



*Breast Cancer  
Screening*

*Women's  
Experience  
of Awaiting  
a Diagnosis*

*Evaluation Report*

*Highlights*

*waiting worry need support*





# Why evaluate women's anxiety levels and social support needs during the wait for a diagnosis after breast cancer screening?

Since 1998, a mammographic screening program for breast cancer addressed to all women between 50 and 69 has been gradually put in place throughout Québec. The program enables early detection of lesions impossible to discern by palpation alone. Since survival rates of affected persons are linked to the stage of the cancer at the time of diagnosis, this program increases the rapidity and effectiveness of the required medical interventions. In 2000, even though breast cancer was still the second ranked cause of death by cancer in women, Canadian statistics indicated a diminishing mortality rate associated with this cancer. This result may be attributed to the implementation of measures such as Québec's breast cancer screening program (Programme québécois de dépistage du cancer du sein or PQDCS).

Between 10 and 12% of women participating in the breast cancer screening program receive abnormal results on their screening mammogram, and require additional tests. Different studies show that the screening and investigation process elicit varying degrees of anxiety. When it was being set up, the PQDCS devised several means of supporting women in order to counter these negative effects. In Montréal, community organizations have also considered this question. The Réseau québécois d'action pour la santé des femmes (RQASF) developed training tools for interventions to support women while they wait for a diagnosis.

It was observed that few women use these resources. Why is this? Do women who are waiting for test results experience anxiety? Is the available social support sufficient and adapted to their needs? Are the women who use these resources satisfied with them? To obtain answers to these questions, the RQASF conducted an evaluation of the **anxiety levels and social support needs** of participants in Montréal's screening program.

## Who are the women who took part in the evaluation?

**All participants** in the breast cancer screening program in the region of Montréal **who, between February 19 and June 9, 2003, received abnormal mammographic screening results** and had to undergo additional examinations before obtaining the final diagnosis received an evaluation questionnaire. There were three stages of data collection, in French and English:

- > two weeks after the letter from the PQDCS announcing abnormal mammographic screening results, a questionnaire was mailed out, based on recognized and validated scientific measuring instruments; other written documentation on the subject was included in this mailing;
- > another letter was mailed out two weeks after the first mailing;
- > telephone contact was made two weeks after the second mailing.

A telephone questionnaire was designed for women who had undergone a biopsy.

Interest in the evaluation is reflected in the **overall participation rate of 66.4%**, a **very satisfactory** result for a mail survey. Furthermore, over two-thirds of the participants offered comments about their experience during the screening process. All together, 951 evaluation questionnaires were mailed out. Of these, 631 admissible questionnaires were compiled and 49 shortened versions were completed over the telephone. One hundred twenty-nine (129) participants refused to respond. The proportion of French-speaking participants (84.8%) is higher

**Table 1**  
**PARTICIPATION IN THE**

STAGES OF THE EVALUATION	N	RESPONSES TO THE ENQUIRY
<b>1<sup>st</sup> mailing</b>	951 Quest. sent Fr.: 782 Eng.: 169	435 45.7%
<b>2<sup>nd</sup> mailing</b>	516 Quest. sent Fr.: 406 Eng.: 110	250 48.4%
<b>Telephone follow-up</b>	266 Women called Fr.: 208 Eng.: 58	152 57.1%
<b>Overview of data collected</b> <b>N: 951</b>		

- 1) "Admissible" questionnaires represent all evaluation participants corresponding with the selection criteria.  
2) "Non-eligible" questionnaires are those completed by participants who did not meet the selection criteria.  
3) Answers to the "short" questionnaires were not counted.

than that of English speakers (15.2%). One participant in five was born outside Canada.

The majority of the women who completed the questionnaire were aged between 50 and 59, born in Canada and living with a spouse. One participant in five lived alone. A little over half of the women had 12 years or less of formal schooling. Family income was \$29,000 and under for 38% of the participants, and \$50,000 or over for 36% of them. Six participants in 10 worked outside the home.

The majority of participants had already had a mammogram taken. Over two-thirds of these women had received abnormal mammographic screening results for the first time.

## ENQUIRY

ELIGIBLE QUESTIONNAIRES <sup>(1)</sup>			NON-ELIGIBLE QUESTIONNAIRES <sup>(2)</sup>			UNCOMPLETED QUESTIONNAIRES			NO ANSWER TO THE ENQUIRY
FRENCH	ENGLISH	TOTAL	FRENCH	ENGLISH	TOTAL	FRENCH	ENGLISH	TOTAL	
341	50	391 89.9%	6	2	8 1.8%	29	7	36 8.3%	
179	45	224 89.6%	4	3	7 2.80%	15	4	19 7.6%	
15	1	16 10.5%	38	11	49 <sup>(3)</sup> 32.2%	59	15	74 48.7%	13 8.6% Neither French or English
535	96	631 66.4%	48	16	64 6.7%	103	26	129 13.5%	13 1.4% 114 12%

questionnaires covering the pre-diagnostic stage, except the biopsy, completed by partici-

by participants whose screening mammograms were taken before the two-month dead-

compiled for the evaluation.

Table 2

## SOCIODEMOGRAPHIC PROFILE OF PARTICIPANTS

INDICATORS	N	%
<b>1. Woman's age</b>		
50 - 54	235	37.7
55 - 59	187	30.0
60 - 64	121	19.4
65 - 69	79	12.7
70 and over	1	0.2
<b>Total answers</b>	<b>623</b>	<b>100</b>
No response	8	
<b>2. Language of correspondence</b>		
French	535	84.8
English	96	15.2
<b>Total participants</b>	<b>631</b>	<b>100</b>
<b>3. Living situation</b>		
Living with a spouse (male or female)	375	61.1
Living alone	165	26.9
Living with one or more children	112	18.2
Living with a friend (male or female)	18	3.0
Living with a parent, brother, sister, etc.	12	2.0
Living with a religious order	3	0.5
Other	7	1.1
No response	17	
<b>4. Woman's birthplace</b>		
Canada	485	79.0
Europe	75	12.2
Africa	14	2.3
Middle East	13	2.1
Asia	12	2.0
Central America	9	1.5
South America	4	0.7
United States	2	0.3
<b>Total answers</b>	<b>614</b>	<b>100</b>
No response	17	
<b>5. Formal education</b>		
7 years or less of schooling	72	11.7
8 to 12 years of schooling	254	41.4
Cepeg or equivalent	104	17.0
University	183	29.9
<b>Total answers</b>	<b>613</b>	<b>100</b>
No response	18	
<b>6. Occupation</b>		
Work outside the home	307	59.6
In the home	146	28.3
Social assistance	27	5.2
Sick/disability leave	23	4.5
Employment insurance	7	1.4
Other	5	1.0
<b>Total answers</b>	<b>515</b>	<b>100</b>
Retired	93	
No response	23	
<b>7. Income</b>		
Under \$9,999	45	9.5
\$10,000 to \$29,999	134	28.4
\$30,000 to \$49,999	124	26.3
\$50,000 or more	169	35.8
<b>Total answers</b>	<b>472</b>	<b>100</b>
Refused to answer	159	

## What are the principal conclusions of the evaluation?

The evaluation had **five specific goals**:

- > evaluate participants' anxiety level;
- > describe their social support needs (emotional, informational, practical);
- > discover what kinds of social support they were offered by health establishments;
- > establish participants' degree of satisfaction with the support they received;
- > identify the improvements to social support desired by participants.

With respect to all of these aspects, the evaluation allowed us to draw the following conclusions.

### ANXIETY

- > Half of the participants were worried at every stage of the screening and additional examinations.
- > Among women who underwent a biopsy, three out of five of them were quite worried or very anxious at every stage of this examination.
- > **Three factors determine anxiety level**: prerequisites, socio-demographic and structural.

#### Prerequisites

- > Prerequisites contributing to increased anxiety levels during additional examinations were identified:
  - a stressful time of life (death or illness of family member or friends, etc.)
  - having been anxious from the start about the prospect of having a screening mammogram taken;
  - having had a mammogram taken in the past, regardless of the result of this earlier screening.

This data suggests the pertinence of early supportive interventions with these participants.

#### Socio-demographic factors

- > **Only age**, among the socio-demographic factors (formal schooling, income, age, etc.), had an impact on women's anxiety level. Women aged 50 to 59 were more anxious than women aged 60 to 69.

#### Structural factors

The PQDCS has explicit standards regarding information and support to be offered by the designated screening centres

(known by the French abbreviation CDD), in other words, private radiology clinics, and the designated assessment centres (known as CRID) attached to hospitals.

- > Among the three principal structural factors (mode of communication, waiting periods, change of establishments), the only determining factors seemed to be the **mode of communication** of the abnormal mammogram and the **waiting periods**.

#### Mode of communication

- > Under the PQDCS, **women are supposed to be informed of an abnormal screening mammogram by their physician**. It was shown, however, that there is a **substantial gap** between this norm and its application: only **two participants out of five** were informed by their physician of an abnormal mammogram.
- > Participants are **less worried** when an abnormal mammogram is **announced by their physician** and they continue to be less worried during the subsequent investigation stages. The physician's involvement as soon as an abnormal result is discovered is thus a determining factor, because it immediately defuses the spiral of anxiety that can develop during the investigation process.
- > **Nearly one-third** of participants heard about their results in a letter from the PQDCS or in a voicemail message. In both of these instances, no one is available to offer the appropriate social support to women who need it.
- > Women were for the most part just as worried when abnormal results were announced to them in person by a CDD employee as when they heard the news via the letter from the PQDCS.

#### Waiting periods

- > The breast cancer screening program specifies deadlines for the waiting periods between each stage in the process. The evaluation reveals that participants experienced significantly longer waiting periods than those specified by the Program, both before learning the result of the screening mammogram and before going for the first additional examination.
- > The **prolongation of the waiting period generally increases participants' anxiety** during the additional examinations.
- > Waiting periods vary from one establishment to the next and from one type of establishment to the next (designated screening centres and designated assessment centres). In general, the waiting period **before going in for additional examinations** was shorter in the designated screening centres.

tres (CDD). On the other hand **these examinations are not conducted more rapidly** in a CDD than in a designated assessment centre (*centre de référence pour investigation désigné* or CRID). More participants who had **biopsies in a CRID obtained their results more quickly** (13 days or less).

### *The establishments*

- > Although the evaluation's findings do not allow us to determine a connection between anxiety level and the move to another establishment during assessment, most participants consider it important to have all their examinations in the same establishment.
- > The PQDCS suggests that additional examinations be conducted in a CRID (designated assessment centre). Most participants, however, had them in a CDD (except biopsies) where, in the majority of cases, they had to pay a fee.
- > **One-third** of participants were not told they could have additional examinations **free of charge** in a **CRID**.

## SOCIAL SUPPORT

- > There are three dimensions to social support: emotional, informational and tangible.
- > Social support (emotional and informational) helped to reduce participants' anxiety. After analyzing our findings, we discovered *the emotional and informational dimensions are in fact closely intertwined and often inseparable in the relationships formed with health professionals*. Women must be able to communicate with health professionals to obtain and understand the information that will help relieve their anxiety.
- > Tangible support refers to elements such as work, parking, schedules, etc. Few problems of this nature were mentioned.

### **The emotional dimension**

- > The breast cancer screening program recommends that participants' anxiety level be evaluated during the screening and investigation periods.
- > The majority of participants expressed their emotions, particularly with members of their immediate circle. In most cases, they were satisfied with the comfort they received.
- > Despite being satisfied with the comfort offered by those close to them, women did not experience significant relief from their anxiety. *Only satisfactory support from health professionals succeeded in reducing their anxiety*. Yet only a limited number of women expressed their emotions to health professionals **because they were not encouraged to do so**.
- > Gaps observed in the support offered:
  - the majority of participants who went to a CDD or CRID received no encouragement whatsoever to talk about their feelings;
  - **nearly half the participants** were not encouraged by their physician to talk about their feelings.

### **The informational dimension**

- > The breast cancer screening program vested the CDDs and CRIDs with the responsibility to inform participants.
- > The majority of women did not look for information. This could be connected with the quality of the information they were given. Because in most cases they were not encouraged to talk about their emotions, in all likelihood it was not possible for them to ask questions.
- > **Most information was transmitted verbally**, whether in the CDDs, CRIDs, or by the physician, and even in the case of biopsies, despite the fact that stress can hinder the ability to understand and retain information.
- > **20% of women who went to CDDs and roughly 10% of those who went to CRIDs or to their physician** received no information.
- > The majority of participants, particularly those who underwent biopsies, said they were given more written documentation during the additional examinations. The women who had access to information in this form, read and understood it and consider it to have been useful in the vast majority of cases.

### *Information about support groups*

- > The breast cancer screening program calls for health professionals to inform women about the availability of support groups. Nevertheless:
  - almost none of the participants were given the name of an individual or group to contact in case of need;
  - no explicit reference to either private or public resources was provided in the letter informing women of abnormal mammogram results.
- > Most participants, especially those who underwent biopsies, wanted references to a resource person or support group. Even if they did not necessarily use the resources, they knew they could call on them at any time, which lessened feelings of powerlessness and in itself constitutes a form of support.

### *The effects of informational support on anxiety*

- > The more women are satisfied with the information they receive, the less they worry.
- > Women's concerns vary greatly when it comes to their need for information. This implies a need to constantly adapt interventions and personalize informational support.



## What are the RQASF's principal recommendations?

The Programme québécois de dépistage du cancer du sein is recent (1998). The following recommendations are about improving the Program's quality and operations, in Montréal and throughout Québec. They are also meant to reaffirm the importance of respecting women's needs and rights—one of the Program's five fundamental principles. Finally, we formulated the recommendations in compliance with the *Canada Health Act*, according to which the federal government's contribution is subject to five conditions: public administration, comprehensiveness, universality, portability and accessibility. In consideration of this, **the RQASF calls on the following bodies:**

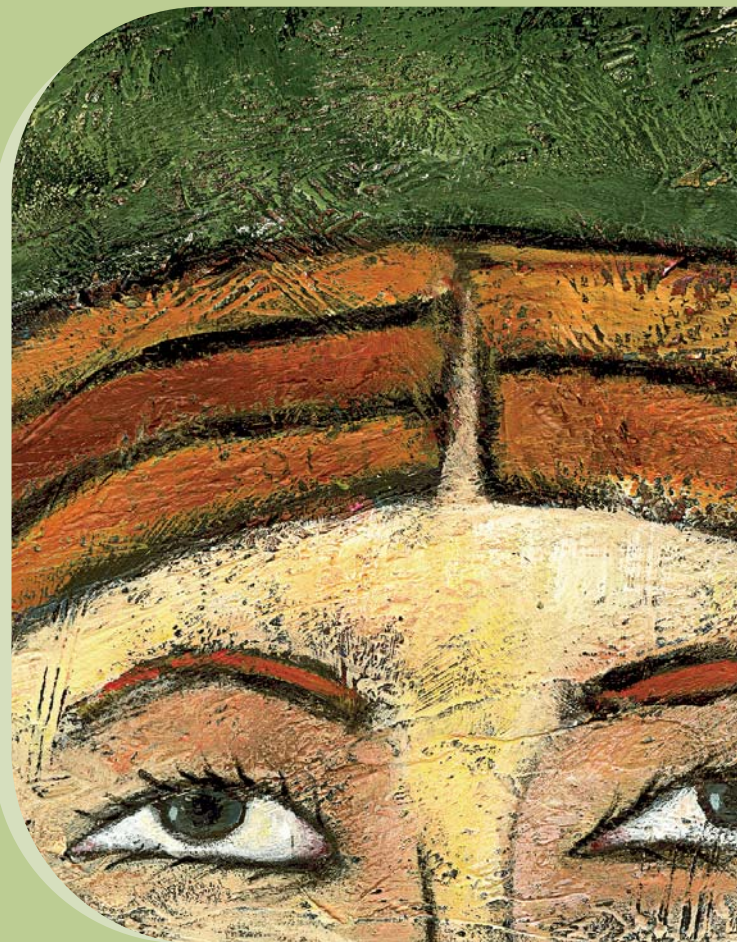
### MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX AND THE PROVINCIAL EXECUTIVE BODY OF THE PQDCS

- Revise the PQDCS' reference framework so that social support throughout the breast cancer screening and investigation processes is clearly defined, integrated into the Program's quality control criteria, implemented and evaluated.
- Immediately revise the PQDCS' reference framework in order to:
  - ensure that all services meet high quality standards and are offered free of charge;
  - offer social support as soon as abnormal results are announced, thereby defusing the spiral of anxiety;
  - ensure that abnormal results are transmitted in person by the woman's physician;
  - guarantee the availability of a coordinating nurse, specially mandated and trained by the PQDCS to offer personalized social support and ensure service continuity in all establishments providing additional examinations;
  - reduce the waiting period between the different stages of the process.
- Commit the funds necessary for revising the reference framework and standards and putting them into application.
- Periodically inventory the existing information tools and ensure their promotion, regular distribution and accessibility; encourage the development of tools adapted to certain groups of women (illiterate, disabled, speaking languages other than French, etc.).
- Enable recourse to the complaint assistance and accompaniment centre (Centre d'assistance and accompagnement aux

plaintes or CAAP) for women who use the services of a private clinic as part of this program.

### PQDCS COORDINATION CENTRE OF MONTRÉAL

- Implement the social support recommendations (free of charge, early social support, personal transmission of results, nurse, and reduction of waiting period).
- Revise accreditation agreements and contracts with designated screening centres to ensure compliance with the provisions of the breast cancer screening program.
- Ensure the availability of ongoing training regarding social support and make it compulsory for all CDD and CRID staff.
- Ensure the availability of ongoing social support training for physicians, in partnership with the RQASF and the different professional associations in question, in particular, the Fédération des médecins omnipraticiens du Québec.





- Conduct a pilot-project in partnership with the RQASF with the purpose of defining, testing and evaluating mechanisms to fully integrate social support in all stages of the breast cancer screening program. Based on the outcome of this project, develop a new social support procedure, the required intervention and information tools, and ensure their promotion, distribution and accessibility.
- Constitute and supervise a team of coordinating nurses reporting to the PQDCS Coordination Centre of Montréal and ensure the services of a nurse in each designated screening centre.
- Set up and promote a complaint processing procedure for PQDCS participants in the Montréal region. This procedure should serve as an evaluation mechanism for the purpose of improving the Program.
- Include in the PQDCS invitation letter detailed contact information, with opening hours, for all participating establishments.
- Conduct a public information campaign to inform women of the importance of going to establishments designated by the PQDCS for screening and additional examinations.

## OTHER WOMEN'S HEALTH RESOURCES

- Inform women of their health-related rights and encourage them to defend these rights to concerned bodies.
- Encourage women to express their problems, concerns, worries and social support needs to the coordinating nurse in the establishment whose breast cancer screening services they use.
- Inform the PQDCS of any problems or irregularities reported by women participating in the Program.

## Conclusion

The conclusions of the RQASF's evaluation coincide with other research on anxiety experienced by women during the breast cancer screening and investigation process. There are nevertheless a number of noteworthy aspects, particularly regarding determinant factors inherent to the Montréal context and to the Québec breast cancer screening program as a whole.

Of particular note is that while the support of family and friends comforts women, it does not significantly reduce the level of anxiety of participants in the screening program. Only early support from health professionals diminishes their anxiety and prevents it from continuing through the subsequent stages. Indeed, the fundamental role of physicians in providing support to women was strikingly clear. This is a very important conclusion in a period where the State is leaving families with all the responsibility for supporting and helping their loved ones.

Another major element is the close relationship between emotional and informational support. Personalized answers to information needs, given by an acknowledged expert in the matter, provide the most satisfactory responses to emotional support needs.

The RQASF's analysis of the evaluation's findings led them to recommend concrete actions to improve the quality and operations of the PQDCS, in order to reduce women's anxiety during breast cancer screening and additional examinations. Women's satisfaction and perhaps their future participation in the Program are at stake.

*Breast Cancer  
Screening*

# Women's Experience while Awaiting a Diagnosis

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