

Population Needs Assessment

**A workbook for assessing patients' and
practitioners' decision making needs.**

M.J. Jacobsen RN MEd
A.M. O'Connor RN PhD
University of Ottawa

TABLE OF CONTENTS	Page
A. What is Population Needs Assessment?	3
B. What is the Rationale or Purpose of a Needs Assessment?	3
I. Why Conduct a Needs Assessment?	3
II. How Can the Results of a Needs Assessment Be Used?	5
C. Planning a Needs Assessment	7
Steps in Planning a Needs Assessment	8
1. Define the <i>objective</i> of the Needs Assessment	8
2. Identify the <i>participants</i>	9
3. Identify the <i>rationale</i> or purpose of the Needs Assessment	10
4. Identify the <i>information</i> you wish to collect.	11
5. Select the <i>methods</i> for collecting the information.	12
6. Develop <i>data collection tools</i> (e.g. interview forms, survey, questionnaire)	13
Information, Methods & Tools Planning Sheets	14
7. Select the <i>sample, sample size</i> and <i>sampling procedure</i>	16
8. Develop a <i>schedule</i>	17
9. Conduct the needs assessment	18
10. Analyse and summarize the results.....	18
11. Present the information	18
D. Glossary of Terms	19
E .Samples of Needs Assessment Tools	21
<i>Practitioner Tools</i>	
a) Personal Interview	22
F. References and Resources	26

**Population Needs Assessment:
Assessing patients' and practitioners' needs regarding shared decision making.**

A. What is a Population Needs Assessment?

A need can be defined as 'a gap between what is and what should be'. A **Needs Assessment** is a study in which data are collected for estimating the needs of a group, community or organization. In the context of decision making, the focus of a needs assessment is on identifying: a) what a patient population needs to make better decisions; and b) what a population of health practitioners need to improve the support they provide to patients during decision making.

B. What is the Rationale or Purpose of a Needs Assessment?

During the assessment, one collects information about the opinions, attitudes and preferences of individuals and groups. The *rationale* or *purpose* of a needs assessment explains why the assessment is being done and how the results will be used.

I. Why Conduct a Needs Assessment?

Needs assessment can help identify:

- what groups want or need;
- whether existing programs or interventions are meeting the needs of those who are supposed to benefit;
- which groups need services, and;
- what might be the best alternatives for meeting those needs

1. Determining what do groups want or need

It is important to assess what groups say they need. According to the Ottawa Decision Support Framework, the focus is on both the patient and the practitioner populations to find out the difficulties they have with decision making. Possible needs include: *decisional conflict and related deficits in knowledge and expectations, values clarity, and support and resources*. Needs may also be specific to the type of decision and characteristics of the patients and practitioners.

Helpful questions that are organized according to the framework include:

DECISION: What decisions do patients have to make? What decisions do practitioners spend time discussing with patients? What decisions do patients/practitioners feel they need assistance?
DECISIONAL CONFLICT: Which decisions are the most important and difficult to make?
FACTORS CONTRIBUTING TO DECISIONAL CONFLICT [knowledge, values clarity, support and resources]: What makes the decision difficult? What is needed? (e.g. for clients: reliable information, support, improved self-confidence and skill in decision making, methods of clarifying and communicating values, etc.; or for practitioners: reliable information, strategies and skills in supporting decision making, etc.)

2. Determining whether existing programs meet the decision support needs

Needs can be defined as 'a gap between what is and what should be'. Therefore it is important to understand what is already being done, and how well it meets the needs of clients and practitioners.

Helpful questions include:

DECISION SUPPORT: What is currently being done? How are these decisions usually made? How do practitioners, (nurses, physicians, others), currently support their clients' decision making? What are the barriers to providing decision support? What are the facilitators to providing decision support? What strategies could be used to overcome the barriers?

3. Determining which groups need services

Needs assessment can help identify groups that are not receiving the decision support they need. This could be a large population or a 'target group'. Perhaps the population in your community has changed, or some groups within the community are not being served by your organization.

Helpful questions include:

PERSONAL AND CLINICAL CHARACTERISTICS: Which groups are not having their needs met? (e.g. All of the women at the community health centre, older women, families with young children, mothers deciding about breastfeeding.) Are there groups involved in health decision making that are currently not served by your organization? (e.g. Mothers are often the gate keepers to their family's health, yet their husbands may be involved in health decisions but not receive any decision support.)

4. Determining the best alternatives for meeting the need

Decision support strategies can be developed for patients or practitioners to meet their needs. Strategies can be general or tailored to a specific decision. Methods of providing the decision support can take various formats. Patient-focused strategies might include: individual or group counselling; role playing; educational materials using pamphlets, audio-booklets; videos; Internet-based strategies, etc. Practitioner-focused strategies might include: continuing education programs; audit and feedback; and written materials in the form of reviews, practice guidelines, clinical algorithms, care maps, etc. Methodologies must be suitable for the participants and the nature of available resources.

Helpful questions include:

SUPPORT AND RESPOURCES: What resources are available to the groups receiving decision support? What are their preferences? What suggestions do they have for disseminating the decision support strategies to others?

II. How Can the Results of A Needs Assessment Be Used?

Needs assessment can be used to:

- plan for programs/services
- help define and solve problems
- establish priorities
- evaluate programs and demonstrate accountability
- raise awareness of needs and potential interventions
- stimulate and involve those with vested interest in the process

1. Developing plans for programs or services

A needs assessment should be the first step in developing plans for programs or services. Programs should meet the needs of those they are designed to serve. To accomplish this, program developers need to know their clients and the areas in which they need decision support, and the feasibility issues in providing that support. Too often programs are designed because someone thinks a program would be a good idea, without determining the needs of those actually involved, both practitioners and clients.

2. Define and solve problems

A needs assessment can determine the difficulty clients and practitioners have making decisions and the contributing factors, and thus point the way to identifying appropriate strategies to address the problems.

3. Establish priorities

A needs assessment can be used to distinguish between decisions that definitely require support and those in which it might be nice to improve decision support, but not absolutely necessary. Measuring the *extent and impact of difficulty clients and patients have making decisions* helps those planning decision support set priorities.

4. Evaluate programs and demonstrate accountability

Needs assessment can identify situations in which current practice is already meeting clients' decision support needs, or be used as a basis for justifying the use of time and resources to develop decision support strategies when current practice is not addressing clients' decision support needs.

5. Raise awareness of needs and potential interventions

In the previous examples, the purpose of the needs assessment was related to how the information collected would be used. However, a needs assessment also raises the awareness of those directly involved in the process. The very act of asking people for information on a topic heightens their awareness of the topic and the issues involved. (e.g. commonalities in decision support needs across groups, availability of practice guidelines or evidence-based information about benefits and risks of health care options, factors contributing to uncertainty in decision making, or the nature and availability of decision support tools such as decision aids).

6. Involve those with vested interests and foster commitment

One of the overriding purposes of a needs assessment is to have the results of the needs

assessment used. In the case of a decision support needs assessment this would include involving all of the following: clients and practitioners; plus, any other individuals or groups affected by the data collection, interpretation of the results, or planning and implementation of the resulting decision support strategy, (e.g. administrators, policy makers, partners, community groups). Involvement of those with vested interests will increase their commitment to acting on and using the results.

C. Planning a Needs Assessment

Steps in Planning a Needs Assessment

1. Define the *objective* of the Needs Assessment
2. Identify the *participants*
3. Identify the *rationale* or purpose of the Needs Assessment
4. Identify the *information* you wish to collect.
5. Select the *methods* for collecting the information.
6. Develop *data collection tools* (e.g. interview forms, survey, questionnaire)
7. Select the *sample, sample size* and *sampling procedure*
8. Develop a *schedule*
9. Conduct the needs assessment
10. Analyse and summarize the results
11. Present the information

Step 2. Identify the *participants*

The participants will include:

-the target group

e.g. defined by age, gender, developmental stage, health status, income, education, and/or location); and

-any others who influence the target group

e.g. family members, community groups, practitioners, administrators, and/or policy makers.

Budget and human resources available will affect the choice of participants. You may wish to list the participants in order of importance in meeting your objective.

<p>Which participants should be included in the Needs Assessment?</p> <p>Target group: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Others influencing target group: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>

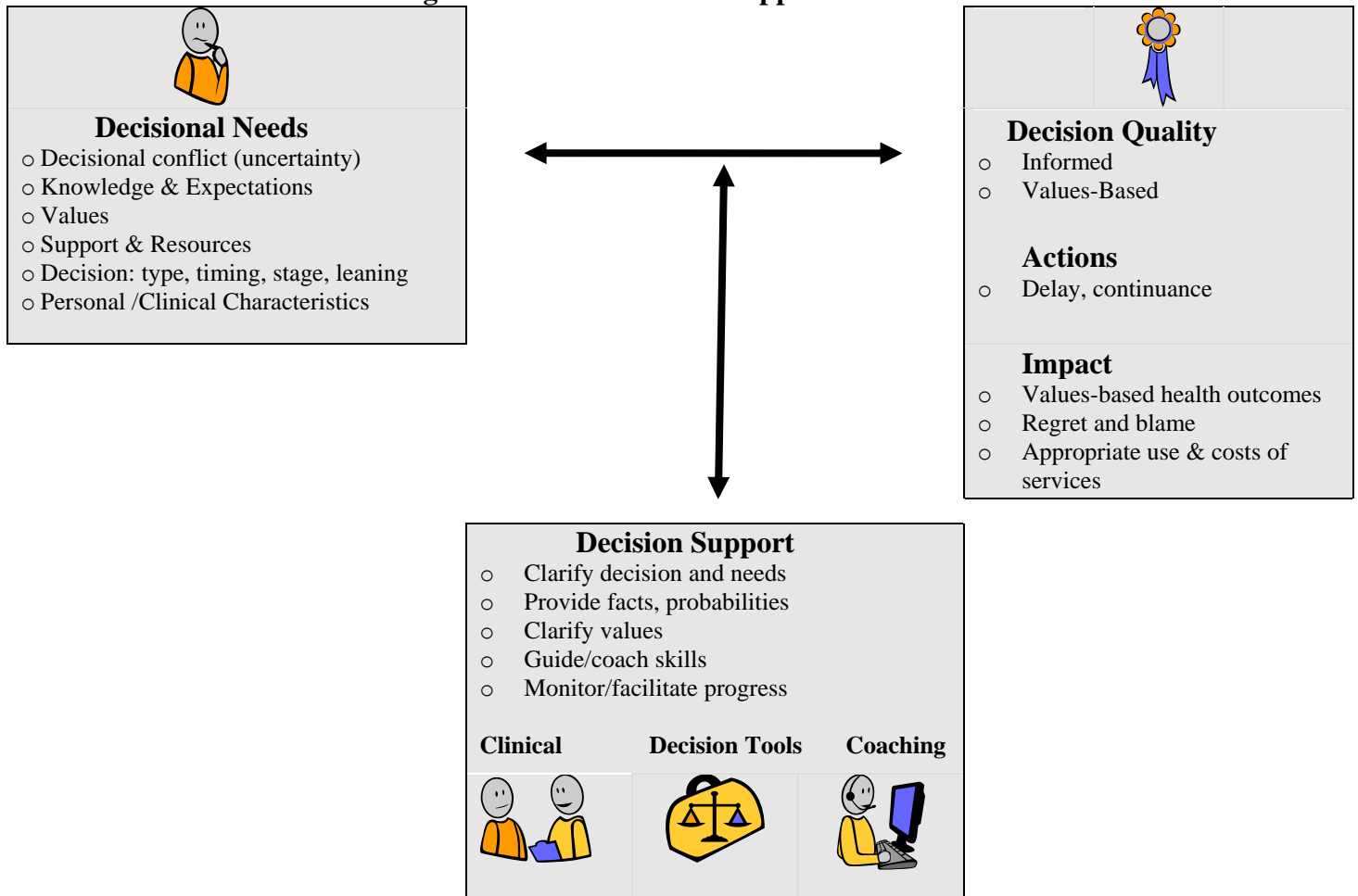
Steps 4, 5 and 6 deal with *Information* to be collected, the *Methods* you will use and the *Tools* you will adapt or develop to conduct your needs assessment. Instructions:

Review steps 4 - 6, and then plan your data collection on the worksheet that follows.

Step 4. Identify the *information* you wish to collect.

The Ottawa Framework for Decision Support outlines the decisional needs and provides guidance for the type of information that should be collected.

Figure 1 Ottawa Decision Support Framework



The framework asserts that participants' [individual, family, population, practitioners] decisional needs will affect decision quality (informed, values-based choices), which in turn affects behavior (e.g. delay), health outcomes, emotions (regret, blame), and appropriate use and costs of services. Unresolved needs adversely affecting decision quality include: decisional conflict; inadequate knowledge and unrealistic expectations; unclear values; inadequate support or resources; complex decision type; urgent timing; unreceptive stages of decision making; polarized leanings toward option; and participant characteristics such as cognitive limitations, poverty, limited education, physical incapacitation. Decision support in the form of clinical counseling, decision aids and coaching can improve decision quality, by addressing unresolved needs.

Table 4. Glossary of Terms for Ottawa Decision Support Framework

DECISIONAL NEEDS
DECISION Type: class or characteristic of the choice that needs to be made [e.g. developmental transition or clinical options (screen, test, treat, palliate)]; number of options, degree of risk/uncertainty, seriousness of outcomes, whether it is irrevocable Timing: time frame or urgency with which a decision needs to be made Stage: phase of decision making: not thinking about options; considering options; close to selecting an option; taking steps towards implementing option; have already carried out choice. Categories are similar to Prochaska's Stages of Change (1), with one important difference. Deciding <u>not</u> to change is a viable option because often there is no recommended course of action, e.g. amniocentesis. Leaning: inclination to choose one option over the other
DECISIONAL CONFLICT Uncertainty about course of action to take when choice among options involves risk, loss, regret, challenge to personal life values
KNOWLEDE & EXPECTATIONS Knowledge: cognizance of the health problem or situation, options, and outcomes Expectation: perceived likelihood or probability of outcomes of each option
VALUES desirability or personal importance of outcomes of options
SUPPORT & RESPOURCES Others' opinions/ practices: perceptions of what others decide or what others think is the appropriate choice. This may include a person's spouse, family, peers, and practitioner(s). For practitioners: the patient, professional peers, and personal network Pressure: perception of persuasion, influence, coercion from important others to select one option Role in decision making: the way a participant is or wants to be involved in decision making; do they prefer to: make the choice themselves after considering opinions; share decision making with another; have others decide after considering their opinion Experience: past exposure to the situation, options, outcomes, decision making process Self-efficacy: confidence or belief in one's abilities in decision making, including shared decision making Motivation: readiness and interest in decision making, including shared decision making Skill: abilities in making and implementing a decision External support: Available, accessible assets from others that are required to make and implement the decision. Types include: information, advice, emotional support, instrumental help, financial assistance, health & social services. Sources include: social networks, professional networks, support groups, voluntary agencies, and the formal health care, education, and social sectors
PERSONAL & CLINICAL CHARACTERISTICS Patient: Age, gender, education, marital status, ethnicity, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social) Practitioner: age, gender, ethnicity, clinical education, specialty, practice locale, experience, counseling style
DECISION SUPPORT:
PATIENT DECISION AIDS Evidence-based tools to prepare people to participate in making specific and deliberated choices among healthcare options in ways they prefer. They supplement (not replace) clinician's counseling and aid decision making by: a) providing evidence-based information about a health condition, the options, associated benefits, harms, probabilities, and scientific uncertainties; b) helping people to recognize the values-sensitive nature of the decision and to clarify the value they place on the benefits, harms, and scientific uncertainties. Strategies include: describing the options in enough detail that clients can imagine what it is like to experience the physical, emotional, and social effects; and guiding clients to consider which benefits and harms are most important to them; and c) providing structured guidance in the steps of decision making and communication of their informed values with others involved in the decision (e.g. clinician, family, friends)
DECISION COACHING Support provided to people facing a decision by a trained facilitator who is supportive but neutral in the decision. Coaching can be provided face to face (individual, group) or using communication technologies (telephone, Internet). Decision coaching is used alone or in combination with patient decision aids. The strategies may include: a) clarifying decision and monitoring needs; b) facilitating access to evidence-based information, verifying understanding, clarifying values, building skills in deliberation, communication, and accessing support; and c) monitoring and facilitating progress in decision making and decision quality.
DECISION QUALITY
QUALITY OF THE DECISION The extent to which the chosen option best matches informed clients' values for benefits, harms, and scientific uncertainties
QUALITY OF THE PROSEE OF DECISION MAKING The extent to which a person is helped to: a) recognize that a decision needs to be made; b) know about the available options and associated procedures, benefits, harms, probabilities, and scientific uncertainties; c) understand that values affect the decision; d) be clear about which features of the options matter most to them (e.g. benefits, harms, and scientific uncertainties); e) discuss values with their clinician(s); and f) become involved in decision making in ways they prefer.

Some sample questions for patients and practitioners are listed for each need:

DECISION: What are the important decisions that you need to make? Why is it important to you?

DECISIONAL CONFLICT: How difficult is this decision to make?

FACTORS CONTRIBUTING TO DECISIONAL CONFLICT [knowledge & expectations, values clarity, support & resources]: What makes the decision difficult?

PROBE KNOWLEDGE: What do you see as the main options you have? What do you see as the main benefits/advantages and risks/disadvantages of the options? Which of these are most important?

PROBE SUPPORT & RESOURCES: How do you usually go about making the decision? Who else is involved? What are the usual/preferred roles in decision making? What will help make this decision? What will get in the way of making this decision? What would help you overcome some of the things that get in the way of your decision making?

CHARACTERISTICS:

Patient: Age, gender, education, ethnicity, marital status, family composition, occupation, languages spoken, location, relevant medical diagnoses and duration, health status, (e.g. physical, emotional, cognitive, social), economic status.

Practitioner: Age, gender, ethnicity, clinical education and specialty, practice locale, years of experience.

Step 5. Select the *methods* for collecting the information.

How will you collect the information you need? The following strategies are frequently used in determining decision support needs. Several of the strategies may be used.

a) *Key informant interviews*

The key informant approach involves collection of information concerning the decision support needs of a group from people who are presumed to be in a key position to know those needs. This is frequently done as an interview, individually or in small groups, but could also be accomplished using questionnaires.

b) *Existing information* (i.e. from data bases, previous studies)

Existing clinical records in a community health clinic might provide information related to the reasons for and frequency of client visits and the type of care provided. Demographic information about the population in the region may be used to identify special needs. A review of the literature might identify perceptions about difficult decisions in similar populations. Indicators of potential problems with decision support might be identified this way.

c) *Focus groups*

A focus group interview is an unstructured discussion involving a group of 5 - 15 people. The moderator guides the discussion according to a written set of questions or topics to be covered. This method permits collection of the viewpoints of many individuals within a short space of time. However, some individuals may not feel comfortable expressing their opinions in front of a group. The discussion is frequently tape recorded for later analysis.

d) *Surveys*

Surveys are methods of obtaining information from a sample of people by self-report. Surveys usually collect quantitative data, but can also collect qualitative data. Surveys can be used to collect information about what people do or plan to do, their knowledge, opinions, attitudes or values. Survey information can be collected through personal interviews, telephone interviews or mailed questionnaires. Resources for developing surveys and questionnaires can be found in the references. Survey research is better suited to collecting a breadth of information rather than probing deeply into complex feelings and behaviours.

Remember, the methods selected must suit the available time and resources (money, equipment, knowledge and skills) of the participants and the researcher.

Step 6. Develop *data collection tools* (e.g. interview forms, surveys, questionnaire)

Examples of some personal interview questions can be found in Section E. You may be able to use existing tools, adapt existing tools to meet your needs or develop tools tailored to your specific situation. Some tools are copyrighted and therefore you will need permission from the developers to use or adapt the tools.

Step 7. Select the *sample*, *sample size* and *sampling procedure*

You cannot collect information from everyone, so you must select a sample or subset whose key characteristics will be representative of your target group and those influencing the target group. The *sample* is the subset of the target population from whom you will collect information. The *sample size* is the number to be included in the sample. The larger the sample the more representative of the population it is likely to be. For populations with greater diversity, larger samples are needed than if there is less diversity. The *sampling method* describes how the sample should be selected. A random sample developed from a sampling frame is more likely to be representative of the population. Sometimes, one needs to be pragmatic and select participants that are conveniently at hand (a convenience sample). It is important to define your sample by the people who will be included or excluded from the being sampled. In smaller-scale needs assessments, one usually determines what can feasibly be done given the constraints of time and finances.

Practitioner Sample

Who will be in your sample? _____

What sample size will you need? _____

Describe your sampling method. _____

Client Sample

Who will be in your sample? _____

What sample size will you need? _____

Describe your sampling method. _____

Step 9. Conduct the needs assessment

Step 10. Analyse and summarize the results

The results of the needs assessment should relate to your initial objective. Statistical analysis programs such as EPI-Info or SPSS might be employed for tabulating and analysing quantitative data. Content analysis methods would be used for qualitative data.

From this, a summary of your of key findings and recommendations for action should be made. This should relate to your rationale or purpose for doing the needs assessment which outlined how the results were to be used.

Step 11. Present the information

Present your summary of key findings and recommendations for action to the participants.

Activity	Start Date	Deadline	Person(s) Responsible
Planning report			
Preparing report			
Presenting report			

D. Glossary of Terms

<i>Benefits/Risks:</i>	The pros and cons of options in a decision. May also be expressed as reasons to choose or not to choose a particular option.
<i>Client Characteristics:</i>	In the Ottawa Decision Support Framework, this includes: age, gender, ethnicity, marital status, family composition, languages spoken, occupation, locale, medical diagnosis and duration of condition, health status (physical, emotional, cognitive, social), economic status.
<i>Focus Group Interview:</i>	An interview in which the respondents are a group of individuals assembled to answer questions on a given topic.
<i>Eligibility criteria:</i>	<i>Inclusion Criteria:</i> The criteria used by a researcher to designate the specific attributes of the target population, and by which subjects are selected for participation in a study. <i>Exclusion criteria</i> may also be identified, (e.g. poor health, inability to read a specific language, etc.).
<i>Key Informant:</i>	People who because of their position in the agency or community, possess information or insights into the group or phenomena of interest, and are willing to share that with the researcher.
<i>Methods (Research):</i>	The steps, procedures, and strategies for gathering and analysing the data in a study. Common methods used for needs assessments include key informant interviews, existing data from databases and previous studies, focus groups, surveys and questionnaires.
<i>Need:</i>	A gap between what is and what should be [using 'need' as a noun]
<i>Needs Assessment:</i>	A study in which data is collected for estimating the needs of an individual, 'target' group, community, or organization; usually used as a guide to resource allocation.
<i>Objective:</i>	Goal of the needs assessment. It should be clear, specific, and measurable, and relevant for the situation. It should identify the target group, the nature of the decision(s), and the scope of the assessment.
<i>Population:</i>	The entire set of individuals having some common characteristic.

<i>Rationale:</i>	The rationale or purpose of a needs assessment explains <u>why</u> the assessment is being done and <u>how</u> the results will be used.
<i>Sample:</i>	A subset of a population selected to participate in a research study.
<i>Sample Size:</i>	The number to be included in the sample.
<i>Sampling:</i>	The process of selecting a portion of the population to represent the entire population.
<i>Probability Sampling:</i>	The selection of subjects or sampling units from a population using random procedures; examples include simple random sampling, cluster sampling, and systematic sampling.
<i>Random Sampling:</i>	The selection of a sample such that each member of a population (or sub-population) has an equal probability of being included.
<i>Cluster sampling:</i>	A form of multi-stage sampling in which large groupings ('clusters') are selected first (e.g. nursing schools), with successive sampling of smaller units (e.g. nursing students).
<i>Systematic Sampling:</i>	The selection of subjects such that every k^{th} (e.g. every 10 th) person (or element) in a sampling frame or list is chosen.
<i>Non-probability Sampling:</i>	The selection of subjects or sampling units from a population using non-random procedures; examples include convenience, judgmental, and quota sampling.
<i>Sampling Frame:</i>	A list of all the elements in the population from which the sample was drawn.
<i>Survey Research:</i>	A type of non-experimental research that focuses on obtaining information regarding the status quo of some situation, often by means of direct questioning of a sample of respondents
<i>Target population (group):</i>	The entire population in which the researcher is interested and to which she or he would like to generalize the results of the study.
<i>Want:</i>	What people say they need. [using 'need' as a verb]

E. Samples of Needs Assessment Methods and Tools

E1. Interview Guide: Practitioner Version

E2. Interview Guide: Patient Version

E1. Personal Interview Questions for Key Informants

PRACTITIONER VERSION

Good morning/afternoon/evening. My name is _____ of _____ [institution] and I am involved with _____ [person] in conducting interviews with practitioner and consumer groups to learn more about the decision making needs people when they are making decisions about _____ [problem X].

During the interview, we will be asking you some questions about the health decisions people might make in your area of practice, for example [decisions/a decision about _____

[insert decisions appropriate to clinical area]

This information will contribute to a better understanding of the decision making needs of patients to improve planning of decision support.

All of the information we collect in this interview will be kept confidential. We'd like your help, It won't take more than _____[insert] minutes.

DECISION

1. What decisions do patients with _____ [problem X] have to make in your practice?

2. Lets focus on one particular decision . . . [NOTE TO QUESTIONNAIRE DEVELOPER YOU NEED TO ADAPT BASED ON WHETHER YOU ARE FOCUSING ON ONE DECISION OR LEAVING IT TO RESPONDENT TO PICK THE MOST IMPORTANT DECISION] insert either" 'the decision about whether ' or 'one that is important and difficult for patients to make (e.g. patients need a lot of help, or practitioner spends a lot of time)'. Which one would you choose?

<p>3. Lets talk about the difficulty people have making this decision about [redacted]. How do patients feel when making this decision?</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p><i>[Probe behavioral manifestations of decisional conflict]</i> Do patients feel:</p> <ul style="list-style-type: none"> <input type="checkbox"/> unsure about what to do? <input type="checkbox"/> worried what could go wrong <input type="checkbox"/> distressed or upset <input type="checkbox"/> constantly thinking about the decision <input type="checkbox"/> wavering between choices or changing their mind <input type="checkbox"/> delaying the decision <input type="checkbox"/> questioning what is important to them <input type="checkbox"/> feeling physically stressed, tense muscles, racing heartbeat, difficulty sleeping]
<p>4. What makes the decision difficult for patients?</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p><i>[Probe factors contributing to decisional conflict]</i> Are patients:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Lacking information about options, benefits, risks <input type="checkbox"/> Lacking information on the <u>chances</u> of benefits and harms <input type="checkbox"/> Confused from information overload <input type="checkbox"/> Unclear about what is important to them <input type="checkbox"/> Feeling unsupported in decision making <input type="checkbox"/> Feeling pressure from others <input type="checkbox"/> Lacking motivation or not feeling ready to make a decision <input type="checkbox"/> Lacking the ability or skill to make a decision

5. What do you see as the main options patients have?

6. What do you see as the main advantages/benefits and disadvantages/risks of the options?

[INSERT BELOW USE BACK OF PAGE FOR MORE COMMENTS]

Option	Advantages/Benefits	Disadvantages/Risks
1.		
2.		
3.		

<p>7. What is your usual role in making this decision?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p>[Probe role:]</p> <p>Do you usually:</p> <p><input type="checkbox"/> Make the decision for the patients</p> <p><input type="checkbox"/> Share the decision with the patients</p> <p><input type="checkbox"/> Provide support or advice for patients to make the decision on their own</p>
-----------------------------------------------------------------------------------------------------------------------------	------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

8. What factors make it difficult for you to support your patients' decision making?

9. What factors make it easier for you to support your patients' decision making?

<p>10. Who else besides yourself and the patient is usually involved in making this decision?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p><i>[Probe:]</i></p> <p><input type="checkbox"/> spouse</p> <p><input type="checkbox"/> family</p> <p><input type="checkbox"/> friend</p> <p><input type="checkbox"/> health care provider</p> <p><input type="checkbox"/> other, specify _____</p>
--------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<p>11. What is their usual role in making this decision (i.e. the person mentioned above)?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p><i>[Probe role:]</i></p> <p>Do you they usually:</p> <p><input type="checkbox"/> Make the decision for the patients</p> <p><input type="checkbox"/> Share the decision with the patients</p> <p><input type="checkbox"/> Provide support or advice for patients to make the decision on their own</p> <p><input type="checkbox"/> Don't know</p> <p><input type="checkbox"/> Other, specify _____</p>
-----------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<p>12. How do patient usually go about making such a decision?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p><i>[Probe decision making behaviour:]</i></p> <p>Do they:</p> <p><input type="checkbox"/> Get information on options</p> <p><input type="checkbox"/> Get information on the chances of benefits and risks</p> <p><input type="checkbox"/> Consider the personal importance of the benefits and risks</p> <p><input type="checkbox"/> Get information on how others go about deciding</p> <p><input type="checkbox"/> Get support from others</p> <p><input type="checkbox"/> Find ways to handle pressure</p>
-------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

13. What would help patients to make this decision?

14. What will hinder patients (get in the way of) making this decision?

15. Is there anything else that would help overcome barriers to decision making?

16. I will list possible ways to help some people with a decision, which ones do you think might be useful to your patients?

<input type="checkbox"/> Counseling from a health practitioner →	IF YES, specify what types
<input type="checkbox"/> Discussion groups of people facing the same decision →	IF YES, specify what type of organization or group
<input type="checkbox"/> Information materials	<p>IF YES, specify content</p> <ul style="list-style-type: none"> <input type="checkbox"/> Health condition <input type="checkbox"/> Options <input type="checkbox"/> Benefits <input type="checkbox"/> Risks <input type="checkbox"/> Probabilities of benefits/risks <input type="checkbox"/> Help considering the personal importance of benefits versus risks <input type="checkbox"/> Guidance in the steps of deliberation and communication <input type="checkbox"/> Other, specify _____ <p>IF YES, specify format</p> <ul style="list-style-type: none"> <input type="checkbox"/> Booklet, pamphlets <input type="checkbox"/> Internet <input type="checkbox"/> Videos/DVDs <input type="checkbox"/> Other, specify _____ <p>IF YES, who do you think should prepare information about the decision</p> <ul style="list-style-type: none"> <input type="checkbox"/> Pharmacies <input type="checkbox"/> Expert medical and health practitioners <input type="checkbox"/> Health societies for specific condition (e.g.Cancer, Heart and Stroke) <input type="checkbox"/> Government <input type="checkbox"/> Insurance companies <input type="checkbox"/> Companies that produce and sell drugs and health products <input type="checkbox"/> Consumer associations <input type="checkbox"/> Not for profit companies that produce health information [e.g. Healthwise] <input type="checkbox"/> For profit companies that produce health information [e.g. WEB MD; BMJ Best Treatments.ORG]

17. Is there anything else that would help you to do a better job supporting your patients' decision making?

CHARACTERISTICS OF PRACTITIONER

18. Age Category (guestimate)

- Twenties
- Thirties
- Forties
- Fifties
- Sixties or more

19. Sex (observe)

1. Male
2. Female

20. Practice Discipline specify _____

21. Practice Specialty

22. Practice Location specify _____

[THANK RESPONDENT]

E2. Personal Interview Questions for Client Key Informants
Consumer/Patient Group Version

Good morning/afternoon/evening. My name is _____ of _____ and I am involved with _____ in conducting a survey to learn more about the needs of people when they are making decisions about [insert health problem].

This information will help us to develop better educational materials for people facing these decisions.

All of the information we collect in this voluntary survey will be kept confidential. We'd like your help. It won't take more than 10 to 15 minutes.

I'm going to give you some examples of health decisions some people [with health problem] face.

For example, some people need to make:

Decisions about ...[insert decisions people with certain health problem may face]

DECISION

1. At this time, what do you think are the most important decisions people with [insert health problem] face?

2. Lets focus on one particular decision . . . [NOTE TO QUESTIONNAIRE DEVELOPER YOU NEED TO ADAPT BASED ON WHETHER YOU ARE FOCUSING ON ONE DECISION OR LEAVING IT TO RESPONDENT TO PICK THE MOST IMPORTANT DECISION] insert either” ‘the decision about whether’ or ‘one that is important and difficult for patients to make (e.g. patients need a lot of help, or practitioner spends a lot of time)’. Which one would you choose?

<p>3. Lets talk about the difficulty people have making this decision about [redacted]. How do patients feel when making this decision?</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p><i>[Probe behavioral manifestations of decisional conflict]</i> Do patients feel:</p> <ul style="list-style-type: none"> <input type="checkbox"/> unsure about what to do? <input type="checkbox"/> worried what could go wrong <input type="checkbox"/> distressed or upset <input type="checkbox"/> constantly thinking about the decision <input type="checkbox"/> wavering between choices or changing their mind <input type="checkbox"/> delaying the decision <input type="checkbox"/> questioning what is important to them <input type="checkbox"/> feeling physically stressed, tense muscles, racing heartbeat, difficulty sleeping]
<p>4. What things make the decision difficult for patients?</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>	<p><i>[Probe factors contributing to decisional conflict]</i> Are patients:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Lacking information about options, benefits, risks <input type="checkbox"/> Lacking information on the <u>chances</u> of benefits and harms <input type="checkbox"/> Confused from information overload <input type="checkbox"/> Unclear about what is important to them <input type="checkbox"/> Feeling unsupported in decision making <input type="checkbox"/> Feeling pressure from others <input type="checkbox"/> Lacking motivation or not feeling ready to make a decision <input type="checkbox"/> Lacking the ability or skill to make a decision

5. Thinking about this decision, what are the options that patients have?

6. What do you see as the main advantages/benefits and disadvantages/risks of the options?

[INSERT BELOW USE BACK OF PAGE FOR MORE COMMENTS]

Option	Advantages/Benefits	Disadvantages/Risks
1.		
2.		
3.		

<p>7. Who else may be involved in making this decision?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p><i>[Probe role in decision making:]</i></p> <p>Do they usually:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Make the decision for the patients <input type="checkbox"/> Share the decision with the patients <input type="checkbox"/> Provide support or advice for patients to make the decision on their own
------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<p>8. How do patient usually go about making such a decision?</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p><i>[Probe decision making behaviour:]</i></p> <p>Do they:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Get information on options <input type="checkbox"/> Get information on the chances of benefits and risks <input type="checkbox"/> Consider the personal importance of
----------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<hr/> <hr/>	<p>the benefits and risks</p> <ul style="list-style-type: none"> <input type="checkbox"/> Get information on how others go about deciding <input type="checkbox"/> Get support from others <input type="checkbox"/> Find ways to handle pressure
-------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

9. What would help patients to make this decision?

10. What will hinder patients (get in the way of) making this decision?

11. Is there anything else that would help overcome barriers to decision making?

12. I will list possible ways to help some people with a decision, which ones do you think might be useful to your patients?

<input type="checkbox"/> Counseling from a health practitioner →	IF YES, specify what types
<input type="checkbox"/> Discussion groups of people facing the	IF YES, specify what type of organization or group

same decision →	
<input type="checkbox"/> Information materials	<p>IF YES, specify content</p> <ul style="list-style-type: none"> <input type="checkbox"/> Health condition <input type="checkbox"/> Options <input type="checkbox"/> Benefits <input type="checkbox"/> Risks <input type="checkbox"/> Probabilities of benefits/risks <input type="checkbox"/> Help considering the personal importance of benefits versus risks <input type="checkbox"/> Guidance in the steps of deliberation and communication <input type="checkbox"/> Other, specify _____ <hr/> <p>IF YES, specify format</p> <ul style="list-style-type: none"> <input type="checkbox"/> Booklet, pamphlets <input type="checkbox"/> Internet <input type="checkbox"/> Videos/DVDs <input type="checkbox"/> Other, specify _____ <hr/> <p>IF YES, who do you think should prepare information about the decision</p> <ul style="list-style-type: none"> <input type="checkbox"/> Pharmacies <input type="checkbox"/> Expert medical and health practitioners <input type="checkbox"/> Health societies for specific condition (e.g. Cancer, Heart and Stroke) <input type="checkbox"/> Government <input type="checkbox"/> Insurance companies <input type="checkbox"/> Companies that produce and sell drugs and health products <input type="checkbox"/> Consumer associations <input type="checkbox"/> Not for profit companies that produce health information [e.g. Healthwise] <input type="checkbox"/> For profit companies that produce health information [e.g. WEB MD; BMJ Best Treatments.ORG]

13. Is there anything else that would help you to do a better job supporting your patients' decision making?

CHARACTERISTICS OF PRACTITIONER

14. Age Category (guestimate)

- Twenties
- Thirties
- Forties
- Fifties
- Sixties or more

15. Sex (observe)

- 3. Male
- 4. Female

16. Duration of experience with health problem _____

17. Role as key informant regarding this health issue _____

[THANK RESPONDENT]

F. References and Resources

1. O'Connor, A.M., Tugwell, P., Wells, G.A., Elmslie, T., Jolly, E., Hollingworth, G., McPherson, R., Bunn, H., Graham, I., and Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. **Patient Education and Counseling**, **33**, 267-279.
2. Abbey-Livingston, D. & Abbey, D.S. (1982). **Enjoying research? A 'how-to' manual on needs assessment**. Toronto: Ontario Ministry of Tourism and Recreation. (Very easy read- Provides an excellent guideline for all aspects of the process of needs assessment.)
3. Polit, D.F. & Hungler, B.P. (1995). **Nursing research - Principles and methods**, 5th ed. Philadelphia: JB Lippincott
4. Dillman, D.A. (1978). **Mail and telephone surveys-The total design method**. New York: John Wiley & Sons. [In depth detail about conducting a survey.]