existing or new health and social services and/or policies are meeting the needs and expectations of seniors and their caregivers, based on their criteria and values of what constitutes good care. It is intended for seniors' organizations, regional health boards, health and home care agencies, family caregivers, and others who may be involved in health care evaluation at the regional or local level across Canada.

Evaluation is the process of acquiring, analyzing and using information about a program, project or service, to assess how well it is working. An evaluation usually includes questions about how the service works (its process) and what impacts it has on its intended beneficiaries (its outcomes). It may also assess factors such as the adequacy of resources and larger policy issues affecting service delivery. The guide makes a unique contribution to existing evaluation resources in several ways:

- It allows for the values and voices of seniors and their caregivers to be heard, along with those of administrators, policy-makers, funders, consultants and service providers.
- It places evaluation within the current context of health reform.
- It outlines in detail an empowering, participatory approach to evaluation.
- It can form the basis for improving the quality and responsiveness of services for seniors and caregivers.

Why Use Participatory Evaluation?

This Guide is written with the assumption that evaluation efforts should reflect what Canadian seniors and their informal caregivers (family and friends) believe is important in health and home care services. The approach which best ensures this is called "participatory evaluation." Participatory evaluation is normally carried out by the people for whom the evaluation is conducted; it is based on the principle that an evaluation should draw upon the physical and intellectual resources of the community concerned with the program that is being evaluated and from whom eventual action is envisaged. Participatory evaluation thus relies on the "grassroots" to share in the development of knowledge and the subsequent implementation of action.

Using this approach, members of NACA conducted interviews and focus groups with seniors and informal caregivers of seniors across Canada in 1996, and asked them to talk about their experiences and expectations of the health or home care services they received. The responses are presented in Table 1 under three main headings: services, service providers and the health care system. Expectations and concerns are expressed as brief descriptions, in words that closely reflect what the seniors and caregivers actually said.

Although the number of people involved in this exploratory study was very small (13 seniors, 12 caregivers and 2 focus groups), the patterns of expectations and concerns were clear and some were distinctly different from what had appeared in previous evaluation literature. No effort has been made yet to verify or rank the importance of the expectations and concerns of the interview participants. In addition, the list may not be exhaustive and different health experiences and use of different health services could elicit different responses. Nevertheless, this list of users' expectations and concerns – and others like it – should be the starting point of a participatory evaluation process that includes the users of health services.

Table 1 Health Care Expectations and Concerns of Seniors and Informal Caregivers

EXPECTATIONS AND CONCERNS	BRIEF DESCRIPTION
1. Services	
Effectiveness	The symptoms are gone; I am in better health; the service did what it was supposed to do.
Sufficiency	No more was done than was really needed; I don't want to be a guinea pig.
Availability	Full range of available services was offered to me, including monitoring after serious illness and help with my yard work.
Continuity and predictability	Professionals need to communicate with one another. I appreciate continuity of staff and worry about continuity during work stoppages.
Acceptability	Services are compatible with my basic values of privacy, dignity. My cultural preferences are respected.
Flexibility and adaptability	Rules for how services are delivered can be adapted as my needs change.
Affordability	Good value for my money; not beyond my means; medications must be affordable or I won't take them.
Accessibility	I need home visits from physiotherapists, lab technicians, doctor; waiting times for appointments are reasonable; services are close to home.
Timeliness	Service offered at right time; service delivered at right speed; no unexpected changes in timing of service to me.
Family-centredness	My family caregivers were included in care planning and instruction.
Control and choice	We had the option to make our own decisions/choices.

EXPECTATIONS AND CONCERNS	BRIEF DESCRIPTION
2. Service Providers	
Clear and honest communication	Having things in writing; giving me all the facts; regular phone contact; show me how and I will learn.
Caring	Feeling I am heard; preserving my "personhood."
Go the extra mile	Service over and above the minimum expectations; I sometimes needed extra teaching, supplies or time.
Anticipate future needs	They seem to know what's ahead and anticipate what I am going to need to do to plan.
Competent and well-trained	Staff are knowledgeable; well-trained; inspire my confidence.
Show interest in individual clients	Genuinely ask for my opinion.
Make time for clients	Give me time to ask questions or even complain if things aren't right; time to do it myself with their guidance.
3. Health Care System	
Adequacy of staff	There are sufficient staff to get the job done.
Availability of transportation	Transportation to services is provided if and when I need it.
Expanded roles for volunteers	Opportunities are provided for retired seniors to assist other seniors and use their knowledge.
Co-ordination of services	Multiple services are well-coordinated, with no gaps.
Appropriate settings for care	Most of my care can be given to me at home, and some at the day hospital; this place feels like home.
Opportunities for self-managed care	We have more control over the recruitment and payment of service providers.
Concerns about medications	I have concerns about delisting needed medications or substituting one drug for another, cheaper equivalent.
More flexibility in new care options	I would like less red tape for new ideas like group homes.

Who Should be Involved in Participatory Evaluation?

A preliminary question concerns the participants of an evaluation effort. Who should be involved? Historically, evaluations were largely conducted by persons outside the organization – academics, consultants, and auditors. Indeed, it was assumed that in order to be accurate and reliable, a completely detached, objective stance must be employed by the evaluator. Personnel and clients served mainly as informants or "subjects" in the process, a process which was often clouded in mystique, as well as frustration and resentment among those whose work or care was at issue. The questions posed were often those of interest to the researcher or evaluator, not necessarily those of concern to the consumers of services.

Participatory evaluation ideally involves the perspectives of a range of stakeholders: funders, management, program delivery personnel, and most importantly, consumers of the health or home care service. This is where seniors and their family caregivers come in. When decisions are being made about what is important to evaluate, and what questions should be asked, seniors and their caregivers should contribute their values, experience, insights and opinions about the service being evaluated. Seniors and their caregivers should be involved as well in the actual conduct of the evaluation. For example, they can contribute to the content of the evaluation questions and of the data collection tools (such as questionnaires) and they can conduct interviews. Seniors and their caregivers can also participate in the interpretation of evaluation findings, and they can generate recommendations based on those findings. Finally, seniors and their caregivers can help to determine how the recommendations can be implemented.

Good evaluation does often require at least one professional who knows how to conduct a systematic inquiry using social science research methods. This evaluation consultant can assist in designing the methods that will be used to gather the necessary information. A good evaluation consultant will recognize the importance of thoroughly understanding a service, appreciate the value of the experience of its consumers, and enlist input of and support from service personnel, before beginning to design an evaluation.

What to Evaluate?

Generally, evaluation will focus on two aspects of a program: its operations and its outcomes. In other words, the central questions will be: Are we doing what we said we would do, and how efficiently are we doing it? and What are the impacts (short-term effects) or outcomes (longer term effects) of our efforts? Knowing why or how a program or policy worked or did not work is as important as knowing that it did or did not.

Evaluations should be made as well of over-arching administrative structures or processes that determine what services are delivered, how and to whom. For instance, control over the delivery of health services has been handed over to regional boards or authorities in several provinces. While regionalization is supposed to improve health service delivery, it is not known yet whether it has achieved its intended benefits, or whether it has had some undesirable outcomes. A list of the potential benefits and risks of regionalization developed by Marcus Hollander is presented in Appendix 1. Suffice it to say here that regionalization is one of many health reforms across Canada that should be evaluated with respect to the expectations of seniors and other Canadians regarding health care.

Many evaluations focus on effectiveness, efforts and efficiency. Assessments of effectiveness examine whether goals and objectives are being realized.

Assessments of efforts are concerned with the kind and quality of activities developed and implemented to satisfy program objectives; they are often highly subjective. Assessments of efficiency determine and assess the relative costs of program operations to achieve goals. These issues are discussed in much greater detail in the remainder of the guide.

When to Evaluate?

Evaluations can be carried out at different stages of a program's development. Ideally, setting the criteria for evaluation is an integral part of the earliest planning of any new program, and certain evaluative questions are asked in on-going monitoring. When evaluation questions are posed at the very beginning of a program, the goals and objectives become clearer to all those involved, and data that can be used in an evaluation study can be collected from the very start.

There are different times when evaluative studies can be carried out. Most commonly, **process evaluations** are done early in a program's implementation, to monitor performance and ensure that operations are running as planned; **outcome evaluations** are undertaken of more established programs to determine their impacts. Both types of evaluation provide useful information for decisions regarding improvements.

It has been suggested by several evaluators that programs and services should be evaluated every second year. Projects which are time-limited should be monitored throughout their implementation and evaluated near the end of their term. The value of having data over time is that one can monitor change, some of which may be attributable to the effects of the program. It also permits exploration of patterns of peoples' experiences, rather than taking snapshots at a single time.

How Long Does It Take to Conduct an Evaluation?

There have been changes in evaluation practice in recent years. Gone are the days of large, long, expensive evaluations, and thick reports. Due to reduced budgets and the need for up-to-date results, evaluations have become more focused and rapid; evaluation reports have become more concise and timely, sometimes consisting of an oral presentation backed-up by some statistical data.

The length of time required for an evaluation depends on the scale, scope and complexity of the program, project or service being evaluated. For example, a service that has five components, covers a large rural region with several small towns, and has a history of frequent changes in management will take longer to evaluate than a single service, with continuous management, in a confined urban catchment area.

The planning phase of an evaluation – planning the design and developing and testing the data collection tools – is extremely important. If this is not done thoroughly, the evaluation will not yield useful and meaningful results, so time is needed for this preparatory stage. The stages or steps of an evaluation are outlined in Chapter 2.

How Much Does Evaluation Cost?

The cost of an evaluation will depend on a number of things: the size and complexity of the program, the scope of the evaluation, the fees of the evaluator and paid assistants, expenses such as travel, long distance telephone/fax charges and office supplies, and the methods that are used to carry out the evaluation. Some methods are considered more expensive than others, because they are more time consuming. For example, personal interviews are an expensive method because of the time it takes to do the interviews, transcribe the conversations and analyze the results. The cost must be weighed against the advantage of having rich, in-depth qualitative information.

Decisions about the scope (how broad), depth (how deep and detailed) and methods of an evaluation study are usually influenced by budgetary restrictions. A professional with experience in conducting evaluations or other applied research, will be able to tell you what can be done for what cost. Often, agencies will contribute in kind to evaluation studies by donating office space, telephone and fax time, office supplies, and volunteer assistance. This can reduce the overall cost of an evaluation. In setting up your evaluation budget, be sure to include money for production and distribution of the evaluation results.

Who Does the Evaluation Belong To?

The evaluation process belongs to all the participants. The evaluation report belongs first to the agency or organization that pays for or commissions the study. This is standard for any kind of applied research. If the agency or organization carries out the evaluation in a **participatory** manner, however, the results also belong to all the participants and stakeholders involved, because it is a product of their collaboration.

An evaluation consultant who practises participatory evaluation will typically share findings from the study in an on-going manner with the rest of the evaluation team or committee, and will share and discuss the final report (including discussions of how to implement recommendations) rather than simply sending it to the agency or organization that paid for the study.

CHAPTER 2: FRAMEWORK FOR A PARTICIPATORY EVALUATION

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Participatory evaluation offers a partnership. We both know some things; neither of us knows everything. Working together we will both know more, and we will both learn more about how to know.

Principles of Participatory Evaluation

"Top Down" versus "Bottom Up" Approaches to Evaluation

Until recently, evaluation of government-funded programs tended to be either descriptive accounts of services offered or summative (outcome) reports conducted by external consultants that recommended the continuation or cancellation of a program, depending on outcomes. These studies tended to use quantitative (number-crunching) research methods. The questions addressed in the evaluation were typically decided by the external evaluators in consultation with program funders and senior managers, whose concerns were primarily "systems driven." For example, they might want to know how much waiting time was reduced in hospital emergency rooms by introducing a 24-hour health information line, or how much money was saved in cutting back homemaker hours in a region or province. This is evaluation "from the top down." The advantages of this approach are that the funders and managers learn just what they think is important to know about the bare bones of a program, project or service, and the data they gather can feed directly into decision-making about such things as budgets.

Currently, however, evaluations tend to include questions about **both** process (accounts of services offered, to whom, when, and how) **and** outcomes (what impact the program has on a certain target group and others affected). Both quantitative and qualitative research methods are used.

The scope and priorities of a participatory evaluation are usually established by a group of stakeholders or participants – including clients or consumers – with diverse perspectives. In addition, the evaluation team usually discusses the recommendations and their implementation with all participants. This is evaluation from "the bottom up."

The principles of participatory or "bottom-up" evaluation are summarized in Health Canada's Guide to Project Evaluation: A Participatory Approach (1996, p.3) as follows:

- Participatory evaluation focuses on learning, success and action. The participants themselves become aware, informed and empowered by the process.
- The evaluation must be useful to consumers, administrators and front-line people who are doing the work that is being evaluated.
- The evaluation process is on-going and includes ways to let all participants use the information from the evaluation throughout the project, not just at the end.
- Recognition of the progression of change – in knowledge, attitudes, skills and behaviour – is built into the evaluation.
- An evaluation steering committee, as opposed to an outside evaluator, is responsible for defining the specific project evaluation questions, the indicators of success and realistic time frames.

Some of the advantages of using a "bottom up" approach to evaluation are that:

- Co-operation from stakeholders, including program personnel, service recipients and others is almost assured by including them in the process.
- A fuller and more detailed understanding of a program/project/service is possible when multiple perspectives are used in evaluation design and data collection.
- New learning is possible when users' experiential knowledge is valued and tapped.
- The results are useful and meaningful to all the people involved and belong to them.

A participatory approach to evaluation therefore means that representatives of all the people affected by a program participate in the process of evaluation, and their knowledge and experience are given equal value. An appropriate evaluation consultant would be one who has experience with grassroots organizations and collaborative efforts and who is comfortable sharing the leadership role and taking direction from the group.

Barriers to Seniors' and Caregivers' Participation

There may be some barriers to seniors' and older caregivers' participation in evaluation or any other formal "scientific" endeavour such as a program evaluation. Potential barriers to participation may be psychological, social or physical in nature.

Psychological barriers may include lack of esteem or confidence among seniors – they may not be aware of the value of their own experience and wisdom. A barrier among older women may be the tendency not to express their opinions, but to let men dominate during consultations. Most older people do not have as many years of formal education as younger people do; in fact, some have problems with literacy because they did not have the opportunity to get an education during the years of the Great Depression and World War II. This may be an embarrassment and prevent them from participating.

Seniors and caregivers from recent immigrant groups may not become involved because they are not familiar with the process of open consultation. Another social barrier to seniors' participation may be discomfort about working with people of higher social status (for example, doctors). Yet another social barrier relates to income and transportation – some seniors and caregivers may not have enough money to own a car or even pay for bus fare to get to meetings.

Physical barriers to older people's participation may include climatic conditions such as ice and snow (which can limit participation for several months of the year), lack of transportation to meetings and inaccessible buildings. Other physical barriers include reduced vision and hearing, which can limit seniors' full participation in meetings and consultations.

Family caregivers have often expressed the view that they are already overworked in their day-to-day roles and have little time for activities which place further demands on them. It is frequently after their loved one is placed in a facility or is deceased that they will find the energy and time to become involved in volunteer activities such as a participatory evaluation. Their knowledge and expertise is invaluable as they have unique first-hand experiences of the realities of caring for a family member with a disability or a chronic illness.

Evaluation facilitators must be aware of these barriers and find ways to overcome them. Many seniors will appreciate meetings held during the day, in buildings that are easily accessible and on major transportation routes, and in rooms that are comfortable, warm and well-lit and have adequate acoustics.

Phases of an Evaluation Process

How do the principles translate into practice? Table 2 provides an overview of the major phases and tasks associated with an evaluation effort. The remainder of this chapter expands on Phase 1 of the evaluation process, the planning phase.

Table 2 The Phases of an Evaluation

PHASES	ACTIVITIES
Phase 1: Planning the evaluation	Clarify the reasons for doing the evaluation
	Learn about the program
	Set up a team or committee with diverse perspectives
	Define the issues and central questions to be addressed
	Agree on indicators of success
	Choose data collection methods and information sources
	Simplify (decide what is "doable")
	Produce a written evaluation plan or framework, including a work plan and budget
Phase 2: Data collection	Pre-test data collection tool
	Train data collection personnel
	Collect data
Phase 3: Data analysis and interpretation	Code or collate raw data
	Conduct analysis according to research questions
	Produce summaries in charts, graphs
Phase 4: Writing and dissemination of report	Complete detailed report of study methods and results
Phase 5: Utilization for program review	Get the results to people who can implement recommendations

Planning for Evaluation

The most important phase of an evaluation is the preparation phase. Preparation involves several steps:

1. Clarifying the reasons for doing the evaluation,
2. Learning about the program you are going to be evaluating in some detail,
3. Setting up a team or committee with diverse perspectives, including seniors and family caregivers,
4. Deciding on evaluation questions and issues,
5. Selecting indicators of success (of both program operations or process and program impacts and outcomes),
6. Choosing data collection methods and information sources,
7. Simplifying (deciding what is "doable"),
8. Producing an evaluation plan or framework.

Each of these steps is described in detail. While they are presented sequentially, one often finds that they do not take place in a rigid order and that steps may need to be revisited along the way. Rather than a prescription, consider the steps

more like a road map, recognizing that often there are multiple routes to any given destination.

Step 1: Clarifying the Reasons for Doing an Evaluation

The very first step is to clarify why one is engaging in this exercise at all. The initiative may have come internally from the staff, board, or from clients, or externally from funding bodies or as an accreditation requirement. Regardless of the source of the initiative, you must identify clearly why you want to evaluate, what you want to evaluate and who will use the information once it is gathered.

The following checklist may be helpful in assessing if an evaluation is needed. Ask yourself, do you need to:

- plan better, that is, plan more in line with the needs of seniors?
- provide concrete evidence for management decisions about program changes?
- generate new knowledge about values, priorities and satisfaction with programs?
- generate new ideas for programs and their modification "from the ground up?"
- assess the cost-effectiveness of a program to justify its funding or request increases from the boards or funding agencies?
- help providers understand what's going well and what needs to be changed in a program?
- make the work of providers more visible to increase their pride in their work?
- contribute to a body of knowledge about the impact of health reform on the lives of seniors?

A related question you want to ask early in the process is: What will the results of evaluation be used for? If the purpose is to identify gaps in programming or a service need, a **needs assessment** is required. If the purpose is to see how well an on-going program is doing so that it can be modified and improved, a **formative** or process evaluation is required. This type of evaluation tends to pay more attention to process (how things are being done) than outcomes, although some impacts (short-term outcomes) can be measured in a formative evaluation. A formative evaluation report will include recommendations for program modification and improvement. Finally, if the purpose is to make a decision about continuing, expanding or cancelling a program, a **summative** or outcome evaluation is needed. A summative evaluation will usually make comparisons to other programs, will pay close attention to cost, and will include recommendations to continue or cancel the program. Many evaluations include both process and outcome components.

Case Example

*A project was undertaken to introduce several respite beds into a long-term care facility. The project was evaluated to see how the process of assessing needs and assigning beds was conducted – a **process** or **formative** goal – and what the effect on the seniors and their families would be – an **outcome** or **summative** goal.*

Step 2: Learning About the Program

Before you can evaluate anything you have to understand it. You will need to read documents that describe the program, its history and activities. You will need to know which staff are responsible for which activities. You may find at this stage that there is simply not enough information written down, in the form of reports and lists and so on, to give you a clear picture of the program. You may have to do some interviewing and perhaps write a program description with a number of blanks in it, and ask the program manager to fill in the blanks. Managers are often pleased to do this, because it means they will ultimately have a written program description that they can use for other purposes. Or you may prefer to portray the program graphically in what is called a "logic model," which is essentially a flow-chart showing program objectives, activities and outcomes usually in boxes connected with arrows.

A complete program description therefore contains a number of elements. These are summarized in the program outline that follows. You will need to modify this according to the unique components of your setting.

PROGRAM OUTLINE

Describing Your Organization/Program/Policy Initiative

Everyone in the evaluation effort will need to have a thorough understanding of the organization, program and/or policies which are being evaluated. The following checklist may be helpful in identifying its significant features.

Philosophy and Goals

Does the organization have a written statement of its philosophy?

- What is the overall purpose or mission of the agency?
- How does the organization view its clients? (i.e., as members, consumers, recipients, etc.)
- Is there a statement of organizational goals and specific program objectives?
- Are the goals clear? consistent with one another? realistic?

Programs and Resources

What programs and services are provided?

- What resources are allocated and used for each program and where do the resources come from?
- Where are there lacks or excesses in resources?

Organizational Structure

Is there an official organizational chart? If not, you may want to create one to better understand the people and their responsibilities. Include volunteer boards and all internal branches.

- Who are all the people involved? What are their roles? How do they relate to one another?
- Who has formal decision-making authority for what types of decisions?

Environment

What are the characteristics of the client groups?

- To what extent and by what means do clients participate in the organizational decision-making?
- What other organizations is this agency affiliated with?
- How do they have input into the organization? How much influence do they exert? What is the relationship to the regional health board, if one exists? How does the community at large value the program?
- What links are there to unions, professional bodies, government regulatory bodies, etc.?

Step 3: Setting Up a Team with Diverse Perspectives

Once the purposes and type of evaluation have been broadly defined, and there is a written and/or graphic description of the program/policy to work from, it is time to create a team or committee of people who are familiar with, and have different perspectives on, the service being evaluated. You will want to consider inviting:

- seniors who are consumers of the program
- friends and family who are informal (unpaid) caregivers of seniors
- someone representing the funding organization or sponsor (e.g., government)
- the program director (who may be the director of several seniors' health or home care programs in one organization)
- members of service delivery staff, "front-liners" such as homemakers and community health workers
- staff from related services who have clients in the program being evaluated (for example, from the Alzheimer Society or from Meals on Wheels)
- other potential partners with knowledge or resources to share such as unions, academics, other seniors' groups or professional associations, and
- a qualified consultant with skills in participatory evaluation methods.

Make it clear in the first meeting of this committee that everyone's opinion has equal weight and everyone's perspective and knowledge is equally valued. In time, you will want to establish team members' individual roles and responsibilities, but it cannot always be done right away, because some individuals may not want to commit to certain responsibilities right away, and because it is wise to allow time for each person's special talents, knowledge and skills to reveal themselves.

Step 4: Deciding on Evaluation Questions and Issues

The first step in deciding on evaluation questions is to identify the program's goals and objectives. They are probably spelled out in a previous funding proposal or you may find them in a program description in a brochure or binder. You will also want to ask the current manager and some of the staff what they perceive the program objectives to be. Sometimes, the direction of a program can change ("drift") over time, due to changes in clientele, in management style, and in the funder's priorities; so the objectives set out in a five or ten-year old proposal or other document may not reflect the current reality.

Most importantly, the written objectives of the agency may not match the actual expectations of staff and/or clients. In this case, whose views should prevail? Thinking back to our assumptions underlying participatory evaluation, it is clear that everyone's views must be considered valid.

Typically, the stated objectives will fall into two categories: objectives that state the way a program will be run, by whom, for whom (process objectives) and objectives that state the intended short-term impacts and/or longer term outcomes on the intended clients or beneficiaries. For example, “This program will reach at least 100 seniors aged 85+ who live alone in the community” is an example of a process objective. An example of an impact objective is: “One of the purposes of the program is to increase family caregivers’ awareness of available support services and community-based emergency response services.” Finally, an example of an outcome objective is: “To reduce the number of cases of elder abuse resulting in hospital admission or use of police services.”

You will also want to monitor unintended and/or unexpected outcomes. These are outcomes which are not reflected in the goals of the program or policy. They can be negative or positive. For example, a **negative** unintended outcome would be that, as a result of reducing funding for homemakers, family caregivers experienced more health problems necessitating visits to their family doctor. A **positive** unexpected (and unintended) outcome would be that, following relocation of a group of seniors with Alzheimer’s Disease to a house during renovation of their institutional facility, the residents became much more alert and began helping with daily tasks in the home. Another type of unintended outcomes is “spin-offs” – secondary services or programs that result from the first one. A spin-off of a recent education program for home care workers in North Vancouver was the creation of a support group by these isolated workers. Remember to include questions about unintended outcomes or spin-offs in your evaluation questions.

In addition to objectives and to intended and unintended outcomes, another source of evaluation questions will be any problems or concerns that are raised by team members about the health or home care service you are evaluating. These issues will have to be analyzed carefully and broken down into questions that can be included in the evaluation.

A warning about issues, or perceived problems. Make sure you are addressing the real issue and that you are gathering data from all of the groups who are affected by the issue. For example, efforts were undertaken in one province to promote the use of generic prescription drugs to reduce the costs of pharmacare. Pharmaceutical companies lobbied strongly against this practice since it reduces their potential for marketing their unique brands of these same drugs. However, when asked for their opinion, most seniors in the province favoured this practice and realized the benefits of reducing drug costs across the system. Had only one group of stakeholders been consulted, the results of the evaluation would have looked very different.

Another illustration is related to the problem of low use of respite programs for many groups, including seniors. In one area, lack of use was interpreted as lack of awareness of the program among the group in need, so more pamphlets were distributed and more outreach was done, but use did not increase. When the situation was investigated in more depth, it was found that lack of use was more

likely to reflect lack of suitability and flexibility of the respite programs offered. Just measuring the number of people who use a respite program and surveying their satisfaction with it, therefore, would miss the point. It would be necessary to find out from people who do not use the service why they do not, to identify the true causes of under-utilization of the service.

The fundamental questions generally addressed in any evaluation are:

WHAT? - Did the program/policy do what it was intended to do?
WHY? - What worked and what didn't work? Why? How was the program experienced?
SO WHAT? - What difference did we make with this work/policy?
NOW WHAT? - What could we do differently in the future?
THEN WHAT? - How will we use the evaluation findings to guide future planning?

Knowing why a program succeeds or fails is even more important than knowing that it does. (Feuerstein,1993)

Each of the five questions above could be asked of several areas of concern in an evaluation. Typically, the areas of concern in evaluations of health/home care services are utilization, effort, impact, and quality. Each are briefly discussed here.

1. **Utilization** refers to who uses the services. Typical questions here include: Is it the intended group? Are they from the intended catchment area? How many? (i.e., Are the numbers what was expected?) How often? (i.e., Was it less or more frequently used than anticipated?) and, In what way? (i.e., Who refers them? What do they really use the service for?)
2. **Effort** refers to the amount of effort it takes to market and deliver the service – the number of staff and volunteer hours and related costs.
3. **Impact** refers to the short-term changes that result from the services – changes to both clients and related programs.
4. **Quality** refers to how well the program is both designed and delivered, from the perspective of both service personnel and clients.

The next step is harder work – breaking down these large, fundamental evaluation questions into small questions that can be answered by examining existing information or seeking new information.

General questions asked in general ways are not very useful because the response is not sufficiently informative. Imagine asking a senior, “How do you like your homemaker service, on a scale of one to five?” The senior’s answer might reflect a number of factors including satisfaction with the number of hours of service per week, the quality of the housework or meal preparation, or even the personal warmth of the homemaker. None of these dimensions would be revealed in an answer to a general question. That is why it is necessary to break down general questions into the smallest reasonable number of questions.

The advantages to having an evaluation team with multiple perspectives is that team members can generate specific questions based on their own values and

experience. Seniors and caregivers who are consumers of health or home care services will have different experiences and values from those who are delivering the program or a related program. These experiences can be a good source of specific questions to ask in an evaluation.

Another source of specific questions is other evaluation studies. It is worth collecting related evaluation studies. Most evaluation reports will include copies of the data collection tools (such as survey questionnaires and telephone interview guides) in appendices at the back of the report. It is perfectly legitimate to “lift” a good question from someone else's study, but make sure the question fits your study. You will need to take the time to customize your evaluation. Common questions can be asked of similar health or home care services in different regions, but each location will probably be different enough to warrant some unique questions as well.

A list of evaluation questions derived from the expectations and concerns expressed by seniors and their family caregivers is presented in the three tables in Appendix 2. These tables are an excellent place to begin looking for ideas for clear, measurable evaluation questions. To illustrate how the process of question development would apply to a given health reform, the following example is provided.

QUESTION DEVELOPMENT

A participatory approach to evaluating a program of Early Discharge Following Surgery

A group of seniors and service providers gathered to determine evaluation questions to be addressed in assessing the value of an early discharge program following surgery in a large metropolitan hospital. All steering committee members compiled questions of relevance to them. The seniors and their caregivers were most interested in the following aspects of the new program:

1. Who were the recipients of the program? Were there any inequities in terms of gender, economic status, race or geographic locale?
2. Was the program effective in reducing unnecessary hospital days without increased risk of complications?
3. Did the program provide adequate home support for people who needed extra assurance or assistance?
4. Was there flexibility in the program for people who experienced post-operative difficulties or who lived alone?
5. Did the program provide sufficient opportunity for family involvement?
6. Did the staff use clear communication, both written and verbal, in preparing clients for the surgery and for discharge?
7. Did staff treat clients with dignity and respect as individuals?
8. Did the staff appear to be knowledgeable and well-trained in their work?
9. Did the staff anticipate clients’ future needs on discharge?
10. Did the overall experience seem co-ordinated and well-planned?
11. Were seniors and their families included in planning the delivery of this service?
12. What did clients like most about the program?
13. What changes would they like to see implemented to improve the service?

Step 5: Selecting Indicators of Success

"Indicators of success" refers to specific, measurable or observable pieces of evidence that serve as criteria for judging whether a program's goals and objectives have been met. Here is where we may begin to see the diversity of values of the participants being fully reflected. It is also where the richness of the diversity can be applied to serve the needs of the various stakeholders. Because this is such an important phase of the planning process, the next chapter is devoted entirely to this step.

Step 6: Choosing Data Collection Methods and Information Sources

There are two general types of data collection methods: quantitative and qualitative. Quantitative methods involve counting things. For example, a mail-out or telephone survey that asks hundreds or thousands of people the same closed questions and then tallies the answers is a quantitative method, as is a content analysis where you count the number of times a certain theme appears in a written source. Quantitative methods are good for getting a broad understanding of something from a large sample and where the goal is to generalize the findings to a whole population. In contrast, qualitative methods often involve observation and personal in-depth interviews and focus groups with open-ended questions. The goal is not to get a frequency count, but to draw out the diversity and richness of individual experiences. This requires openness and keen observation skills on the part of the researcher.

Data collection methods must suit the nature of the question being asked. Generally, survey (quantitative) questionnaires are useful for gathering factual information – the who, what and where questions. How and why questions, which require some probing and perhaps observation, are better answered using open-ended interviews or focus groups, that is, a more qualitative approach.

Information sources may include any or all of the perspectives represented on your evaluation team, that is:

- seniors who are service recipients
- caregivers of seniors
- program managers
- program staff
- staff from affiliated or related programs which have the same clientèle
- agency records that may go back a number of years
- government planning documents or administrative records

In Chapter 4 you will find a detailed presentation of methods to obtain and analyze information from various sources.

Step 7: Simplifying - Making it Doable

Having defined the issues and questions that you want to address in the evaluation and having worked very hard in determining indicators of program achievement as well as data collection methods and sources of information, it is time to step back and ask yourselves: "Is this doable?"

Look realistically at the reason you are conducting the evaluation in the first place, your deadline, the amount of time everyone on the team has at their disposal, the budget, the skills of your team, and ask yourselves if you can really accomplish all you have said you want to do.

If not – and this is not unusual – ask yourselves questions such as: Do we really need to know the answer to that question to meet our evaluation objectives? What do we really need to know this year? and Is that question really so important that we have to wait six months to get the answer from a government department? and so on.

Then simplify. If you have not done an evaluation before, it is probably ambitious enough to ask four or five questions about process (how the program is run) and four or five questions about impacts (short-term outcomes) or outcomes (longer term consequences).

Step 8: The First Product – An Evaluation Framework

The first product is an evaluation framework, that is, the plan for assessing the performance of a program. It becomes the guidebook that is followed for the rest of the evaluation process. It will usually be written by the professional who has been facilitating the process to date, one who is familiar with evaluation, familiar with the program in question, and who has experience in conducting applied social research. It contains the key questions that will be addressed in the evaluation and the key steps that will be taken to answer those questions. It may be a combination of text and graphics. An evaluation framework includes three key components – the rationale and approach, a program description and an evaluation plan. Each is described in detail. Various funding bodies will have their own modifications of these categories, so you may need to adapt them if you are applying for a grant to conduct the evaluation.

1. **Rationale and Approach**
   - an explanation of the purposes of evaluating the particular program
   - identification of the intended audience for the final evaluation report
   - an explanation of the approach to evaluation (for example, a participatory approach)
   - identification of the stakeholders involved in the evaluation process

2. **Program Description**
   - a program description, sometimes including a graphic portrayal of the program, called a "logic model"
   - clear identification of program objectives

3. **Evaluation Plan**
   - identification of the program components to be evaluated (that is, which aspects of its operations and its impacts will be evaluated)
   - a list of the key issues or questions to be addressed
   - identification of indicators of program success
   - a list of the sources of information that can be accessed to answer the evaluation questions
   - a description of the methods that will be used for data collection
   - a plan or sequence of steps that will be followed in collecting and analyzing data
   - a work schedule that shows when and by whom all activities will be completed
   - a budget accounting for all evaluation costs including: personnel, benefits, travel, office rent, telephone, faxing, postage, stationery, equipment needs, consulting fees, and other expenses. The budget should provide for both dollar contributions as well as payment-in-kind.

CHAPTER 3: SELECTING INDICATORS OF SUCCESS

3

As mentioned in Chapter 2, one way of thinking about program processes and outcomes is in terms of success indicators. These are the identifiable changes which indicate whether or not the goals have been achieved. An indicator is a marker, comparable to a road sign. It shows if you are on the right road, how far you have travelled, and how far you still have to go to reach your destination. Indicators show progress and help to measure change.

Purpose of Indicators and their Measures

Success indicators reflect a group's assumptions about what is expected from the program or policy being evaluated. They may be quantified into a number (such as a percentage, rate or ratio) or level of satisfaction. They may also be described qualitatively by people who are experiencing a program.

A general rule is that asking about the same thing in different ways, using different methods to collect data, makes you more confident that you are learning the truth. Another general rule is that indicators of success, if they are to be measurable, have to be very specific. In the case of a 24-hour tele-health service, an indicator of success may be that "there is a high per capita utilization rate." This is too vague. A measurable indicator of success would be "there is at least an 80 per cent utilization rate among the 500 seniors targeted for this service in the region in 1996." A measurable outcome indicator would be "at least 75 percent of users surveyed will describe at least one new coping strategy they have used which they learned about through the tele-health service."

Numbers do not tell the whole story, however. Remember that we are not only interested in the fact that the program worked. We want to know more about how it worked and what aspects worked best. An observable (but not measurable) success indicator would be that users of the tele-health service would describe specific examples of how using the service helped them in their ability to self-diagnose common, non-emergency health conditions. The next chapter discusses the various data collection methods used for gathering data about each of these different kinds of indicators.

Standards of Good Indicators

How do you know if you have a good set of indicators? The following criteria will be helpful in addressing this question:

- The indicators must be useful to decision makers.
- The indicators must be sensitive to changes in the phenomena which they are describing.
- Measurement values of the indicator should show some variability over time and between groups.
- The data needed to support the indicator must be available at an affordable cost.
- Indicators must be mutually exclusive: they should not duplicate one another.
- They must reflect the values and priorities of the participants.
- They need not have been used by others if they can yield new information.
- They may have been used elsewhere and the results can be compared.
- They should be easily understood by those involved in the evaluation.

In addition to these practical considerations, you would want to be sure that the indicator directly and accurately measured what it is supposed to measure (i.e., validity), that data on the indicator can be gathered consistently over time (i.e., reliability) and that the results will be useful by multiple audiences to make decisions (i.e., utility).

There are also several issues to consider concerning time. The first is that time equals money for a professional consultant and for any salaried employees. Second, the more elaborate your evaluation study, the more work time it will take to carry out. And third, the more external sources of information you have to review, such as government documents and agency records, the more lapsed time you must allow so that you can fit comfortably into others' schedules. Keep these constraints in mind when you decide on indicators of success and the methods that will be required to measure them. A final time-related consideration concerns the need to produce information that is historically current so as to inform policy and program decisions.

Indicators, Indicators and More Indicators

There are as many kinds of indicators as there are evaluation questions. Common kinds include those reflecting availability, relevance, accessibility, coverage, quality, efficiency and impact. In Appendix 2, examples of indicators developed by Marcus Hollander are presented for each of the evaluation questions developed to reflect seniors' and caregivers' expectations and concerns regarding health care.

We can illustrate this process by building on the evaluation questions posed in the box on page 20 (Early Discharge Program). Table 3 presents indicators developed to respond to those questions using the values expressed by seniors and their families (Table 1, p. 6).

Table 3 A Participatory Approach to Evaluating an Early Hospital Discharge Program

EVALUATION QUESTIONS	EXAMPLES OF INDICATORS
Who were the recipients of the program?	Number, age, marital status, residence, income of clients
Were there any inequities in terms of gender, economic status, race or geographic local?	Similar client rates to population rates in terms of marital status, gender, cultural group, income and residence
Was the program effective in providing reduced hospital days without increased risk of complications?	Similar annual complication rate between new decreased hospital stay program and previous program
Did the program provide adequate support for people who needed extra assurance or assistance?	Clients will rate as adequate the amount of support available to them
Was there flexibility in the program for people who experienced post-operative difficulties or who lived alone?	Clients will provide examples of adaptations which were made to suit their individual needs
Did the program provide sufficient opportunity for family involvement?	Primary caregivers will describe their satisfaction with being involved in the teaching and follow-up care
Did the staff use clear communication, both written and verbal, in preparing clients for the surgery and for discharge?	80% of clients will rate the written and verbal communication as satisfactory or better
Did staff treat clients with dignity and respect as individuals?	80% of clients will rate the dignity they felt as satisfactory or better
Were the staff knowledgeable and well-trained in their work?	All staff have appropriate professional credentials and have attended regular in-service programs to update their knowledge
Did the staff anticipate clients' future needs on discharge?	Clients will be able to describe ways in which their future needs were anticipated
Did the overall experience seem co-ordinated and well-planned?	80% of clients will rate co-ordination as satisfactory or better
What did clients like most about the program? What changes would they like to see implemented to improve the service?	Clients will describe aspects of program they liked and be comfortable suggesting improvements

CHAPTER 4: SELECTING A DESIGN AND DATA COLLECTION METHODS

4

Once the objectives of a program are established and the indicators of success are clearly laid out, the next step in evaluation is to select ways of collecting data. The scope of this guide permits only a brief overview of the types of methods that can be used in collecting data. In Appendix 2, a number of suggestions for data collection are made with reference to each of the indicators listed. Your evaluation consultant should be helpful in assisting you with the task of selecting the most appropriate data collection method. As well, a number of the references in the bibliography provide further details concerning evaluation methods.

Selecting a Research Design

The Use (or Non-use) of Experimental Design in Evaluation
The classic experimental model requires randomly assigning people to "control" and "experimental" groups and randomly assigning the treatment or program to these groups. Quantitative measures are taken both before and after the treatment or program, and statistical tests are done to determine if there was a difference between the control and treatment groups. The goal of an experiment is to be able to generalize the findings to the wider population of interest.

The classic experiment has limited use in contemporary participant evaluation. This is because it is rarely possible (or desirable) to randomly assign people and treatments in the real world. It is also difficult to keep people "blind" as to which group they are in as is done in drug trials when a "placebo" is given. And, generalizing the findings to the population of interest is rarely a goal in program evaluation. For these and many other reasons, evaluation usually does not follow this model in its purest form.

Quasi-experimental Designs
Modifications of the true experimental design are often termed "quasi-experimental." These designs are often more appropriate to evaluation efforts which take place in the real world, with all its constraints. They are not without limitations which must be taken into account when interpreting the results. Here are some of the commonly employed quasi-experimental designs:

- **Nonequivalent control group designs** – These are commonly used in evaluations. Efforts are made to find a group that is similar (but not identical) to the one getting the program, and before and after measurements (e.g., using a survey) are taken from both groups.

- **Time series and time lapse designs** – Time series and time lapse designs are useful as they can provide valuable information about the effects of a program over time. A baseline measurement is taken before exposure to the program (e.g., a test of knowledge about home support services), then periodically to monitor progress. Follow-up after the program is ended is possible, to see whether the effects of the program last after three months, six months or a year for example. This is important as we often want to know whether program benefits last over time. (This longer term follow-up is not limited to this design.)
- **Before and after design** – Evaluators may choose to take before and after measures of a single program group, with no controls involved. The disadvantages include that one cannot be sure that changes seen are a result of the program effect. These models may be adequate for formative evaluation questions but are less satisfactory for summative or outcome evaluations.

Descriptive Studies and Other Types of Non-experimental Designs
Many fine approaches to evaluation are available which do not entail experimental design. Several of these are presented below, but again, one should obtain more information about their use prior to adopting any of them.

- **Participant observation** – Participant observation involves actually joining a group and recording one's observations through careful field notes which are subsequently analyzed. This is a good method for describing the internal culture and the "feel" of a program. To illustrate, a sociologist could take on a job as an orderly in a long-term care facility in order to observe and describe the ways that decisions are made about patient care.
- **Feminist approaches to participatory evaluation** – Feminist participatory research encourages paying attention to the differences and similarities of perceptions of issues among men and women. It is generally aimed at reducing discrimination based on patriarchy, race, socio-economic status or others. These approaches may work well for situations where seniors are feeling "marginalized" from mainstream society and want to address the social or political inequities.

Data Collection Methods and their Sources

A number of data collection methods are available to evaluators. It is often the case that more than one method will be employed in a single evaluation – including collecting a mix of both quantitative and qualitative data. Quantitative data are data which can be quantified into fixed units. Many surveys use scales asking people to rate something on a scale of 1 to 5. These ratings are then treated

as real numbers and form the basis of statistical tests. Qualitative data, on the other hand, do not involve measurement. It may consist of stories, conversations, art work, photographs, etc. The following sections examine a number of qualitative and quantitative data collection methods.

Qualitative Data Collection Methods

There exists a wide range of qualitative data collection methods. Some of the most commonly-used ones are discussed in this section. People conducting qualitative interviews need clear, precise instructions about how to carry them out successfully. Appendix 3 provides a set of guidelines that was used to guide a training session for seniors who were going to carry out two interviews each – one with a senior and one with a family caregiver of another senior.

Focus Groups: Focus groups capitalize on communication between participants to generate data. They are widely used to get the public's impression of things, examine people's understandings of illness and of health services. They are also effective for exploring attitudes and needs of staff. They are well-suited to many participatory evaluation endeavours. In such groups, participants can respond to a series of open-ended questions, explore issues of relevance to themselves, using their own vocabulary. It allows evaluators to gather stories, jokes and other forms of day-to-day interaction which are not captured in responses to direct questions. The method facilitates criticism and exploration of different solutions and thus is useful for working with disempowered people who feel all of their problems result from their own inadequacies. Focus groups do not discriminate against people who cannot read or write and can facilitate input from those who are reluctant to be interviewed on their own. Group discussions are usually tape-recorded and transcribed. Conducting a focus group requires specialized knowledge about the size, composition and format of the group. Appendix 4 provides a sample set of instructions for setting up a focus group. Note the attention paid to the setting, recruitment and guarantee of confidentiality.

Open-ended Individual Interviews: Open-ended interviews are useful for exploring people's experience of a program. Generally, a series of standard questions are posed in order to elicit the views or stories of participants. Interviewers are trained to probe for more detail and to ask for clarification. The interviews are often tape-recorded and transcribed and may be given back to the informants to see if that is what they meant or if they wish to add anything. Appendix 5 presents the open-ended interview questions asked of seniors in the NACA study of seniors' and caregivers' expectations.

Photography: Sometimes a picture can be worth 1000 words, as the Chinese proverb says. As in other types of data collection, it is important to have people's permission to use their photograph. Pictures can help to record changes before, during and after a program. They can be used to stimulate discussion and group analysis and can often capture richer detail than the eye or the pen. Pictures can produce emotional responses, help to raise questions, reveal biases, reveal changes, and assist in decision-making. For example, the STEPS Project in Victoria, BC, used pictures of cracks in sidewalks to convince city officials that repairs were needed. Post-repair pictures revealed that the program was effective in producing change.

Case Studies: A case study is a detailed description and analysis of a single event (e.g., a fall), a situation (e.g., being widowed), a person (e.g., a program participant who dropped out), a group (e.g., a caregivers' support group), an institution or program provided in detail within its own context. Case studies have long-standing use in law, medicine and social work. A case study can be done of an exemplary home support program to fully explore the values, attitudes, training, morale of staff and clients. Such a rich description of the program may yield more about its success or failure than quantitative methods.

Case studies can also be used after an evaluation is done, in order to provide a clearer picture of explained or unexplained findings. For example, a caregiver support group in one community was found to produce important changes in participants' abilities to cope with their role. A similar group in a neighbouring community did not prove to be useful to the participants. Compiling case studies of these two groups might shed new light on what aspects of the leadership, group process and group content may have contributed to these very different outcomes. Remember, knowing why a program worked is as important as knowing that it did!

Critical Incident Analysis: During the life of a program, certain events may occur which can affect the program or its participants. One useful way of documenting these is through critical incident reports. An individual or group may describe the same event (e.g., a sudden change of government policy concerning eligibility requirements, part way through a program) or people may describe different events pertaining to a common theme (e.g., describe an incident in the program which contributed to your feeling more empowered.) These reports may be in a written format on a special form or they may take place in individual or group interviews.

Quantitative Data Collection Methods

Surveys: Surveys may be carried out by mailing them to participants, by asking the questions during a telephone interview or in a face-to-face format. Each has advantages and disadvantages. All rely on a clear, well-written questionnaire that conforms to certain standards. Mailed surveys disadvantage people who cannot read or write but they are often less costly to carry out than individual interviews. Returns of the questionnaires (response rate) can be increased by limiting the number of questions, using targeted mailings with a follow-up phone call, and paying attention to literacy level, language and visual presentation.

Telephone surveys and face-to-face surveys have the advantage of increasing accessibility and reaching people who cannot read or write. They also allow respondents to ask questions if they are unsure about the meaning of a question. Some seniors are suspicious about phone calls or home visits from strangers so it is important that they be given information about the evaluation directly from program personnel if possible. Both types of interviews are more time-consuming and costly so it may be necessary to include fewer numbers of people. Careful interviewer training is important to make sure all participants are asked the same questions in the same way.

Entire books have been written about the composition of a good questionnaire. There are many ways of asking people questions. These include but are not limited to the following:

- **Checklists:** A checklist may allow for one choice, a selection of choices rated for example from 1 (most important) to 5 (least important), or multiple selections (i.e., check all of the following which apply to you). Include a category of "other" and one for "none."
- **Forced choice:** These are questions which require a yes or no response. It is a good idea to include "no opinion" or "uncertain."
- **Multiple choice questions:** There are different ways of asking multiple choice questions but each is designed to force a choice among alternatives.
- **Scales:** There are many kinds of scales. They are useful in finding out about people's opinions. One type is an agreement scale which asks people to indicate whether they agree strongly, agree, disagree or disagree strongly with a particular statement. The center number (i.e., 3 in a 5 point scale) is reserved for undecided.

You may want to use some standardized published scales for measuring program impact on things like life satisfaction, stress, health status, activities of daily living and so forth. Again, the scales must be reflective of the evaluation questions and indicators laid out in your evaluation plan. Using existing scales has the advantage of allowing you to compare your results with published evaluations

using the same scales. The major disadvantage is that they are often so general so as not to have been part of a particular program's objectives and programming activities. Appendix 6 provides examples of scales used to measure physical well-being. Since it would be costly to examine everyone in a study to determine their health status, evaluators often use indicators of health. Notice the different indicators included in the questions in Appendix 6.

It is important to get a group of participants that is representative of the entire population of interest. If not, the results will not be regarded as valid. In simple terms, in a true random sample, every client must have an equal chance of being selected, although this cannot always be achieved perfectly. Typically, representativity is determined by comparing the people who end up in the sample with the entire population of interest: if the two groups are similar, the sample is considered to be representative.

Use of Secondary Data

For many reasons, you may want to use agency data collected for other reasons or government records in your evaluation. This is usually referred to as secondary data analysis. Secondary analysis can also be done on qualitative data but it is more rare. Again there are a number of advantages and disadvantages to using secondary data.

Agency data can be very useful for compiling a profile of clients and specifics of the program in question. If you have the luxury of planning the evaluation when the service is being planned, you can make sure that all of the information you will want is included in intake forms for example. Often service providers will not include some of the detail needed for an evaluation.

Government records can provide useful data as well. Standard data is compiled by local areas on such things as deaths, hospital admissions and census data. Assistance may be needed to access this data and the requests must be well formulated and pertinent. It can be costly but often the people who compile such records are only too happy to see someone making use of it. It is most useful for making broad comparisons between health areas or provinces. It is useful for addressing broader questions concerning the impact of reform in different jurisdictions.

Collecting the Data

How Often to Collect Data?

The issue of how often to collect data is directly related to your evaluation design. If you are using a pre-test post-test design, you will want to collect data at least twice – once as a baseline, pre-program measure and again at the end of the program. If you are looking to see whether the effects last over time, you will

need to go back in six or twelve months, depending on what you have set as your indicators for success. It costs money each time you carry out a survey or have a focus group so you may also be restricted in terms of your budget as to how many times is reasonable. If you want good information on individual agency contacts, you may want to consider a short feedback sheet for use with each encounter.

Who Should Collect Data?

Interviews can theoretically be done by anyone. However, in participatory research, there is much to be said for engaging seniors to interview other seniors. Younger interviewers may not have the status or ability to inspire confidence. In general, the best interviewers are naturally friendly, polite, tactful, sensitive, intelligent, self-confident, reliable, patient and in good health. They can be enthusiastic but must be able to control their own feelings and opinions so as to not influence the responses of the participants. Sensitivity as to language and cultural differences must be exercised as well.

Regardless of who carries out the interviews, a proper training program should be undertaken. For example, for surveys, it is important that each question be asked exactly as it appears on the questionnaire.

Obtaining Consent from Participants

Anyone being asked to participate in an evaluation should sign a consent form. There should never be any coercion to participate. An example of a consent form is included in Appendix 7. The only exception to the need for a signature is where a person is mailed the questionnaire and consent is implied if they return it. Informed consent usually includes all of the following:

- A full description of the purpose of the interview and how the information will be used
- A statement outlining the confidentiality of individual responses
- Advisement that participants are free to participate in none, some or all of the evaluation and that if they decline, no adverse effects will result such as reduced service
- A full statement of any risks or benefits which they might encounter from participating or reassurance that there are no risks. A benefit often offered is to receive a copy of the final evaluation report or attend a public presentation of the results
- An invitation to express any concerns or particular requirements
- If relevant, consent to have the interview tape-recorded with confirmation that once the data have been transcribed and analyzed, the tapes will be erased
- The full name and phone number of the researcher or the organization carrying out the research

CHAPTER 5: DATA ANALYSIS AND INTERPRETATION

5

Once your data is collected you are faced with the job of preparing it for analysis and then drawing conclusions about those results. The process will vary according to the type of data collected. While it is beyond the scope of this guide to present all there is to know about data analysis, some general guidelines and procedures are outlined to assist you in the process. In participatory evaluation, opportunities should be available for all steering committee members to be involved in analyzing the data and interpreting the results. Once you have your results, you will need to compile a report. The final section in this chapter outlines guidelines for preparing the final report of an evaluation.

Analyzing Qualitative Data

Qualitative data is usually available in the form of written or transcribed text acquired through interviews, focus groups, document analysis, diaries and field notes. For program evaluations, one would analyze the material using the evaluation study questions as a guide. After an initial sorting of the information into these general areas, either by hand or using computer software, one begins to look for themes and patterns which emerge in the data. Sub-codes are applied to these themes in order to describe the ideas. This coding and labeling process can be quite challenging and it works well to have a small group to collaborate on the task and verify the interpretation of the coding. It is helpful to leave as much text as possible in the speaker's own words in order to help clarify the meaning of the category.

Analyzing Quantitative Data

Quantitative data is usually gathered in surveys, agency records and from government sources. The most expedient way of coding and analyzing quantitative data is by computer using a specialized software such as SPSS (Statistical Package for Social Sciences). If you don't have the expertise among the steering committee members, it is not a bad idea to hire someone such as a university student to carry out this task. Graduate students often have the necessary statistical know-how and can in turn learn from your project.

The ways data are usually presented include: averages, ranges, percentages and rates. Bar charts, pie charts, graphs and tables can be effective ways of presenting descriptive data. Again, organize the data analysis according to the key

evaluation questions which were posed. If you have posed questions which involve differences between groups or between measurements before and after a program, you may wish to use statistics to help you determine if the changes are statistically significant, that is, over and above differences that could be expected by chance. Statistics need not be complicated or bewildering but you do need to know from the beginning if this is the approach needed as there are stricter guidelines that must be followed in collecting data and coding it.

Compiling and Sharing the Evaluation Results

You have now completed your data analysis and wish to present your evaluation findings. Alternatively, you may find it more meaningful to produce regular short progress reports as the evaluation progresses. In addition to – or instead of – a written report, other useful ways of sharing evaluation results include newsletters, information sheets, posters, drama, slides, or videos. Again, a cost will be attached to the final reporting process. Key questions to consider are who will write the report and who will be the primary readers. Funding agencies sometimes have their own requirements of what is to be in the final report.

A typical report follows the same steps as the evaluation process. Here is a general guide for what to include in a generic report:

1. **Front Cover:** This should include the title, name and location of program; names of those who carried out the evaluation; key sponsoring agencies; period covered by the report; and the date of the report.
2. **An Executive Summary:** This is a one page overview of what was evaluated, the key findings and any recommendations arising from the findings. Senior executives sometimes may only read this page so it should be a good summary of important messages you wish to convey.
3. **Table of Contents:** This contains the list of the contents in clear, logical order.
4. **Background Information:** This section provides a brief history of the project or policy, a description of the program components and who formed the evaluation steering committee.
5. **Description of the Evaluation:** Here one usually includes the purpose of the evaluation, the key evaluation questions which were addressed, the related indicators of program success, a description of the methods and sources that were used for data collection along with why these were chosen, any limitations of the methods or resources, who collected the data and how questionnaires were distributed and returned. You may also include where and how the evaluation materials were tested prior to use and any training that was done.

6. **Evaluation Results:** Here one presents the results of the evaluation. It is useful to present as much information as possible in tables, graphs or picture format so that people can see at a glance what was learned. It is also useful to include first-hand accounts of respondents, in their own words. It makes the report more authentic and interesting to read. Keep in mind not only the question: Did it work? but also the questions: What aspects worked? Why or Why not did it work? and What could be done differently?
7. **Conclusions and Recommendations:** Conclude by summarizing what you did and what you found out. It may seem repetitive, but again, some people will turn immediately to this section to see what came of the evaluation effort. This is also where you can make recommendations based on the evaluation findings as well as suggestions for how others might build on your work. While it is tempting to go beyond the study findings in your recommendations, this practice is not advisable. Some people prefer to have the recommendations in a separate section. Include how, when and by whom the recommendations can be implemented.
8. **Appendices:** You may want to include copies of questionnaires, summaries of raw data, or other material to supplement your report. A reference list of sources consulted is also useful.

CONCLUSION

Participatory evaluation can provide project managers, policy-makers, administrators, boards and front line service providers with valuable information on the programs and projects they administer. Because it relies on the whole spectrum of people involved in the programs, including the users, it can be an extremely effective tool in measuring successes or shortcomings, in understanding the underlying causes, and in eliciting data to support recommendations and improvements.

This evaluation Guide has provided basic information on the use of a participatory approach to evaluate the effects of new or reformed programs on seniors and their caregivers. Efforts were made to present the information clearly and simply. While it is possible to do evaluations without any outside help, readers are encouraged to take advantage of the many professional resources available to them so as to ensure that the results of their participatory evaluation efforts are meaningful and worthwhile.

It is our hope that this Guide has demystified the process and motivated you to become involved.

APPENDIX 1

TABLE 1: THE BENEFITS OF REGIONALIZATION

POLITICAL BENEFITS	RATIONALE
Greater Democratization	Allows for greater participation in the democratic process by people at the local community level.
Greater Input into Policy	Allows the public better access and input into the policy-making process because they are closer to decision makers.
Reduction of Regional Disparities	Re-allocation from have to have-not regions can be more easily defended if allocations are made on a per capita or formula basis in a regionalized system.
Spreading the Blame	Regionalization splits responsibility between politicians at the central and local levels, thereby allowing for a spreading of the blame for any failure to meet local needs.
Increased Political Accountability	Local politicians and board members are more likely to be accountable to the local population than are central politicians who are far away.
Strength through Diversity	In nations, states or provinces made up of diverse and sometimes antagonistic groups, regionalization can give such groups greater autonomy while retaining them in the larger collective.
ADMINISTRATIVE BENEFITS	**RATIONALE**
Increased Administrative Accountability	Local administrators have to deal with local issues and grievances directly and have to respond to local concerns.
Greater Integration and Co-ordination of Services	Local officials, reporting to local boards, are more able to overcome institutional, attitudinal, physical and administrative constraints on the effective operation of health services.
Better Planning and Resource Allocation	Local officials are more aware of local circumstances, constraints and opportunities and, therefore, can develop plans that are responsive to, and meet the needs of, local communities. Local citizens are also more likely to have an opportunity to provide input.
Cost Reduction	Due to local knowledge, redundancy and service duplication can be reduced or eliminated by local planners and administrators.
Better Management and Program Implementation	Reducing centralized control over local administration allows local managers the freedom to manage services with fewer "unnecessary" constraints from the centre.
Increased Intersectoral Co-ordination	In addition to the increased integration and co-ordination of health services, there is also a greater probability of intersectoral co-ordination with organizations outside the health field.
Increased Emphasis on Community and Preventive Services	To the extent that local administrators have some form of global budget, it is easier for them to transfer funds between institutional and community services and to emphasize health promotion.

Excerpt from Hollander, Marcus: "Assessing the Impacts of Health Reforms on Seniors", Part 1. Ottawa : NACA, 1997.

TABLE 2: THE RISKS INHERENT IN REGIONALIZATION

RISKS RELATED TO CONCEPTUAL PROBLEMS	RATIONALE
Poor Conceptualization	This may happen when there is not a clear understanding of the various concepts of regionalization. Options such as delegation may be overlooked if there is a rush to devolve authority to newly-created boards.
Poor Fit between Objectives and the System Devised	The system of regionalization adopted may not be congruent with the desired objectives, or different actors may hold different objectives. For example, political and financial goals may clash if politicians desire greater local autonomy through elected boards, while bureaucrats do not wish to provide the additional funds required to establish such boards.
Incorrectly Defining the Appropriate Geographic Unit	The implications of the geographic boundaries chosen for the model to be developed are significant. There is often a tendency for larger geographic units such as regions to centralize at their level. If the goal is to empower local people, control may have to be devolved to very small communities. However, such communities may be too small to have a full range of services. How does one strike the right balance?
POLITICAL RISKS	**RATIONALE**
Overcoming the Tendency to Centralization	There are strong, ongoing tendencies towards centralization as ministers are still answerable in the legislature, irrespective of whether or not local boards are supportive or antagonistic.
Local Potentates	Local boards or other political bodies may be captured by individuals who are already publicly powerful at the local level, who may wish to increase their power, and who may see membership on the new boards as a stepping stone to higher elected office.
Local Opposition	To the extent that political parties opposed to the party in power at the centre are able to capture control over local boards, such opposition groups can use local boards as power bases to oppose the government in power.
ADMINISTRATIVE RISKS	**RATIONALE**
Problems of Co-ordination	Regionalization often reveals that poor coordination and a lack of integration exists among the vertically organized programs located at the centre. It is often difficult for the centre to respond to such problems due to the magnitude of the changes required to correct such problems, e.g., a major reorganization of divisions.
Relations with Decentralized Organizations	Relations between the central administration and the newly regionalized local bodies can easily become strained over a number of matters such as the degree of local authority, accountability requirements, budgets, and other such matters. Strained relations may result in sub-optimal service delivery.

POLITICAL RISKS	RATIONALE
Geographic Boundaries	It is highly desirable that existing sets of geographic boundaries, in place prior to regionalization, be made as coterminous as possible. This may require changes in legislation and may raise concerns at the local level as to which boundaries will be used.
Composition of Local Boards	If boards are elected, they have a legitimate claim to speak for local interests, even against the central government. If they are appointed, they may be more compliant but may be perceived to lack legitimacy and moral authority.
Authority of Local Boards	The power of local boards can range from almost no real authority, to responsibility for planning, to some authority over service delivery, to significant control through the power of taxation. If the rhetoric of local empowerment confronts the reality of continued central control, there may be difficulties.
Method of Funding Services	Local governments or boards are often dependent for funding on the centre. If funding is based on a historical allocation, existing inequities may be perpetuated. If a new population-based, age and sex adjusted funding mechanism is implemented, there may be a political outcry from areas which lose funding through a reallocation of resources.
Budgeting, Expenditure Control and Priorities	If budget control is tight, local boards may be refused permission to transfer funds to restructure service delivery in accordance with local priorities. If control is loose, then the consistency of service delivery across regions may come into question. In addition, local boards may not wish to follow priorities mandated by the central government.
Administrative Control	The degree of administrative control can again vary from tight to loose. Tight control restricts the response to local needs while loose control decreases the authority of the centre to ensure equal services across regions and to protect minorities or unpopular groups from discriminatory practices.
Local Planning	Problems may arise as central governments may provide funding on an annual basis as approved by the legislature, and budgets may not be approved by the legislature until some months into the new fiscal year. Therefore, plans may become subordinate to the operational requirements of staying within budget if actual expenditures for the first quarter are greater than the funding which is ultimately approved.
Impacts on Administration at the Centre	Experience indicates that the process of regionalization often leads to a major restructuring of public servants at the centre from operational activities to planning, policy development, and monitoring. Such changes can cause strain and conflict. Public servants may be reluctant to reduce their authority by giving resources to local boards.
Staffing at the Local Level	Another problem area may be the ability to attract well qualified planners and administrators to work for local boards. There may be relatively few qualified people available. In addition, those who are qualified may not wish to relocate to small or isolated areas. Furthermore, increased local staffing for administration may increase overall costs.

Excerpt from Hollander, Marcus: "Assessing the Impacts of Health Reforms on Seniors", Part I. Ottawa : NACA, 1997.

APPENDIX 2

TABLE 1: INDICATORS RELATED TO SERVICES

QUESTION	INDICATOR(S)
Do seniors receive effective, high quality services?	• Ratings of seniors and their informal caregivers for each type and sub-type of service, on a five point scale, in regard with services. • Amount of time spent by staff with clients, and the quality of that time, by type of service. • Percentage of services which are accredited, by type of service. • Percentage of staff with appropriate professional credentials, by type of service. • Percentage of clients, by level of care, whose health or care level improves, remains constant, or deteriorates over a one year period in facilities and home care. • Percentage of clients with a clear care plan and clearly stated objectives for care in all forms of care services. • Percentage of clients in community based, residential and home based care who are admitted to an acute care hospital.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Survey research Focus groups Public consultations Comparisons across New Health Authorities (NHAs)* and to provincial average
This indicator provides information on how much time staff spend with seniors and the perceived quality of that time.	Interviews Workload measurement studies Focus groups
National or provincial quality assurance and accreditation proocedures provide some measure of assurance of quality.	Inspection of documents Interviews; Comparisons across NHAs and to provincial average
This indicator gives an indication of the quality and professional credentials of staff.	Inspection of documents Interviews; Comparisons across NHAs and to provincial average
Continuing Care is essentially a care based system; thus, an important goal is to maintain clients at their optimum level of functioning for as long as possible.	Clinical data
Documented care plans with clearly stated goals are an indication of proper, professional, and client focused care.	Clinical data
This measure will allow for a better comparison of the cost-effectiveness of community versus residential care across the range of non-acute services and may flag problems if home based clients are not cared for adequately or have care needs beyond what can be handled in the community.	Clinical data

* *New Health Authority or NHA refers to any new authority put in place to administer health programs, projects, services in the course of decentralization or other health reforms. It can refer to a regional board, a primary care agency, an integrated health system, etc.*

TABLE 1: Indicators Related to Services (cont'd)

QUESTION	INDICATOR(S)
Do seniors have adequate and sufficient services?	• Ratings of seniors and their informal caregivers on a five point scale of the extent to which services seem to be sufficient and adequate, by type of service. • Service units for each type, and sub-type, of service by NHA such as: · GPS per l,000 population · Specialists, by category, per 1,000 pop · Hospital beds per 1,000 pop · Long Term Care Facility beds per 1,000 pop, 65 years of age or older · Acute psychiatric beds per 1,000 pop · Geriatricians per 100,000 pop, 65 years of age or older · Average homemaker hours by level of care · Group home spaces per 1,000 pop, 19 years of age or older · Adult Day Care spaces per 1,000 pop, 65 years of age or older · Average Home Nursing and Rehabilitation hours/visits by level of care for longer term clients · Number of hours of nursing, rehabilitation, and homemakers per 1,000 pop, 65 years of age or older. • Staff to client ratios within hospital and institutional services, overall and for professional staff, ancillary staff and administrative staff, by level of care or case mix indicator.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Survey Comparisons across NHAs and to provincial average Time trends analysis
Utilization comparisons provide a good picture of service volumes, but it should be noted that not all services provided may actually be needed.	Ministry and NHA data Comparisons across NHAs, to provincial and average and across provinces. Comparisons to standards deemed appropriate by a panel process
Staffing comparisons are useful in that two NHAs may have the same number of beds, but their beds to staff ratios may differ even after the care needs of clients have been accounted for.	Ministry and NHA Data Comparisons across NHAs, to provincial average, across provinces and internationally

TABLE 1: Indicators Related to Services (cont'd)

QUESTION	INDICATOR(S)
Are services available and accessible and provided at a time that is suitable for the client?	• Ratings of seniors and their informal caregivers on a five point scale of the availability, accessibility and timeliness of services, by category of service, e.g., hospital, home care, adult day care centres. • Waiting times in institutions by key services such as eating, bathing, toileting, relief of pain. • Perceived appropriateness of the times at which services are provided. • Lengths of waiting lists, and waiting times, on average and by facility or professional care provider (e.g., specialist physician) for all types of services, e.g., waiting list and length of wait for heart surgery, for admission to long term care facilities, mental health community residences, adult day care services, homemaker services and so on. • Percentage of clients and families who experience no delays or very modest delays in access to services, by type of service. • Percentage of clients and families who experience delays in moving between institutions or regions, by category of service.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Surveys Focus groups
This indicator focuses on a key care issue for seniors, i.e., provision of basic services related to physical functioning.	Interviews Focus groups Participant observation
This indicator focuses on the suitability to seniors of when services are provided, i.e., whether services are provided to meet agency needs or the needs of the seniors.	Interviews Focus groups
Waiting list may be inflated with people on the list who do not need services immediately, but they are still a useful comparative measure.	Ministry data Comparisons, by type of service, across NHAs to provincial average, across provinces and internationally
This indicator gives a sense of what proportion of clients are receiving prompt service.	Ministry data Comparisons, by type of service, across NHAs, to provincial average and across provinces
This may indicate systems blockages or problems with co-ordination.	Ministry data Comparisons, by type of service, across NHAs, to provincial average and across provinces

TABLE 1: Indicators Related to Services (cont'd)

QUESTION	INDICATOR(S)
Is there an appropriate continuity of services and are the services provided predictable?	• Ratings of seniors and their informal caregivers on a five point scale of the continuity and predictability of services. • Number of new agencies starting per year, and old agencies closing down per year, by type of service. • Number of agencies with more than a 5% increase or decrease in staffing. • Staff turnover rate, by agency, for each type of service. • Percentage of agencies with policies to allow staff to care for the same clients over time, by type of service.
Are services acceptable and appropriate?	• Ratings of seniors and their informal caregivers on a five point scale regarding the acceptability and appropriateness of services. • Extent of client and family involvement in the selection of services (e.g., long term care facility) and the development of their care plans. • Level of satisfaction, by type of service, for clients and families regarding: · protection of confidentiality · friendliness of staff and administration · approachability of staff and administration · social events · crafts and hobbies · input into agency decision-making · access to preferred staff who come into the home · timeliness of home care staff • Percentage of clients who complain about the care provided.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This indicator gives a sense of agency level turnover or stability.	Ministry and NHA data
This is a measure of stability based on agency level growth or decline.	Ministry, NHA and Agency data
This is a measure of staff turnover. High turnover will mean that services may not be predictable.	Ministry, NHA and Agency data
This is a measure of consistency or predictability of staff services.	Inspection of documents
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This is a measure of the extent of family involvement and family-centred care.	Clinical notes Interviews
These are measures of satisfaction for clients and for their informal caregivers.	Surveys Focus groups Public consultation
This is a red flag indicator about the quality of care.	Clinical notes

TABLE 1: Indicators Related to Services (cont'd)

QUESTION	INDICATOR(S)
Are services flexible and adaptable?	• Ratings of seniors and their informal caregivers on a five point scale about the flexibility and adaptability of care, by type of service.
	• Percentage of seniors, and their informal caregivers, who perceive service providers to be flexible and adaptable in regard to the provision of care, by type of service.
Are services affordable?	• Ratings of seniors and their informal caregivers on a five point scale about the affordability of health care services overall, and by type of service.
	• Costs of accessing care.
	• Analysis of the nature and amount of user fees by type of service and the extent to which such fees are reasonable.
Is the care that is provided family-focused?	• Ratings of seniors and their informal caregivers on a five point scale, by type of service, of the extent to which care is family-focused.
	• Extent of seniors' involvement in decisions about their care.
	• Percentage of cases with families, by type of service in which families: · are involved in care planning · feel they can speak freely to staff · feel they can speak freely to administration · feel they can request reasonable changes to care plan · are not consulted about care decisions.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
It is important to obtain the views of seniors and of their informal caregivers about the degree of flexibility and adaptability in service provision.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This indicator provides a measure of the costs to seniors of traveling to a site where care is provided.	Interviews Focus groups
Fees can be compared across NHAs and across provinces.	Ministry, NHAs and facility data Panel process
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This indicator provides a measure of the extent to which the senior is involved in family based care decisions.	Interviews Focus groups
This provides some context for the extent to which families are involved in care. It is a useful measure if tracked over time and across NHAs.	Surveys Comparisons across NHAs and to provincial average Time trends analysis

(This table is excerpted from Hollander, Marcus: "Assessing the Impacts of Health Reforms on Seniors, Part II: A Model for analyzing Health Reforms: A Structure, Process and Outcome Approach" Ottawa: NACA, 1998.)

TABLE 2: INDICATORS RELATED TO SERVICE PROVIDERS

QUESTION	INDICATOR(S)
Are service providers reviewed by a provincial or national accreditation body on a regular basis?	Are agencies reviewed and/or accredited? (yes or no)
Is the nature and quality of communication provided by care staff appropriate?	• Ratings of seniors and their informal careivers on a five point scale, by type of service, of the quality of written and oral communication. • Ratings of seniors and their informal caregivers on the clarity of written communications, by type of service, for: · description of policies · description of services · care plans · choices and options for service · care objectives for the client · rights of appeal. • Ratings of seniors and their informal caregivers of verbal communication, by type of service, for: · initial contact · choices and option for service · care planning · provision of care · discharge planning · accessibility of staff to talk to them about issues.

RATIONALE	DATA SOURCES AND METHODS
Almost all of the values related to service providers are typically included in a comprehensive accreditation process.	Agencies, accreditation bodies, Ministries of Health
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs* and to provincial average Time trends analysis
These are measures of the adequacy of written communications.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
These are measures of the adequacy of verbal communications.	Surveys Comparisons across NHAs and to provincial average Time trends analysis

** New Health Authority or NHA refers to any new authority put in place to administer health programs, projects, services in the course of decentralization or other health reforms. It can refer to a regional board, a primary care agency, an integrated health system, etc.*

TABLE 2: Indicators Related to Service Providers (cont'd)

QUESTION	INDICATOR(S)
Are staff caring, and do they take the necessary time with clients, show an interest in clients, go the extra mile for clients and anticipate and plan for future needs?	• Ratings by seniors and their informal caregivers of staff on a five point scale, by type of service, about: · caring · taking time · going the extra mile · anticipating future needs · showing an interest in the client.
Are staff well trained and competent?	• Ratings by seniors in care and their families, by type of service, regarding: · the caring nature of staff · the extent to which staff take the time to listen to problems and show an interest in the client · adequacy of the time spent with the client · extent to which the agency seems understaffed · extent to which staff go beyond the call of duty to care for the client or explain things to family · extent to which care staff look ahead and plan for the future, i.e., lining up possible placements to another agency. • Ratings of seniors and their informal caregivers on a five point scale, by type of staff and type of agency, of the competence of staff. • Ratings of seniors and their informal caregivers, by type of service, regarding: · percentage of staff with appropriate certificates, licences and so on · number of training days provided to staff for each agency, by type of staff and type of service · existence of policies to facilitate training opportunities for staff.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
These are basic indicators of the extent of caring and compassion for, and interest in, the client.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
· This is a measure of professional training	Agency data
· This is a measure of the extent to which the agency supports staff training and certification	Agency data
· This is a measure of the extent to which the agency supports staff training and certification.	Agency policy manual

TABLE 2: Indicators Related to Service Providers (cont'd)

QUESTION	INDICATOR(S)
Are clients treated with respect and dignity?	• Ratings of seniors and their informal caregivers on a five point scale, by type of staff and type of agency, of the extent to which seniors in care are treated with respect and dignity.
Are there enough staff and volunteers in agencies to properly care for clients?	• Existence, or not, of a code of ethics, policies or "clients bill of rights" to ensure that clients are treated with dignity and respect.
	• Ratings of seniors and their informal caregivers on a five point scale, by type of agency, of the adequacy of staff and volunteers.
	• Comparisons of staffing levels, controlling for differences in case mix, across agencies, by type of agency.
	• Ratio of volunteers to staff.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the questions.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This is a measure of the extent to which the agency has gone to ensure that clients are treated with respect and dignity.	Agency information
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Agency staffing information
This may be a bit complex in terms of the analysis to be conducted; it also requires that case mix classification systems are in place.	Agency data, statistical analysis
This is a comparative measure of the use of volunteers.	Agency data

(This table is excerpted from Hollander, Marcus: "Assessing the Impacts of Health Reforms on Seniors, Part II: A Model for analyzing Health Reforms: A Structure, Process and Outcome Approach" Ottawa: NACA, 1998.)

TABLE 3: INDICATORS RELATED TO THE SERVICE DELIVERY SYSTEM

QUESTION	INDICATOR(S)
Are services adequately co-ordinated?	• Ratings of seniors and their informal caregivers, on a five point scale, of the degree of service co-ordination before and after reforms. • Number of hospitals with discharge planning/utilization management groups to facilitate co-ordination of discharges to community agencies. • Extent to which home and community based services are co-ordinated with each other, and with institutional services. • Existence of blockages to inter-agency and inter-regional transfers, due to policy, financial incentives, or other reasons. • Extent to which there is a better balance and mix of services in a region after reforms.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs* and to provincial average Time trends analysis
This measure addresses the degree of linkage between acute hospitals and home and community based services.	Hospital information Time trends analysis
This indicator addresses the degree of co-ordination among community services and across the institutional-community continuum.	Panel process Interviews Focus groups of seniors
This measure addresses structural and process matters which inhibit co-ordination. If possible, it would also be appropriate to count the number of blockages.	Panel process Interviews
This would be hard to determine empirically and is, therefore, measured by seniors' perceptions of the extent to which they feel there is a better mix of services.	Panel process Quantitative analysis

** New Health Authority or NHA refers to any new authority put in place to administer health programs, projects, services in the course of decentralization or other health reforms. It can refer to a regional board, a primary care agency, an integrated health system, etc.*

TABLE 3: Indicators Related to the Service Delivery System (cont'd)

QUESTION	INDICATOR(S)
Are medications prescribed appropriately and are they affordable?	• Ratings of seniors and their informal caregivers of the appropriateness and affordability of medication prescribing, on a five point scale. • Extent of training, on an annual basis, of physicians and other care providers about medications, their use, interactions and effects. • Number of problems recorded due to reference-based pricing. • Average number of prescriptions for seniors by age and sex groups, and types of condition and disability. • Proportion of seniors in care having moderate to severe side-effects from medications. • Out-of-pocket costs of medications. • Extent of review of clients' prescriptions by physicians and pharmacists.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This is a measure of the knowledge of drugs by formal care providers.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
Some seniors noted problems related to taking generic drugs.	Ministry data Surveys
This is a measure of overall prescribing practices for seniors.	Ministry data Time trends analysis Comparison across NHAs and to provincial average
This is an indicator of the degree of discomfort of taking medications and may be a clinical trigger to review the clients' medications.	Interviews Clinical data
This is a measure of costs to seniors of using medications.	Interviews Pharmacy data
This is a measure of how often the full range of medications prescribed for seniors is reviewed by their caregivers.	Surveys of health professionals Focus groups with clients

TABLE 3: Indicators Related to the Service Delivery System (cont'd)

QUESTION	INDICATOR(S)
Are health services available and appropriate after reforms?	• Ratings of seniors and their informal caregivers on a five point scale of the overall effects of reforms for them, and of the availability and appropriateness of services. • Seniors' perceptions of the major benefits and major shortcomings of reforms. • Seniors' perceptions of the availability and appropriateness of services. • Rates of service units/pop. for all types of services (i.e., are there more or fewer services after reforms?). • Number of new types of services adopted after reforms. • Extent to which ancillary and socio-medical services are available before and after reforms such as: · seniors' transportation · palliative care · adult day care · assistance devices programs · friendly volunteer visitor programs · massage therapy. · alarm systems · home renovations · other services • Extent to which waiting lists for facilities, surgery, community services, and so on have been shortened, or lengthened, by type of service.

RATIONALE	DATA SOURCES AND METHODS
This indicator provides seniors' and caregivers' views of the question.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This indicator is an exploration of the pros and cons of regionalization from the perspective of seniors.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This is a measure of the extent seniors feel services are still available and appropriate.	Surveys Comparisons across NHAs and to provincial average Time trends analysis
This is a basic measure of the resources in the health care system.	Ministry data Time trends analysis and analysis across NHAs
This is an indicator of innovation in service delivery.	Ministry and NHA data
A measure of the extent to which services from other sectors have been linked to services in the health sector. Seniors need a range of services outside of health care to assist them due to their functional deficits.	Ministry and NHA data Time trends analysis Comparisons across NHAs and to provincial average
Waiting lists are an inexact measure, but it may be useful to look at trends over time.	Ministry and NHA data Time trends analysis Comparisons across NHAs and to provincial average

(This table is excerpted from Hollander, Marcus: "Assessing the Impacts of Health Reforms on Seniors, Part II: A Model for analyzing Health Reforms: A Structure, Process and Outcome Approach" Ottawa: NACA, 1998.)

APPENDIX 3

SAMPLE GUIDELINES FOR THE CONDUCT OF A QUALITATIVE INTERVIEW

In preparation for the interview:
- call the seniors whom you wish to interview to arrange a convenient appointment time and place
- test out tape recorder and get extra batteries
- try a test run of the interview with a friend or two if you can. (Get them to give you feedback about your interviewing techniques.)

During the Interview

Take with you the tape recorder, tape, extra batteries, tissues and interview questions. Sit in comfortable chairs facing each other (eye contact is good). Use nods and other non-verbal encouragement to help the interviewees go on.

Describe why you are doing the interview and why you are taping it. Ensure them of the confidential nature of the interview and get signed consent. Test the tape recorder again before you start.

Explain that there are no right or wrong answers. All points of view – both positive and negative – are valued.

A major problem in this type of interviewing is lack of specificity in answers. We have provided some probe sentences in Appendix 5 to use if people don't have much to say. But before you use those, try some of the following:

- Could you tell me a little more about (or elaborate on) that?
- Call you expand on that idea?
- Can you give me an example of that?
- Can you tell me about a specific time when this issue arose for you?
- I didn't quite understand what you meant by that. Can you find some different words to help me understand?
- Is there anything else related to this that you would like to say?

What to do if:

1. The person cries or expresses anger during the interview: It's ok if they feel sadness, anger or other feelings during the interview. Offer them a tissue and sit quietly with them for a few minutes. Only touch or hug if it seems welcome. Keep in mind you did not cause these feelings but may have allowed for them to express them and feel heard. Overall, many older people find this type of interview very satisfying and like to feel they are helping others by sharing their own stories.

2. The person asks to stop the interview: End it without question. They have the right to stop the interview or the tape at any time. Find another person to interview if possible.

3. The tape recorder fails: Rebook the interview when you get it working or replaced.

4. The person seems depressed or needs information or support: Offer to have a professional in the community call them. Call your local home care nursing office to find a number for a nurse or social worker.

APPENDIX 4

SAMPLE GUIDELINES FOR ORGANIZING A FOCUS GROUP SESSION

Thank you for agreeing to organize a focus group meeting to enable selected seniors to talk about their views of health care. The participants should be told that the interview will be tape-recorded for analysis, but no names will be used in reporting the results. They are free to not attend the group or once attending, they may refuse to answer any question asked of them.

Offer possible times for the group to meet. Explain the likely duration of the session. Please select a room that is quiet, accessible, has comfortable seating for 10, has a place to make coffee and is near to a washroom.

People who participate in this group should have had recent encounters with the health care system and should be comfortable expressing their views in the English language. In order to have a balanced group, try to ensure that there is an equal mix of men and women, younger (age 65 to 75) and older seniors (age 75 +), and people who are married or living with someone plus those who are widowed, divorced or single. Below you will find a grid to assist you in making the group member selection. Try to have a balance of these three characteristics but if you are getting close to the end and can't fill one or more of the slots, try to find someone who has had lots of experience with health care and is willing to share their impressions. Seven participants would be an adequate number.

NAME	GENDER	AGE	MARITAL STATUS
1			
2			
3			
4			
5			
6			
7			
8			

APPENDIX 5

SAMPLE INTERVIEW SCHEDULE (USED FOR A QUALITATIVE STUDY OF SENIORS' VIEWS OF HEALTH CARE)

Introduction

Thank you for agreeing to participate in this interview. As you know, you are being interviewed as part of a project being conducted by (name of organization). Given that in recent years, there have been a number of changes in the health care system, (name of organization) is concerned whether seniors are receiving satisfactory care. We would like to hear your views on health care and your experience in obtaining it. This information will help us better plan for future modifications that may be needed.

Your answers to the questions will remain confidential. Your participation is voluntary so feel free to decline from answering any questions you wish. The interview should take approximately 30 minutes of your time and I will be using a tape-recorder so that I don't miss any of the important things you may wish to say.

Are there any questions you wish answered before we begin?
(Note to interviewer - This is a friendly reminder - make sure the tape recorder is on.)

---

1. General Information

I am first going to ask you a few general questions about yourself and your health.

1.1 How old were you on your last birthday?

1.2 Gender - Male or Female (Do not ask question – circle one)

1.3 Who else lives in your home?

1.4 Would you say you live in a rural or an urban community?
(If in doubt, record name of city/town/municipality)

1.5 What is the first language spoken in your home?

1.6 Are any other languages spoken in your home?

1.7 For your age, would you say, in general your health is:

❒ Excellent ❒ Good ❒ Fair
❒ Poor ❒ Bad ❒ Don't know

2. Health Care Utilization

Now I'd like to ask you about the types of services you are receiving or have received during the last year.

2.1 Have you used any of the following services during the last year? How often have you used the service in the past 6 months?

SERVICE	HOW OFTEN USED?
home maker services	______________
home nursing services	______________
meal delivery	______________
respite care	______________
participation in a hospital or community-based day program for seniors	______________
physiotherapy	______________
family doctor visits	______________
medical specialist visits (e.g., cardiologists, rheumatologist, ophtalmologists)	______________
other health providers (e.g., chiropractors, massage therapists, homeopaths)	______________

2.2 Are you receiving any other services, not on this list, that you would like to mention? How often do you use these other services?

2.3 What kind of care do you look for from the people who provide these services?

Probes: What do you expect of these caregivers? How do you want to be treated? How do you feel after seeing your doctor, a medical specialist? How do you feel after a visit by the home care nurse, a homemaker, etc.?

2.4 In addition to the health care people you've already mentioned, does anyone else help you in your home or when you go outside for any reason (e.g., appointments, banking, shopping, groceries, movies, to visit with friends or family)?

Probes: Do you have family/relatives/neighbours who help you? In what ways do they help you?

3. Health Services

3.1 Thinking about the services you are receiving, I would like to know the reasons why you need these services.

Probes: How important are these services in helping 1.) you manage activities necessary for living independently in the community; 2.) others who are providing you with care? In what ways do they enhance your quality of life, ensure your basic needs are met, prevent admission to a hospital or nursing home, assist you to improve so you can manage your own care?

3.2 Over all, how would you describe your recent experiences with the services you are receiving?

Probes: Would you say that your experiences have been very good, satisfactory or not good at all? Have some experiences been better or worse than others? How do you feel after a visit with the doctor, massage therapist or after the homemaker or nurse leaves your home? Was it difficult for you to get information about the services or to actually obtain the service?

3.3 I would also be interested in hearing your views on how well the services you receive are co-ordinated.

Probes: For example, the workers may be always changing but are workers kept up-to-date on your needs. Is your family kept informed and involved in the planning of your care? Is your doctor aware of the home care services you are receiving?

3.4 In your view, what kind of services do you need to meet your health needs adequately?

Probes: What are the range of health services that you feel you need currently? Where should these services be located - in the hospital or in the community? Are there other services not directly related to health care like transportation, grocery shopping etc. that you feel you need to help you live in the community?

3.5 Have you any suggestions for making the health care system better for seniors in general, now or in the future?

4. Health System Delivery Changes

4.1 We are very interested in hearing about any changes that may have occurred in your community regarding the way health services are being delivered. Thinking back over the last year, have you encountered any changes in the way your health care needs are being met?

Probes: What has happened? Are some services easier to get than others? Does the home care nurse or home maker change often? Are you having to pay for services that were previously paid for by the government or a private insurance company?

4.2 Have any of these changes made a difference to the quality of care you receive or your quality of life?

Probes: For example, based on your own experience, would you say that it is now easier, harder or about the same to see your family doctor or a medical specialist, get home care service or get admitted to hospital. Would you give me some examples?

4.3 Are you aware of any changes in the health services in your province or community?

Probes: For example- Have any hospitals been closed or mergers taken place? Are you now paying for any services that were previously paid for partially or completely by government (medications, home nursing services)? Have you encountered any changes in eligibility criteria for certain services such as home help or home nursing?

Thank you for taking part in this interview.

APPENDIX 6

SAMPLE PHYSICAL HEALTH QUESTIONNAIRE (QUANTITATIVE QUESTIONNAIRE)

1. About how many times have you seen a doctor during the past six months other than as an inpatient in a hospital? *[Include psychiatrist visits]* ___________ times

2. During the past six months how many days were you so sick that you were unable to carry on your usual activities - such as going to work or working around the house?

   ❒ None
   ❒ A week or less
   ❒ More than a week but less than one month
   ❒ 1-3 months
   ❒ 4-6 months
   ❒ Not answered

3. How many days in the past six months were you in a hospital for physical health problems? ___________ days

4. How many days in the past six months were you in a nursing home, or rehabilitation centre for physical health problems? ___________ days

5. Do you feel that you need medical care or treatment beyond that you are receiving at this time?

   ❒ yes
   ❒ No
   ❒ Not answered

6. Are you experiencing any of the following illnesses at the present time? *(CHECK "YES" OR "NO" FOR EACH OF THE FOLLOWING. IF "YES", ASK: "How much does it interfere with your activities, not at all, a little (some), or a great deal?" and check the appropriate box.)*

Yes	No	Not at all	A little	A great Deal	Illness
					Arthritis or rheumatism
					Glaucoma
					Asthma
					Emphysema or chronic bronchitis
					Tuberculosis
					High blood pressure
					Heart trouble
					Circulation trouble in arms or legs
					Diabetes
					Ulcers (of the digestive system)
					Other stomach or intestinal disorders or gall bladder problems
					Liver disease
					Kidney disease
					Urinary tract disorders and prostate trouble
					Cancer or leukaemia
					Anaemia
					Thyroid or other gland problems
					Skin disorders (ulcers, sores, rashes)
					Speech problems/hearing/vision
					Bone disorders (e.g. osteoporosis)
					Effects of stroke

APPENDIX 7

SAMPLE FORM: CONSENT TO BE INTERVIEWED

I, the undersigned, voluntarily agree to participate in an interview conducted by (name, organization and phone number). I understand that the purpose of the study is to explore people's experiences with the health care system. This is part of an evaluation study of health services for seniors.

I may refuse to answer any question asked of me and may stop the interview at any time. I also understand that I may refuse to participate in the study and this will not affect any services I am receiving.

I understand the interview is being tape-recorded and after the analysis, the tape will be erased. My name will not be used in any published reports of this study. The interview will last about one hour. There are no risks to my participation and I may receive a copy of the final evaluation report if I wish.

Signed ______________________________________

Date ____

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