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Report of the Working Group on the Integration of Screening and Diagnosis for the Canadian Breast Cancer Screening Initiative

The National Committee for the Canadian Breast Cancer Screening Initiative (CBCSI) is responsible for the federal/provincial/territorial and interprovincial review, discussion and action on matters of mutual interest or concern related to the early detection and screening of breast cancer. It was established in 1990 following the National Workshop on the Early Detection of Breast Cancer that was held in 1988, and the subsequent report submitted to the federal/provincial/territorial Conference of Deputy Ministers of Health.

The CBCSI is a partnership between Health Canada, provincial/territorial screening programs and governments, professional associations, non-governmental agencies, and women.The Committee continues its work today as a component of Phase II (1998-2003) of the Canadian Breast Cancer Initiative,focussing its activities on public education, health promotion, program focussed awareness issues; and program development, evaluation, and information sharing issues.

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- The Provincial organized screening programs of Alberta, British Columbia, Manitoba, Newfoundland, Nova Scotia, Ontario, and Saskatchewan, which supplied the data to the Working Group on the Integration of Screening and Diagnosis for inclusion into the report. In particular Jon Tonita for generating the timeliness data for Saskatchewan in Tables 4 to 7.

- The members of the Working Group on the Integration of Screening and Diagnosis for their contribution to the analysis and writing of the report. Membership of the Working Group included Dr. Ivo Olivotto (Chair), Screening Mammography Program of British Columbia; Dr. Judy Caines, Nova Scotia Breast Screening Program; Dr. Vivek Goel, University of Toronto; Brenda Irvine, Ontario Breast Screening Program; Lisa Kan, Screening Mammography Program of British Columbia; Dr. Lucie Lemieux, Programme québecois de dépistage du cancer du sein; Dr. Ron McAuley, Family Physician; Renée McGilly, Consumer; Dr. Doug Mirsky, Ottawa Regional Breast Health Centre; Dr. Margaret Sabine, Ontario Breast Screening Program; Christian Bancej, Health Canada; Anna Maria Calabretta, Health Canada; Dr. Eric Nicholls, Health Canada; Judy Snider, Health Canada. The Working Group's mandate and membership are also listed in Appendix A.

- Dr. Lucie Lemieux, Programme québecois de dépistage du cancer du sein, for reviewing the French version.

- Sheila Penney, Consultant for the literature review and first draft of the report.

- The National Committee for the Canadian Breast Cancer Screening Initiative (CBCSI) for its reviews of this document.

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Definitions Used in Tables

- Abnormal Call Rate: % of all screens called abnormal
- Abnormal Call Rate for radiologist detected abnormality = radiologist detected abnormality/modality mammography or mammography + CBE
- Abnormal Call Rate for clinical examiner detected abnormality = clinical examiner detected abnormality/modality CBE or mammography + CBE
- Abnormal Call Rate for both radiologist and clinical examiner detected abnormality = both detected abnormality/modality mammography + CBE
- Biopsy Rate: % women with abnormal screen (and completed follow-up) having a surgical biopsy
- Radiologist Biopsy Rate:%women with exclusively radiologist-detected abnormal screen (and completed follow-up) having a surgical biopsy
- Clinical examiner Biopsy Rate:%women with exclusively clinical examiner-detected abnormal screen (and completed follow-up) having a surgical biopsy
- Both Biopsy Rate:%women with both clinical examiner- and radiologist-detected abnormal screen (and completed follow-up) having a surgical biopsy
- Biopsy Yield Ratio: % of women biopsied with a final diagnosis of invasive cancer or DCIS
- Radiologist Biopsy Yield Ratio: % of women with a radiologist-detected abnormality biopsied with a final diagnosis of invasive cancer or DCIS
- Clinical examiner Biopsy Yield Ratio: % of women with a clinical examiner-detected abnormality biopsied with a final diagnosis of invasive cancer or DCIS
- Both Biopsy Yield Ratio:% of women with a clinical examiner and radiologist-detected abnormality biopsied with a final diagnosis of invasive cancer or DCIS
- Positive Predictive Value (PPV): % of women with an abnormal screen found to be invasive cancer or DCIS
- Radiologist PPV: % women with a radiologist-detected abnormal screen found to be invasive cancer or DCIS
- Clinical examiner PPV: % women with a clinical examiner-detected abnormal screen found to be invasive cancer or DCIS
- Both PPV:% women with radiologist and clinical examiner-detected abnormal screen found to be invasive cancer or DCIS
- Cancer: includes malignant and DCIS

EXECUTIVE SUMMARY

Introduction

In response to concerns raised at a workshop on organized breast cancer screening held in April/97 in Ottawa, a Working group on the Integration of Screening and Diagnosis was established. The mandate of the Working group was to identify and assess the current diagnostic process after an abnormal breast screening examination for Canadian women. If gaps were identified, steps to achieve timely and seamless integration of screening and assessment were to be proposed.

The Working group performed a literature review on the causes and consequences of diagnostic delay, surveyed screening programs (nationally and internationally), to determine existing standards and targets, and reviewed the timeliness to diagnosis for women age 50-69 years with abnormal breast screening examinations in organized breast screening programs as experienced in 1996.

Main Findings

1. Description of the Diagnostic Process

Between 5-14% of women age 50-69 attending an organized breast screening program in Canada in 1996 were found to have an abnormality requiring further diagnostic evaluation. The likelihood that this abnormality would turn out to be cancer was 4-13%.

Except in selected jurisdictions, the diagnostic process after an abnormal breast screening examination involves:

- Notification of the abnormal result to the family physician and client
- Often a physical examination by the family physician

- Referral of the woman for diagnostic breast imaging which may include comparison of the screening mammogram with previous films; additional mammogram views of the area of the breast thought to be abnormal on the screening mammogram and/or breast ultrasound
- 15-30% of women required surgical assessment and/or biopsy to finalize the diagnosis

2. Timeliness to Diagnosis

We found that on average, women waited many weeks for a diagnosis after an abnormal breast screening. There was substantial variation in the time to diagnosis between and within programs. For example, the median times to diagnosis for women having a core or open biopsy was between 6.0 and 9.6 weeks depending on the program. A substantial minority (10% or more) of women in each program waited 12 or more weeks for a diagnosis if a biopsy was required.

There was also substantial variation in the diagnostic sequence and types of investigation used between and within programs. For example, among women having a biopsy, the proportion done as core biopsies ranged from 3.3% to 89.6%, depending on the program. Greater use of core biopsy was associated with shorter times to diagnosis. The two programs using core biopsies most frequently had among the shortest times to diagnosis, the lowest open biopsy rates and highest biopsy yield rates.

Long delays to diagnosis are associated with substantial anxiety, personal and family disruption. A recent report in the literature suggests that a delay to diagnosis and definitive treatment as short as 3-6 months also may be associated with worse survival from breast cancer.

3. Recommendations for Timeliness Targets for Canadian Organized Breast Screening Programs

a) Definitions

- The **start of the diagnostic** interval is the date of the abnormal screen
- The **first assessment procedure** is the first imaging or physician visit after an abnormal screen
- The **date of diagnosis** is the date of:
  - the first pathologic or cytologic diagnosis of cancer or
  - the last biopsy with benign findings or
  - the last intervention prior to a recommendation to return to screening or return for early recall
- The **assessment process** for women only ends when they are informed of the results of diagnosis

b) Timeliness targets:

Timeliness targets were set by consensus among members of the Working Group after review of existing program standards in Canada and internationally and the time to diagnosis already achieved for approximately 50% of women in organized breast screening programs in Canada in 1996.

- Abnormal screen to notification of the client
  - 100% to be notified
  - ≥90% to be notified within 2.0 weeks
- Notification of the client to first assessment
  - ≥90% within 2.0 weeks
- The total duration from abnormal screen to first assessment
  - ≥90% within 3.0 weeks
- First assessment to diagnosis *if no open biopsy*
  - ≥70% within 1.0 week
  - ≥90% within 2.0 weeks

- First assessment to diagnosis *if open biopsy performed*
  - ≥70% within 3.0 weeks
  - ≥90% within 4.0 weeks
- Diagnosis to notification of the client
  - ≥90% within 1.0 week

It is recognized that these intervals are still long times to wait for a diagnosis especially since further time is usually required to notify the woman of the results after the last test is complete. Achieving these timeliness targets however, would represent a substantial improvement over usual practice in 1996.

4. Achieving Timeliness

Programs with dedicated interdisciplinary assessment clinics affiliated with screening centres can easily achieve the timeliness targets stated above. Greater use of imaging directed core biopsy as compared to open biopsies could substantially reduce the interval to diagnosis for many women. Community-specific initiatives to design process changes that facilitate the diagnostic process without building dedicated assessment centres are being investigated.

5. Future Directions

i) The Canadian Breast Cancer Screening Initiative, Health Canada and individual breast screening programs should review and adopt the definitions and timeliness targets proposed herein.

ii) Programs should communicate the timeliness targets to stakeholders and clients of their programs.

iii) Programs should support the development of appropriate infrastructure, staffing and communication systems within their regions to meet the timeliness targets for the integration of screening and diagnosis.

iv) The Canadian Breast Screening Database maintained by the Laboratory Centre for Disease Control, Health Canada, Ottawa, should be structured so that these timeliness targets can be properly evaluated.

v) The timeliness to diagnosis should be reassessed and timeliness targets re-evaluated within 5 years.

vi) Women with abnormal breast screening examinations should have access to pertinent information and support including a description of what could and should be happening and the timeliness targets for each step in the process.

vii) The date women are notified of the assessment results is clearly the "end of the episode" from the woman's perspective. Programs should evaluate the timeliness with which women are notified of the results of investigations.

FINAL REPORT

Introduction

A necessary part of breast cancer screening is the identification of women with abnormal screens who require further assessment. During assessment, some women with screening abnormalities are found to have breast cancer, usually before it can be felt by the woman or her physician. This early detection enables earlier effective treatment that results in reduced mortality from breast cancer. Reduction in breast cancer mortality is the justification for initiating and supporting organized breast cancer screening.

Except in selected jurisdictions, the diagnostic process after an abnormal breast screening examination in Canada involves:

- Notification of the abnormal result to the family physician and client
- Often a physical examination by the family physician
- Referral of the woman for diagnostic breast imaging which may include comparison of the screening mammogram with previous films; additional mammogram views of the area of the breast thought to be abnormal on the screening mammogram and/or breast ultrasound
- For approximately 15-30% of women additional surgical consultation and/or biopsy is required to finalize the diagnosis

Between <1% and 20% of women with abnormal screens will be found to have breast cancer depending on the age, screening history of the client and the method by which the abnormal screen was detected; mammogram alone, clinical examination alone or both. This means that following assessment, most women will not be found to have cancer. It is recognized that being informed of an abnormal screen and the subsequent investigations to determine whether a breast cancer is present, may cause morbidity for these healthy women because many live for a period of time

in fear of a cancer diagnosis. The morbidity includes, but is not limited to, an acute increase in anxiety and the discomfort, time and expense of additional tests. Breast screening programs have a responsibility to minimize these adverse consequences of screening.

Delays during the assessment of an abnormal breast cancer screening and poor integration of screening and diagnosis were identified as areas of significant concern requiring action at a Workshop on Organized Breast Cancer Screening held in Ottawa in April 1997. To address this issue, a Working Group on the Integration of Breast Cancer Screening and Diagnosis (the Working Group) was established by the Canadian Breast Cancer Screening Initiative (CBCSI) in November 1997.

The Working Group conducted a literature review focusing on the causes and consequences of delay after an abnormal screen and a survey of current Canadian and international timeliness targets and standards. The Working Group also reviewed the time to diagnosis after an abnormal screen in an organized breast cancer screening program in Canada in 1996 using data reported to the Canadian Breast Screening Database (CBCSD) maintained by the Laboratory Centre for Disease Control (LCDC) in Ottawa.

This report is a summary of the investigations, conclusions and recommendations of the Working Group as of November 1999. The membership and terms of reference of the Working Group are attached as Appendix A.

Methods

Literature review

A literature review of the causes and consequences of delay after an abnormal breast cancer screening, with emphasis on psychosocial effects, was commissioned by the Working Group and funded by Health Canada. The review included published articles and reviews current to January 31, 1999. MEDLINE and CANCERLIT for the years 1966-January 1999, were used to select pertinent references by matching the following terms: *Breast Neoplasms (MeSH) and Mammography (MeSH) and the concepts

(delay, abnormal, assessment, follow-up, standards, psychological issues) searched either as title or abstract keywords or as sub-headings. Over 180 articles were identified and abstracts compiled. After review of all abstracts, potentially pertinent articles were obtained, copied and categorized. References relevant to analysis of the causes and consequences of delay to diagnosis after an abnormal screen are listed in Appendix B.

Review of existing International and Canadian timeliness standards or targets

Program documents from organized national programs for breast screening in Australia and the United Kingdom (UK), from the European Commission and from the Food and Drug Administration which accredits mammography facilities in the United States were examined for statements regarding the timeliness of assessment interventions after an abnormal breast screen. In addition, each Canadian organised breast screening program was contacted and requested to supply any documentation or policies pertaining to the timeliness of investigations after an abnormal screen.

Waiting times after an abnormal screen in organized breast screening programs in Canada, 1996

Established in 1993, the CBCSD is a national breast screening surveillance system that facilitates the monitoring and evaluation of breast cancer screening across Canada through the collection of data on women screened at provincial screening programs. The database is maintained by LCDC and is managed and advised by the Database Management Sub-Committee, which includes representation from Health Canada and the directors of provincial/territorial breast screening programs. To evaluate waiting times to various stages of assessment following an abnormal screening examination, data from seven provincial programs providing data to the CBCSD were analyzed.

Women who received a breast screening in 1996 and had an abnormality detected by a radiologist or during a clinical examination by a trained nurse or technologist or by both a radiologist and clinical examination,

were eligible for analysis. Differences occurred in how provinces reported the end of assessment. Some programs considered 6-month recall imaging as part of an assessment interval, whereas others considered follow-up completed once a recommendation for early recall was made. To exclude exaggeration of the time to diagnosis due to 6-month early recall, women who received diagnostic imaging at 22 weeks or beyond, were considered to have completed follow-up with a recommendation for early recall at the test prior to the recall image. Analysis of each time interval was restricted to women with complete follow-up and valid information recorded in the database on the assessment endpoint of interest.

First imaging was operationally defined as the first diagnostic mammogram or ultrasound after an abnormal screening mammogram. First assessment was the first imaging or physician visit (where collected) after an abnormal mammogram. The date of diagnosis was defined to be the date of the first pathologic diagnosis of cancer, or the last biopsy with benign findings, or the last intervention prior to a recommendation to return to screening or return for early recall. Time intervals were calculated for the interval from screen to first assessment, screen to first imaging, screen to diagnosis and from first assessment to diagnosis.

Evaluation of intervals was performed for all study subjects with abnormal screens and further stratified according to whether they received a biopsy as part of their investigation process. A biopsy included either open surgical biopsy with or without fine wire localization or a core biopsy but excluded fine needle aspiration when used alone. Time intervals were also evaluated by method of detection of the abnormal screen; by mammography alone, by clinical examination alone or both. If a woman had more than one abnormal screen in 1996, the first abnormal screen was used.

All analyses were conducted using SAS Release 6.12 software (Copyright ©1989-1996 by SAS Institute Inc., Cary, NC, USA.). Time intervals were evaluated in weeks. For each interval, the median, range and 25th, 75th and 90th percentiles were reported for each breast screening program. Timeliness data in this report have been presented anonymously but each province contributing data was provided with its own data.

Results

Literature review

The literature review found extensive evidence that acute anxiety is a real consequence of an abnormal breast cancer screening[29, 35, 40, 59]. Receipt of notification of an abnormal screen was identified as one peak stress period[51,59], there may be others[29]. Anxiety may persist for several months after resolution of the screening episode, even after the woman has been informed that she does not have cancer[24, 29, 40, 51].

Anxiety is an adverse consequence of screening which can be minimized by:

- **Reducing the duration of assessment**. While all studies recommend minimizing delay, at least one cautioned that some women require time to adjust to the diagnostic information and process, especially if cancer is diagnosed[51].
- **Improved communication, especially regarding the reason for recall**. Studies identified that women's preferences varied regarding how and from whom they receive information about an abnormal screen. Interventions designed to improve communication were found to reliably reduce anxiety during the assessment interval[25,31,51]. As compared to improving communication, there was less clear evidence that simply shortening the assessment interval will have as beneficial an effect on a woman's anxiety[26,27,34,39,43,44,45,50,55,56].

Review of existing International and Canadian timeliness standards or targets

There was considerable variation across programs with respect to the existence of standards or targets and the time frames for investigation after an abnormal mammogram. The UK and Australian national programs and the organized breast screening programs in British Columbia (BC), Ontario, Quebec and Nova Scotia had statements about targets or standards defining durations for some or all intervals during the

investigation of an abnormal breast screen. These standards or targets are summarized in Appendix C and were considered in formulating the recommendations made in this report.

Time to diagnosis after an abnormal breast screen in organized programs in Canada, 1996

Seven organized breast screening programs provided service to women in Canada in 1996 and had data available for analysis. The seven programs were in BC, Alberta, Saskatchewan, Manitoba, Ontario, Nova Scotia and Newfoundland. The programs commenced operations between 1988 and 1996 and provided widely varying numbers of screens in 1996 (Table 1). In addition, the type of screening intervention and the age inclusion criteria varied between programs. Screening performance outcomes of these programs are reported elsewhere[62-66]. To improve the homogeneity of comparisons between programs, analysis was restricted to screening examinations provided to women age 50 to 69 years at the time of screening.

In 1996, 203,338 women age 50 to 69 years underwent screening in the seven programs studied (Table 2). Depending on the program, 4.8% to 14.1% of women screened were recalled for further assessment due to an abnormality detected by either a radiologist, a clinical examiner or both (Table 3).

Among those screened, 14,105 women (6.9%) had an abnormal screening examination and were eligible for analysis of the interval from screen to further assessment (Table 4). For 22% to 57% of women, investigation was concluded with a single reported procedure (Table 4). For 15% to 30% of women, a tissue biopsy (core or open surgical biopsy) was part of the assessment process (Table 3). The median time from the abnormal screen to the first assessment ranged from 1.9 to 3.9 weeks, depending on the program, and was not significantly different whether women went on to have a tissue biopsy or the assessment concluded without a biopsy. The median time to first imaging ranged from 2.1 to 4.5 weeks, depending on the program, and was similar for those receiving and not receiving a biopsy.

Table 1
Organized Breast Cancer Screening Programs in Canada: Usual practices, 1996

Program	Program Start Date	Mammography Interval	Clinical Breast Exam on Site?	Target Population	Includes Women Aged 40-49 years?	Includes Women Aged 70+ years?	Number of Screening Visits 1996
British Columbia	1988	Annual*	No	50-74	Yes	Yes	166,744
Yukon	1990	Biennial	No	50-69	Yes	Yes	N/A
Alberta	1990	Biennial	No	50-69	Yes	Yes	14,696
Saskatchewan	1990	Biennial	No	50-69	No	Yes	28,891
Manitoba	1995	Biennial	Yes: Nurse or Technologist	50-69	No	No	13,598
Ontario	1990	Biennial	Yes: Nurse	50-69	No	Yes	67,763
New Brunswick	1995	Biennial	No	50-69	Yes	No	N/A
Nova Scotia	1991	Biennial	Yes: Technologist	50-69	Yes	Yes	15,548
Newfoundland	1996	Biennial	Yes: Nurse	50-69	No	No	3,119
Programs Started After 1996							
Quebec	1998	Biennial	No	50-69	No	No	0
Prince Edward Island	1998	Biennial	Yes: Technologist	50-69	Yes	Yes	0

* In mid-1997, BC changed its recall frequency for women aged 50+ years to biennial.

Table 2
Screening Volume for Women Aged 50-69 Years and Cancers Detected by Program, 1996 (Initial and Rescreens)

Program	# screens	# of women with abnormal screen[1]	# program detected cancers	#Program-Detected Cancers by Modality of Detection (radiologist/clinical examiner/both)
A	12422 [6]	593 [3]	73 [52/21][2],[7]	73/0/0
B	54537 [5] [462/22/54053]	5666 [4] [2824/2251/591]	320 [275/45][7]	189/18/113
C	3116 [5] [28/0/3088]	438 [4] [221/183/34]	17 [15/2][7]	11/0/6
D	13062 [5] [544/14/12504]	1570 [4] [1075/398/97]	103 [88/15][7]	83/3/17
E	10393	486 [4] [274/37/175]	46 [40/6][7]	21/1/24
F	86474 [6]	4782 [3]	316 [254/62][7]	316/0/0
G	23334 [6]	1807 [3]	116 [96/20][7]	116/0/0

[1] includes women with an abnormal screen who do not have complete diagnostic follow-up including those who are lost to follow-up and those still in process

[2] four women from Program A were classified as non-program and program detected cancers and counted twice, so really this cell should be 69(50/19) if they are truly non-program cancers.

[3] all abnormalities were detected exclusively by radiologist

[4] numbers in square brackets are breakdowns by (radiologist only detected/clinical examiner only detected/both)

[5] numbers in square brackets are breakdowns by screening modality (mammography only/CBE only/both)

[6] reported screening modality as mammography exclusively

[7] numbers in square brackets are breakdowns by malignant/DCIS

Table 3
Selected Outcomes for Women Aged 50-69 Years by Program, 1996 (Initial and Rescreens)

Program	abnormal call rate	biopsy rate[3]		biopsy yield ratio[3]		PPV[3]
		open[1]	all[2]	open[1]	all[2]	
A	4.8%[4]	12.3%	24.7%	46.4%	47.5%	13.0%
B	10.4% [5.2/4.2/1.1] [5]	14.2% [15.3/8.2/30.8][5]	17.2% [19.7/8.8/35.3][5]	42.3% [45.5/11.0/64.3][5]	35.4% [35.8/10.3/56.6][5]	6.1% [7.0/0.9/20.4][5]
C	14.1% [11.0/5.9/1.1] [5]	9.8% [17.8/0.5/8.8][5]	19.5% [23.8/11.0/38.2][5]	19.0% [15.8/0.0/33.3][5]	20.2% [21.6/0.0/46.1][5]	4.0% [5.0/0.0/17.6][5]
D	12.0% [8.2/3.2/0.8] [5]	21.0% [22.3/14.3/37.2][5]	21.4% [22.8/14.6/38.4][5]	33.9% [39.8/5.4/46.9][5]	33.9% [39.5/5.3/48.5][5]	7.5% [9.2/0.8/19.8][5]
E	4.7%[6]	5.4% [5.1/2.7/6.3][5]	29.7% [29.7/2.7/35.4][5]	53.8% [42.9/100/63.6][5]	31.3% [25.9/100/37.1][5]	9.5% [7.7/2.7/13.7][5]
F	5.5%[4]	13.8%	15.0%	42.4%	41.5%	6.7%
G	7.7%	17.4%	17.4%	38.0%	38.0%	6.6%

[1] open biopsy includes open biopsy with or without fine wire localization
[2] all biopsies include open biopsies, core biopsies and unspecified biopsies
[3] calculated in women who have completed diagnostic follow-up
[4] all abnormalities were detected exclusively by radiologist
[5] numbers in square brackets represent outcome broken down by radiologist/clinical examiner/both
[6] abnormal call rates could not be broken down by radiologist/clinical examiner/both because only screening modality=mammography was reported

Table 4
Weeks from abnormal screen to Diagnosis, Women Aged 50-69 Screened in Provincial Programs, 1996
***includes all women screened abnormal*†**

Program	% Completing with a Single Reported Procedure	25%	50%	75%	90%	Range
A	21.6%	2.7	4.3	7.1	11.9	0.4-56.6
B	51.0%	1.9	3.4	6.9	14.3	0-83.1
C	45.2%	2.0	5.3	11.7	22.7	0-60.0
D	57.3%††	3.1	5.0	9.4	15.1	0-72.7
E	49.5%††	3.1	4.0	6.4	9.0	0.1-110.4
F	38.5%	2.0	3.1	5.3	8.4	0-35.4
G	56.9%††	2.9	4.1	6.6	11.1	0-62.7

† abnormal screens are included regardless of whether a clinical examiner/radiologist or both detected it

†† Program does not report physician visits so the proportion of women completing with a single procedure may be over-estimated

The overall median times from abnormal screen to diagnosis ranged from 3.1 to 5.3 weeks and for 10% of women it took longer than 8.4 to 22.7 weeks to arrive at a final diagnosis, depending on the program (Table 4). The need for an open or core biopsy lengthened the time to diagnosis in all provinces. Women completing assessment without an open or core biopsy waited a median of 2.9 to 4.3 weeks but even without a biopsy, 10% of women waited more than 7.0 to 23 weeks for a final diagnosis (Table 5). For women receiving an open or core biopsy, 50% waited 6.0 to 9.6 weeks or longer to complete assessment, depending on the program and for 10% the diagnosis was not finalized until after 12.0 to 21.9 weeks from the abnormal screen (Table 6). The two programs (A&E) that most frequently employed core biopsy had average times to diagnosis if a biopsy was *not* done but had among the shortest median intervals from

screen to diagnosis if a biopsy *was* performed. Fewer women in these two programs experienced exceedingly long waits; 90% of women had a diagnosis within 13 weeks in both programs.

Table 5
Weeks from abnormal screen to Diagnosis,
Women Aged 50-69 Screened in Provincial Programs, 1996
includes only women screened abnormal who did not have biopsy†

Program	% Completing with a Single Reported Procedure	25%	50%	75%	90%	Range
A	26.3%	2.6	3.7	6.0	11.1	0.7-56.6
B	60.6%	1.7	3.0	5.4	13.7	0-83.1
C	55.8%	1.6	4.3	9.9	23.0	0-60.0
D	75.1%††	2.9	4.3	8.0	14.0	0-64.3
E	69.8%††	3.0	3.9	5.1	7.7	0.1-110.4
F	45.4%	1.9	2.9	4.4	7.0	0-35.4
G	67.7%††	2.7	3.7	5.3	8.3	0-62.7

† abnormal screens are included regardless of whether a clinical examiner/radiologist or both detected it

†† Program does not report physician visits so the proportion of women completing with a single procedure may be over-estimated

Table 6
Weeks from abnormal screen to Diagnosis,
Women Aged 50-69 Screened in Provincial Programs, 1996
includes only women screened abnormal who had a biopsy†

Program	% Completing with a Single Reported Procedure	25%	50%	75%	90%	Range
A	6.8%	4.6	6.1	9.3	13.0	0.4-55.4
B	4.6%	4.0	6.2	10.1	15.3	0-64.1
C	2.6%	6.0	9.6	13.3	21.9	0-36.9
D	5.4%††	5.3	8.4	11.9	16.9	1.0-72.7
E	1.4%††	4.0	6.0	8.8	12.0	1.0-35.6
F	0.7%	4.7	6.6	9.4	12.4	0.6-31.0
G	7.7%††	5.7	7.9	11.1	20.3	1.3-60.9

† abnormal screens are included regardless of whether a clinical examiner/radiologist or both detected it

†† Program does not report physician visits so the proportion of women completing with a single procedure may be over-estimated

In every program, women experienced highly variable times to diagnosis. For instance, whereas 25% of women receiving an open or core biopsy completed assessment within 4.0 to 6.0 weeks, for a further 25% it took longer than 8.8 to 13.3 weeks. For women not requiring a biopsy, the corresponding 25th and 75th percentile times to diagnosis were 1.6 to 3.0 and 4.4 to 9.9 weeks respectively, depending on the program.

Table 7 summarizes the median durations for several important intervals in the assessment process. The numbers presented are the median and range of weeks observed between the seven programs evaluated.

Table 7
Summary of Various Assessment Intervals in Provincial Screening Programs†, Women Aged 50-69: Median and Range Between Programs

Interval	Median (Range) Times in Weeks Between Programs		
	All Women	**Unbiopsied Women**	**Biopsied Women††**
Screen to First Assessment	2.4(1.9-3.9)	2.4(1.7-3.9)	2.4(2.0-3.6)
Screen to First Image	3.5(2.1-4.5)	3.5(2.1-4.7)	3.1(2.0-3.7)
Screen to Diagnosis	4.2(3.1-5.3)	3.8(2.9-4.3)	6.4(6.0-9.6)
First Assessment to Diagnosis	0.1(0.0-0.9)	0(all = 0)	4.2(1.6-6.2)

† abnormal screens are included regardless of whether a clinical examiner/radiologist or both detected it
†† includes open biopsy ± wire localization, other biopsy, and core biopsy

Four of the seven programs included both a clinical and mammographic component as part of the screening intervention. Overall, mammographic abnormalities (with or without an abnormal clinical examination) accounted for 12,473 of 15,342 (81.3%) of the abnormal screens and 969 of 991 (97.8%) of the program detected cancers. A second analysis of time intervals was undertaken restricted to women with an abnormal screen detected as a result of an abnormal mammogram (with or without an abnormal clinical examination). Women with normal mammograms but an abnormal clinical examination were excluded from this second analysis. The intervals from screen to first assessment, first assessment to diagnosis and screen to diagnosis were comparable to those observed for all abnormal screens (data not shown). For example, the median intervals from screen to diagnosis for women receiving a biopsy after a radiologist detected abnormality were 5.9 to 9.1 weeks depending on the program as compared to 6.0 to 9.6 weeks for all women with abnormal screens requiring biopsy.

Discussion and Recommendations

Women with abnormal screens attending an organized breast screening program in Canada in 1996 waited many weeks to receive a diagnosis. The interval to diagnosis varied considerably within each province and also between provinces. In each province it took longer to arrive at a diagnosis if a biopsy was performed. Fifteen to 30% of women received an open surgical or core biopsy as part to their investigations. Greater variation in the time to diagnosis occurred within programs as compared to between programs. In each province, some women received a diagnosis relatively promptly while others waited exceedingly long intervals. In each program, the 25% of women with the longest times to diagnosis waited approximately twice as long as the 25% of women with the promptest diagnoses. This amounted to waits of 2 to 8 weeks longer if no biopsy was performed and 5 to 7 weeks longer if a biopsy was required, depending on the program.

Ten percent of women in each program waited longer than 12 weeks (range 12 to 22 weeks depending on the program) if a biopsy was performed and longer than 7 weeks (range 7 to 23 weeks depending on the program) if a biopsy was not performed. It is unknown if delays of 12 to 22 weeks from a screen-detected abnormality will effect a woman's chance of cure if she is diagnosed with breast cancer. It is worrisome that a recent publication suggests that delays to treatment as short as three to six months in women with symptomatic breast cancer are associated with poorer survival[68].

Programs varied with respect to the sequence of investigations after an abnormal screen. In particular, the use of core biopsies to obtain a tissue diagnosis varied widely. Core biopsies can often be performed without the need for surgical consultation and the need to wait for time to be available in hospitals or daycare surgical facilities to accomplish the biopsy. For two programs, core biopsies were used significantly more often in the evaluation of an abnormal screen. Fifty-one percent and 90% of patients having a tissue diagnosis from these programs had a core biopsy as compared to 3% to 27% in other programs. The two programs with the most frequent use of core biopsy had among the shortest median and 90th percentile times to diagnosis if a biopsy was performed and the highest

open biopsy yield ratios. The more prompt diagnoses in these programs may be attributed to access to core biopsy for investigation or due to other alterations in the diagnostic sequence. It should be noted the time to diagnosis in these programs was average if a biopsy was not required. Not all breast screening abnormalities are suitable for imaging directed core biopsy[68-70] and not all jurisdictions have access to this technology. Greater use of core biopsies in Canada should facilitate the diagnostic work-up and reduce delay for a substantial minority of women.

Although some women may prefer to wait for diagnostic investigations in order to schedule other family, work or social commitments this accounts for a minority of women[71]. There is a considerable body of evidence that an abnormal breast cancer screening precipitates acute anxiety[29, 35, 40, 59] especially upon receipt of notification of the abnormal screen[51,59]. Anxiety may persist for several months after resolution of the screening episode, even after the woman has been informed that she does not have cancer[24, 29, 40, 51].

Only some screening programs have articulated standards or targets for the timeliness of investigation after an abnormal screen. The UK and Australian national screening programs, supported by national legislation in each country, have mandated the development of interdisciplinary assessment clinics affiliated with screening centres. Similar programs have developed in some jurisdictions in Canada[65,72]. For the majority of women in Canada however, the prevailing practice is for the breast screening program to notify the woman and her family practitioner that an abnormality has been identified and the family physician is then responsible for initiating and co-ordinating the diagnostic evaluation. This may take multiple visits to different health care providers and facilities.

One of the three main priorities for action identified at a Workshop on Organised Breast Cancer Screening, hosted by Health Canada in Ottawa in April 1997, was to improve the integration of screening and diagnosis. To facilitate such efforts it is necessary to achieve consensus on the definitions for the start and end of the diagnostic process and reasonable timeliness standards for the different phases of the diagnostic process. By considering existing time standards established by Canadian programs

and internationally and the timeliness already achieved for half of women attending organised programs in Canada, a set of definitions and timeliness targets is proposed.

Definitions of dates and procedures in the Diagnostic Process after an abnormal breast screen

- The **start of the diagnostic interval** is the date of the abnormal screen
- The **first assessment procedure** is the first imaging or physician visit after an abnormal screen
- The **date of diagnosis** is the date of:
  - The first pathologic or cytologic diagnosis of cancer or
  - The last biopsy with benign findings or
  - The last intervention prior to a recommendation to return to screening or return for early recall
- The **assessment process** for women only ends when they are informed of the results of diagnosis

Timeliness targets for Canadian Breast screening programs

Investigation of an abnormal screen should be completed as promptly as possible while respecting that some women may prefer some delay in the process to allow time for adjustment.

Timeliness targets for several important intervals should be:

1. Abnormal screen to notification of the client
   - 100% to be notified
   - ≥90% to be notified within 2.0 weeks
2. Notification of the client to first assessment
   - ≥90% within 2.0 weeks
3. The total duration from abnormal screen to first assessment
   - ≥90% within 3.0 weeks

4. First assessment to diagnosis *if no open biopsy*
    - ≥70% within 1.0 week
    - ≥90% within 2.0 weeks
5. First assessment to diagnosis *if open biopsy performed*
    - ≥70% within 3.0 weeks
    - ≥90% within 4.0 weeks
6. Diagnosis to notification of the client
    - ≥90% within 1.0 week

Discrepancy between proposed timeliness standards and women's experiences after an abnormal breast screen in an organized program in Canada, 1996

The table below compares the timeliness targets proposed in this report and the experience for the 90th percentile of women with abnormal breast screening examinations in organised programs in Canada in 1996

It is recognized that the Working group proposed intervals are still long. If a woman was investigated "within targets", but at the outer limit for each of the intervals above, the time from an abnormal screen to diagnosis could be as long as 5.0 weeks without an open biopsy and 7.0 weeks with an open biopsy. Achieving the timeliness targets proposed however, would still represent a substantial improvement over usual practice in 1996.

For an individual woman, the anxiety about an abnormal screen extends from the date she knows the screen is abnormal until she is informed that the screening episode is resolved with either a benign or cancer diagnosis. A limitation of our analysis of timeliness to diagnosis is that the Canadian Breast Screening Database does not collect the date the client is notified that she has an abnormal screen. This date is collected as part of the care process by most Canadian programs. To facilitate future analyses and monitoring of efforts to improve the timeliness to diagnosis, the CBCSD should begin collecting the date the woman and/or her family physician are notified of the abnormal screen.

Table 8
Discrepancy between proposed timeliness standards and women's experiences after an abnormal breast screen in an organized program in Canada, 1996

	Integration Working group recommendation 1999	Status in 1996 (range of values between programs for 90th percentile)
Abnormal screen to notification of the client	≥90% within 2.0 weeks	Not collected
Notification of the client to first assessment	≥90% within 2.0 weeks	Not collected
Total duration from abnormal screen to first assessment	≥90% within 3.0 weeks	4.6 to 9.4 weeks
First assessment to diagnosis (*without* an open biopsy)	≥90% within 2.0 weeks	0 to 18 weeks
First assessment to diagnosis (*with* an open biopsy)	≥90% within 4.0 weeks	8.9 to 18 weeks
Diagnosis to notification of the client	≥90% within 1.0 weeks	Not collected
Total duration from abnormal screen to diagnosis (*without* an open biopsy)	≥90% within 5.0 weeks	7.0 to 23.0 weeks
Total duration from abnormal screen to diagnosis (*with* an open biopsy)	≥90% within 7.0 weeks	12.0 to 21.9 weeks

In addition, it is recognized that the estimates of intervals to diagnosis reported here are conservative estimates. We considered the date of diagnosis to be the date of a biopsy confirming cancer or benign findings or the date of the last recorded intervention prior to the woman returning to screening or being placed on early recall. In each instance, additional time, usually several days as a minimum, are required to report the diagnostic intervention to an attending physician or surgeon and for that

clinician to communicate results to the woman. Currently, no program in Canada collects or systematically evaluates this last step in the diagnostic process, the communication of the final result to the woman. Obtaining such information need not be problematic. An estimate of the interval from the last test until the woman is informed of the diagnosis could be obtained from women themselves. A project in Northwestern Ontario has demonstrated that women are quite reliable in reporting this information (B. Irving, personal communication). A large survey of the diagnostic process after an abnormal screen within the Screening Mammography Program of BC in 1998 has also shown close correlation between self-reported intervals to diagnosis and those measured by assessing physician billing data collected for administrative purposes (T.G. Hislop, personal communication). Periodic telephone or written follow up and satisfaction surveys four to six months after an abnormal screen could incorporate questions about the timing and consequences of diagnostic follow up including whether the woman feels that a final diagnosis was made and when this was communicated to her. Another strategy could be for the screening program to insert a survey instrument into a sample of the abnormal results letters, which each program sends to their clients. The survey could request that women record dates of various tests and physician interactions after an abnormal screen. These survey instruments could then be collected and dates of interaction could be compared to dates of service recorded in physician billing files or on diagnostic intervention reports that are currently collected by each screening program. Such efforts could enable programs and Health Canada to monitor the quality of diagnostic care after an abnormal screen.

Programs such as those in the UK, Australia and certain other jurisdictions[65,72], have dedicated assessment clinics for women with screen detected abnormalities and regularly achieve or surpass the timeliness targets proposed in this report. In the absence of such clinics it is still possible that several process changes might improve the diagnostic experience for women. Improved communication and facilitated referral from the screening centre to existing diagnostic imaging centres for women with mammographic abnormalities might shorten the time to first assessment. Greater use of imaging directed core biopsies could reduce the number of women requiring open biopsy and shorten the interval from

first assessment to diagnosis. More streamlined referral pathways for women requiring open surgical biopsy may also reduce the interval from first assessment to diagnosis. These and other strategies may assist health care providers to achieve the timeliness targets in this report. Different models to improve the diagnostic process are being developed and evaluated, not only for the timeliness of investigation but client satisfaction, anxiety and health system costs as well (TG Hislop personal communication). Breast screening programs in Canada should support the development of appropriate infrastructure, staffing and communication systems to meet the timeliness targets proposed in this report. This need not require wholesale revamping of the process of breast diagnostic care especially in communities without large enough population densities to support the development of specialized interdisciplinary breast diagnostic clinics.

Future Directions

i) The Canadian Breast Cancer Screening Initiative, Health Canada and individual breast screening programs should review and adopt the definitions and timeliness targets proposed herein.

ii) Programs should communicate the timeliness targets to stakeholders and clients of their programs.

iii) Programs should support the development of appropriate infrastructure, staffing and communication systems within their regions to meet the timeliness targets for the integration of screening and diagnosis.

iv) The Canadian Breast Screening Database maintained by the Laboratory Centre for Disease Control, Health Canada, Ottawa, should be structured so that these timeliness targets can be properly evaluated.

v) The timeliness to diagnosis should be reassessed and timeliness targets re-evaluated within 5 years.

vi) Women with abnormal breast screening examinations should have access to pertinent information and support including a description of what could and should be happening and the timeliness targets for each step in the process.

vii) The date women are notified of the assessment results is clearly the “end of the episode” from the woman’s perspective. Programs should evaluate the timeliness with which women are notified of the results of investigations.

Appendix A

Terms of Reference and Membership, Working group on the Integration of screening and diagnosis

Mandate

To identify and assess the current diagnostic process after an abnormal breast screening for women within an organized breast screening program in Canada. If gaps are identified, to suggest steps to achieve timely, seamless integration of screening and assessment for women with abnormal screening mammograms in Canada.

Target Groups

Screening programs, care providers, women at risk, women living with breast cancer, policy makers.

Activities

With respect to the diagnostic process subsequent to an abnormal mammogram:

- Survey, describe and evaluate the current process in Canada.
- Collect evidence regarding best practices nationally and internationally.
- Develop guidelines, standards and targets for the timeliness and components of the diagnostic process.
- Using the above, make recommendations about optimal models for integrated screening / assessement centres.

Membership

Chosen to reflect the interdisciplinary nature of the diagnostic process and the regions of Canada

Dr. Ivo Olivotto (Chair)
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APPENDIX B

Reference List assembled during literature review of the causes and consequences of delay with additional references cited in this report

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APPENDIX C

Review of timeliness standards or targets from International and Canadian organized breast screening programs

European Commission: No time standards set for the assessment process.

USA [***Food and Drug Adminisration (FDA) / American College of Radiology (ACR)***]**:** No time standards set for the assessment process.

Australia:

- 95% of women to be notified of results within 10 working days of screening.
- 70% of women to be provided with definitive diagnosis or recommendation for biopsy within 2 working days of first assessment visit.
- >90% of women to have first assessment within 10 working days.
- <5% of women assessed to be invited for further assessments.

UK [***National Health Service Breast Screening Program (NHSBSP)***] :

- 95% notified within 10 working days
- >90% assessments within one day
- surgical consult to take place at assessment clinic whenever possible
- referral to surgical consult within 1 week
- 90% to have an interval of 2 weeks or less from surgical consult to open biopsy (diagnostic)
- 90% to have an interval of 3 weeks or less from surgical consult to open biopsy (therapeutic)

Canada (National):

- *Quality Determinants of Organized Breast Screening Programs* (1997)
  p. 55: "There must be a timely, fail-safe mechanism to ensure that follow-up of the suspicious lesion has taken place. The Screening Program should verify within six (6) weeks that this has taken place."
- Canadian Clinical Practice Guideline #2 (Investigation of lesions detected by mammography), *CMAJ* 1998;158:S9-S14 (3 Suppl). No timeliness standards articulated.

British Columbia
(Screening Mammography Program of BC / BC Cancer Agency):

- Abnormal screen to report result:
  - ≤3 working days
- Report to first diagnostic imaging:
  - ≤5 working days
- Diagnostic imaging to surgical consult:
  - ≤5 working days
- Surgical consult to complete open biopsy:
  - ≤5 working days

Nova Scotia (NS Breast Screening Program):

- Abnormal screen to first assessment
  - ≤3 weeks
- First assessment to end of assessment
  - ≤2 weeks
- End of assessment to definitive surgery
  - ≤5 weeks

Québec (Programme québecois de dépistage du cancer du sein):

- Abnormal screen to first assessment:
  - 90% of women ≤12 working days
- First assessment to definitive diagnosis OR decision to biopsy:
  - 70% of women ≤5 working days

Ontario (Ontario Breast Screening Program):

- Abnormal screen to first assessment visit:
  - *Minimum standard:* None
    Goal: ≤10 working days
- Referral to complete assessment at community facility:
  - *Minimum standard:*
    50% of women ≤10 working days
    60% ≤15 working days
    70% ≤20 working days.
    Goal: >85% of women ≤10 working days
- Referral to complete assessment at comprehensive centres:
  - *Minimum standard:*
    >75% of women ≤10 working days, and
    ≤10% to require multiple visits
    Goal: >95% of women ≤10 working days and ≤5% to require multiple visits
- Biopsy recommendation to open biopsy:
  - *Minimum standard:*
    Recording of wait times
    Trying for ≤10 working days
    Goal: 70% of women ≤10 working days

- Definitive diagnosis to notification of primary care provider:
  - *Minimum standard:*
    100% < 10 working days
    Goal: 100% < 10 working days
    If cancer is found OR if biopsy is necessary, referring physician to be notified same day

- Diagnosis of cancer to referral to regional cancer centre:
  - *Minimum standard:*
    There must be access to referral
    Goal: < 5 working days