



# **Decisional Needs Assessment in Populations**

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

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

1999 [updated 2013]

<b>Table of Contents</b>	<b>Page</b>
1.0 Introduction.....	3
1.1 What is a Population Needs Assessment? .....	3
1.2 What is the Rationale or Purpose of a Needs Assessment?.....	3
2.0 Why Conduct a Needs Assessment?.....	3
2.1 Determine what do groups want or need .....	3
2.2 Determine whether existing programs meet the decision support needs.....	3
2.3 Determine which groups need services .....	4
2.4 Determine the best alternatives for meeting the need.....	4
3.0 How Can the Results of A Needs Assessment Be Used? .....	5
3.1 Develop plans for programs or services .....	5
3.2 Define and solve problems.....	5
3.3 Establish priorities .....	5
3.4 Evaluate programs and demonstrate accountability .....	5
3.5 Raise awareness of needs and potential interventions .....	5
3.6 Involve those with vested interests and foster commitment .....	6
4.0 Planning a Needs Assessment.....	6
4.1 Step1. Define the <i>objective</i> of the Needs Assessment .....	7
4.2 Step 2. Identify the <i>participants</i> .....	8
4.3 Step 3. Identify the <i>rationale</i> or purpose of the needs assessment .....	9
4.4 Step 4. Identify the <i>information</i> you wish to collect.....	10
4.5 Step 5. Select the <i>methods</i> for collecting the information. ....	13
4.6 Step 6. Develop <i>data collection tools</i> (e.g. interview forms, surveys, questionnaire) .....	13
4.7 Step 7. Select the sample, sample size and sampling procedure .....	15
4.8 Step 8. Develop a <i>schedule</i> .....	16
4.9 Step 9. Conduct the needs assessment and Analyse .....	17
4.10 Step 10. Summarize and present the information .....	17
Appendices.....	18
A. Key definitions.....	18
B. Samples of Needs Assessment Methods and Tools .....	20
B1. Personal Interview Questions for Key Informants.....	21
B2. Personal Interview Questions for Client Key Informants .....	26
B3. Telephone survey regarding complex health decisions .....	31
B4. Telephone survey regarding managing hip or knee osteoarthritis .....	45
References and Resources .....	51

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

## 1.0 Introduction

### 1.1 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.

### 1.2 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.

## 2.0 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

### 2.1 Determine 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 with?

**DECISIONAL CONFLICT:** Which decisions are the most 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.)

### 2.2 Determine 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?

### **2.3 Determine 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.)

### **2.4 Determine 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; decision coaching, educational materials using pamphlets, videos/DVDs; 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, preference reports, care maps, etc. Methodologies must be suitable for the participants and the nature of available resources.

*Helpful questions include:*

**SUPPORT AND RESOURCES:** 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?

### 3.0 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

#### 3.1 Develop 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 such as practitioners, clients, program managers, policy makers, etc.

#### 3.2 Define and solve problems

A needs assessment can determine the difficulty clients, practitioners and other stakeholders have making decisions as well as the contributing factors. This information is useful in identifying appropriate strategies to address the problems.

#### 3.3 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.

#### 3.4 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.

#### 3.5 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).

### 3.6 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.

## 4.0 Planning a Needs Assessment

### Steps in Planning a Needs Assessment

- 4.1 Step 1. Define the objective of the Needs Assessment
- 4.2 Step 2. Identify the participants
- 4.3 Step 3. Identify the rationale or purpose of the needs assessment
- 4.4 Step 4. Identify the information you wish to collect.
- 4.5 Step 5. Select the methods for collecting the information.
- 4.6 Step 6. Develop data collection tools (e.g. interview forms, surveys, questionnaire)
- 4.7 Step 7. Select the sample, sample size and sampling procedure
- 4.8 Step 8. Develop a schedule
- 4.9 Step 9. Conduct the needs assessment and Analyse
- 4.10 Step 10. Summarize and present the information



**4.2 Step 2. Identify the participants**

Participants include the target group who shares in the decision making process as well as stakeholders who have some influence on the decision making process.

The participants usually include:

**-the target group**

*e.g. patients defined by age, gender, developmental stage, health status, income, education, and/or location) as well as practitioners defined by age, gender, education, specialty, location; and*

**-any other stakeholders 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.

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

**4.3 Step 3. Identify the *rationale* or purpose of the needs assessment**

The *rationale* or *purpose* of a needs assessment explains why it is important to have this information (why the assessment is being done) and how the results will be used. This includes identifying and involving those who will receive and use the results.

The following is an example of a rationale

*Women are usually the gatekeepers to family health, thus, personal and family health is affected by the decisions women make. A needs assessment focused on identifying the decision making issues women find important would be the first step in developing programs or services to meet those needs.*

*Needs, barriers and facilitators are unknown, but are necessary to develop programs that improve decision making and the decision making and health of women and families. Needs assessment tools can help identify the factors that are most common in contributing to difficulty in making decisions. This permits tailoring of the decision support to address the specific factors contributing to problems in decisions making.*

*One of the standards of care for practitioners is to promote self-care of their clients, both in terms of decisions and actions. Involving clients in the needs assessment increases the likelihood that clients will take a more active role with their practitioners in making and implementing health decisions.*

<b>Why is it important to have this information?:</b>
<b>How will the results be used?</b>

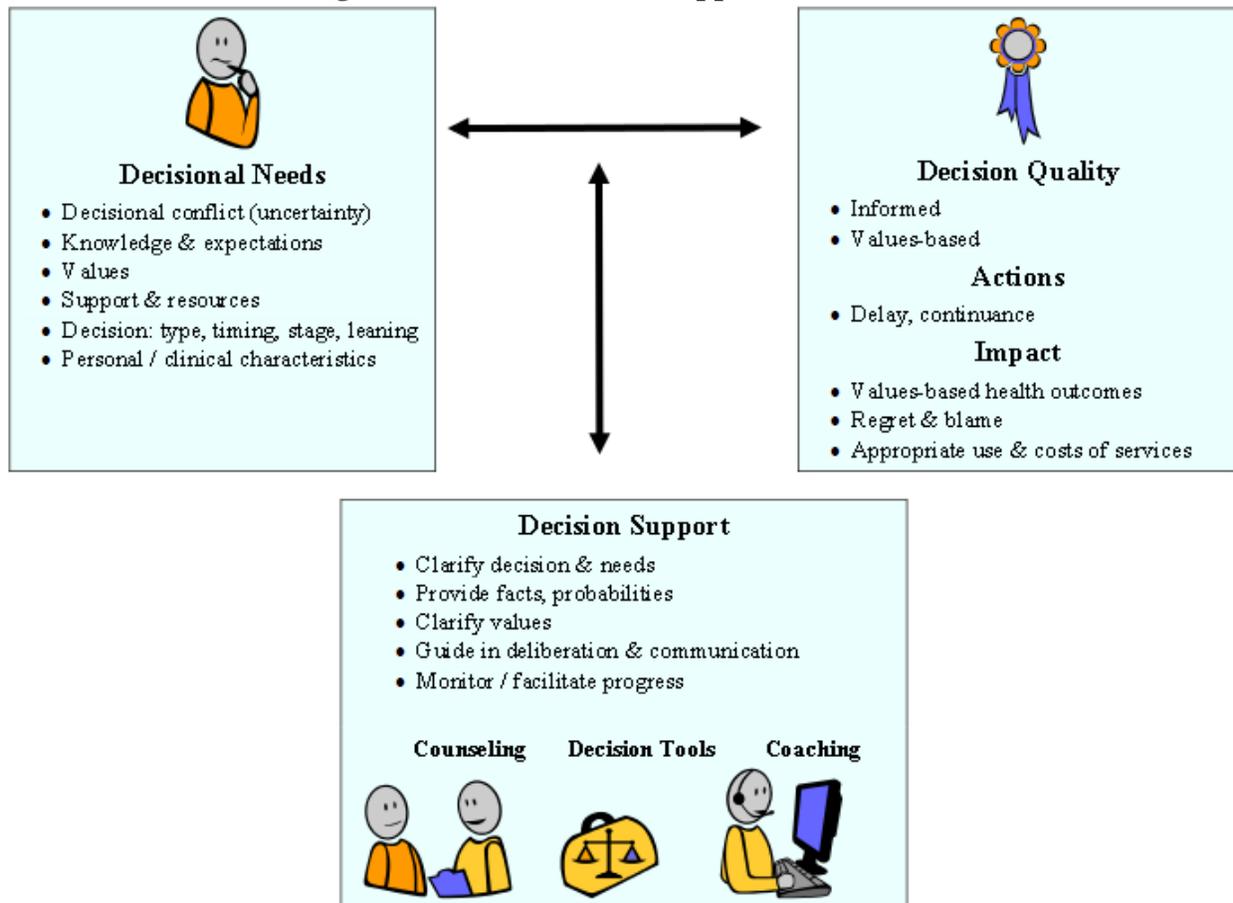
Steps 4 to 6 deal with *Information* to be collected, the *Methods* you will use and the *Tools* you will **adapt or develop to conduct your needs assessment**.

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

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

The Ottawa Framework for Decision Support outlines the decisional needs of those involved in decision making and provides guidance for the type of information that can 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, and/or physical incapacitation. Decision support in the form of clinical counseling, decision aids and coaching can improve decision quality, by addressing unresolved needs. Definitions of these elements in the framework are defined in Table 4.4.

Table 4.4 Glossary of Terms for Ottawa Decision Support Framework

<b>DECISIONAL NEEDS</b>
<p><b>DECISION</b>  <b>Type:</b> 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  <b>Timing:</b> time frame or urgency with which a decision needs to be made  <b>Stage:</b> 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.  <b>Leaning:</b> inclination to choose one option over the other</p>
<p><b>DECISIONAL CONFLICT</b>  uncertainty about course of action to take when choice among options involves risk, loss, regret, challenge to personal life values</p>
<p><b>KNOWLEDGE &amp; EXPECTATIONS</b>  <b>Knowledge:</b> cognizance of the health problem or situation, options, and outcomes  <b>Expectation:</b> perceived likelihood or probability of outcomes of each option</p>
<p><b>VALUES</b>  desirability or personal importance of outcomes of options</p>
<p><b>SUPPORT &amp; RESOURCES</b>  <b>Others' opinions/ practices:</b> 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  <b>Pressure:</b> perception of persuasion, influence, coercion from important others to select one option  <b>Role in decision making:</b> 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  <b>Experience:</b> past exposure to the situation, options, outcomes, decision making process  <b>Self-efficacy:</b> confidence or belief in one's abilities in decision making, including shared decision making  <b>Motivation:</b> readiness and interest in decision making, including shared decision making  <b>Skill:</b> abilities in making and implementing a decision  <b>External support:</b> 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 &amp; social services. Sources include: social networks, professional networks, support groups, voluntary agencies, and the formal health care, education, and social sectors</p>
<p><b>PERSONAL &amp; CLINICAL CHARACTERISTICS</b>  <b>Patient:</b> Age, gender, education, marital status, ethnicity, occupation, locale, diagnosis &amp; duration of condition, health status (physical, emotional, cognitive, social)  <b>Practitioner:</b> age, gender, ethnicity, clinical education, specialty, practice locale, experience, counselling style</p>
<b>DECISION SUPPORT</b>
<p><b>PATIENT DECISION AIDS</b>  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).</p>
<p><b>DECISION COACHING</b>  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.</p>
<b>DECISION QUALITY</b>
<p><b>QUALITY OF THE DECISION</b>  The extent to which the chosen option best matches informed clients' values for benefits, harms, and scientific uncertainties</p>
<p><b>QUALITY OF THE PROSESS OF DECISION MAKING</b>  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.</p>

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

**DECISION:** What are the important decisions that patients need to make? Let's focus on one particular decision ....?

**DECISIONAL CONFLICT:** Let's talk about the difficulty patients have making this decision. How do patients feel when making this decision?

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

**KNOWLEDGE:** What do you see as the main options? What do you see as the main benefits/advantages and risks/disadvantages of the options?

**VALUES:** Which of these benefits/advantages and Disadvantages/Risks are most important?

**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.

#### 4.5 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.

#### 4.6 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.



**4.7 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.



#### 4.9 Step 9. Conduct the needs assessment and Analyse

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.

#### 4.10 Step 10. Summarize and present the information

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

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.

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

## Appendices

### A. Key definitions

<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 $k^{\text{th}}$ (e.g. every 10 <sup>th</sup> ) 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]

**B. Samples of Needs Assessment Methods and Tools**

Appendices B1 and B2 includes standardized **semi-structured interview** questions that are based on the Ottawa Decision Support Framework [see below]. Appendices B3, B4 and B5 include telephone survey questions with structured response categories.

The questions can be adapted for questionnaires, interview guides, or focus groups with key informants. One version is for practitioners and one is for patient/consumer key informants. If questions are posed in person, we recommend that two people attend the interviews: one to pose questions and one to transcribe the answers. Compare notes after the session to ensure the accuracy of your interpretation. If there is only one person conducting interviews, tape record the interview for later verification.

Framework Class	Framework Variable	B1 Practitioner Interview Q#	B2 Patient Interview Q#	Comments
	Decisional conflict-uncertain	3		
	Knowledge, Expectations	4		
	Values	4		
	Support & Resources	4,7,10,11		
	Decision type, timing, stage, leaning	1,2,5,6		
	Personal/clinical characteristics	18		
Decision Support	<ul style="list-style-type: none"> <li>▪ Clarify decision and needs</li> <li>▪ Provide facts, probabilities</li> <li>▪ Clarify values</li> <li>▪ Guide/coach/support skills</li> <li>▪ Monitor/facilitate progress</li> </ul>	8,9,10 12, 13, 14,15 16,17		
Decision Quality, Actions, Impact	<ul style="list-style-type: none"> <li>○ Informed</li> <li>○ Values-Based</li> <li>○ Delay, continuance</li> <li>○ Values-based health outcomes</li> <li>○ Satisfaction, regret and blame</li> <li>○ Appropriate use, costs of services</li> </ul>			Not assessed in this questionnaire See 5.1

Practitioner Q#	Patient Q#	Item
1	1	Decisions made by patients
2	2	Focus on one decision [chosen by you or by respondent]
3	3	Decisional difficulty [probe manifestations of decisional conflict]
4	4	Factors contributing to difficulty [probe knowledge, values, support deficits]
5	5	Options
6	6	Benefits and Risks
7	-	Practitioner's usual role in decision making [probe role]
8	-	Practitioner's barriers: supporting patients' decision making
9	-	Practitioner's facilitators: supporting patients' decision making
10	7	Others participants in decision making
11	7	Other participants' roles
12	8	Usual patient strategies in decision making [probe strategies to address knowledge deficits, unrealistic expectations, support]
13	9	Facilitators; patients' decision making
14	10	Barriers: patients' decision making
15	11	Anything else to overcome barriers
16	12	Possible strategies for decision support [counselling, groups, information]
17	13	Anything else that would help support patients in decision making
18-22	14-17	Participant characteristics

**B1. 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 will take about X to Y minutes to complete.

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

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><i>[Probe role:]</i></p> <p><b>Do you usually:</b></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><i>[Probe:]</i></p> <ol style="list-style-type: none"> <li>1. spouse</li> <li>2. family</li> <li>3. friend</li> <li>4. health care provider</li> <li>5. other, specify _____</li> </ol>
---	--

<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><i>[Probe role:]</i></p> <p><b>Do you they usually:</b></p> <ol style="list-style-type: none"> <li>6. Make the decision for the patients</li> <li>7. Share the decision with the patients</li> <li>8. Provide support or advice for patients to make the decision on their own</li> <li>9. Don't know</li> <li>10. Other, specify _____</li> </ol>
--	---

<p>12. How do patient usually go about making such a decision?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p><i>[Probe decision making behaviour:]</i></p> <p><b>Do they:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Get information on options</li> <li><input type="checkbox"/> Get information on the chances of benefits and risks</li> <li><input type="checkbox"/> Consider the personal importance of the benefits and risks</li> <li><input type="checkbox"/> Get information on how others go about deciding</li> <li><input type="checkbox"/> Get support from others</li> <li><input type="checkbox"/> Find ways to handle pressure</li> </ul>
--	--

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	IF YES, specify content <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
	IF YES, specify format <input type="checkbox"/> Booklet, pamphlets <input type="checkbox"/> Internet <input type="checkbox"/> Videos/DVDs <input type="checkbox"/> Other, specify _____

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)**

- Male
- Female

20. **Practice Discipline** specify \_\_\_\_\_

21. **Practice Specialty** specify \_\_\_\_\_

22. **Practice Location** specify \_\_\_\_\_

[THANK RESPONDENT]

**B2. 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 will take about X to Y 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 with making this decision about [redacted]. How do/did you feel when making this decision?</p> <hr/>	<p><i>[Probe behavioural manifestations of decisional conflict]</i>  <b>Do you feel:</b>  <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>
<p>4. What things make the decision difficult for you?</p> <hr/>	<p><i>[Probe factors contributing to decisional conflict]</i>  <b>Are you:</b>  <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</p>

5. Thinking about this decision, what are the options that you 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 with you?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p><i>[Probe role in decision making:]</i></p> <p><b>Do they usually:</b></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>8. How do you 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><b>Do they:</b></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>
--	---

9. What would help you to make this decision?

---



---



---

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

---



---



---

11. Is there anything else that would help overcome these 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 you?

<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	IF YES, specify content <ul style="list-style-type: none"> <li><input type="checkbox"/> Health condition</li> <li><input type="checkbox"/> Options</li> <li><input type="checkbox"/> Benefits</li> <li><input type="checkbox"/> Risks</li> <li><input type="checkbox"/> Probabilities of benefits/risks</li> <li><input type="checkbox"/> Help considering the personal importance of benefits versus risks</li> <li><input type="checkbox"/> Guidance in the steps of deliberation and communication</li> <li><input type="checkbox"/> Other, specify</li> </ul> <hr/> IF YES, specify format <ul style="list-style-type: none"> <li><input type="checkbox"/> Booklet, pamphlets</li> <li><input type="checkbox"/> Internet</li> <li><input type="checkbox"/> Videos/DVDs</li> <li><input type="checkbox"/> Other, specify _____</li> </ul>

13. Is there anything else that would help better support you in decision making?

---



---



---

**CHARACTERISTICS OF CONSUMER/PATIENT GROUP**

**14. Age Category (guestimate)**

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

**15. Sex (observe)**

- Male
- Female

**16. What is the highest grade or level of education you completed?**

- Less than grade 9
- Some high school
- High school diploma
- Trade certificate/diploma
- Some college
- College diploma/degree
- Some university
- University undergraduate degree
- University graduated degree (Masters and PhD)

**17. Duration of experience with health problem \_\_\_\_\_**

[THANK RESPONDENT]

**B3. Telephone survey regarding complex health decisions**

These questionnaires were conducted over the telephone and had more structured response items.

Results published: O'Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie T. [A survey of the decision-making needs of Canadians faced with complex health decisions](#). Health Expect. 2003 Jun;6(2):97-109.

**Satisfactory Decisions Survey**

Good evening. My name is \_\_\_\_\_ of Factor Research calling on behalf of medical researchers at the University of Ottawa. We are doing a national survey to learn more about how people make decisions related to their health. This information will help us to develop better educational materials for patients facing these difficult decisions. Your phone number has been chosen randomly from a list of numbers generated by a computer. In other words, we do not know your name or address. All of the information we collect in this voluntary survey will be kept confidential. We would like your help; it won't take more than 10 to 15 minutes.

A. Would you be willing to help us by answering a few questions now?

- Yes [Skip to B]  
 No [Ask...]

Would there be a better time for me to call you?

- Yes: When? \_\_\_\_\_  
 (Date and time)  
 No: Alright. But before you go I'd like to ask you just a few quick questions for comparative purposes. [Skip to Q52]

B. Before we go further, are you 18 years of age or older?

- Yes [Continue]  
 No [Ask to speak to a member of the household 18 years of age or older and repeat introduction.]

We are interested in talking to you about a complex health decision that you have faced. To help you, I'm going to give you some examples of simple and more complex health decisions.

An example of a simple health decision would be taking an antibiotic for an infection. Usually your doctor recommends a treatment and you do not get very involved in the decision making.

We are interested in more complex or difficult health decisions --When you have to consider the pros and cons of the options-- and there is no right or wrong choice. **[Read if necessary: Pros are advantages and cons are disadvantages. For example, if you were considering taking a new medication, a pro would be that it would make you better and a con would be its side effects.]**

With this type of decision, your choice depends on your personal situation and what is most important to you. These decisions may involve:

- discussing the decision with your doctor or others;
- reading written materials; and
- taking a bit more time to consider what you want to do.

Some complex health decisions include things such as questions about birth control, pregnancy and childbirth, surgery, taking medications with serious side effects, or placement of an elderly relative.

1. Can you think of a complex health decision that you made in the past that you would be willing to discuss with me?

- Yes: What was that decision? \_\_\_\_\_ [*Skip to Q4*]
- No

2. Would it help if I read a list of some health decisions people may make?

- Yes [*Read list below*]
- No: Alright. Now I'd like to ask you just a few quick questions for comparative purposes.  
[*Skip to Q52*]

#### LIST

- Decisions about birth control (condoms, birth control pills, vasectomy, or tubal ligation)
- Decisions about pregnancy and childbirth (prenatal testing, type of childbirth, method of feeding, what to do about an unplanned pregnancy)
- Decisions for your children (circumcision or medication for attention deficit disorder)
- Decisions about surgery (chronic back pain, painful joints, chronic bowel problems, hysterectomy for bleeding problems, lumpectomy or mastectomy for breast cancer, prostate problems, or self-donating blood before surgery)
- Decisions about taking medication when lifestyle changes such as diet and exercise are not enough (to lower cholesterol, to control blood sugar, or to prevent heartburn)
- Decisions about using stronger medications with a risk of serious side effects when the safer treatments are not working (stronger sleeping pills, stronger pain killers, stronger pills to control anxiety, or diet pills to control obesity)
- Decisions at the time of menopause such as whether to take hormone therapy
- Decisions for an elderly relative (care at home versus an institution, nursing care in the home or care facility, or dialysis treatments at home or in hospital)
- Other decisions? [*Respondent initiated*] \_\_\_\_\_

3. Have you been in a position to make one of the decisions I just described and be willing to talk about it with me?

- Yes: What was that decision? \_\_\_\_\_ [Continue]  
 No: [Skip to Q61]

4. What were the options you had to consider?

---

---

---

5. Which option did you choose?

---

6. How long ago did you make this decision?

- Within the last 12 months  
 From 1 to 5 years ago  
 Over 5 years ago  
 Don't remember  
 No response/refused

7. Did you think about the pros and cons when considering the options? [**Read if necessary:** Pros are advantages and cons are disadvantages. For example, if you were considering taking a new medication, a pro would be that it would make you better and a con would be its side effects.]

- Yes  
 No

Now I'm going to give you a list of reactions that some people have when making a complex decision. Please let me know whether you experienced these at any time when you were making your decision.

	<b>Yes</b>	<b>Unsure</b>	<b>No</b>
8. When considering your options, did you feel <b>unsure</b> about what to do? .....	1	2	3
9. When considering your options, did you <b>worry</b> what could go wrong if you made a choice?.....	1	2	3
10. When considering your options, did you feel <b>distressed</b> or <b>upset</b> ? .....	1	2	3
11. When considering your options, did you feel like you couldn't get the decision <b>off your mind</b> ? .....	1	2	3
12. When considering your options, did you <b>waiver</b> (or keep changing your mind) between the choices that you faced?.....	1	2	3
13. When considering your options, did you want to <b>delay</b> the decision? .....	1	2	3
14. When considering your options, did you <b>question</b> what was important to you? .....	1	2	3
15. When considering your options, did you feel <b>physically stressed</b> , for example did you have tense muscles, a racing heartbeat, or difficulty sleeping? .....	1	2	3
16. Now let's discuss <b>who</b> was involved in making the decision about [ <i>State decision</i> ]. Excluding your doctor, was anyone else involved in making the decision?			
<input type="checkbox"/> Yes: Who was that? _____ [ <i>Read column A in Q17</i> ]			
<input type="checkbox"/> Unsure [ <i>Read column B in Q17</i> ]			
<input type="checkbox"/> No [ <i>Read column B in Q17</i> ]			

17. Which of the following situations best describes **how** the decision was made? [*Read column A or B as determined in Q16*]

COLUMN A	COLUMN B
<input type="checkbox"/> We decided on our own	<input type="checkbox"/> I decided on my own
<input type="checkbox"/> We decided after considering our doctor's opinion	<input type="checkbox"/> I decided after considering my doctor's opinion
<input type="checkbox"/> We decided with our doctor	<input type="checkbox"/> I decided with my doctor
<input type="checkbox"/> Our doctor decided after considering our opinion	<input type="checkbox"/> My doctor decided after considering my opinion
<input type="checkbox"/> Our doctor decided on his or her own	<input type="checkbox"/> My doctor decided on his or her own
<input type="checkbox"/> Other [ <i>specify</i> ] _____	<input type="checkbox"/> Other [ <i>specify</i> ] _____
<input type="checkbox"/> Don't know [ <i>Go to Q20</i> ]	<input type="checkbox"/> Don't know [ <i>Go to Q20</i> ]

18. If you had to do it all over again, which way would you prefer to make the decision?

- The same way [*Go to Q20*]
- Unsure [*Go to Q20*]
- Differently

19. [*If differently to Q18*] How would you make the decision differently? [*Read column A or B as appropriate*]

COLUMN A	COLUMN B
<input type="checkbox"/> We would decide on our own	<input type="checkbox"/> I would decide on my own
<input type="checkbox"/> We would decide after considering our doctor's opinion	<input type="checkbox"/> I would decide after considering my doctor's opinion
<input type="checkbox"/> We would decide with our doctor	<input type="checkbox"/> I would decide with my doctor
<input type="checkbox"/> Our doctor would decide after considering our opinion	<input type="checkbox"/> My doctor would decide after considering my opinion
<input type="checkbox"/> Our doctor would decide on his or her own	<input type="checkbox"/> My doctor would decide on his or her own
<input type="checkbox"/> Other [ <i>specify</i> ] _____	<input type="checkbox"/> Other [ <i>specify</i> ] _____
<input type="checkbox"/> Don't know	<input type="checkbox"/> Don't know

Now I'm going to ask you about the steps you took in considering the decision about [*State decision*].

	<b>Yes</b>	<b>Unsure</b>	<b>No</b>
20. Did you get information on the <b>options</b> , their pros and cons? ...	1	2	3
21. Did you get information on <b>how likely</b> each of the pros and cons were? .....	1	2	3
22. Did you take time to consider <b>how important</b> each of the pros and cons were to you in making the decision? .....	1	2	3

23. a) Did you get information on what **others** decide or recommend?

- Yes
- Unsure [*Skip to Q24*]
- No [*Skip to Q24*]

b) Who?

- Personal doctor
- Other doctor(s)
- Other patient(s)
- Spouse/partner
- Other [*specify*] \_\_\_\_\_

	<b>Yes</b>	<b>Unsure</b>	<b>No</b>
24. Did you consider ways to handle <b>pressure</b> from others?.....	1	2	3
25. Did you get <b>support</b> from others in making the decision?....	1	2	3

26. Did you do anything else to make your decision?

- Yes [*specify*] \_\_\_\_\_
- Unsure
- No

27. Is there anything else that you did **not** do, but that you would advise others to do in making this decision?

- Yes [*specify*] \_\_\_\_\_
- Unsure
- No

Sometimes a complex decision is made more difficult because you do not have enough information, you are not sure what is important to you, or you do not have support from others to make a choice. When you were considering your decision about [*State decision*]...

	Yes	Unsure	No
28. Did you feel that you <b>knew</b> enough about the options, their pros and cons?.....	1	2	3
29. Did you feel that you knew <b>how likely</b> each of the pros and cons were? .....	1	2	3
30. Did you feel that you were clear about what was <b>personally important</b> to you? (e.g., how important the pros were to you, how important the cons were to you?).....	1	2	3
31. Did you have enough information on what <b>others</b> decide or recommend?.....	1	2	3
32. Did you feel <b>pressure</b> from others to select an option you were not sure about? .....	1	2	3
33. Did you feel that you had enough <b>support</b> from others to make the decision? .....	1	2	3
34. Did you feel <b>motivated</b> or ready to make the decision? .....	1	2	3
35. Did you feel you had the <b>ability</b> or <b>skill</b> to make this type of decision? .....	1	2	3

36. Did you feel that the decision was difficult for any **other** reason?

- Yes [*specify*] \_\_\_\_\_
- Unsure
- No

Now I'm going to give you a list of things that might show that someone had made a **satisfactory** decision about [*State decision*]. Please tell me which ones you think are **necessary** for showing that someone had made a satisfactory decision, which ones would be **nice to have**, but are not necessary, and which ones are **not necessary**.

	Necessary	Nice to have	Not necessary	Not sure
37. Knowing the main <b>options</b> and their <b>pros</b> and <b>cons</b> ? .....	1	2	3	9
38. Knowing <b>how likely</b> the major pros and cons are?.....	1	2	3	9
39. <b>Being clear</b> about which pros and cons are important to you? .....	1	2	3	9
40. Making a choice that <b>agrees</b> with what is personally important to you? .....	1	2	3	9
41. Knowing what <b>others</b> decide or recommend?.....	1	2	3	9
42. Being <b>satisfied</b> with the <b>way</b> you make a decision? .....	1	2	3	9
43. Being <b>satisfied</b> with the choice you make?.	1	2	3	9
44. <b>Carrying out</b> the decision that you make? .	1	2	3	9

45. Can you think of anything else that would show that a person had made a **satisfactory** decision?

- Yes [*specify*] \_\_\_\_\_
- Unsure
- No

There are many ways to learn more about the available options when you are making a difficult decision.

46. Which of the following ways to learn about the options would you prefer? [*Read list. Mark all that apply*]

- Personal counselling from your doctor
- Discussion groups of people facing the same decision
- Information materials [*Continue if checked, otherwise Skip to Q52*]
- Other [*specify*] \_\_\_\_\_

47. What format of information materials would you prefer? [*Read list. Mark all that apply*]

- Booklets or pamphlets
- Videos
- Audiotapes
- CD-ROMs
- Internet
- Other [*specify*] \_\_\_\_\_

48. Who do you think should prepare the information? [*Mark all that apply*]

- Pharmacies
- Societies (Canadian Cancer Society, Heart & Stroke Foundation, etc.)
- Medical and health care specialists
- Government
- Consumer associations
- Private companies that sell drug and health products
- Insurance companies
- Community/support groups
- Other [*specify*] \_\_\_\_\_

**[IF the respondent HAS NOT made a decision in the past Skip to Q52]**

49. Do you anticipate having to make another complex health decision in the near future?

- Yes
- No I'd like to ask you just a few quick questions for comparative purposes. [*Skip to Q52*]

50. What options might you have to consider?

\_\_\_\_\_

51. How difficult will it be to make this decision? Would you say...

- Not at all difficult
- A little difficult
- Somewhat difficult
- Very difficult
- Unsure

Just a few more questions about yourself to help us analyze the information you have given us. Remember that all of your responses are confidential.

52. What language do you speak most often in the home? [*Do not read list. Choose all that apply*]

- English
- French
- Italian
- Chinese
- German
- Other [*specify*] \_\_\_\_\_
- Refused

53. What is your current marital status? [*Do not read*]

- Single/never married
- Married (*and not separated*) or living common-law
- Separated
- Divorced
- Widowed
- Refused

54. What is the highest grade or level of education you have completed? [*Do not read*]

- Less than grade 9
- Some high school
- High school diploma
- Trade certificate/diploma
- Some college
- College diploma/degree
- Some university
- University degree
- Refused

55. In which of the following age groups are you?

- 18-24
- 25-29
- 30-34
- 35-39
- 40-44
- 45-49
- 50-59
- 60-69
- 70 or more
- Refused

56. Are you currently:

- Working at a job or business
- Looking for work
- A student
- Retired
- Homemaking
- Other [*specify*] \_\_\_\_\_
- Refused

57. Could you give us the first three characters in your postal code?

[*This will allow only identification to the community level*] \_\_\_\_\_

58. This is the last question. In general, how well do your income and investments currently satisfy your needs? Would you say... [*Read list*]

- Very well
- Adequately
- Not very well
- Totally inadequately
- [*Don't know --Do not read*]
- Refused

**Thank you very much for your help. This information will help us improve educational materials for people facing difficult health care decisions.**

59. Respondent gender. [*Do not ask*]

- Male
- Female

60. Province of Respondent [*Do not ask*]

- Newfoundland/Labrador
- Prince Edward Island
- Nova Scotia
- New Brunswick
- Quebec
- Ontario
- Manitoba
- Saskatchewan
- Alberta
- British Columbia
- Northwest Territories
- Yukon Territories

**THANK YOU FOR YOUR WILLINGNESS TO PARTICIPATE  
IN THIS IMPORTANT RESEARCH.**

**[FOR PEOPLE WHO ANTICIPATE HAVING TO MAKE A DECISION IN THE FUTURE...]**

61. Do you anticipate having to make a health decision in the near future?

- Yes
- No I'd like to ask you just a few quick questions for comparative purposes. [*Skip to Q52*]

62. What options might you have to consider?

---

63. How difficult will it be to make this decision? Would you say...

- Not at all difficult
- A little difficult
- Somewhat difficult
- Very difficult
- Unsure

Sometimes a complex decision is made more difficult because you don't have enough information, you're not sure what's important to you, or you don't have support from others to make a choice. When you consider your decision about [*State Decision from Q62*]...

	Yes	Unsure	No
64. Do you feel that you <b>know</b> enough about the options, their pros and cons?.....	1	2	3
65. Do you feel that you know <b>how likely</b> each of the pros and cons are?.....	1	2	3
66. Do you feel that you are clear about what is <b>personally important</b> to you? (e.g., how important the advantages are to you, how important the disadvantages are to you?) .....	1	2	3
67. Do you have enough information on what <b>others</b> decide or recommend?.....	1	2	3
68. Do you feel <b>pressure</b> from others to select an option you are not sure about? .....	1	2	3
69. Do you feel that you have enough <b>support</b> from others to make the decision? .....	1	2	3
70. Do you feel <b>motivated</b> or ready to make the decision? .....	1	2	3
71. Do you feel you have the <b>ability</b> or <b>skill</b> to make this type of decision? .....	1	2	3

72. Do you feel that the decision is difficult for any **other** reasons?

- Yes [*specify*] \_\_\_\_\_
- Unsure
- No

73. Now let's discuss **who** will be involved in making the decision about [*State Decision*]. Excluding your doctor, will anyone else be involved in making the decision?

- Yes: Who was that? \_\_\_\_\_ [*Read column A in Q74*]
- Unsure [*Read column B in Q74*]
- No [*Read column B in Q74*]

74. Which of the following situations best describes **how** the decision will be made? [*Read column A or B as determined in Q73*]

COLUMN A	COLUMN B
<ul style="list-style-type: none"> <li><input type="checkbox"/> We will decide on our own</li> <li><input type="checkbox"/> We will decide after considering our doctor's opinion</li> <li><input type="checkbox"/> We will decide with our doctor</li> <li><input type="checkbox"/> Our doctor will decide after considering our opinion</li> <li><input type="checkbox"/> Our will doctor decide on his or her own</li> <li><input type="checkbox"/> Other [<i>specify</i>] _____</li> <li><input type="checkbox"/> Don't know</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> I will decide on my own</li> <li><input type="checkbox"/> I will decide after considering my doctor's opinion</li> <li><input type="checkbox"/> I will decide with my doctor</li> <li><input type="checkbox"/> My doctor will decide after considering my opinion</li> <li><input type="checkbox"/> My doctor will decide on his or her own</li> <li><input type="checkbox"/> Other [<i>specify</i>] _____</li> <li><input type="checkbox"/> Don't know</li> </ul>

-----GO TO PREAMBLE TO Q37 -----

---

**B4. Telephone survey regarding managing hip or knee osteoarthritis**


---

### **Needs Assessment Questionnaire: Exploring decisions about managing hip or knee osteoarthritis**

**Now that you have agreed to participate in the study, and mentioned that you have recently made a decision about your OA, I will begin to ask you questions about your current approach to managing your osteoarthritis, your past experiences making a decision about your osteoarthritis, and what type of information you would need to make future decisions.**

---

#### **Part I**

---

1. Have you sought the care of / from any of the following health professionals for your hip or knee OA? Please indicate yes or no to the following list I will read to you:

- | Yes                      | No                       |   |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Acupuncturist   |
| <input type="checkbox"/> | <input type="checkbox"/> | Chinese Doctor (Chinese Medicine)   |
| <input type="checkbox"/> | <input type="checkbox"/> | Chiropractor  |
| <input type="checkbox"/> | <input type="checkbox"/> | Dietitian / Nutritionist  |
| <input type="checkbox"/> | <input type="checkbox"/> | Emergency room / urgent care centre / walk-in clinic  |
| <input type="checkbox"/> | <input type="checkbox"/> | <a href="#">Exercise physiologist</a> / <a href="#">Personal trainer</a> / <a href="#">Health coach</a> |
| <input type="checkbox"/> | <input type="checkbox"/> | Foot specialists (chiroprodists/podiatrists)  |
| <input type="checkbox"/> | <input type="checkbox"/> | Homeopathic doctor  |
| <input type="checkbox"/> | <input type="checkbox"/> | <a href="#">Massage therapist</a>   |
| <input type="checkbox"/> | <input type="checkbox"/> | Naturopathic doctor   |
| <input type="checkbox"/> | <input type="checkbox"/> | Nurse / Nurse practitioner  |
| <input type="checkbox"/> | <input type="checkbox"/> | Occupational therapist  |
| <input type="checkbox"/> | <input type="checkbox"/> | Osteopath   |
| <input type="checkbox"/> | <input type="checkbox"/> | Pharmacist  |
| <input type="checkbox"/> | <input type="checkbox"/> | Physician   |
| <input type="checkbox"/> | <input type="checkbox"/> | Physiotherapist   |
| <input type="checkbox"/> | <input type="checkbox"/> | Rheumatologist  |
| <input type="checkbox"/> | <input type="checkbox"/> | Surgeon   |
| <input type="checkbox"/> | <input type="checkbox"/> | Other: _____  |

---

**Part II: Making a Decision**


---

You noted earlier that you made a treatment decision (i.e. decided to start, stop, switch, or not use a specific treatment) about your hip or knee OA in the past 6 months. Please think about the last time you made a decision about managing your OA.

2. Can you tell me what the decision was about?

Please specify: \_\_\_\_\_

*For the rest of the interview, I would like you to want them to think about this OA treatment decision – when you*

When you were thinking about your options for this recent decision.....

3. Did you feel worried about what could go wrong?

- Yes
- No
- Unsure \*Do not read this as a response option. Only indicate if participant seems unsure*
- Cannot recall \*Do not read this as a response option. Only indicate if participant cannot recall*

4. Did you feel distressed or upset?

- Yes
- No
- Unsure \*Do not read this as a response option. Only indicate if participant seems unsure*
- Cannot recall \*Do not read this as a response option. Only indicate if participant cannot recall*

5. Did you feel like you couldn't get the decision off your mind?

- Yes
- No
- Unsure \*Do not read this as a response option. Only indicate if participant seems unsure*
- Cannot recall \*Do not read this as a response option. Only indicate if participant cannot recall*

6. Did you feel waiver (or keep changing your mind) between the choices that you faced?

- Yes
- No
- Unsure \*Do not read this as a response option. Only indicate if participant seems unsure*
- Cannot recall \*Do not read this as a response option. Only indicate if participant cannot recall*

7. Did you want to delay the decision?

- Yes
- No
- Unsure \*Do not read this as a response option. Only indicate if participant seems unsure*
- Cannot recall \*Do not read this as a response option. Only indicate if participant cannot recall*

8. Did you question what was important to you?

*(Note to interviewer: This can include things such as risks/ benefits, effect on psychosocial or physical outcomes, pain levels etc. that may result from the decision)*

- Yes
- No
- Unsure *\*Do not read this as a response option. Only indicate if participant seems unsure*
- Cannot recall *\*Do not read this as a response option. Only indicate if participant cannot recall*

9. Did you feel physically or mentally stressed (have tense muscles, a racing heart beat or difficulty sleeping) about making this decision?

- Yes
- No
- Unsure *\*Do not read this as a response option. Only indicate if participant seems unsure*
- Cannot recall *\*Do not read this as a response option. Only indicate if participant cannot recall*

10. Were you able to play the role you wanted in the decision?

- Yes
- No
- Unsure *\*Do not read this as a response option. Only indicate if participant seems unsure*
- Cannot recall *\*Do not read this as a response option. Only indicate if participant cannot recall*

11. Comments *(Note to interviewer: please record any additional comments here if relevant):*

---



---



---



---



---

### **Part III: Preparation for decision making.**

---

When considering this same treatment decision about your hip or knee OA (i.e. decided to start, stop, switch, or not use a specific treatment):

12. Did you know which options were available to you?

- Yes
- No

13. Did you know the benefits and risks of each option?

- Yes
- Unsure
- No

14. Did you know how likely (the chances of) each of the benefits and harms were?

- Yes
- Unsure
- No

15. Were you clear about which benefits and harms matter most to you?

- Yes
- Unsure
- No

16. Did you choose without pressure from others?

- Yes
- Unsure
- No

17. Did you have enough support and advice to make a choice?

- Yes
- Unsure
- No

18. Did you feel motivated or ready to make the decision?

- Yes
- Unsure
- No

19. Did you feel you had the ability or skill to make this type of decision?

- Yes
- Unsure
- No

20. Did you feel sure about the best choice for you?

- Yes
- Unsure
- No

---

### **Part III: Steps in Decision-Making**

---

The following questions ask about the steps you took in considering this same treatment decision about your hip or knee OA (i.e. decided to start, stop, switch, or not use a specific treatment):

21. Did you have information on the options, and their benefits and harms?

- Yes
- Unsure
- No

22. Did you have information on how likely each of the benefits and harms were to occur?

- Yes
- Unsure
- No

23. Did you get information on what others decide or recommend?

- Yes
- Unsure
- No

23a. If yes, from whom?

- Personal doctor
- Other doctors
- Spouse/partner
- Other (Specify: \_\_\_\_\_)

25. Did you do anything else to make your decision?

- Yes (Specify: \_\_\_\_\_)
- Unsure
- No

#### Part IV Future Decisions

26. If you have to make a future OA treatment decision (i.e. decided to start, stop, switch, or not use a specific treatment), what information would you want? (Check all that apply).

- Information about OA
- Information about drug therapies
- Information about non-drug therapies (such as exercise, acupuncture)
- Help considering the personal importance of the benefits and risks
- Guidance in the steps of making a decision
- Information on what others decide or recommend
- Other (Specify: \_\_\_\_\_)

27. In what format would you prefer this information? *Read list, and check all that apply.*

- Booklets or pamphlets
- Videos/DVDs
- Internet
- CD-ROMs
- Television
- Radio
- Newspapers
- Magazines
- Personal communication with your doctor
- Discussion groups with other people living with OA, including online discussions and social networks
- Information sessions held in your community
- Other (Specify: \_\_\_\_\_)

28. What sources of information would you consider trustworthy? *Read list, and check all that apply.*

- Pharmacies
- Societies (Canadian Arthritis Society, etc.)
- Medical and health care specialists
- Governments (including health departments)
- Health insurance companies
- Private companies that sell drugs and health products
- Consumer associations
- Not-for-profit companies that produce health information
- Other: \_\_\_\_\_

---

**Part VI: Demographics**

---

Just a few more questions about yourself will help us analyze the information you have given us. Remember that all of your responses are confidential.

29. What is the highest grade or level of education you completed?

- Less than grade 9
- Some high school
- High school diploma
- Trade certificate/diploma
- Some college
- College diploma/degree
- Some university
- University undergraduate degree
- University graduated degree (Masters and PhD)

30. What is your year of birth and age? 19 \_\_ \_\_ , Age \_\_\_\_\_

31. *Interviewer: please indicate participants' sex:*

- Female
- Male

Thank you very much for completing this questionnaire. This information will help us improve educational materials for people facing difficult health care decisions.

Next, we will be mailing you a copy of a decision aid that has been developed to help people like yourself understand the different treatment options for OA. We ask that you complete the decision aid on your own after you receive it in the mail. I will be calling you again after you receive this package to complete another set of questions that will ask about your opinions on the decision aid.

Date and Time of next call will be: \_\_\_\_\_ at \_\_\_\_\_ am/pm

## References and Resources

1. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, McPherson R, Bunn H, Graham I, Drake E. [A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation.](#) Patient Educ Couns. 1998 Mar;33(3):267-79.
2. Abbey-Livingston D, Abbey DS. [Enjoying research? A 'how-to' manual on needs assessment.](#) Toronto: Ontario Ministry of Tourism and Recreation. 1982. [Very easy read- Provides an excellent guideline for all aspects of the process of needs assessment.]
3. Polit DF, Hungler BP. **Nursing research - Principles and methods**, 5th ed. Philadelphia: JB Lippincott. 2004.
4. Dillman DA. **Mail and telephone surveys-The total design method.** New York: John Wiley & Sons. 1978. [ In depth detail about conducting a survey.]

Following are published examples of needs assessments that have used the methodology in this workbook

- Baldé A, Légaré F, Labrecque M. [Assessment of needs of men for decision support on male sterilization.](#) Patient Educ Couns. 2006 Nov;63(3):301-7. Epub 2006 Jul 26.
- Bunn H, Lange I, Urrutia M, Campos MS, Campos S, Jaimovich S, Campos C, Jacobsen MJ, Gaboury I. [Health preferences and decision-making needs of disadvantaged women.](#) J Adv Nurs. 2006 Nov;56(3):247-60.
- Doull M, O'Connor A, Jacobsen MJ, Robinson V, Cook L, Nyamai-Kisia C, Tugwell P. [Investigating the decision-making needs of HIV-positive women in Africa using the Ottawa Decision-Support Framework: Knowledge gaps and opportunities for intervention.](#) Patient Educ Couns. 2006 Nov;63(3):279-91. Epub 2006 Sep 18.
- Johnston JC, Durieux-Smith A, Fitzpatrick E, O'Connor A, Benzies K, Angus D. [An assessment of parents' decision-making regarding paediatric cochlear implants.](#) Canadian Journal of Speech-Language Pathology and Audiology, 2008 32, 169-182.
- Jolicoeur LJ, O'Connor AM, Hopkins L, Graham ID. [Women's decision-making needs related to treatment for recurrent ovarian cancer: a pilot study.](#) Can Oncol Nurs J. 2009 Fall;19(3):117-21.
- Kavanaugh K, Savage T, Kilpatrick S, Kimura R, Hershberger P. [Life support decisions for extremely premature infants: report of a pilot study.](#) J Pediatr Nurs. 2005 Oct;20(5):347-59.
- Légaré F, Stacey D, Dodin S, O'Connor A, Richer M, Griffiths F, LeBlanc A, Rousseau JL, Tapp S. [Women's decision making about the use of natural health products at menopause: a needs assessment and patient decision aid.](#) J Altern Complement Med. 2007 Sep;13(7):741-49.
- Mitra D, Jacobsen MJ, O'Connor A, Pottie K, Tugwell P. [Assessment of the decision support needs of women from HIV endemic countries regarding voluntary HIV testing in Canada.](#) Patient Educ Couns. 2006 Nov;63(3):292-300. Epub 2006 Jul 28.

- Murray MA, O'Connor AM, Fiset V, Viola R. [Women's decision-making needs regarding place of care at end of life.](#) J Palliat Care. 2003 Fall;19(3):176-84.
- O'Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie T. [A survey of the decision-making needs of Canadians faced with complex health decisions.](#) Health Expect. 2003 Jun;6(2):97-109.
- Stacey D, DeGrasse C, Johnston L. [Addressing the support needs of women at high risk for breast cancer: evidence-based care by advanced practice nurses.](#) Oncol Nurs Forum. 2002 Jul;29(6):E77-84.
- Stacey D, Menard P, Gaboury I, Jacobsen M, Sharif F, Ritchie L, Bunn H. [Decision-making needs of patients with depression: a descriptive study.](#) J Psychiatr Ment Health Nurs. 2008 May;15(4):287-95. doi: 10.1111/j.1365-2850.2007.01224.x.
- Tan J, Stacey D, Barankin B, Bissonnette R, Gulliver W, Lui H, Shear N, Bhatti S. [Support needed to involve psoriasis patients in treatment decisions: survey of dermatologists.](#) J Cutan Med Surg. 2011 Jul-Aug;15(4):192-200.
- Tan J, Stacey D, Fung K, Barankin B, Bissonnette R, Gulliver W, Lui H, Shear N, Jackson C, Zhang X. [Treatment decision needs of psoriasis patients: cross-sectional survey.](#) J Cutan Med Surg. 2010 Sep-Oct;14(5):233-9.
- Taylor-Clapp, S. [Patients Decision Making Needs Regarding Circumcision of Male Newborns.](#) Unpublished MScN Thesis. 2001. University of Ottawa.