



# Proposals

## to Facilitate Access to the Quebec Breast Cancer Screening Program for Women with Activity Limitations

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## PREFACE

Through research, it is becoming increasingly possible to improve access to health care services for all citizens. Evidence-based data on target populations, as well as evolving investigation techniques and treatment options have demonstrated the importance of early diagnosis in dealing with diseases that affect patients' quality of life and life expectancy. The systemic approach now being employed to treat specific diseases calls for public health measures that address all segments of the target population, in accordance with the principles of universality and equity in the delivery of public services.

Unfortunately, the planning and application of such population-based approaches is often aimed at what one might label "average citizens." In this context, where do people with special needs—including people with disabilities—fit in? Despite their underlying principles, public health programs often fail to take the special needs of this group into account. This study proposes a rigorous examination of various elements that can hinder or facilitate access to population-based programs for persons living with various forms of disability.

Many of the proposals that have emerged out of this research project seem simple, but they could play a crucial role in increasing the success of a screening program that has already demonstrated its effectiveness in reducing breast cancer mortality rates. We are confident that these proposals, if implemented, would have a direct impact on the quality of the services delivered through the program and make a real difference in the lives of many women, regardless of whether they have special needs or not.

Upon the publication of this report, I would like to congratulate the research team for its excellent work and for the proposals that have emerged from it. These proposals are relevant to all persons targeted by the program and are of particular importance to those who have limitations or disabilities. We are confident that implementation of these proposals within the Quebec breast cancer screening program (PQDCS) and, potentially, other formal screening programs in Canada, will have a tangible impact on the effectiveness of these programs and the quality of the services they deliver, not to mention the quality of life of many of our loved ones and fellow Canadians. Health is a fundamental right which, for the vast majority of people who live with disabilities or limitations, could be guaranteed through measures that are far more simple than many might assume.

Dr. Gaétan Filion MD, FRCP(c), MSc

Dr Gaétan Filion is a physiatrist. He has represented the Collège des médecins du Québec on the Accès santé project of the Association québécoise pour l'intégration sociale. Dr. Filion is the director of professional services at CSSS Vaudreuil-Soulanges, the director of medical affairs at the Centre montréalais de réadaptation, as well as the head of the pediatric rehabilitation program and a board member at the Jewish Rehabilitation Hospital. He also receives funding from the Fonds de recherche en santé du Québec (FRSQ) to pursue research into motor disorders in children.

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Maria Barile and Wassila Hadjabi, Action Femmes Handicapées de Montréal;  
France Belleau, PQDCS regional service coordination centre, Quebec City (Québec-Capitale-Nationale);  
Laurenne Blais, Institut de réadaptation en déficience physique du Québec-Centre interdisciplinaire de recherche en réadaptation et intégration sociale;  
Karima Hallouche, PQDCS regional service coordination centre, Montreal;  
Diane Larocque, PQDCS regional service coordination centre, Laval;  
Lucie Leclair-Arvisais, Centre de réadaptation en déficience intellectuelle Pavillon du Parc;  
Tony Leroux, Institut Raymond Dewar-Centre de recherche interdisciplinaire en réadaptation du Montréal métropolitain;  
France Séguin, PQDCS regional service coordination centre, Outaouais.

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Office des personnes handicapées du Québec;  
Relais-Femmes;  
Regroupement des aveugles et amblyopes du Montréal métropolitain.

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TABLE OF CONTENTS

PREFACE ..... iii  
ACKNOWLEDGEMENTS .....iv  
TABLE OF CONTENTS.....v  
HIGHLIGHTS .....2  
EXECUTIVE SUMMARY .....4  
REPORT.....8  
    1. Project objectives.....8  
    2. Relevance .....8  
    3. Methodology .....9  
    4. Project stages .....9  
    4.1 Stage 1: Identification of improvement targets .....9  
        4.1.1 Conduct.....9  
        4.1.2 Participants .....10  
        4.1.3 Interview plan .....11  
        4.1.4 Data processing and analysis .....11  
        4.1.5 Outcome: improvement targets.....11  
    4.2 Stage 2: Delphi survey .....14  
        4.2.1 Procedure .....14  
        4.2.2 Participants .....14  
        4.2.3 The questionnaires .....15  
        4.2.4 Data processing and analysis .....15  
        4.2.5 Outcome: 25 proposals for action .....16  
    4.3 Stage 3: Articulation of action proposals .....20  
        4.3.1 Conduct.....20  
        4.3.2 Participants .....20  
        4.3.3 Outcome: decision-making levels identified for the various proposals .....20  
    5. Project outcomes and further perspectives.....21  
    6. Additional resources .....22  
BIBLIOGRAPHY .....23  
APPENDICES .....25  
APPENDIX A.....26  
APPENDIX B .....31  
APPENDIX C .....45  
APPENDIX D.....47  
APPENDIX E .....71  
APPENDIX F .....73



## Proposals

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Accès au dépistage du cancer du sein. Vers des stratégies adaptées aux femmes présentant des besoins particuliers –  
Projet de recherche financé par les Instituts de Recherche en Santé du Canada (IRSC) (no réf. IHS80006)

## HIGHLIGHTS

The goal of this study was to identify measures to facilitate access to the Programme québécois de dépistage du cancer du sein (PQDCS), the Quebec breast cancer screening program, for women with activity limitations. In keeping with the program's focus on service quality, the study outlines 25 proposals to improve access to the PQDCS for women with activity limitations resulting from impairments of a motor, sensory, psychological or intellectual nature. Implementation of these proposals will require action on the part of several different decision-making levels (local, regional, Quebec government).

The study was carried out in three stages. The initial stage involved semi-structured interviews (n=124) in five regions of Quebec with women aged 50 to 69 years, with staff members at designated centres, and with representatives of organizations that work with people with activity limitations. The content of these interviews was analysed, a process which resulted in the identification of 64 proposals. These proposals were submitted to a group of experts (n=31) who were invited to participate in a Delphi survey process. In this second stage, 25 proposals were determined to be especially useful and feasible, which is to say that a strong consensus was achieved in their regard ( $\geq 80\%$ ). Finally, consultations were held with resource persons (n=11) in order to determine which decision-making levels (local, regional, Quebec government) were likely to play a key role in implementing the various proposals for action. The twenty-five proposals that emerged out of this process have been divided into five major fields of action.

- **Providing tools for designated centre personnel.** Two checklists and two sets of guidelines have been proposed. These tools focus on adapting the intake process for women with activity limitations and are intended to provide support for intake personnel when taking appointments and helping clients complete program consent forms. Three proposals deal with training, training complements, and the development of teaching materials on breast cancer screening practices for women with activity limitations.
- **Improving the screening program invitation.** Six proposals focus on making a number of changes to the presentation and content of information documents.
- **Adapting physical environments and materials.** Five proposals relate to the physical adaptation of designated centres, the accessibility and adaptation of mammography equipment, and the dissemination of information on centre accessibility.
- **Mobilizing key players.** Five proposals are intended to mobilize community resources and increase physician involvement in the delivery of breast cancer screening services for women with activity limitations, through the development of awareness materials and training options.
- **Identifying and disseminating best practices.** Two of the proposals focus on the identification of adaptation measures in screening centres, on finding ways to consult women with activity limitations when evaluating the effectiveness of such measures and, ultimately, on applying successful measures across the province.

Given the prevalence of activity limitations in the age group targeted by the PQDCS, implementation of the proposals that have emerged out of this study would benefit a substantial number of women who live with motor, sensory, psychological or intellectual impairments, as well as other groups of women with special needs.



# Proposals

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## EXECUTIVE SUMMARY

**Background and objectives.** Unless special measures are in place to assist them, women with activity limitations are less likely to benefit from breast cancer screening services than women in the general population. The goal of this study was to identify measures that can facilitate participation in the Programme québécois de dépistage du cancer du sein (PQDCS, the Quebec breast cancer screening program, for women who have activity limitations resulting from motor, sensory, psychological or intellectual impairments. Specifically, the study sought to: (1) identify barriers and facilitators that influence access to the PQDCS for women with activity limitations; (2) propose measures to improve access to the program for these women; and (3) recommend these measures to the decision-making levels best able to oversee their implementation.

**Methodology.** The study was carried out in three stages. In the initial stage, 1,120 semi-structured interviews were conducted with women aged 50 to 69, as well as with staff members at designated centres and representatives of organizations that work with people with activity limitations. An analysis of these interviews resulted in the identification of 64 proposals for action. In the second stage, these proposals were submitted to a group of experts from the PQDCS and organizations that provide services for people with activity limitations (n=31), using a two-round Delphi survey process. Each proposal was evaluated on the basis of two criteria: usefulness and feasibility. The list of 64 proposals was narrowed down to those considered to be especially useful and feasible by 80 % or more of the evaluators. After the Delphi survey, a consultation (step 3) was carried out with the members of the project advisory committee and invited resource persons (n=11) in order to identify the decision-making levels best able to implement the various proposals for action (local, regional, Quebec government).

**Results.** A total of 25 proposals for action were identified as priorities after it was agreed, by consensus that they were both useful and feasible. These proposals were grouped into five major fields of action: (1) providing tools for designated centre personnel; (2) improving the screening program invitation; (3) adapting physical environments and materials; (4) mobilizing key players; (5) identifying and disseminating best practices. The proposals were then referred to PQDCS officials, designated centres, physicians, partner organizations of the PQDCS, as well as facilities and organizations that provide services for people with activity limitations. Implementation of these proposals will require action on the part of several government levels (local, regional, Quebec government). The table that follows lists the 25 proposals and identifies the corresponding implementation levels.

**Conclusion.** Given the prevalence of activity limitations in the age group (50-69 years) targeted by the PQDCS and in view of the barriers to access that have been identified with respect to the program, the proposals that have emerged out of this study would benefit a substantial number of women who present motor, sensory, psychological or intellectual impairments, as well as other groups of women with special needs. Program participation and early detection rates would also improve.

25 Proposals for Action

		Local	Regional	Quebec
<b>1- PROVIDING TOOLS FOR DESIGNATED CENTRE PERSONNEL</b>				
1.1	Provide a checklist for designated screening centres (CDDs) and designated investigation referral centres (CRIDs) indicating the instructions that should be provided systematically to all women who make appointments.			•
1.2	Develop a checklist that intake personnel can use to summarize the content of the <i>Formulaire d'autorisation de transmission des renseignements relative à la participation au PQDCS</i> (Authorization form for the transmission of information related to participation in the PQDCS) in a simple, standardized fashion.			•
1.3	When taking appointments, systematically ask women whether they have special needs that should be taken into account in preparing their intake.			•
1.4	Retain information concerning the characteristics of women with activity limitations in the patient records of the relevant CDD.	•		
1.5	Add content dealing with clinical breast screening practices for women with activity limitations to PQDCS training module II for CDD-CRID personnel ( <i>Sensibilisation à l'approche envers les femmes visées par le PQDCS</i> ) (Awareness of approach used with women targeted by the PQDCS).			•
1.6	Develop teaching materials for CDD-CRID personnel that deal with clinical breast screening practices for women with activity limitations.			•
1.7	Through training and teaching materials provide information to technologists regarding mammography positioning techniques for people with activity limitations.			•
<b>2- IMPROVING THE SCREENING PROGRAM INVITATION</b>				
2.1	In the invitation letter, highlight the information women need to retain.		•	
2.2	In the invitation letter, encourage women to mention any special needs they might have when they make their appointments.		•	
2.3	In the invitation letter, encourage women with activity limitations to contact the PQDCS regional service coordination centre to obtain additional information.		•	
2.4	Standardize program correspondence across all regions, incorporating the strategies considered most useful in terms of helping women understand and make use of the information they are given.			•
2.5	When sending out invitation letters staple a list of regional CDDs to the letter or provide the two as a two-sided photocopy.		•	
2.6	In each region, identify the site and equipment accessibility characteristics of CDDs and provide this information in the invitation letter.		•	

**THE PQDCS AND WOMEN WITH ACTIVITY LIMITATIONS: PROPOSALS**

		Local	Regional	Quebec
<b>3- ADAPTING PHYSICAL ENVIRONMENTS AND MATERIALS</b>				
3.1	Prominently display the PQDCS logo in CDDs and CRIDs so that women can orient themselves more easily.		•	
3.2	In each region, identify the centres that offer accommodations for different types of activity limitations.		•	
3.3	Ensure that each centre has at least one accessible change room.	•		
3.4	When a woman's special needs are known ahead of time, ensure that the necessary equipment and support are available on the day of her appointment.	•		
3.5	Ensure that CDDs and CRIDs keep gowns of different sizes on hand.	•		
<b>4- MOBILIZING KEY PLAYERS</b>				
4.1	Designate a person to act as a liaison between the CDD, the CRID and any community resources that may need to be mobilized to assist women who require additional tests.		•	
4.2	Through training or teaching materials on the PQDCS, sensitize institutional/organizational representatives in every region, as well as representatives of residential facilities that house women with activity limitations who fall within the program's target age group.			•
4.3	Through training or teaching materials, remind physicians that annual clinical breast examinations constitute an appropriate preventive practice for women with activity limitations.			•
4.4	Through training or teaching materials, sensitize physicians to the importance of providing information on the PQDCS to women with activity limitations who fall within the program's target age group.			•
4.5	Through training or teaching materials, provide physicians with strategies for helping women with activity limitations undergo mammography screening.			•
<b>5- IDENTIFYING AND DISSEMINATING BEST PRACTICES</b>				
5.1	Incorporate questions aimed at women with activity limitations into regional evaluations of PQDCS service quality.			•
5.2	Analyse regional initiatives aimed at women with activity limitations in order to evaluate their effectiveness and potentially apply them on a national scale.			•



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## REPORT

### 1. Project objectives

The goal of this study was to identify measures to facilitate participation in the Programme québécois de dépistage du cancer du sein (PQDCS), the Quebec breast cancer screening program, for women living with activity limitations. Specifically, the study sought to: (1) identify barriers and facilitators that influence access to the PQDCS for women with activity limitations; (2) propose measures to improve access to the program for these women; and (3) recommend these measures to the decision-making levels best able to oversee their implementation. In keeping with the program's focus on service quality, the study outlines 25 proposals to improve access to the PQDCS for women who live with activity limitations resulting from motor, sensory, psychological or intellectual impairments. Implementation of these proposals will require action on the part of several different decision-making levels (local, regional, Quebec government).

### 2. Relevance

Equal access is a guiding principle of breast cancer screening programs in Canada. The terms of reference of the Quebec breast cancer screening program (PQDCS) stipulate that the program must be “(translation) fair and accessible to all sub-groups of the population” (p. 8) [1]. Similarly, the guidelines of the Working Group on Quality Determinants of Organized Breast Cancer Screening Programs stipulate that programs must include “strategies for women from special groups [including] women with disabilities” (p.7)[2].

Women with activity limitations constitute a far from negligible proportion of the population targeted by Canadian breast cancer screening programs (ages 50 to 69). Data generated by the Enquête québécoise sur les limitations d'activités (EQLA) indicate that motor, sensory, psychological and intellectual impairments affect 15.2 % of the population when all types of limitations are taken into account, with prevalence rates of 13.4 % for mobility impairments, 9.9 % for hearing impairments, 5.5 % for intellectual impairments<sup>1</sup> and mental illness, and 3.2 % for vision impairments [3]. Rates for Canada as a whole are similar, according to the Participation and Activity Limitation Survey (PALS)[4].

Women who have significant activity limitations (also referred to as disabled women or women living with disabilities) are less likely to get a mammogram than other women [5, 6]. These women encounter barriers at various points of contact with organized breast cancer screening programs [7, 8] and are at risk of being diagnosed at a more advanced stage of disease [9]. Although organized breast cancer screening programs are encouraged to provide accommodations for women with activity limitations [10], many such programs include no formal or systematic measures for women with special needs, even though women in this category share known risk factors with other women (heredity, nulliparity) and may present certain factors associated with screening difficulty (e.g., a high rate of obesity in women with intellectual disability).

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<sup>1</sup> Surveys of this type are known to under-represent people with intellectual disability (Havercamp, Scandlin, & Roth, 2005; Statistics Canada, 2003).

A number of studies, most of them conducted in Europe, the United States and Australia, have shown that women with activity limitations face a number of barriers in the area of breast cancer screening. Some of these studies deal with specific types of limitations [1, 5, 6, 8, 11-13], while others look at impairments in a more generic fashion [8, 14-19]. According to the results of these studies, barriers to access are generally connected to four different types of factors: personal factors (e.g., difficulty communicating or maintaining a position during mammography); relational factors (e.g., fear of health professionals, physicians' weak propensity to recommend mammography); organizational and systemic factors (e.g., insufficient time allocated for consultations, lack of interprofessional collaboration); and environmental factors (e.g., physical distance from clinics, transportation problems).

This study was motivated by problems observed in other countries with respect to access to organized breast cancer screening programs for women with activity limitations. It was undertaken in order to identify access barriers to the PQDCS, as well as appropriate solutions. It is the first major study ever undertaken in Quebec or Canada to identify concrete strategies for increasing participation in organized breast cancer screening programs for women with activity limitations. The study reflects the priorities of the Canadian Breast Cancer Screening Initiative, which seeks to ensure that organized breast cancer screening programs in Canada do a better job of targeting groups of vulnerable and difficult-to-reach women [20].

### **3. Methodology**

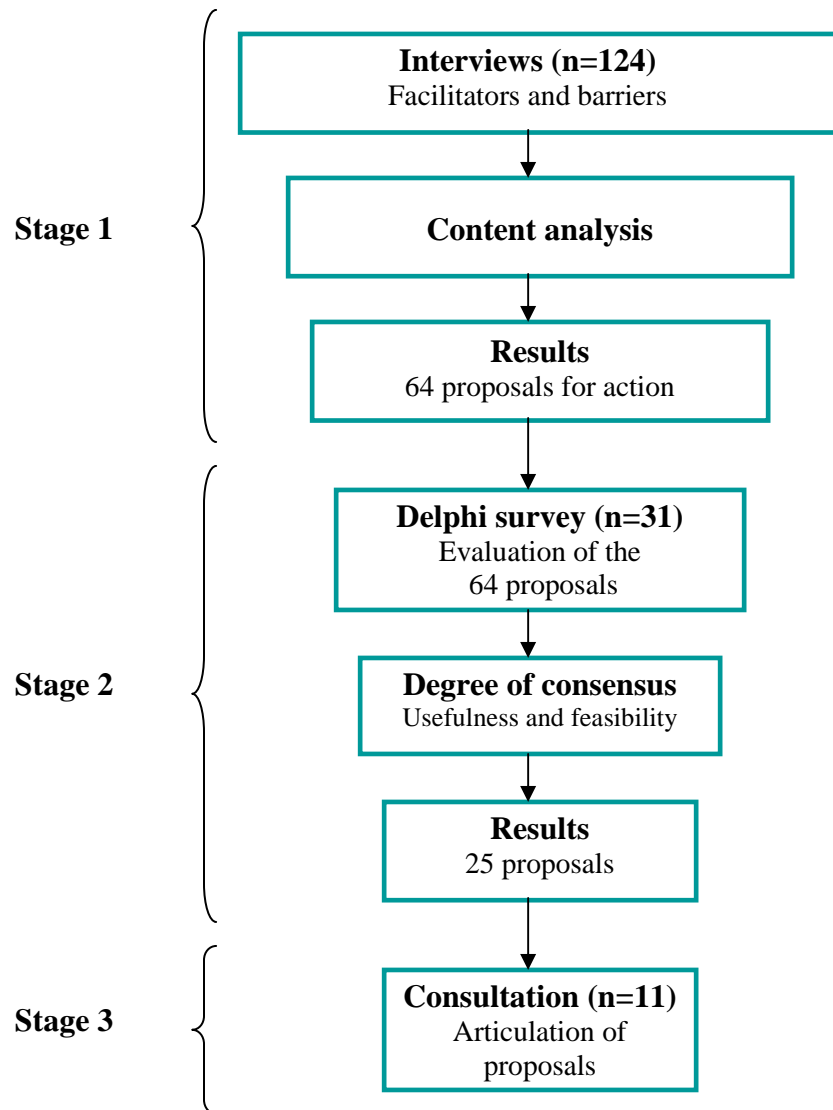
The study was carried out in three consecutive stages, (each associated with one of the project's three objectives): (1) semi-structured interviews; (2) a Delphi survey; and (3) a consultation to identify the decision-making levels (local, regional, Quebec government) best able to implement the proposals (see Figure 1).

### **4. Project stages**

#### **4.1 Stage 1: Identification of improvement targets**

##### *4.1.1 Conduct*

In order to identify barriers and facilitators to PQDCS access and, ultimately, the measures that will need be implemented to make the program more accessible to women with activity limitations, a series of semi-structured interviews was conducted in five administrative regions of Quebec, between March and November 2007.

**Figure 1. Stages of the research project**

#### 4.1.2 Participants

The interviews (120 in total) were carried out with 124 persons from five separate participant groups: (G1) women between the ages of 50 and 69 who had activity limitations and were also PQDCS participants (n=27); (G2) women between the ages of 50 and 69 who had activity limitations but were not PQDCS participants (n=18); (G3) women between the ages of 50 and 69 who did not have activity limitations but were PQDCS participants (n=21); (G4) screening centre employees (n=29); and (G5) representatives of facilities or associations that work with people with activity limitations (n=29), a group which included three physicians. The participants were recruited from the following administrative regions: Capitale-Nationale, Montréal, Outaouais, Laval and Montérégie. Their characteristics are presented in detail in Appendix A.

#### *4.1.3 Interview plan*

The interview plan was designed to explore—with respect to every stage of the PQDCS—access barriers, access facilitators, and ideas for improving access (see Appendix B: Sample interview plan and Appendix C: schematic representation of the PQDCS). Similar interview plans comprising open-ended questions were used with all five participant groups. The interview plans were composed of four sections, which varied slightly depending on the group to which they were addressed:

- Section 1: health self-perception (G1, G2 and G3) or nature of respondent's work (G4 and G5);
- Section 2: participants' past experience dealing with the health system (G1, G2 and G3) or past experience as a provider of services/support to people with activity limitations; (G4 and G5).
- Section 3: systematic exploration of barriers, facilitators and suggestions for improving the various components of the PQDCS for people with activity limitations.
- Section 4: synthesis questions designed to link or complete content discussed in the course of the interview.

#### *4.1.4 Data processing and analysis*

Data processing was carried out with the aid of QSR N'Vivo software. Data elements associated with barriers, facilitators and proposals for improving access were identified in order to prepare the Delphi survey (stage 2). This content was segmented and encoded (units of meaning) by a team of four research assistants who had received the necessary training. The material was encoded in two ways: (a) in relation to emerging issues or issues identified in the scientific literature (mixed procedure); and (b) by category (facilitator, barrier or proposed improvement). When 20 % of the processed material was submitted to an interjudge agreement process, a median correlation coefficient of 0.80 was established, representing a high degree of agreement.

#### *4.1.5 Outcome: improvement targets*

Through a process of analysis, a number of PQDCS access issues and improvement targets were identified. The issues identified with the aid of the analysis grid were grouped into 12 improvement target categories: access to program information, appointment taking, site-related considerations, data collection, participant consent, intake and preparation, mammography, women with complex profiles, physicians, community resources, program parameters, and PQDCS promotion. Below we provide a synthesis of the barriers and facilitators that were identified in each of these categories. These barriers and facilitators constitute the empirical basis for the proposals submitted in the Delphi survey (stage 2).

- *Access to program information.* The PQDCS provides much information in the form of written documents. The letter of invitation to participate in the PQDCS and the recall letter are two documents that serve, respectively, as an incentive to participate in the program and as a reminder. Since these letters also have the same value as a referral, they can often save women a trip to their doctor's office. However, some women are unable to absorb the important information provided in these letters and may, as a result, fail to bring the documents they need to have with them in order to have a mammogram performed (the invitation letter, a physician referral, films of earlier mammograms, as the case may be).

Certain criticisms have also been expressed with regard to these letters: the print is too small, important information is inadequately highlighted, certain formulations or terms are too complex, too much information is provided. Women with intellectual disability or vision impairments may have difficulty with written documents, as may women with low literacy or education levels. For these women, access to program information is conditional upon having a person in their entourage who can explain the content to them.

- *Appointment taking.* There are a variety of barriers that can prevent women from making an appointment for a mammogram. Some of them technical (e.g., being put on hold, complex telephone systems), while others are procedural (e.g., when appointments are only taken at certain times of the month). Also, the more time passes between the date the appointment is made and the date of the actual examination, the greater the chances that the person will forget her appointment or that her situation will change (e.g., loss of motivation or change in mental health status). Moreover, assistance from a friend or loved one is often needed to ensure that the appointment is made and that the person attends.
- *Site access considerations.* CDDs and CRIDs do not all offer the same degree of physical accessibility. Building access and spatial orientation inside buildings may constitute barriers for women with motor or sensory impairments, as well as for women with a low level of literacy (issues include signs, the width of corridors, toilets and change rooms, the availability of elevators, etc.).
- *Data collection.* The clinical information questionnaire that patients are asked to complete before undergoing mammography is said to be difficult to fill out, particularly for women who have difficulty reading or understanding information. Women or their personal attendants may be unable to provide the information requested (e.g., date of the last mammogram, hormone therapy status, etc.).
- *Participant consent.* The *Formulaire d'autorisation de transmission de renseignements relative à la participation des femmes au PQDCS* (authorization form for the transmission of information related to participation in the PQDCS) is part of the participant consent process. Although necessary, this form is difficult to read or to understand for many women (layout, length of text, complex words or formulations); some women require the assistance of a third party in order to understand the content of this form and provide their signature. To save time and facilitate comprehension, intake personnel often verbally summarize the content of this form for clients. This approach is primarily used with women who have difficulty reading or assimilating information. Questions have been raised about the ability of certain women to understand the content of this form, about the relevance of much of the information it contains, and about possible alternative approaches to presenting its content. Given these considerations, it may be difficult to obtain a person's informed consent in certain cases.
- *Intake and preparation of women with activity limitations.* When women with activity limitations arrange their appointments they do not always receive all the information they need in order to prepare for the examination. Similarly, if CDDs and CRIDs could obtain information on women's special needs ahead of time, it would be easier for them to make the necessary accommodations (e.g., make necessary adjustments to their equipment, or allocate more time or additional personnel for the examination). However, such prior knowledge

might also give rise to discriminatory practices (e.g., refusal of access, systematic referral to other CDDs) arising out of the concern that women with special needs require more time or preparation in order to undergo mammography. Questions were raised as to the best approach for collecting information on women's needs, as well as the nature of the data to be collected and the issue of data retention. Some participants also expressed concern that accessing certain information on women's special needs might constitute a violation of the principle of confidentiality.

- *Mammography.* Some women with activity limitations have incorporated mammography into their regular health checks. However, the procedure can trigger fears connected with difficult aspects of women's lives (e.g., body image, past negative experiences). In some cases, the discomfort, pain or embarrassment that mammography can cause is exacerbated by certain constraints associated with the mammography equipment or the positioning technique used. Moreover, certain CDDs and CRIDs do not have adapted equipment (wheelchairs, patient lifts, etc.) or the support staff needed to provide mammography services to women with special needs.
- *Women with complex profiles.* Some women with activity limitations present more complex profiles than others. The term "complex profile" refers to the exceptional nature of a person's condition, including the nature and severity of their limitations and/or the existence of associated problems (chronic illness, behavioural problems). For women who fall into this category, mammography can be a particularly difficult procedure to undergo. Questions were raised as to: the appropriateness or feasibility of providing screening mammography for these women; the criteria that should guide the decision to perform the examination; and the availability of resources to provide screening services for women with complex needs.
- *Physicians.* The attending physician (family doctor) is viewed as a key person in the dissemination of information on breast cancer screening and in providing support for women with activity limitations as they grapple with the decision to undergo mammography. Physician recommendation to obtain mammography (whether supported by a referral or not) constitutes an incentive for women and for CDD and CRID personnel. Consequently, physicians who fail to perform this role are indirectly influencing women's use of mammography and their subsequent need for additional tests and cancer treatments.
- *Community resources.* Mammography requires relatively complex planning for women who have mobility problems, who use accessible transportation, or who count on the support of a third person (such as an interpreter or personal attendant). These women must sometimes contend with limited community resources (e.g., restricted accessible transportation service areas, lack of interpreters), as well as limitations in their residential living environment. Finally, the difficulties associated with reaching women who live in residential facilities through regular mail (e.g., women with intellectual disability) have raised questions regarding information access and the decision-making process with respect to screening mammography.
- *Program parameters.* A number of CDDs and CRIDs have developed regional or local initiatives to address the needs of women with activity limitations. These include measures

to: adapt written documents; prepare women for mammography; collect intake information; organize the work of CDDs and CRIDs; and manage additional tests.

- *PQDCS promotion.* The PQDCS and breast cancer screening in general could be promoted more effectively if more diverse means were employed to encourage screening, disseminate information throughout the year, and recruit spokespersons with whom women can identify. Promotional campaigns are seen as crucial opportunities to reach women with activity limitations in a more direct fashion.

## 4.2 Stage 2: Delphi survey

The purpose of the Delphi survey was to identify proposals to facilitate access to the PQDCS for women in the study target population. The Delphi survey method uses successive questionnaires (consultation rounds) to consult a group of experts on a poorly documented issue [21]. The experts' anonymity is guaranteed throughout the process by virtue of the fact that each of them responds individually to a questionnaire which they receive from the investigators and must then return. Without revealing the identity of the other experts consulted, participants learn about each other's views after each successive consultation round, thus enabling them to revisit or reaffirm their own positions. Although the primary objective is to develop group positions, the Delphi process can also serve to bring differences of opinion to light.

### 4.2.1 Procedure

The survey began on November 20, 2007 and was completed on February 29, 2008. The experts' views were collected with the aid of two questionnaires which they received by regular mail, as well as by e-mail. The first questionnaire was sent out on November 20, 2007 and the second on January 21, 2008. Participants were initially given two weeks to complete each questionnaire. A reminder was sent out approximately three days before the deadline for returning the questionnaires. A second reminder was sent out one week after the deadline to participants who had failed to return the completed questionnaire. In some instances a third reminder was given by telephone, along with an extension for completing the questionnaire.

### 4.2.2 Participants

Experts were selected to participate in the survey based on peer recognition and the positions they occupied. Their names were suggested by members of the project advisory committee, on the basis of information obtained through individual interviews or from websites of interest. Three types of participants were sought: PQDCS experts performing different roles within the program, persons with expertise in the delivery of support services to people with activity limitations (due to impairments of a psychological, intellectual, physical or sensory nature), and experts in the organization of more general services, including those related to cancer control.<sup>2</sup> A special effort was made to invite at least one expert from each of Quebec's administrative regions.

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<sup>2</sup> Tables 1 and 2 in Appendix E show the distribution of participants for each consultation round, according to their areas of expertise and the size of the population centre in which they work.

The questionnaire for the first round of the survey was sent out to 48 experts in November 2007. Thirty-one of these experts returned their completed questionnaire, a response rate of 64.5 %. The questionnaire for the second round of the survey was sent out to the 31 experts who had returned the first questionnaire. Twenty-six of them returned a completed questionnaire, which represents a response rate of 84 % for the second questionnaire and an overall retention rate of 54 %.

The characteristics of the Delphi survey participants are outlined in Appendix E (tables 1 and 2). Close to three-quarters of the participants have expertise that is directly relevant to the PQDCS. Approximately one in five worked in the greater Montreal area (over 1,000,000 inhabitants), approximately half worked in a large city (100,000 to 999,999 inhabitants), and a quarter in smaller centres (10,000 to 99,999 inhabitants). Eleven of Quebec's seventeen administrative regions were represented.

#### *4.2.3 The questionnaires*

Two questionnaires were designed for the Delphi survey, one for each consultation round. Each of 64 proposals for action was linked to one of the twelve improvements targets that emerged out of the interviews carried out during the first stage of the project. Background information on the barriers and facilitators identified in those interviews (stage 1) preceded each set of proposals. Each proposal was to be evaluated on a four-point scale according to two criteria: usefulness and feasibility. The scale also included a "no opinion" option. The second questionnaire was limited to the 10 proposals for which no favourable or unfavourable consensus had been reached in the first consultation round. In both questionnaires, participants were invited to justify their positions in a section reserved for "Comments" after each proposal. The formula of background information followed by proposals was repeated in the second questionnaire. However, when the second questionnaire was designed, a synthesis of the comments compiled in the first round was included in the presentation of each of the 10 proposals that were to be resubmitted to participants. A copy of the first round questionnaire is provided in Appendix D.

#### *4.2.4 Data processing and analysis*

The table of Delphi survey results presented in Appendix F describes the results obtained in both consultation rounds. In order to achieve consensus on a given proposal, a rate of agreement of 70 % or more had to be achieved with respect to the "useful" criterion in the first round. This rate of agreement was based on a dichotomous "favourable/unfavourable" variable created by combining the results obtained for the "not at all" and "not very" favourable answers (which is to say the "unfavourable" answers) and those obtained for the "somewhat" and "very" favourable answers. In the first survey round, a consensus was achieved for 54 of the 64 proposals (84 %) with respect to the "useful" criterion. Of this number, a consensus of opinion was also achieved for 38 proposals with respect to the "feasible" criterion. In each case, consensus indicated a favourable opinion with respect to the proposal of interest.

The second survey round dealt with the 10 proposals for which no consensus had been achieved with respect to the "useful" criterion and, in some cases, the "feasible" criterion as well. In the case of the 10 proposals that were resubmitted in the second round, consensus was achieved on one criterion or the other in two instances only. An analysis of the responses obtained on the second questionnaire revealed differences of opinion that a third round was not likely to resolve. The survey was therefore terminated at this point (see Appendix F).

*4.2.5 Outcome: 25 proposals for action*

After studying distributions and in order to identify the most useful and feasible proposals among those for which a consensus was reached on both criteria, a consensus threshold equal to or greater than 80 % was applied to the results. The Delphi survey process made it possible to isolate 25 proposals out of the original 64. These were labelled priority proposals since they had been found to be the most useful and most feasible of the original 64. The 25 proposals were grouped into five major fields of action (see Table 1):

- 1- Providing tools for designated centre personnel
- 2- Improving the screening program invitation
- 3- Adapting physical environments and materials
- 4- Mobilizing key players
- 5- Identifying and disseminating best practices

## 1- PROVIDING TOOLS FOR DESIGNATED CENTRE PERSONNEL

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The first category of priority proposals is of interest to CDD and CRID personnel; the purpose of these proposals is to provide tools that will help centre workers adapt their intake procedures in order to better serve women with activity limitations. These proposals are designed to address a number of barriers identified by centre personnel and clients at different stages in the screening process, in areas such as participant consent, the intake process, and the preparation of women with activity limitations.

## 2- IMPROVING THE SCREENING PROGRAM INVITATION

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The second category of proposals relates to the invitation to participate in the PQDCS. The purpose of these proposals is to modify program information documents in order to make them more accessible to women with activity limitations. Proposed modifications relate to both the form of these documents (presentation), as well as their content (additions). The proposals in this category seek to address barriers that can prevent women from gaining access to program information.

## 3- ADAPTING PHYSICAL ENVIRONMENTS AND MATERIALS

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The third category of proposals comprises measures to physically modify CDD and CRID sites and equipment in order to accommodate the needs of women with activity limitations. Another objective is to disseminate information on the accessibility of different screening centres. The proposals in this category are designed to address reported access barriers to screening sites and to mammography services.

## 4- MOBILIZING KEY PLAYERS

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The fourth category of proposals seeks to increase physician involvement and to mobilize community resources in the promotion of breast cancer screening for women with activity limitations. These proposals are designed to address barriers that are primarily associated with physicians and community resources.

## 5- IDENTIFYING AND DISSEMINATING BEST PRACTICES

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The fifth category of proposals relates to initiatives that have already been implemented in order to reach women with activity limitations and accommodate their needs. The purpose of these proposals is to identify measures and practices that have been found to be effective in reducing barriers and improving access to the program.

Table 1. Priority proposals and implementation levels

		Local	Regional	Quebec
<b>1- PROVIDING TOOLS FOR DESIGNATED CENTRE PERSONNEL</b>				
1.1	Provide a checklist for designated screening centres (CDDs) and designated investigation referral centres (CRIDs) indicating the instructions that should be provided systematically to all women who make appointments.			•
1.2	Develop a checklist that intake personnel can use to summarize the content of the <i>Formulaire d'autorisation de transmission des renseignements relative à la participation au PQDCS</i> (Authorization form for the transmission of information related to participation in the PQDCS) in a simple, standardized fashion.			•
1.3	When taking appointments, systematically ask women whether they have special needs that should be taken into account in preparing their intake.			•
1.4	Retain information concerning the characteristics of women with activity limitations in the patient records of the relevant CDD.	•		
1.5	Add content dealing with clinical breast screening practices for women with activity limitations to PQDCS training module II for CDD-CRID personnel ( <i>Sensibilisation à l'approche envers les femmes visées par le PQDCS</i> ) (Awareness of approach used with women targeted by the PQDCS).			•
1.6	Develop teaching materials for CDD-CRID personnel that deal with clinical breast screening practices for women with activity limitations.			•
1.7	Through training and teaching materials provide information to technologists regarding mammography positioning techniques for people with activity limitations.			•
<b>2- IMPROVING THE SCREENING PROGRAM INVITATION</b>				
2.1	In the invitation letter, highlight the information women need to retain.		•	
2.2	In the invitation letter, encourage women to mention any special needs they might have when they make their appointments.		•	
2.3	In the invitation letter, encourage women with activity limitations to contact the PQDCS regional service coordination centre to obtain additional information.		•	
2.4	Standardize program correspondence across all regions, incorporating the strategies considered most useful in terms of helping women understand and make use of the information they are given.			•
2.5	When sending out invitation letters staple a list of regional CDDs to the letter or provide the two as a two-sided photocopy.		•	
2.6	In each region, identify the site and equipment accessibility characteristics of CDDs and provide this information in the invitation letter.		•	

**THE PQDCS AND WOMEN WITH ACTIVITY LIMITATIONS: PROPOSALS**

		Local	Regional	Quebec
<b>3- ADAPTING PHYSICAL ENVIRONMENTS AND MATERIALS</b>				
3.1	Prominently display the PQDCS logo in CDDs and CRIDs so that women can orient themselves more easily.		•	
3.2	In each region, identify the centres that offer accommodations for different types of activity limitations.		•	
3.3	Ensure that each centre has at least one accessible change room.	•		
3.4	When a woman's special needs are known ahead of time, ensure that the necessary equipment and support are available on the day of her appointment.	•		
3.5	Ensure that CDDs and CRIDs keep gowns of different sizes on hand.	•		
<b>4- MOBILIZING KEY PLAYERS</b>				
4.1	Designate a person to act as a liaison between the CDD, the CRID and any community resources that may need to be mobilized to assist women who require additional tests.		•	
4.2	Through training or teaching materials on the PQDCS, sensitize institutional/organizational representatives in every region, as well as representatives of residential facilities that house women with activity limitations who fall within the program's target age group.			•
4.3	Through training or teaching materials, remind physicians that annual clinical breast examinations constitute an appropriate preventive practice for women with activity limitations.			•
4.4	Through training or teaching materials, sensitize physicians to the importance of providing information on the PQDCS to women with activity limitations who fall within the program's target age group.			•
4.5	Through training or teaching materials, provide physicians with strategies for helping women with activity limitations undergo mammography screening.			•
<b>5- IDENTIFYING AND DISSEMINATING BEST PRACTICES</b>				
5.1	Incorporate questions aimed at women with activity limitations into regional evaluations of PQDCS service quality.			•
5.2	Analyse regional initiatives aimed at women with activity limitations in order to evaluate their effectiveness and potentially apply them on a national scale.			•

### 4.3 Stage 3: Articulation of action proposals

Upon completion of the Delphi survey, a final consultation was organized in order to discuss the implementation of the proposals identified in stage 2 and to outline dissemination strategies for that purpose. The exercise consisted of identifying the appropriate implementation level (local, regional, Quebec government) for each proposal. The meeting also provided an opportunity to verify the formulation of the various proposals in order to make them more precise or to eliminate superfluous elements.

#### 4.3.1 Conduct

This final consultation was part of a working day held on September 29, 2008. In the course of this day, the 25 proposals were analysed in a group setting in order to identify the appropriate implementation level for each one. The proposals were presented to the group with the aid of multimedia supports. Participants were invited to give their views as to the persons, organizations or agencies best able to implement the various proposals. Where more than one decision-making level was concerned, participants were asked to identify the one that was most likely to play a crucial role in approving the measure in question.

#### 4.3.2 Participants

The participants in the final consultation (n=11) included eight members of the advisory committee<sup>3</sup> and three representatives of organizations that work with people with sensory or physical activity limitations. These organizations were also partners in the research project.

#### 4.3.3 Outcome: decision-making levels identified for the various proposals

Through this final consultation, it was possible to determine the decision-making level best able to implement each of our 25 proposals for action (see Table 1). Although implementation of certain proposals may require the participation of several persons (or operational levels), participants were asked to identify the level most likely to play a crucial role in implementing each proposal. Of the 25 proposals, it was determined that 52 % fell under the jurisdiction of central (Quebec) government bodies, whereas 32% fell within the purview of regional authorities and 16 % were primarily of concern to local authorities. Central government bodies were most often linked to proposals in the following categories: “Providing tools for CDD and CRID personnel” (6/7), “Mobilizing key players” (4/5) and “Identifying and disseminating best practices” (2/2). For regional authorities the relevant proposals were more likely to be in the category related to “Improving the program invitation” (5/6). Proposals in the “Physical adaptations” category were determined to be the responsibility of both local and regional authorities (3/5 and 2/5 respectively). It should be noted that at any given decision-making level, more than one entity may be required to play a role. For example, the development of certain training tools may require the authorization of the PQDCS

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<sup>3</sup> In addition to the co-researchers, the advisory committee was composed of program officers (at the regional and provincial levels) and representatives of community/institutional resources and research teams working with people with activity limitations. Two meetings were held in each year covered by the project (six meetings in all) but committee members were also consulted individually on a variety of issues.

ministerial coordinator, as well as the support and cooperation of an organization such as the Office des personnes handicapées du Québec (OPHQ).

### **5. Project outcomes and further perspectives**

This study is the first designed to identify concrete solutions for improving access to an organized breast cancer screening program for women with activity limitations. The proposals put forward are of interest not only to PQDCS officials, but also to designated centre personnel (CDDs and CRIDs) and various program partners, including physicians and the personnel of facilities and organizations that work with people with activity limitations. Implementation of these proposals will require the involvement of a variety of decision-makers at the local, regional and Quebec government levels.

Given the prevalence of activity limitations in the age group targeted by the PQDCS, we believe that these proposals, if implemented, would increase access to the program for a substantial number of women and that this would in turn improve early detection rates. These proposals should also benefit other women with special needs (e.g., women with a low level of literacy or other difficulties in the area of communication). Since breast cancer screening programs are reasonably similar across Canada, the results of this study should be transferable to other Canadian programs and may well foster the integration of new program quality assurance criteria.

## 6. Additional resources

The research project involved a number of activities than now constitute additional resources. References to the most significant of these resources are provided below.<sup>4</sup>

### *Research report*

Proulx, R., Lemétayer, F., Mercier, C., Jutras, S & Major, D. (2009, mai)  
*Pistes d'action pour faciliter l'accès au programme québécois de dépistage du cancer du sein aux femmes ayant des limitations d'activités*, Montréal: Équipe Déficience intellectuelle, troubles envahissants du développement et intersectorialité. 85 pages.

Online availability  
[www.interteddi.ca](http://www.interteddi.ca)  
[www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca)

### *Poster*

Proulx, R., Mercier, C., Lemétayer, F., Major, D., & Jutras, S. (2008, Novembre).  
*Adapter le PQDCS aux femmes avec une incapacité : 25 pistes*. Poster presented at the 12<sup>th</sup> Journées annuelles de santé publique, November, 17, 2008, Quebec City, Quebec.

[www.interteddi.ca](http://www.interteddi.ca)  
[www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca)

### *Symposium proceedings*

Proulx, R., Lemétayer, F., Mercier, C., Jutras, S., & Major, D. (2008).  
 Défis en matière d'accès au dépistage du cancer du sein pour les femmes présentant une déficience intellectuelle. *Revue Francophone de la Déficience Intellectuelle*, 19, 21-25.

[www.rfdi.org](http://www.rfdi.org)

### *Oral paper*

Proulx, R., Céline Mercier, Diane Major, Sylvie Jutras & Fanny Lemétayer (Novembre, 2008). *Access to breast cancer screening for women with disabilities*. Canadian Breast Cancer Screening Initiative National Meeting, Toronto.

[www.interteddi.ca](http://www.interteddi.ca)

### *Pedagogical tool*

Collective work. (2008). *Prendre soin de ma santé, c'est aussi m'occuper de la santé de mes seins*. Relais-Femmes, CRDI Gabrielle-Major, CR Lisette-Dupras, CR de l'Ouest de Montréal, ID, PDD and Intersectoriality team.

[www.interteddi.ca](http://www.interteddi.ca)

### *Research team programming (health and intellectual disability)*

Intellectual Disability, Pervasive Developmental Disorders and Intersectoriality Team:  
[www.interteddi.ca](http://www.interteddi.ca)

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If you wish to obtain copies of the booklet, please contact Claude Leclair or Danielle Chrétien at the *l'Institut québécois de la déficience intellectuelle* : 514-725-7245.

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# Proposals

## to Facilitate Access to the Quebec Breast Cancer Screening Program for Women with Activity Limitations

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## **APPENDIX A**

### **DESCRIPTION OF STAGE 1 PARTICIPANTS**

### *Procedure*

The interviews were conducted in March and October 2007. Each lasted an average of 66 minutes and was recorded. Most (121) were individual interviews, but on three occasions two people from the same background were interviewed at the same time.

### *Participants*

Interviews were done with 124 participants from five administrative regions of the PQDCS, representing five program stakeholder groups.

- Group 1: women between the ages of 50 and 69 who had activity limitations and were also PQDCS participants (n=27);
- Group 2: women between the ages of 50 and 69 who had activity limitations but were not PQDCS participants (n=18);
- Group 3: women between the ages of 50 and 69 who did not have activity limitations but were PQDCS participants (n=21);
- Group 4: workers (intake staff, radiology technicians, other) and physicians associated with CDD and CRID activities (n= 29);
- Group 5: representatives of regional PQDCS partners, organizations working with disabled persons, specialized service centres, organizations involved in the promotion of women's health, and professional associations (n=29).

The tables that follow provide a profile of the population that participated in Stage 1 of the study.

Table 1 presents the distribution of women interviewed for the study (groups 1, 2 and 3) according to certain sociodemographic characteristics. In terms of age, most participants were 50-54 (44.6 %), 55-59 (21.5 %) or 60-64 (20 %). An examination of participants' family situations revealed that half were single (with or without children). The proportion of women with a low level of education (high school or less) and of more educated women was roughly the same. Only 8 women lived in a residential facility: most lived in a private residence or housing cooperative. Finally, 52.3 % of participants had an annual income of less than \$20,000.<sup>5</sup>

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<sup>5</sup> In 2006, the average personal income in Quebec was \$23,273 (Statistique Québec [www.stat.gouv.qc.ca](http://www.stat.gouv.qc.ca)).

**Table 1**  
**Sociodemographic Characteristics of Participants**  
**in groups 1, 2 and 3**

<b>Characteristics</b>	<b>Group 1</b>	<b>Group 2</b>	<b>Group 3</b>	<b>Total *</b>
	Number	Number	Number	Number
<b>Age group</b>				
49 and under	-	1	-	1
50-54	13	7	9	<b>29</b>
55-59	5	3	6	<b>14</b>
60-64	6	2	5	<b>13</b>
65-69	3	3	1	7
70 or over	-	1	-	1
<b>Family situation</b>				
Single, with or without children	11	12	9	<b>32</b>
Living with partner, with or without children	10	3	12	<b>25</b>
Living with co-residents	5	1	-	6
Other	1	1	-	2
<b>Education</b>				
Elementary not completed	2	1	-	3
Elementary completed	5	2	-	7
High school completed/ not completed	9	6	7	<b>22</b>
College/technical school completed/not completed	4	4	7	<b>15</b>
Bachelor's degree completed/not completed	4	2	4	<b>10</b>
Post-graduate studies completed/not completed	1	1	3	5
Other	1	1	-	2
Missing	1	-	-	1
<b>Accommodations</b>				
Apartment	10	7	8	<b>25</b>
Own home	9	6	13	<b>28</b>
Residential facility	5	3	-	8
Housing cooperative	1	1	-	2
Other	2	-	-	2
<b>Annual personal income</b>				
Under \$10,000	6	2	-	<b>8</b>
\$10,000 to \$19,999	12	8	6	<b>26</b>
\$20,000 to \$29,999	5	3	3	<b>11</b>
\$30,000 to \$39,999	-	-	2	2
\$40,000 to \$49,999	1	1	4	6
\$50,000 or more	2	-	4	6
Missing	1	3	-	4

\* The total corresponds to the sum of the values for the three groups.

Tables 2 and 3 present the key characteristics of the persons who composed group 4 (workers and physicians associated with CDDs and CRIDs) and group 5 (representatives of: regional PQDCS partners, organizations working with disabled persons, specialized service centres, organizations involved in the promotion of women’s health, and professional associations).

Group 4 was composed primarily of radiology technicians (13/29) who perform screening mammographies, and secretaries and receptionists (10/29). Almost as many professionals were working in public or private CDDs (12/29) as in CRIDs or CDD-CRIDs (13/29). The other professionals were working in a CCSR (3/29) or a CSSS (1/29). Most had several years of professional experience. Indeed, 25/29 had 11 or more years of experience. Finally, 80 % had 5 years or more of experience connected with the PQDCS.

<b>Characteristics</b>	<b>Total Number</b>
<b>Profession</b>	
Physician	1
Nurse	4
Radiology technician	<b>13</b>
Secretary/receptionist	<b>10</b>
Research or liaison officer	1
<b>Type of workplace</b>	
Private CDD	<b>8</b>
Public CDD	4
CRID	<b>8</b>
CDD-CRID	5
CCSR	3
CSSS	1
<b>Years of professional experience</b>	
5 or less	1
6-10	3
11-15	4
16-20	2
21-25	6
25 or more	<b>13</b>
<b>Years of experience connected with the PQDCS</b>	
1-2	1
3-4	5
5 or more	<b>23</b>

Group 5 participants occupied a variety of professions and were variously associated with public service organizations (10/27), community-based organizations or associations (14/27), and para-governmental organizations (3/27). As with group 4, group 5 participants had many years of experience.

**Table 3**  
**Sociodemographic characteristics of group 5 participants**

<b>Characteristics</b>	<b>Total Number</b>
Profession	
Physician	<b>5</b>
Nurse	1
Radiology technician	3
Specialized educator	2
Manager	<b>5</b>
Research or liaison officer	2
Worker or counsellor	<b>9</b>
Psychologist	1
Other	1
Type of workplace	
Public service organization	<b>10</b>
Community-based organization or association	<b>14</b>
Para-governmental organization	3
Number of years of professional experience	
5 or less	5
6-10	6
11-15	1
16-20	3
21-25	4
25 or more	<b>10</b>

## **APPENDIX B**

### **SAMPLE INTERVIEW PLAN – GROUP 1 – STAGE 1**



## L'ACCÈS AU DÉPISTAGE DU CANCER DU SEIN POUR LES FEMMES AYANT DES BESOINS PARTICULIERS

Research project funded by the Canadian Institutes of Health Research (CIHR)  
(Reference number IHS80006)

### **GROUP 1 INTERVIEW PLAN**

#### **For women with special needs who have participated in the Quebec breast cancer screening program (PQDCS)**

Hello and thank you for agreeing to meet with me today to discuss the Quebec breast cancer screening program (PQDCS) and the issue of program access for women with special needs.

The purpose of this research project is to gain a better understanding of the barriers that women with motor, sensory, psychological or intellectual impairments encounter in the area of breast cancer screening. Another goal is to find ways to ensure that all women can enjoy equal access to breast cancer screening.

The PQDCS was established in 1998 in various regions of Quebec with the purpose of reducing breast cancer mortality rates. The program targets women between the ages of 50 and 69, the age group at greatest risk of developing breast cancer. The program invites women to undergo mammography every two years and offers a range of related services. The program is also required to adapt its services in order to accommodate women with special needs, including those who have activity limitations resulting from a condition that cannot be entirely mitigated by personal support, technical aids or medications.

Although we know from studies and field observation that women with activity limitations do not enjoy equal access to breast cancer screening programs, there are no clear guidelines for improving access for women who fall into this category. As a result, opportunities for early detection are also fewer for these women.

My questions will relate to breast cancer screening, but some will also deal with your personal health and your experience dealing with the health system in general. There are no “right” or “wrong” answers. What interests us is your point of view as a woman.

*☞ Present the consent form.*

Before you decide whether to go forward with the interview, I would like to read this consent form with you. It contains more detailed information about our research project.

☞ *Read the form and obtain the person's signature.*

⊕ *Start the recording.*

## **A. Health concerns and dealings with the health care system**

Let's begin the interview. Before discussing the issue of breast cancer screening, I would like to speak with you about your general state of health and what's important to you when you access the health care system.

1. What does the term "health" mean to you?
2. Do you consider yourself healthy?

### Sub-question

What do you do to take care of your health? Can you provide examples?

3. Would you say that you are worried (concerned) or optimistic about your health? Can you tell me a little more? Can you provide examples?

### Sub-question

If optimistic: what makes you optimistic?

If worried: what is it that worries you?

4. Do you have specific concerns about your health?

☞ *If the person mentions breast cancer outright, say:*

Do you have any other health concerns?

5. Do you feel at risk of developing cancer?
6. Do you feel at risk of developing breast cancer?
7. Do you think your health concerns are similar to those of other women your age or are they different?
8. What do you value most when utilizing health services or dealing with health professionals?
9. Do you sometimes encounter problems when dealing with the health care system or health professionals? *If yes:* What kinds of problems? Ask for examples.

### Sub-questions

Are there things you find particularly irritating? *If yes:* What would those be?

*Reformulation:* Are there specific things that bother you when you deal with the health system or health professionals?

## B. Information on breast cancer screening use

Now let's look at the issue of breast cancer screening.

10. What is the first thing that comes to mind when you hear the words “breast cancer screening”?

There are three primary breast cancer screening methods: breast self-examination, clinical examination by a doctor in the context of a medical examination (breast palpation) and mammography, which is an X-ray of the breasts.

11. Have you used one of these methods during the past two years?

☞ *If yes:* What prompted you to \_\_\_\_\_ (mention the method(s) used)?

☞ *If more than one method was mentioned, ask:*

Of \_\_\_\_\_ (mention the methods used), is there one that you view as more important? *If yes:* Why?

### Number of mammograms

12. Approximately how many mammograms have you had in your life?

☞ *If the person mentions a frequency (e.g., every two years for the past 10 years), translate this frequency into an approximate number and validate with the person. For example: So you've had five mammograms?*

### Timing of last mammogram

13. Do you remember when you had your (last) mammogram?

☞ *Note: do not say “last” if the person has had only one mammogram.*

*If the person mentions a date or time of year (e.g., last January), translate this information into months/years. Example: So, it was approximately 8 months ago?*

### Location of last mammogram

14. Can you tell me where you had your (last) mammogram?

☞ *Offer a choice of answers from the list of designated screening centres (CDDs) in the participant's region.*

☞ *State the name of the Centre out loud. Example: So you went to... (re: recording).*

15. How did you learn that it was possible to get a mammogram?

### Sub-questions

Did you receive information about it? *If yes:* Where did this information come from?

Did you read it somewhere? Did someone speak to you about it? Did a doctor discuss it with you?

The mammography experience

16. Before discussing the different stages of the program in detail, can you briefly describe your experience of mammography for me?

<b>C. Stages of the PQDCS</b>
-------------------------------

Now, let's discuss the Quebec breast cancer screening program – the PQDCS. I'm going to ask you a series of questions that deal with the different stages of the program.

*☞ Present the “Stages of the PQDCS” diagram.*

This diagram shows the various stages that women go through when they participate in the PQDCS.

*☞ Name some of the stages from the following list:*

(1) the mammography invitation; (2) making an appointment; (3) travel (to the clinic or hospital designated as a screening centre) and intake; (4) signing the consent form; (5) waiting and undressing before entering the radiology room; (6) the mammographic examination; (7) getting the results; (8) if the mammogram is clear and shows no problem, recall in 24 months for a new examination; (9) if the results are abnormal, additional tests and diagnostic procedures; (10) referral to oncology if necessary.

We will now discuss each of these stages. I'm interested in the experience you've had with respect to each of them.

A single mammogram

*☞ If the participant has had only one mammogram, state:*

17. You underwent your first mammogram with the PQDCS, but you may not have received notification for your second examination yet. Is that the case?

More than one mammogram

*☞ If the participant has had more than one mammogram, state:*

Since you've had more than one mammogram, I'll ask you to focus primarily on your last mammogram. However, don't hesitate to refer to your other mammogram experiences when answering these questions.

*☞ In order to gain an understanding of participants' experiences and their possible referents, ask every participant the following:*

18. After your screening mammogram, were you told that you needed to undergo additional tests in order to investigate an inconclusive result or an abnormality of some kind?

*If yes:* So that I may have a better understanding of your situation, can you tell me about the results of these additional tests?

*Then say:* Thank you for providing these additional details.

Let's begin by talking about the mammography invitation.

### **1. Mammography invitation**

The most common way to join the PQDCS is by responding to the invitation letter that is sent to all women at age 50. Women can also join the program by obtaining a referral for a mammogram from their doctor. Let's take a few minutes to examine the invitation letter.

*Show the participant a copy of the invitation letter.*

**19.** Do you recall ever receiving a letter like this inviting you to have a mammogram?

*If yes:* sub-questions:

Did you read the letter?

Did you look at it or discuss it with someone else?

What did you do with the letter?

Let's spend a few minutes on the content of this letter.

*Read the most important parts of the letter and present the brochure that comes with it.*

**20.** What do you think of this letter and the information that comes with it?

**21.** Did you have trouble understanding or knowing what do with the mammography invitation? (In what way – examples).

*Reformulation:* Did something about this letter make you uncomfortable or disturb you?

*If no, ask:*

In general, do you have difficulty with things you receive in the mail?

**22.** Did someone or something help you or is there someone or something that could have helped you understand and use this letter?

*Note:* The participant may refer to personal resources, persons, or means used.

*This comment applies to all questions of this type.*

**23.** Has your doctor spoken to you about breast cancer screening?

#### Sub-questions

What kind of information did he or she provide?

Has your doctor spoken to you about the PQDCS?

Has he or she ever offered or given you a mammography referral?

*If yes:* Did you use it?

**24.** In the end, what motivated you to have a mammogram?

25. What did you use to obtain the mammogram: the invitation letter you received in the mail or a referral from your doctor? (or both?)

Now we're going to look at another step in the process – making an appointment for a mammogram.

## **2. Making an appointment**

26. How did this go for you?

### Sub-questions

How did the exchange with the clinic or centre go when made the appointment?

Did you contact them yourself?

☞ *If yes:*

Do you remember how they greeted you?

Do you remember how the information was provided to you?

☞ *If no:*

Who contacted them for you?

27. Did you encounter any problems when you made the appointment? (What kinds of problems – examples).

*Reformulation:* Did something make you uncomfortable or disturb you?

☞ *If no, ask:*

In general, do you have difficulty making medical appointments?

28. Did someone or something help you make the appointment, or is there someone or something that could have helped you make it?

## **3. Travel to the clinic/centre and intake process**

You had your last mammogram at \_\_\_\_\_

☞ *Name the designated clinic or facility.*

*If the respondent attended more than one CDD, invite her to speak about the one where she had her last mammogram and to make comparisons with the other CDD if she wishes. This comment applies to all questions of this type.*

### **Travel**

29. How did you get to your appointment?

*Reformulation:* Did you use public transportation? Accessible transportation? A car? Afterwards, did someone drive you home?

30. Did you have any problem getting to the clinic/centre or to the reception desk? (What kinds of problems – examples)

31. *Reformulation:* Was it easy to get to your appointment?

☞ *If no, ask:*

Generally speaking, do you have difficult getting places, for example to a medical appointment?

32. Did someone or something help you get to the clinic/centre or could something or someone have helped you get there?

### **Intake**

Let's talk a bit about the intake process at the clinic or centre where you had your (last) mammogram.

33. How would you describe the manner in which you were greeted when you arrived at the reception desk?

#### **Sub-questions**

How did the staff treat you?

How did they go about telling you what you needed to do when you arrived?

What kind of information did they provide?

34. Did you encounter any particular problems during the intake process at the clinic/centre? (What kinds of problems – examples)

*Reformulation:* Did something make you uncomfortable or disturb you?

☞ *If no, ask:*

In general, do you experience problems when you present yourself at a medical clinic or hospital?

35. Did someone or something help you when you arrived at the clinic/centre or is there someone or something have could have helped you?

### **4. Signing the authorization form**

Before getting your mammogram, you were probably asked to sign an authorization form like this one. This is the “*Formulaire d'autorisation de transmission des renseignements relative à la participation au PQDCS*” (authorization form for the transmission of information related to participation in the PQDCS).

☞ *Show the participant a copy of the authorization form.*

36. Do you recall the manner in which they presented this form to you, how they explained it and asked you to complete it? Can you tell me something about that?

Let's take a few minutes to examine the content of this form.

☞ *Read the key passages of the form.*

37. What are your impressions of this form?

38. Did you have any problems understanding or completing this form? (What kinds of problems – examples)

*Reformulation:* Did something make you uncomfortable or disturb you?

☞ *If no, ask:*

In general, do you have trouble completing forms or questionnaires?

39. Did someone or something help you or could someone or something have helped you understand and sign the form?

### **5. Waiting period and undressing**

Between the time you arrived at the clinic/centre and the time you went into the mammography room, you were probably asked to wait for a while and were subsequently taken to a changing room.

40. Can you tell me what that was like for you?

#### Sub-questions

What was your experience like during this stage of the process?

Approximately how long did you have to wait before they called you?

How did they call you?

Did you understand what you were expected to do? Did their instructions seem clear to you?

How did you find the facilities (comfort/discomfort)?

41. Did you encounter any problems while waiting or undressing? (What kinds of problems – examples)

*Reformulation:* Did something make you uncomfortable or disturb you?

☞ *If no, ask:*

In general, when you go for X-rays, do you encounter problems while waiting or undressing?

42. Did someone or something help you while you waited or undressed or is there someone or something that could have helped?

### **6. Mammography**

We will now discuss the mammography process itself, which is to say the experience of having your breasts X-rayed.

43. Can you tell me how things went for you when you had your (last) mammogram?

Sub-questions

How did you feel during the examination? What was the experience like for you?

How did the staff treat you?

What did they say to you?

How did they go about positioning you for the mammogram?

Was it necessary to carry out the procedure more than once in order to get a successful image?

*[Place to leave personal effects; discomfort during the examination; comfort (room temperature); guide installation; breathing instructions; wait time while films are being developed; etc.]*

44. Did you experience any problems with the mammography process itself? (What kinds of problems – examples)

*Reformulation:* Did something make you uncomfortable or disturb you?

*☞ If no, ask:*

When you go for X-rays, do you generally encounter problems, either with the staff or the equipment?

45. Did someone or something help you during the mammography or is there someone or something that could have helped?

*☞ If, at the start of the interview, the participant indicated that she also underwent additional tests, skip ahead to section 9 Additional tests.*

*☞ Otherwise, proceed with section 7 Communication of results.*

**7. Communication of results**

46. How did things go after the mammogram? Can you tell me about the waiting period and the manner in which your results were communicated to you?

Sub-questions

Did anyone tell you how things would unfold after the mammogram?

Approximately how long did you have to wait after the mammogram to get your results?

Did you receive your results in the mail?

How did you feel while you were waiting for your results?

*☞ Show a sample copy of a results letter.*

You probably received a letter like this one indicating your mammogram results.

Let's take a few minutes to examine this sample letter.

*☞ Read out the key passages of the letter.*

47. What was your impression of the letter you received?

Sub-question

Did you discuss it with anyone?

48. Did you encounter any problems with respect to the waiting period or the communication of your results? (What kinds of problems – examples)

Sub-question

Did you have any problem obtaining or understanding your results?

Did something make you uncomfortable or disturb you about this process?

49. In terms of the communication of your results, did someone or something help you or is there someone or something that could have helped?

50. In addition to the letter, did you receive a call from your doctor or some other designated person informing you of your results or telling you what to do next?

### **8. 24-month recall**

The Quebec breast cancer screening program sends out a letter calling women back for screening every two years. This is referred to as the recall procedure.

*☞ Show the participant a sample recall letter.*

51. Did you receive a letter like this one?

*If yes:*

What was your impression of the recall letter you received?

52. With respect to the recall letter and recall procedure, is there anything that you find (or found) difficult or that posed a problem for you? (What kind of problem – examples)

*Reformulation:* Did something make you uncomfortable or disturb you about the letter or the 24-month recall procedure?

53. Did someone or something help you or is there someone or something that could have helped you with respect to the recall procedure?

*☞ Pursue and complete the interview by moving on to Section D. Synthesis questions.*

### **9. Additional tests (if applicable)**

Some women have to undergo additional tests if their mammography results show something unusual or abnormal that requires further investigation.

54. This seems to have been the case with you. Is that correct?

*☞ If you discover that, in fact, the participant did not undergo additional tests, go back to section 7. Communication of results and then move on to sections 8. 24-month recall and D. Synthesis questions.*

55. How did you find out that you would have to undergo additional tests?

Sub-questions

In the days that followed your mammogram, did your doctor or some other person contact you to inform you that you would need to have additional tests?

What did they tell you?

56. Can you tell me what you had to do in order to undergo these tests?

Sub-questions

Who: Did you make the necessary appointment yourself?

Where: Where did you have the additional tests?

Time: From the time you were told that additional tests would be necessary, how long did you have to wait for the tests?

57. What was this waiting period like for you?

58. Thinking of how the tests were done or the procedure that was used to determine whether there really was a problem, is there anything that you find (or found) difficult or that posed a problem for you? (What kind of problem – examples)

59. Did someone or something help you during this period or is there someone or something that could have helped you undergo the additional tests and wait for your results?

60. Did someone or something help you when you received your results?

*☞ If the person has not already provided this information, ask:*

What did the additional tests reveal?

*☞ If the results were negative (no cancer), and regardless of whether other problems were uncovered (cysts, etc.), complete sections 8 24-hour recall and D. Synthesis questions.*

*☞ If the results were positive (cancer diagnosis) complete sections 10 Oncology referral and D. Synthesis questions.*

**10. Oncology referral (if applicable)**

After receiving the results of your additional tests, you were referred for treatment.

61. Can you tell me anything about the support you received during the treatment period?

62. Do you think your personal condition influenced the care you received or the way you approached your treatments?

#### D. Synthesis questions

We've just talked about the different stages that women go through with the Quebec breast cancer screening program.

63. What is your overall impression of the PQDCS process?

You mention a number of difficulties you experienced at different stages in the breast cancer screening program. For examples, you mentioned the following problems \_\_\_\_\_  
(name a few).

64. Do you think that all women experience these problems or do you think these problems are related to your particular situation? Take some time to think about each of the stages we discussed (*reshow the diagram illustrating the different stages of the program*).

65. What helped you the most during this experience? In other words, what provided the greatest help to you in terms of dealing with the difficulties you encountered?

66. Thinking again of each of the steps we discussed, can you think of anything that was lacking or that needs to be improved?

67. Do you think that your needs were taken into account throughout this process (the program)?

68. In the beginning, your reasons for getting a mammogram were \_\_\_\_\_ (mention the reasons stated at the beginning of the interview, if any). Did your experience with the program allow you to achieve this (permit this)?

69. When all is said and done, would you say that your experience of mammography and the breast cancer screening program in general was similar to your experience with other health services or was it different in some way?

70. Is there anything that you would like to add concerning your experience with the screening program? Can you suggest any improvements to the program?

⊖ Stop recording.

Thank you for taking the time to answer my questions and for answering them so carefully.

As indicated in the consent form for this study, our interview will conclude with two questionnaires. The first is a personal information questionnaire which I will ask you to complete

with me. Then I will ask you to complete the second questionnaire on your own. The second questionnaire is a personal satisfaction questionnaire relating to mammography.

- ☞ *Complete the personal information questionnaire.*
- ☞ *Have the participant complete the mammography satisfaction questionnaire.*
- ☞ *If, on the consent form, the participant indicated that she would like to receive a summary of the results, remind her that a summary will be forwarded to her.*

☞ *After both questionnaires have been completed, say:*

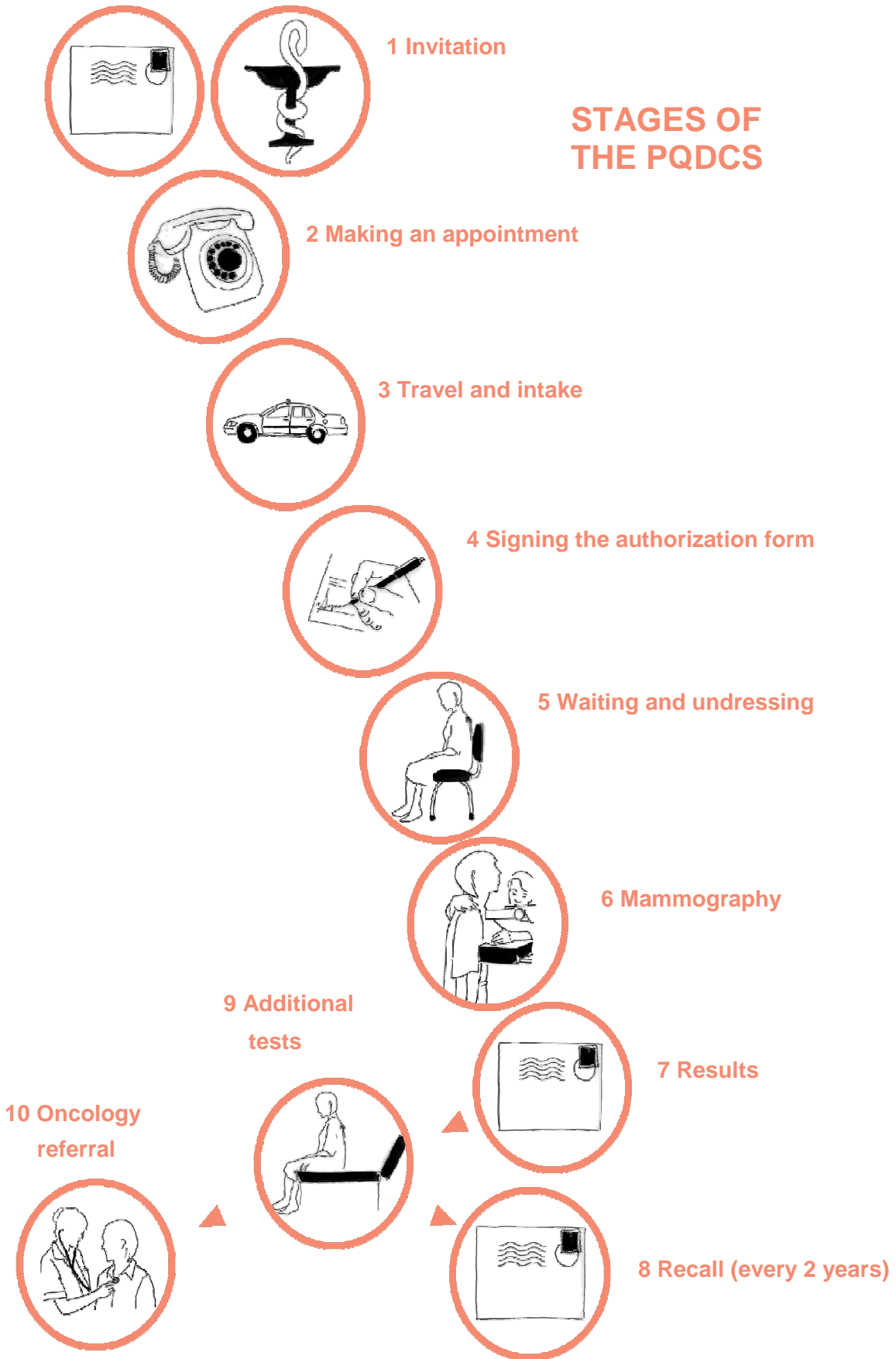
This concludes our meeting. On behalf of the members of the research team and their partners, I'd like to thank you again for your time. Your answers will help us gain a better understanding of the challenges faced by women who participate in the Quebec breast cancer screening program (PQDCS). We believe that the proposals that will emerge from this process will benefit all women with special needs and all women who encounter barriers to participation in the PQDCS.

- ☞ *Give the person the \$20 compensation and ask her to sign a receipt.*
- ☞ *Provide a program brochure.*
- ☞ *If applicable, provide the contact information of a resource person at the regional PQDCS office.*

## **APPENDIX C**

### **SCHEMATIC REPRESENTATION OF THE PQDCS**

# STAGES OF THE PQDCS



## **APPENDIX D**

### **DELPHI SURVEY QUESTIONNAIRE ROUND 1 (STAGE 2)**



## L'ACCÈS AU DÉPISTAGE DU CANCER DU SEIN POUR LES FEMMES AYANT DES BESOINS PARTICULIERS

### **DELPHI SURVEY QUESTIONNAIRE ON PROPOSALS TO IMPROVE ACCESS ROUND 1**

The goal of this questionnaire is to obtain your views on the usefulness and feasibility of a variety of proposals to improve access to the Quebec breast cancer screening program (PQDCS) for women who experience significant limitations in their day-to-day activities as a result of:

- a motor impairment (completely or partially disabled)
- a hearing impairment (deaf or hard of hearing)
- a visual impairment (blind or visually impaired)
- an intellectual impairment (intellectually disabled)
- a psychological impairment (mental health problems).

This questionnaire is based on an analysis of a series of interviews that were conducted in recent months with 124 participants (see attached document entitled “Research Project Presentation”). Through these interviews, we were able to identify various elements that impede or facilitate access to the PQDCS for women with activity limitations. The questionnaire presents 12 improvement targets that emerged from this analysis. For each of these targets, a range of proposals to facilitate access to the PQDCS are proposed. Although the primary objective is to facilitate access for women with activity limitations, a number of these proposals may also be of benefit to women in general.

This Delphi survey questionnaire will enable us to consult a group of experts (of which you are one) on an individual basis. The questionnaire results will be communicated to you in approximately two weeks. At that time, we will tell you which of the proposals were found, by consensus, to be both useful and feasible. The proposals for which no consensus was achieved will be resubmitted to you. You will then have an opportunity to express an opinion a second time after reviewing the responses of the other experts in the group and the distribution of those responses.

## INSTRUCTIONS

You can complete this questionnaire on a computer (online version) or on paper. In either case, **it is important that you answer all the questions.**

Please evaluate each of the proposals in the questionnaire according to the following **two criteria:**

- **Usefulness**                      *“Yes it is important!”*
- **Feasibility**                      *“Yes it can be done!”*

---

### EXAMPLE:

#### Proposal:

Draw up a list of regional resources that offer services to persons with activity limitations for dissemination to PQDCS-accredited centres.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In this example, the respondent felt that disseminating a list of resources that promote access to the PQDCS would be very useful and that implementing this measure was somewhat feasible.

---

Please check “No opinion” only when you are unable to express an opinion one way or another.

If you have any comments or suggestions for improving these proposals, please include them in the space provided for this purpose.

At the end of the questionnaire, you will be asked to identify the five proposals that you consider to be the most useful of all.

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE.

## TARGET 1: IMPROVING ACCESS TO PROGRAM INFORMATION

### Background

The PQDCS provides much information in the form of written documents. Of these, the letter of invitation to participate in the PQDCS and the recall letter are generally appreciated. These documents serve, respectively, as an incentive to participate in the program and as a reminder. Since these letters also have the same value as a referral, they can often save women a trip to their doctor's office. However, some women are unable to absorb the important information provided in these letters and may, as a result, fail to bring the documents they need to have with them in order to get a mammogram (the invitation letter, a doctor's referral, films of earlier mammograms, as the case may be). Certain criticisms have also been expressed with regard to these letters: the print is too small, important information is inadequately highlighted, certain formulations or terms are too complex, too much information is provided. Women with intellectual disability or vision impairments may have difficulty with written documents, as may women with low literacy or education levels. For these women, access to program information is conditional upon having a person in their immediate circle who can explain the content to them.

### Proposals

- 1.1 Develop alternative formats of the invitation letter and make these available upon request. Three formats are seen as priorities: (1) a simplified and illustrated version for persons with reading difficulties; (2) a Braille version for women who are blind; and (3) a large print version for women with impaired vision.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

- 1.2 In the invitation letter, encourage women with activity limitations to contact the PQDCS regional service coordination centre to obtain additional information.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

1.3 Illustrate the different stages of the program in the form of a diagram to be added to the invitation letter.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

1.4 Illustrate the different stages of the CDD appointment process in the form of diagram and make this resource available to women and intake personnel.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

1.5 In the *Formulaire d'autorisation de transmission de renseignements relative à la participation au PQDCS* (Authorization form for the transmission of information related to participation in the PQDCS), insert a box that women can check to request that information on the program be provided to them in an alternative format (Braille, large print, simplified-illustrated version) or forwarded to a third party of their choice.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

1.6 Modify the *Formulaire d'autorisation de transmission de renseignements relative à la participation au PQDCS* to provide an option whereby women can request that the program contact them by telephone.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

1.7 Develop a new form wherein women can instruct the PQDCS to communicate with them in the format that best suits their needs.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

1.8 In the invitation letter, highlight the information women need to retain (e.g., use of 14 point font or large print).

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

1.9 When sending out the invitation letter, staple a list of regional CDDs to the letter or provide the two as a two-sided photocopy.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

1.10 When a woman is scheduled to have a mammogram in a CDD other than the one in which she had her last mammogram, ensure that the films are mailed to the new CDD.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

## TARGET 2: SIMPLIFYING THE APPOINTMENT-MAKING PROCESS

### Background

While most women manage to contact the CDD on their own, a variety of barriers can prevent women from making an appointment for a mammogram. Some of these barriers are technical (e.g., being put on hold, complex telephone systems), while others are procedural (e.g., when appointments are only taken at certain times of the month). Also, the more time passes between the date the appointment is made and the date of the actual examination, the greater the chances that the person will forget her appointment or that her situation will change (e.g., loss of motivation or change in mental health status). It has also been pointed out that women with certain kinds of activity limitations may require assistance to make an appointment.

### Proposals

- 2.1 Provide CDDs and CRIDs with options for making appointments in writing (by fax, e-mail, TDD keyboard) and mention these options in the invitation letter.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 2.2 Provide CDDs and CRIDs with options for making appointments in writing (by fax, e-mail, TDD keyboard) and mention these options in the invitation letter.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 2.3 Provide each CCSR with the means to communicate in writing (by fax, e-mail, TDD keyboard) and indicate this option in the invitation letter.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 2.4 Shortly before each appointment (e.g., 1-3 days), remind women of the date and time of their appointment by telephone or in writing.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

**TARGET 3: SITE ACCESS CONSIDERATIONS**

**Background**

CDDs and CRIDs do not all offer the same degree of physical accessibility. Building access and spatial orientation inside buildings may constitute barriers for women with motor or sensory impairments, as well as for women with a low level of literacy (issues include signs, the width of corridors, toilets and change rooms, the availability of elevators, etc.).

**Proposals**

- 3.1 In each region, identify the site and equipment accessibility characteristics of CDDs and provide this information in the invitation letter.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

- 3.2 Adopt guidelines and timelines for the installation and quality control of equipment (e.g., stair lifts, wheelchairs, patient lifts) in CDDs and CRIDs.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

3.3 Prominently display the PQDCS logo in CDDs and CRIDs so that women can more easily find their way around.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

3.4 Equip CDDs and CRIDs with visual indicators (floor markings, colour coding) and sound indicators (e.g., beeps to identify obstacles) in order to facilitate spatial orientation for women with vision or hearing impairments.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

3.5 Lower CDD and CRID reception counters to provide easier access for women who use a wheelchair.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

3.6 Ensure that each centre has at least one accessible change room (spacious enough to accommodate a personal attendant, guide dog, wheelchair, etc.).

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

3.7 Allow women who use a wheelchair to undress in the examination room.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

**TARGET 4: FACILITATING DATA COLLECTION**

**Background**

The clinical information questionnaire that patients are asked to complete before undergoing mammography is said to be difficult to fill out, particularly for women who have difficulty reading or understanding information. Women or their personal attendants may be unable to provide the information requested (e.g. the date of the last mammogram, hormone therapy status, etc.).

**Proposals**

4.1 Attach the clinical information questionnaire to the invitation letter so that women will be able to complete it ahead of time.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

4.2 For subsequent mammograms, re-use the clinical information questionnaire already completed at the CDD and simply update the information.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

4.3 Find the date of the last mammogram in SI-PQDCS and provide it in the recall letter.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

**TARGET 5: PARTICIPANT CONSENT**

**Background**

The *Formulaire d'autorisation de transmission de renseignements relative à la participation des femmes au PQDCS* (authorization form for the transmission of information related to participation in the PQDCS) is part of the participant consent process. Although necessary, this form is difficult to read and to understand for many women (layout, length of text, complex words or formulations); some women require the assistance of a third party in order to understand the content of this form and provide their signature. To save time and facilitate comprehension, intake personnel often verbally summarize the content of this form for clients. This approach is primarily used with women who have difficulty reading or assimilating information. Questions have been raised about the ability of certain women to understand the content of this form, about the relevance of much of the information it provides, and about possible alternative approaches to presenting its content. Given these considerations, it may be difficult to obtain a person's informed consent in certain cases.

**Proposals**

5.1 Attach the *Formulaire de transmission de renseignements relative à la participation des femmes au PQDCS* to the invitation letter so that women can read it before their appointment.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

5.2 Provide the *Formulaire d'autorisation de transmission de renseignements relative à la participation des femmes au PQDCS* upon request to allow women to review it before their appointment.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

5.3 Develop a checklist that intake personnel can use to summarize the content of the form in a simple, standardized fashion.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

5.4 Develop a simplified version of the *Formulaire d'autorisation de transmission de renseignements relative à la participation des femmes au PQDCS* (composed of key words and illustrations) and make it available to women and intake personnel.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

## TARGET 6: INTAKE AND PREPARATION OF WOMEN WITH ACTIVITY LIMITATIONS

### Background

Appointment taking offers an excellent opportunity to share information with women and to identify their needs. When women with activity limitations arrange their appointments they do not always receive all the information they need in order to prepare for the examination. Similarly, if CDDs and CRIDs could obtain information on women's special needs ahead of time, it would be easier for them to make the necessary accommodations (e.g., make necessary adjustments to their equipment, or allocate more time or additional personnel for the examination). However, such prior knowledge might also give rise to discriminatory practices (e.g., refusal of access, systematic referral to other CDDs) arising out of the concern that certain women require more time or preparation in order to undergo mammography. Questions were raised as to the best approach for collecting information on women's needs, as well as the nature of the data to be collected and the issue of data retention. Some participants also expressed concern that accessing certain information on women's special needs might constitute a violation of the principle of confidentiality.

### Proposals

- 6.1 Provide a checklist for CDDs and CRIDs indicating the instructions that should be given systematically to all women who make appointments.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

\_\_\_\_\_

- 6.2 Add content dealing with clinical breast screening practices for women with activity limitations to PQDCS training module II for CDD personnel (*Sensibilisation à l'approche envers les femmes visées par le PQDCS*) (Awareness of approach used with women targeted by the PQDCS).

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

\_\_\_\_\_

6.3 Develop teaching materials (e.g., an information leaflet) for CDD-CRID personnel that deal with clinical breast cancer screening practices for women with activity limitations.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: _____					

6.4 For each region, draw up a list of resources that offer services to persons with activity limitations and provide this information to CDDs and CRIDs.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: _____					

6.5 When taking appointments, systematically ask women whether they have special needs that should be taken into account in preparing their intake.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: _____					

6.6 In the invitation letter, encourage women to mention any special needs they might have when they make their appointments.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: _____					

6.7 Integrate into the provincial SI-PQDCS database new categories for the identification of women’s special needs in the areas of communication, personal assistance, and access to screening sites and equipment. This information could then be conveyed to the CCSRs to facilitate program follow up activities (e.g., recalls, communication of results).

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: _____					

6.8 Establish a regional database containing any information women might wish to disclose regarding their special needs in the areas of communication, personal assistance, and access to screening sites and equipment. This data would be managed by the CCSRs to facilitate program follow up activities (e.g., recalls, communication of results).

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: _____					

6.9 Retain information concerning the characteristics of women with activity limitations (types of limitations and special needs) in the patient records of the relevant CDD.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: _____					

6.10 In each region, identify the centres that offer accommodations for different types of activity limitations.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: _____					

## TARGET 7: ADAPTATION OF THE MAMMOGRAPHY PROCESS

### Background

Some women with activity limitations have incorporated mammography into their regular health checks. However, the procedure can trigger fears connected with difficult aspects of women's lives (e.g., body image, past negative experiences). In some cases, the discomfort, pain or embarrassment that mammography can cause is exacerbated by certain constraints associated with the mammography equipment or the positioning technique used. Moreover, certain CDDs and CRIDs do not have adapted equipment (wheelchairs, patient lifts, etc.) or the support staff needed to provide mammography services to women with special needs.

### Proposals

- 7.1 When a woman's limitations are known ahead of time, ensure that the necessary equipment and support (assistant technologist) are available on the day of the appointment.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 7.2 Offer women the possibility of getting a mammogram in a seated position.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 7.3 Allocate funds for the purchase of adapted equipment (e.g., adjustable chairs, patient lifts) in regions that lack such equipment.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

7.4 Through training and teaching materials (e.g., information leaflet) provide technologists with information on mammography positioning techniques for persons with motor limitations.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

7.5 Ensure that CDDs and CRIDs have gowns of different sizes on hand.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

7.6 Ensure that CDDs and CRIDs have gowns with velcro ties on hand.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

**TARGET 8: ESTABLISHING GUIDELINES FOR  
 COMPLEX SITUATIONS**

**Background**

Some women with activity limitations present more complex profiles than others. The term “complex profile” refers to the exceptional nature of a person’s condition, including the nature and severity of their limitations and/or the existence of associated problems (chronic illness, behavioural problems). For women who fall into this category, mammography can be a particularly difficult procedure to undergo. Questions were raised as to: the appropriateness or feasibility of providing screening mammography for these women; the criteria that should guide the decision to perform the examination; and the availability of resources to provide screening services for women with complex needs.

## Proposals

- 8.1 Develop and distribute to CDDs and CRIDs a practice guide providing strategies to accommodate women with activity limitations in the PQDCS (e.g., less time in the waiting room, postponement of appointments for women whose emotional state is unstable).

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

- 8.2 Establish guidelines that could be used to determine whether women with complex profiles are in fact able to provide informed consent to screening.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

- 8.3 Establish follow up guidelines for women who are unable to undergo mammography or whose mammography results are inconclusive.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

- 8.4 Establish decision support guidelines for the referral of women with complex profiles to oncology or treatment.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

- 8.5 Establish guidelines concerning the use of tranquilizers in connection with mammography screening and additional tests.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

## TARGET 9: STRENGTHENING PHYSICIANS' COMMITMENT TOWARD WOMEN WITH LIMITATIONS

### Background

The attending physician (family doctor) is viewed as a key person in the dissemination of information on breast cancer screening and in providing support for women with activity limitations as they grapple with the decision to undergo mammography. Physician recommendation to obtain mammography (whether supported by a medical referral or not) constitutes an incentive for women. Some have suggested that the role of the referring physician in helping women with activity limitations come to a decision with regard to mammography, as well as their role in facilitating women's access to additional tests and oncology treatment, needs to be supported and strengthened.

### Proposals

- 9.1 Through training or teaching materials, sensitize physicians to the importance of recommending CDD-based screening mammography to women with activity limitations who fall within the target age group of the PQDCS.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 9.2 Through training or teaching materials, remind physicians that annual clinical breast examinations constitute an appropriate preventive practice for women with activity limitations.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 9.3 Through training or teaching materials, provide physicians with strategies for helping women with activity limitations undergo mammography screening.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

## TARGET 10: MOBILIZING COMMUNITY RESOURCES

### Background

Mammography requires relatively complex planning for women who have mobility problems, who use accessible transportation or who count on the support of a third party (such as an interpreter or personal attendant). These women must sometimes contend with limited community resources (e.g., restricted accessible transportation service areas, lack of interpreters), as well as limitations in their residential living environment. Finally, the difficulties associated with reaching women who live in residential facilities through regular mail (e.g., women with intellectual disability) have raised questions regarding information access and the decision-making process with respect to screening mammography.

### Proposals

- 10.1 Through training or teaching materials on the PQDCS, sensitize institutional/organizational representatives in every region, as well as representatives of residential facilities (e.g., group homes) for women with functional limitations who fall within the program's target age group.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 10.2 Develop a general framework agreement with accessible transportation systems to facilitate the development of local and regional agreements.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 10.3 Develop a general framework agreement with local support services to facilitate access to personal attendants when the need arises.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

- 10.4 Develop a general framework agreement with local interpreter services in order to facilitate access to interpreters when the need arises.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

**TARGET 11: REVIEWING AND IMPROVING PROGRAM PARAMETERS**

**Background**

A number of CDDs and CRIDs have developed regional or local initiatives to address the needs of women with activity limitations. These include measures to: adapt written documents; prepare women for mammography; collect intake information; organize the work of CDDs and CRIDs; and manage additional tests.

**Proposals**

- 11.1 Analyse regional initiatives aimed at women with activity limitations in order to evaluate their effectiveness and potentially apply them on a national scale.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_

11.2 Standardize program correspondence (invitations, recalls, reminders, etc.) across all regions, incorporating the strategies considered to be most useful in terms of helping women understand and make use of the information they are given.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

11.3 Designate a person to act as a liaison between the CDD, the CRID and any community resources that may need to be mobilized to assist women who require additional tests or cancer treatment.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

11.4 Incorporate questions aimed at women with activity limitations into regional evaluations of PQDCS quality or client satisfaction.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

11.5 Incorporate information on the submission of complaints into PQDCS documents.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

**TARGET 12: INCLUDING WOMEN WITH ACTIVITY LIMITATIONS IN PQDCS PROMOTIONAL ACTIVITIES**

**Background**

The PQDCS and breast cancer screening in general could be promoted more effectively if more diverse means were employed to encourage screening, disseminate information throughout the year, and recruit spokespersons with whom women can identify. Promotional campaigns are seen as crucial opportunities to reach women with activity limitations in a more direct fashion.

**Proposals**

12.1 Identify and put forward strategies to target women with activity limitations in the context of PQDCS promotional campaigns.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

12.2 Identify and put forward strategies to target women with activity limitations in the context of cancer campaigns.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

12.3 In the invitation letter or in an accompanying document, include a reference to the DVD *Autour des seins* and include information on how to obtain it. The DVD provides simple information in several languages (including Quebec sign language) on breast cancer screening and the PQDCS.

	Not at all	Not very	Somewhat	Very	No opinion
<b>Useful</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Feasible</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments: \_\_\_\_\_  
 \_\_\_\_\_

## CONCLUSION: PRIORITY PROPOSALS AND COMMENTS

From among the proposals listed above, select and identify by number (e.g., 3.2) the five you think would be most useful in terms of improving access to breast cancer screening for women with activity limitations resulting from a motor, sensory, intellectual or psychological impairment.

Proposal 1

Proposal 2

Proposal 3

Proposal 4

Proposal 5

If you have any comments or suggestions to make with regard to the facilitators, barriers or proposals discussed in this questionnaire, please provide them below.

**THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.**

**PLEASE RETURN:**

- **BY MAIL: THE *FORMULAIRE DE CONSENTEMENT À LA RECHERCHE* (RESEARCH CONSENT FORM) WITH YOUR SIGNATURE, (RETAIN THE SECOND COPY FOR YOURSELF), AND THE *QUESTIONNAIRE D'ENQUÊTE DELPHI* (DELPHI SURVEY QUESTIONNAIRE), USING THE POSTAGE-PAID ENVELOPE.**
- **BY E-MAIL: SAVE THE *FORMULAIRE DE CONSENTEMENT À LA RECHERCHE*, ADDING YOUR ELECTRONIC SIGNATURE (IF YOU DO NOT HAVE AN ELECTRONIC SIGNATURE, PLEASE COMPLETE THE PAPER VERSION OF THE FORM AND RETURN IT IN THE POSTAGE-PAID ENVELOPE). SAVE THE *QUESTIONNAIRE D'ENQUÊTE DELPHI* AND COMPLETE IT ON LINE. ATTACH BOTH THE QUESTIONNAIRE AND THE CONSENT FORM TO YOUR E-MAIL AND FORWARD TO:**

**ACCESDEPISTAGE.CRLD@SSSS.GOUV.QC.CA**

## **APPENDIX E**

### **DESCRIPTIVE TABLES OF DELPHI SURVEY PARTICIPANTS (STUDY 2)**

Table 1. Characteristics of participants in each consultation rounds

<b>Participants' areas of expertise</b>	<b>Mailed out 1st round</b>	<b>Returned 1st round</b>	<b>Returned 2nd round</b>
PQDCS experts - management <sup>6</sup>	21	15	13
PQDCS experts - training	3	2	1
PQDCS experts - services	7	4	3
PQDCS experts - quality assurance	2	2	2
Experts in the delivery of support services to persons with activity limitations	11	8	7
Experts in the field of cancer control	2	0	0
Experts in the field of service organization	2	0	0
<b>TOTAL</b>	<b>48</b>	<b>31</b>	<b>26</b>

Table 2 illustrates the distribution of participants in each consultation round, according to the size of the population cluster in which they work. Approximately one participant in five works in the greater Montreal area (more than 1,000,000 inhabitants), approximately half work in large cities (100,000 to 999,999 inhabitants) and a quarter work in smaller centres (10,000 to 99,999 inhabitants). The participants represented eleven of Quebec's seventeen administrative regions.

Table 2. Characteristics of participants' places of work

<b>Participants' places of work</b>	<b>Mailed out 1st round</b>		<b>Returned 1st round</b>		<b>Returned 2nd round</b>	
Metropolitan More than 1,000,000 inhabitants	11	23.0 %	7	22.5 %	5	19.0 %
Urban - large city 100,000 to 999,999 inhabitants	22	46.0 %	16	51.5 %	13	50.0 %
Urban – smaller centre 10,000 to 99,999 inhabitants	12	25.0 %	7	22.5 %	7	27.0 %
Rural-semi-rural Fewer than 10,000 inhabitants	3	6.0 %	1	3.5 %	1	4.0 %
<b>TOTAL</b>	<b>48</b>		<b>31</b>		<b>26</b>	

<sup>6</sup> Corresponds to persons attached to CCSR in 11 different regions.

## **APPENDIX F**

### **TABLE OF DELPHI SURVEY RESULTS (STAGE 2)**

**RESULTS OF DELPHI SURVEY QUESTIONNAIRE**

<b>TARGET 1: IMPROVING ACCESS TO PROGRAM INFORMATION</b>								
<b>Proposals for action</b>		Round	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			Unfavourable	Favourable		Unfavourable	Favourable	
1.1	Develop alternative formats of the invitation letter and make these available upon request. Three formats are seen as priorities: (1) a simplified and illustrated version for persons with reading difficulties; (2) a Braille version for women who are blind; and (3) a large print version for women with impaired vision.	1	0.0	<b>100.0</b>	✓	16.1	<b>77.4</b>	✓
1.2	In the invitation letter, encourage women with activity limitations to contact the PQDCS regional service coordination centre to obtain additional information.	1	12.9	<b>87.1</b>	✓	9.7	<b>87.1</b>	✓
1.3	Illustrate the different stages of the program in diagram form to be added to the invitation letter.	1	38.7	61.3	---	12.9	<b>80.6</b>	✓
		2	46.2	53.9	---			
1.4	Illustrate the different stages of the CDD appointment process in diagram form and make this resource available to women and intake personnel.	1	35.5	58.1	---	12.9	<b>74.2</b>	✓
		2	38.5	53.8	---			
1.5	In the <i>Formulaire d'autorisation de transmission de renseignements relative à la participation au PQDCS</i> (Authorization form for the transmission of information related to participation in the PQDCS), insert a box that women can check to request that information on the program be provided to them in an alternative format (Braille, large print, simplified-illustrated version) or forwarded to a third party of their choice.	1	6.5	<b>93.6</b>	✓	22.6	<b>77.4</b>	✓
1.6	Modify the <i>Formulaire d'autorisation de transmission de renseignements relative à la participation au PQDCS</i> to provide an option whereby women can request that the program contact them by telephone.	1	25.8	67.7	---	32.2	61.3	---
		2	19.2	<b>76.9</b>	✓ <sup>2</sup>	57.7	34.6	---

**Key**

- ✓ Consensus
- ✓<sup>2</sup> Consensus achieved on the second round
- No consensus

**RESULTS OF DELPHI SURVEY QUESTIONNAIRE**

1.7	Develop a new form wherein women can instruct the PQDCS to communicate with them in the format that best suits their needs.	1	16.1	<b>77.4</b>	✓	29.1	64.6	---
1.8	In the invitation letter, highlight the information women need to retain (e.g., use of 14 point font or large print).	1	0.0	<b>96.8</b>	✓	6.5	<b>87.1</b>	✓
1.9	When sending out the invitation letter, staple a list of regional CDDs to the letter or provide the two as a two-sided photocopy.	1	9.7	<b>80.6</b>	✓	6.5	<b>80.7</b>	✓
1.10	When a woman is scheduled to have a mammogram in a CDD other than the one in which she had her last mammogram, ensure that the films are mailed to the new CDD.	1	6.4	<b>90.4</b>	✓	25.9	64.5	---
<b>TARGET 2: SIMPLIFYING THE APPOINTMENT-MAKING PROCESS</b>								
Proposals for action		Round	Useful (%)			Feasible (%)		
			Unfavourable	Favourable		Unfavourable	Favourable	
2.1*	Provide CDDs and CRIDs with various options for making appointments in writing (by fax, e-mail, TDD keyboard) and mention these options in the invitation letter.	1	29.1	<b>71.0</b>	✓	48.4	41.9	---
2.3	Provide each CCSR with the means to communicate in writing (by fax, e-mail, TDD keyboard) and indicate this option in the invitation letter.	1	32.2	61.3	---	38.7	48.4	---
		2	50.0	50.0	---	57.7	38.4	---
2.4	Shortly before each appointment (e.g., 1-3 days), remind women of the date and time of their appointment by telephone or in writing.	1	0.0	<b>100.0</b>	✓	29.1	67.7	---

\* Proposal 2.2 repeats proposal 2.1 due to a past error that went unnoticed during the design phase for the first round questionnaire. We did not see the point of communicating the results for that proposal.

**Key**

- ✓ Consensus
- ✓<sup>2</sup> Consensus achieved on the second round
- No consensus

## RESULTS OF DELPHI SURVEY QUESTIONNAIRE

<b>TARGET 3: SITE ACCESS CONSIDERATIONS</b>								
<b>Proposals for action</b>		Round	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			Unfavourable	Favourable		Unfavourable	Favourable	
3.1	In each region, identify the site and equipment accessibility characteristics of CDDs and provide this information in the invitation letter.	1	9.7	<b>90.3</b>	✓	12.9	<b>83.9</b>	✓
3.2	Adopt guidelines and timelines for the installation and quality control of equipment (e.g., stair lifts, wheelchairs, patient lifts) in CDDs and CRIDs.	1	9.7	<b>83.8</b>	✓	19.4	<b>71.0</b>	✓
3.3	Prominently display the PQDCS logo in CDDs and CRIDs so that women can more easily find their way around.	1	9.7	<b>90.3</b>	✓	6.5	<b>90.3</b>	✓
3.4	Equip CDDs and CRIDs with visual indicators (floor markings, colour coding) and sound indicators (e.g., beeps to identify obstacles) in order to facilitate spatial orientation for women with vision or hearing impairments.	1	16.1	<b>80.6</b>	✓	38.7	48.4	---
3.5	Lower CDD and CRID reception counters to provide easier access for women who use a wheelchair.	1	22.6	<b>77.5</b>	✓	35.5	58.1	---
3.6	Ensure that each centre has at least one accessible change room (spacious enough to accommodate a personal attendant, guide dog, wheelchair, etc.).	1	0.0	<b>100.0</b>	✓	12.9	<b>80.6</b>	✓
3.7	Allow women who use a wheelchair to undress in the examination room.	1	16.2	<b>77.5</b>	✓	19.3	67.7	---

### Key

- ✓ Consensus
- ✓<sup>2</sup> Consensus achieved on the second round
- No consensus

## RESULTS OF DELPHI SURVEY QUESTIONNAIRE

<b>TARGET 4: FACILITATING DATA COLLECTION</b>								
<b>Proposals for action</b>		Round	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			Unfavourable	Favourable		Unfavourable	Favourable	
4.1	Attach the clinical information questionnaire to the invitation letter so that women will be able to complete it ahead of time.	1	25.9	<b>71.0</b>	✓	19.4	<b>74.2</b>	✓
4.2	For subsequent mammograms, re-use the clinical information questionnaire already completed at the CDD and simply update the information.	1	3.2	<b>93.6</b>	✓	12.9	<b>77.4</b>	✓
4.3	Find the date of the last mammogram in SI-PQDCS and provide it in the recall letter.	1	29.1	<b>71.0</b>	✓	19.3	61.3	---
<b>TARGET 5: PARTICIPANT CONSENT</b>								
<b>Proposals for action</b>		Round	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			Unfavourable	Favourable		Unfavourable	Favourable	
5.1	Attach the <i>Formulaire de transmission de renseignements relative à la participation des femmes au PQDCS</i> to the invitation letter so that women can read it before their appointment.	1	22.6	<b>77.5</b>	✓	19.3	<b>77.5</b>	✓
5.2	Provide the <i>Formulaire d'autorisation de transmission de renseignements relative à la participation des femmes au PQDCS</i> upon request to allow women to review it before their appointment.	1	35.5	64.5	---	35.5	61.3	
		2	38.5	61.5	---	19.2	<b>77.0</b>	✓ <sup>2</sup>
5.3	Develop a checklist that intake personnel can use to summarize the content of the form in a simple, standardized fashion.	1	6.5	<b>93.5</b>	✓	0.0	<b>93.6</b>	✓
5.4	Develop a simplified version of the <i>Formulaire d'autorisation de transmission de renseignements relative à la participation des femmes au PQDCS</i> (composed of key words and illustrations) and make it available to women and intake personnel.	1	9.7	<b>87.1</b>	✓	22.6	67.7	---

### Key

- ✓ Consensus
- ✓<sup>2</sup> Consensus achieved on the second round
- No consensus

**RESULTS OF DELPHI SURVEY QUESTIONNAIRE**

<b>TARGET 6: INTAKE AND PREPARATION FOR WOMEN WITH ACTIVITY LIMITATIONS</b>								
<b>Proposals for action</b>		Round	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			Unfavourable	Favourable		Unfavourable	Favourable	
6.1	Provide a checklist for CDDs and CRIDs indicating the instructions that should be given systematically to all women who make appointments.	1	3.2	<b>96.8</b>	✓	3.2	<b>93.5</b>	✓
6.2	Add content dealing with clinical breast screening practices for women with activity limitations to PQDCS training module II for CDD personnel ( <i>Sensibilisation à l'approche envers les femmes visées par le PQDCS</i> ). (Awareness of approach used with women targeted by the PQDCS).	1	0.0	<b>100.0</b>	✓	0.0	<b>96.8</b>	✓
6.3	Develop teaching materials (e.g., an information leaflet) for CDD-CRID personnel that deal with clinical breast cancer screening practices for women with activity limitations.	1	3.2	<b>96.7</b>	✓	6.5	<b>90.3</b>	✓
6.4	For each region, draw up a list of resources that offer services to persons with activity limitations and provide this information to CDDs and CRIDs.	1	12.9	<b>83.8</b>	✓	16.1	<b>77.4</b>	✓
6.5	When taking appointments, systematically ask women whether they have special needs that should be taken into account in preparing their intake.	1	3.2	<b>96.8</b>	✓	9.7	<b>87.1</b>	✓
6.6	In the invitation letter, encourage women to mention any special needs they might have when they make their appointments.	1	6.4	<b>93.6</b>	✓	16.1	<b>80.6</b>	✓
6.7	Integrate into the provincial SI-PQDCS database new categories for the identification of women's special needs in the areas of communication, personal assistance, and access to screening sites and equipment. This information could then be conveyed to the CSSRs to facilitate program follow up activities (e.g., recalls, communication of results).	1	6.5	<b>87.1</b>	✓	29.0	54.8	---

**Key**

- ✓ Consensus
- ✓<sup>2</sup> Consensus achieved on the second round
- No consensus

### RESULTS OF DELPHI SURVEY QUESTIONNAIRE

6.8	Establish a regional database containing any information women might wish to disclose regarding their special needs in the areas of communication, personal assistance, and access to screening sites and equipment. This data would be managed by the CCSRs to facilitate program follow up activities (e.g., recalls, communication of results).	1	13.0	<b>77.5</b>	✓	22.6	58.1	---
6.9	Retain information concerning the characteristics of women with activity limitations (types of limitations and special needs) in the patient records of the relevant CDD.	1	9.7	<b>90.3</b>	✓	9.7	<b>83.9</b>	✓
6.10	In each region, identify the centres that offer accommodations for different types of activity limitations.	1	3.2	<b>96.8</b>	✓	3.2	<b>90.3</b>	✓
<b>TARGET 7: ADAPTATION OF THE MAMMOGRAPHY PROCESS</b>								
Proposals for action		Round	Useful (%)			Feasible (%)		
			Unfavourable	Favourable		Unfavourable	Favourable	
7.1	When a woman's limitations are known ahead of time, ensure that the necessary equipment and support (assistant technologist) are available on the day of the appointment.	1	0.0	<b>96.8</b>	✓	6.5	<b>80.6</b>	✓
7.2	Offer women the possibility of getting a mammogram in a seated position.	1	3.2	<b>93.5</b>	✓	6.5	<b>71.0</b>	✓
7.3	Allocate funds for the purchase of adapted equipment (e.g., adjustable chairs, patient lifts) in regions that lack such equipment.	1	3.2	<b>96.8</b>	✓	29.0	54.9	---
7.4	Through training and teaching materials (e.g., information leaflet) provide technologists with information on mammography positioning techniques for persons with motor limitations.	1	3.2	<b>93.6</b>	✓	6.5	<b>83.8</b>	✓
7.5	Ensure that CDDs and CRIDs have gowns of different sizes on hand.	1	9.7	<b>90.3</b>	✓	0.0	<b>93.6</b>	✓
7.6	Ensure that CDDs and CRIDs have gowns with velcro ties on hand.	1	9.7	<b>87.1</b>	✓	12.9	<b>77.4</b>	✓

#### Key

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- No consensus

**RESULTS OF DELPHI SURVEY QUESTIONNAIRE**

<b>TARGET 8: ESTABLISHING GUIDELINES FOR COMPLEX SITUATIONS</b>								
<b>Proposals for action</b>		Round	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			Unfavourable	Favourable		Unfavourable	Favourable	
8.1	Develop and distribute to CDDs and CRIDs a practice guide providing strategies to accommodate women with activity limitations in the PQDCS (e.g., less time in the waiting room, postponement of appointments for women whose emotional state is unstable).	1	12.9	<b>83.9</b>	✓	16.1	<b>77.4</b>	✓
8.2	Establish guidelines that could be used to determine whether women with complex profiles are in fact able to provide informed consent to screening.	1	29.1	61.3	---	32.3	58.1	---
		2	26.9	69.3	---	38.5	53.8	---
8.3	Establish follow up guidelines for women who are unable to undergo mammography or whose mammography results are inconclusive.	1	16.1	<b>71</b>	✓	16.1	67.7	---
		2	34.6	65.4	---	30.8	65.4	---
8.4	Establish decision support guidelines for the referral of women with complex profiles to oncology or treatment.	1	16.1	64.5	---	16.2	58.1	---
		2	26.9	61.6	---	26.9	57.2	---
8.5	Establish guidelines concerning the use of tranquilizers in connection with mammography screening and additional tests.	1	45.1	38.7	---	38.7	38.7	---
		2	69.2	23.0	---	61.5	26.9	---

**Key**

- ✓ Consensus
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- No consensus

**RESULTS OF DELPHI SURVEY QUESTIONNAIRE**

<b>TARGET 9: STRENGTHENING PHYSICIANS' COMMITMENT TOWARD WOMEN WITH LIMITATIONS</b>								
<b>Proposals for action</b>		<b>Round</b>	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			<b>Unfavourable</b>	<b>Favourable</b>		<b>Unfavourable</b>	<b>Favourable</b>	
9.1	Through training or teaching materials, sensitize physicians to the importance of recommending CDD-based screening mammography to women with activity limitations who fall within the target age group of the PQDCS.	1	6.5	<b>93.6</b>	✓	16.1	<b>80.7</b>	✓
9.2	Through training or teaching materials, remind physicians that annual clinical breast examinations constitute an appropriate preventive practice for women with activity limitations.	1	3.2	<b>96.7</b>	✓	12.9	<b>80.6</b>	✓
9.3	Through training or teaching materials, provide physicians with strategies for helping women with activity limitations undergo mammography screening.	1	9.7	<b>90.4</b>	✓	16.1	<b>80.7</b>	✓
<b>TARGET 10: MOBILIZING COMMUNITY RESOURCES</b>								
<b>Proposals for action</b>		<b>Round</b>	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			<b>Unfavourable</b>	<b>Favourable</b>		<b>Unfavourable</b>	<b>Favourable</b>	
10.1	Through training or teaching materials on the PQDCS, sensitize institutional/organizational representatives in every region, as well as representatives of residential facilities (e.g., group homes) for women with functional limitations who fall within the program's target age group.	1	3.2	<b>96.8</b>	✓	9.7	<b>83.8</b>	✓
10.2	Develop a general framework agreement with accessible transportation systems to facilitate the development of local and regional agreements.	1	9.7	<b>77.4</b>	✓	25.8	58.1	---

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### RESULTS OF DELPHI SURVEY QUESTIONNAIRE

10.3	Develop a general framework agreement with local support services to facilitate access to personal attendants when the need arises.	1	3.2	<b>87.1</b>	✓	9.7	<b>74.2</b>	✓
10.4	Develop a general framework agreement with local interpreter services in order to facilitate access to interpreters when the need arises.	1	6.5	<b>87.1</b>	✓	22.6	67.8	---
<b>TARGET 11: REVIEWING AND IMPROVING PROGRAM PARAMETERS</b>								
Proposals for action		Round	Useful (%)			Feasible (%)		
			Unfavourable	Favourable		Unfavourable	Favourable	
11.1	Analyse regional initiatives aimed at women with activity limitations in order to evaluate their effectiveness and potentially apply them on a national scale.	1	3.2	<b>96.8</b>	✓	12.9	<b>83.8</b>	✓
11.2	Standardize program correspondence (invitations, recalls, reminders, etc.) across all regions, incorporating the strategies considered to be most useful in terms of helping women understand and make use of the information they are given.	1	3.2	<b>93.6</b>	✓	3.2	<b>90.3</b>	✓
11.3	Designate a person to act as a liaison between the CDD, the CRID and any community resources that may need to be mobilized to assist women who require additional tests or cancer treatment.	1	3.2	<b>93.6</b>	✓	9.7	<b>83.9</b>	✓
11.4	Incorporate questions aimed at women with activity limitations into regional evaluations of PQDCS quality or client satisfaction.	1	3.2	<b>96.8</b>	✓	3.2	<b>93.6</b>	✓
11.5	Incorporate information on the submission of complaints into PQDCS documents.	1	19.3	<b>77.4</b>	✓	16.1	<b>80.7</b>	✓

**Key**

- ✓ Consensus
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**RESULTS OF DELPHI SURVEY QUESTIONNAIRE**

<b>TARGET 12: INCLUDING WOMEN WITH ACTIVITY LIMITATIONS IN PQDCS PROMOTIONAL ACTIVITIES</b>								
<b>Proposals for action</b>		Round	<b>Useful (%)</b>			<b>Feasible (%)</b>		
			Unfavourable	Favourable		Unfavourable	Favourable	
12.1	Identify and put forward strategies to target women with activity limitations in the context of PQDCS promotional campaigns.	1	9.7	<b>83.8</b>	✓	32.3	61.3	---
12.2	Identify and put forward strategies to target women with activity limitations in the context of cancer campaigns.	1	12.9	<b>83.8</b>	✓	22.6	<b>71.0</b>	✓
12.3	In the invitation letter or in an accompanying document, include a reference to the DVD <i>Autour des seins</i> and include information on how to obtain it. The DVD provides simple information in several languages (including Quebec sign language) on breast cancer screening and the PQDCS.	1	35.5	58.1	---	25.8	<b>70.9</b>	✓
		2	42.3	50.0	---			

**Key**

- ✓ Consensus
- ✓<sup>2</sup> Consensus achieved on the second round
- No consensus