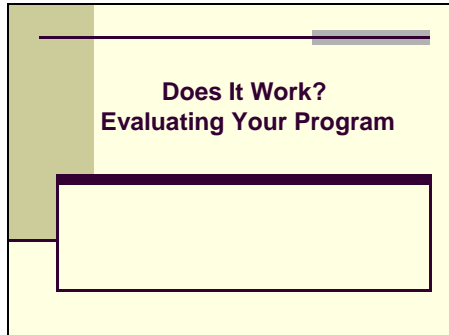
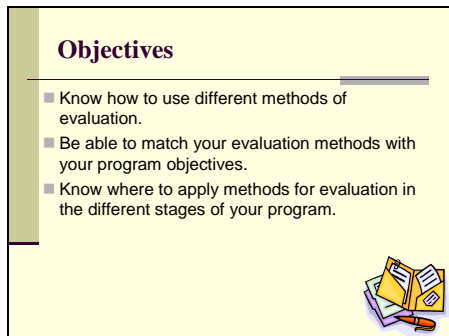


Handout #1: Slides

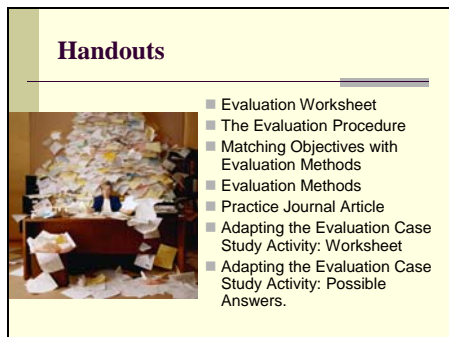
Slide 1



Slide 2



Slide 3



Slide 4

Questions

- When you think of evaluation, what first comes to mind?
- How do you define evaluation?

Slide 5

The Purposes of Evaluation

Evaluation helps you to:


- See whether program objectives were met
- Document the strengths and weaknesses of the program
- Have data for keeping good financial records
- Improve staff member skills in planning, conducting, and evaluating activities
- Meet grant or contract requirements
- Promote public relations and awareness
- Find out the extent to which a program or its components are appropriate for other populations or settings
- Add to the knowledge base of health education program design
- Identify hypotheses about behavior for future evaluation.

From Windsor et al., 1994

Slide 6

Process Evaluation

- Process evaluation can find problems early on in the program.
 - It includes an assessment of the staff, budget review, and how well the program is doing overall.
 - For this kind of evaluation, it may be useful to keep a log sheet to record each of your activities.



From Windsor et al., 1994

Slide 7

Impact Evaluation


- Impact evaluation can tell if the program has a short-term effect on the behavior, knowledge, and attitudes of your population.
- It also measures the extent to which you have met your objectives.

From Green and Kreuter, 1991

Slide 8

Outcome Evaluation


- Outcome evaluation looks to see if the long-term program goals were met. These goals could be changes in rates of illness or death, as well as in the health status of your population.



From McKenzie & Smeltzer, 1997

Slide 9

Activity

- In the first column of  Handout #2: Evaluation Worksheet, write down a personal goal and objective. For example:
 - Goal: I want to lose weight.
 - Objective: I want to lose 10 pounds in 2 months.

Slide 10

Activity

- In the second column, write one activity that will help you achieve your objective. For example:
 - I am going to learn ways to reduce the calories I eat each day and eat only 1,300 to 1,500 calories a day.
- In the third column, write one way to measure if your activity is working. For example:
 - I am going to keep a journal of what I eat, including how many calories.
 - I am going to weigh myself once a week.

Slide 11

Activity

- In the fourth column, write what you hope to learn from your evaluation activity. For example:
 - I hope to learn how many calories I am eating and how much weight I am losing each week.
- In the fifth column, write down the materials you will need to conduct your evaluation. For example:
 - I will need a journal, a writing instrument, a book with the calorie content of common foods, and a scale.

Slide 12

Activity

- In the sixth column, write what you hope to learn from your evaluation method that would tell you if you are achieving your goal. For example:
 - I hope to learn from the journal writing exercise that I am eating between 1,300 and 1,500 calories a day and am losing 1 to 2 pounds a week.
 - After 2 months I hope to learn that I have lost 10 pounds.

Slide 13

So What?

- In order for your personal plan to work, you need to think about how you are going to get from one step to the next.
 - Think about how you are going to find out if you have achieved your goals and objectives.
 - Would you set a goal that you want to lose weight without ever measuring your weight loss?

Slide 14

Discussion Question

- Q: When should you begin to think about program evaluation?
- A: From the very beginning.
 - Evaluation should be a part of the whole planning and implementation process.
 - Do not misinterpret the order in which you are receiving this module. It does not mean that evaluation comes last.

Slide 15

Evaluate From the Beginning

- Evaluation begins with your audience or needs assessment.
 - Use the data you collect about your audience to find out how it is affected by the health issue before your intervention. This is your "baseline."
 - The baseline will help you to measure the effect that your program has on your audience.
 - The outcome of your program has no value if you do not know where your audience was before the start of the program.

Slide 16

Pre- and Post-Evaluation

- You may develop a way to compare the baseline data from the needs assessment with the final outcome of your program. This will let you see if you have achieved your objectives.



Slide 17


Questions

- Now that you know when you should evaluate, how do you do it?
- If you have done an evaluation before, how did you select your methods?

Slide 18

The Evaluation Procedure


- Planning—Develop the questions, consult with the program stakeholders or resources, make a timeline
- Data Collection—Pilot testing. How will the questions be asked? Who will ask them?
- Data Analysis—Who will analyze the data and how?
- Reporting—Who will report and how? Who will receive the data and when? How will it affect the program?
- Application—How could your results be applied in other places?

( Refer to Handout #3: The Evaluation Procedure.)

Slide 19

Program Objectives and Evaluation

- Your objectives should be measurable so that they can be evaluated.
- The evaluation should be in line with your objectives.




Slide 20

Objective	Result	Evaluation
<i>Program Objective</i>	Changes in morbidity, mortality, and quality of life	<ul style="list-style-type: none"> • What is the outcome? • Is there a change in health status and is it attributed to the program?
<i>Behavioral Objective</i>	Changes in behavior, behavioral adaptation	<ul style="list-style-type: none"> • What is the impact? • Has a new, healthier behavior been adopted, and can it be attributed to the program?
<i>Learner Objective</i>	Changes in knowledge, attitude, practices, etc.	<ul style="list-style-type: none"> • Is there the requisite change in knowledge, attitudes, habits, and skills needed for behavior change?
<i>Process Objective</i>	Adherence to timeline tasks, completion of activities, efficient use of resources	<ul style="list-style-type: none"> • Is the program working? • Are people attending? • Are the methods appropriate?

Slide 21

Pilot Testing


- You may want to do a pilot test in order to evaluate the effect of your program. (A pilot test is a practice run using a small group who are similar to your target audience.)



Slide 22

Pilot Testing


- In a pilot test you collect feedback about the program from this test group. You evaluate the pilot program, and make needed changes in your program before you carry it out with the wider audience.
- It gives you a chance to see if there are any major problems before you commit yourself to the program.
- Pilot testing lets you get an idea of possible evaluation results.



Slide 23

Q: When Should Evaluation Be Made a Part of Your Program?


A: During program adaptation.



- For a program to be "evidence-based," it must have been evaluated. Therefore, each program you use will already have some suggested evaluation methods.
- Keep in mind how the changes you make to the program will affect your evaluation methods.
- You may need to adapt these methods to your needs and resources.

Slide 24

Replicating the Evaluation



- Evidence-based programs have already done some type of evaluation.
- Look to see how the program was evaluated before. Try to use the same methods.

Slide 25

Evaluation Methods

- Evaluation methods can be found in journal articles about the original study.
- Contacting the project officer for your selected program can also be helpful.
 - This person can give you input on any challenges or obstacles you may find when doing the evaluation.

Slide 26

Activity Results

- **Goal:** Evaluate the usefulness of the information aid for women with a family history of breast cancer.
- **Objectives:**
 - 1. Evaluate women's satisfaction with the aid
 - 2. Assess the effect of the aid on women's knowledge, breast cancer-related anxiety, risk perception, and attitudes toward screening.
- **Evaluation Method:** Questionnaires

Slide 27

Changing Your Evaluation Methods

You may change your evaluation methods if:

- You do not have the same resources as they had in the original program.
- The methods do not fit your objectives.
 - This should *rarely* be the case. The objectives should not have changed much from the original program.
- The methods will not be appropriate for your audience.

Slide 28

Case Study Activity

Intervention protocol:

- Introductory mailing.
- Home visits and group meetings with video, visual aids, and counseling focused on barriers to Pap test screening.
- Help with logistics. This could include referral to local clinics, scheduling appointments, interpreter services at clinics, and help with transportation.

Slide 29

Evaluation Worksheet

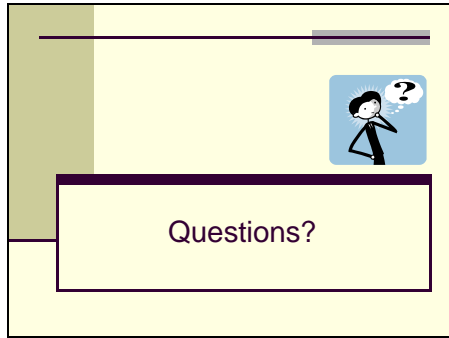
- **Evaluation Activities column**
 - Look for possible evaluation activities. They should be based on the goals and objectives as well as planned program activities.
- **Evaluation Results column**
 - Brainstorm about what you hope to learn from the evaluation.
- **Evidence of Activities and Quality column**
 - Brainstorm about what kinds of materials will be needed.
 - For example, a focus group would require a question guide and consent forms. You might need instruction materials for the participants.
- **Evidence of Results column**
 - Think about what kind of results would show that an objective has been met.

Slide 30

Objectives

- Know how to use different methods of evaluation.
- Be able to match your evaluation methods with your program objectives.
- Know where to apply methods for evaluation in the different stages of your program.

Slide 31



Handout #2: Evaluation Worksheet

				MONITORING	OUTCOME EVALUATION
Goals/Objectives	Overall Intervention (General Strategies)	Evaluation Activities	Evaluation Results	Evidence of Activities and Quality	Evidence of Results

Handout #3: The Evaluation Procedure

From: McKenzie, J.F., and Smeltzer, J.L. (2001). *Planning, Implementing, and Evaluating Health Promotion Programs: A Primer*. 3rd Ed. Allyn and Bacon: Boston, MA, 274–275.

Planning

- Review the program goals and objectives.
- Meet with the stakeholders to determine what general questions should be answered.
- See if you have the resources you need to conduct the evaluation; budget for additional costs.
- Hire an evaluator, if needed.
- Develop the evaluation design.
- Decide which evaluation instruments will be used and, if needed, who will develop them.
- Find out if the evaluation questions reflect the goals and objectives of the program.
- Decide if you want to include the questions of other groups, such as program administrators, facilitators, planners, participants, and funders.
- Decide when the evaluation will be conducted; develop a timeline.

Data Collection

- Decide how the information will be collected (e.g., surveys, records and documents, telephone interviews, personal interviews, observation).
- Decide who will collect the data.
- Plan and conduct a pilot test.
- Review the results of the pilot test to refine the data collection tool and the data collection procedures.
- Decide who will be included in the evaluation (e.g., all program participants or a random sample of participants).
- Conduct the data collection.

Data Analysis

- Decide how the data will be analyzed.
- Decide who will analyze the data.
- Conduct the analysis. Allow for several interpretations of the data.

Reporting

- Find out who will receive the results.
- Decide who will report the findings.
- Find out how and in what form the results will be disseminated.
- Discuss how the findings of your evaluation will affect the program.
- Decide when the results of impact, outcome, or summative evaluation will be made available.
- Disseminate the findings.

Application

- Determine how the results can be implemented.

Handout #4: Matching Objectives with Evaluation Methods

Objective	Result	Evaluation
Program objective	Changes in morbidity, mortality, and quality of life	<ul style="list-style-type: none">• What is the outcome?• Is there a change in health status? Did it change because of the program?
Behavioral objective	Changes in behavior, behavioral adaptation	<ul style="list-style-type: none">• What is the impact?• Has a new, healthier behavior been adopted? Can the program take credit for the change?
Learner objective	Changes in knowledge, attitude, practices, etc.	<ul style="list-style-type: none">• Is there enough change in knowledge, attitudes, habits, and skills needed for behavior change?
Process objective	Adherence to timeline tasks, completion of activities, efficient use of resources	<ul style="list-style-type: none">• Is the program working?• Are people attending?• Are the methods appropriate?

(Adapted from Deeds, 1992)

Handout #5: Evaluation Methods

Overview of Methods to Collect Information (by Carter McNamara, Ph.D.; last revision: February 16, 1998)

Evaluation Type	Evaluation Goal	Specific Questions	Activities
Process	<ul style="list-style-type: none"> This evaluation involves judging the activities or strategies of your project. This often involves looking at what has been done, who has been reached, and the quality of the activities. It involves seeking answers to questions. 	<ul style="list-style-type: none"> Has the program reached the appropriate people? Are all the program activities progressing as planned? If not, why? Were any changes made to the intended activities? If so, why? Are materials, information, and presentations of good quality? Are the participants and other key people satisfied? 	<ul style="list-style-type: none"> Assessment of staff performance Review of program documents Program review Documentation review Observation.
Impact	<ul style="list-style-type: none"> This evaluation involves judging the extent to which your program has had an immediate effect on the knowledge, attitudinal, and behavioral changes of the target population. It measures whether you have met these objectives. 	<ul style="list-style-type: none"> What progress has been made toward achieving the goal? To what extent has the program met its objectives? How effective has the program been at producing changes? Are there any factors outside of the program that have contributed to (or prevented) the desired change? Has the program resulted in any unintended change? 	<ul style="list-style-type: none"> Surveys.
Outcome	<ul style="list-style-type: none"> This evaluation will determine whether and how well the long-term program goals have been achieved. 	<ul style="list-style-type: none"> What progress has been made toward achieving the goals? To what extent has the program met its objectives? How effective has the program been at producing changes? Are there any factors outside the program that have contributed to or prevented the desired change? Has the program resulted in any unintended change? 	<ul style="list-style-type: none"> Surveys.
Formative	<ul style="list-style-type: none"> Typically carried out during the development or improvement of a program to identify problems with implementation and efficacy. Results are used to revise intervention components, data collection instruments, or procedures. 	<ul style="list-style-type: none"> How can we improve the intervention/program? Have the right questions been asked on the survey? Was sufficient evidence-based information provided to promote knowledge, attitude, or a change in behavior? 	<ul style="list-style-type: none"> Focus group Pilot test an intervention Semi-structured interviews.

The following table provides an overview of the major methods used for collecting data during evaluations.

Method	Overall Purpose	Advantages	Challenges
Questionnaires, Surveys, Checklists	<ul style="list-style-type: none"> Used to quickly and/or easily get a lot of information from people in a nonthreatening way. 	<ul style="list-style-type: none"> Can complete anonymously Inexpensive to administer Easy to compare and analyze Can administer to many people Can get a lot of data Many sample questionnaires already exist. 	<ul style="list-style-type: none"> Might not get useful feedback Wording can bias client's responses Are impersonal May need sampling expert for surveys Does not get the full story.
Interviews	<ul style="list-style-type: none"> Used to fully understand someone's impressions or experiences or to learn more about their answers to questionnaires. 	<ul style="list-style-type: none"> Provide a full range and depth of information Develop a relationship with client Can be flexible with the client. 	<ul style="list-style-type: none"> Can take a significant amount of time Can be hard to analyze and compare Can be costly Interviewer can bias client's responses.
Documentation review	<ul style="list-style-type: none"> Used to obtain an impression of how a program operates without interrupting the program through a review of applications, finances, memos, and minutes. 	<ul style="list-style-type: none"> Provide comprehensive and historical information Does not interrupt program or client's routine in program Information already exists Few biases about information. 	<ul style="list-style-type: none"> Often takes much time Information may be incomplete Need to be quite clear about what data are needed Not a flexible means to get data; data are restricted to what already exists.
Observation	<ul style="list-style-type: none"> Used to gather accurate information about how a program actually operates, particularly about processes. 	<ul style="list-style-type: none"> Can view operations of a program as they are actually occurring Can adapt to events as they occur. 	<ul style="list-style-type: none"> Can be difficult to interpret seen behaviors Can be complex to categorize observations Can influence behaviors of program participants Can be expensive.
Focus groups	<ul style="list-style-type: none"> Explore a topic in depth through group discussion (e.g., about reactions to an experience or suggestion, understanding common complaints) Useful in evaluation and marketing. 	<ul style="list-style-type: none"> Quickly and reliably get common impressions Can be an efficient way to get a greater range and depth of information in a short time Can convey key information about programs. 	<ul style="list-style-type: none"> Can be hard to analyze responses Need good facilitator for safety and closure Difficult to schedule.

Method	Overall Purpose	Advantages	Challenges
Case studies	<ul style="list-style-type: none"> Fully describe a client's experiences in a program Allow for the conduct of a comprehensive examination through cross-comparison of cases. 	<ul style="list-style-type: none"> Fully describe a client's experience in a program, including input, process, and results Powerful way of portraying the program to outsiders. 	<ul style="list-style-type: none"> Can be time consuming to collect, organize, and describe Represent depth of information, rather than breadth.

Handout #6: Practice Journal Article

Canadian Family Physician 2003, 49: 56-63

Educating women about breast cancer

An intervention for women with a family history of breast cancer

Ellen Warner, MD, MSC, FRCPC, FACP June C. Carroll, MD, CCFP, FCFP Ruth E. Heisey, MD, CCFP, FCFP
Vivek Goel, MD, MSC, FRCPC Wendy S. Meschino, MD, CCFP, FRCPC, FCCMG H. Lavina A. Lickley, MD,
PHD, FRCSC Brian D. Doan, PHD, CPSYCH Pamela L. Chart, MDCM Vanessa Orr, MA Shelley Lothian, MA

As a result of media attention to breast cancer in general and to hereditary breast cancer in particular, women with a family history of breast cancer want information about their risk of getting cancer and strategies for preventing it and detecting it early. While up to 20% of women have a family history of breast cancer, only 5% have a history that suggests they have inherited a genetic mutation that puts them at greatly increased risk of breast and ovarian cancer.¹ Most women overestimate their risk of breast cancer attributable to family history.²⁻⁶ For most women, family history has a negligible or, at most, moderate effect on their risk. Education about the true risk might decrease anxiety and avoid unnecessary referral to high-risk clinics and unnecessary investigations.

An “information aid” is an educational tool that uses an unbiased approach to present all aspects of an issue in a comprehensive, easily understood format. Information aids facilitate health care providers’ communication with patients by helping patients identify important questions they want to ask these health care providers and by giving patients information they can share with family and friends and discuss after visiting a physician.⁷

We developed an information aid consisting of a booklet (grade 8 reading level) and a 30-minute audiotape. We hope it will help women with a family history of breast cancer to identify for themselves the risk attributable to their family history in the context of other risk factors. Women with a low-risk family history, assuming they have no other important risk factors, can then be followed using screening recommendations for the general population. Women with a higher-risk family history are encouraged to consult their family physicians to decide whether they are at moderate risk or high risk.⁸ Women at moderately increased risk should be considered for earlier or more frequent screening and prophylactic antiestrogens.^{9,10} High-risk women should be offered referral to specialized clinics for counseling about prevention and surveillance strategies and possibly genetic testing.

In previous work, we tested the information aid in a pilot study of 67 women on a waiting list for a hereditary cancer clinic.¹¹ The aid significantly increased knowledge, did not increase depression or anxiety, and decreased worry about breast cancer, particularly among lower-risk women.¹¹

The goal of this study was to evaluate, in a family practice setting, the usefulness of the information aid for women with a family history of breast cancer. The study’s specific objectives were to evaluate women’s satisfaction with the aid and to assess the effect of the aid on women’s knowledge, breast cancer-related anxiety, risk perception, and attitudes toward screening.

METHODS

Development of the information aid and pilot-test results have been previously published.¹¹ In brief, the content was developed by a multidisciplinary team of health care professionals and breast cancer survivors and their relatives through focus groups, literature review, and key informants. Topics include

breast cancer pathogenesis, risk factors, prevention, screening, and presentation; an overview of breast cancer genetics; and criteria to help women identify their risk level themselves. Three case scenarios of women at low, moderate, and high risk of breast cancer are presented at the beginning of the booklet and followed throughout. The audiotape can be used while reading the booklet to supplement the information read.

The information aid was first pilot-tested in a hereditary cancer clinic population and was then modified according to comments received.¹¹ An 11-item Breast Cancer and Heredity Knowledge (BCHK) scale was developed and validated specifically for this purpose.¹²

Recruitment

For this study, 405 family physicians were randomly selected from the membership list of the College of Family Physicians of Canada's (CFPC) National Research System (NaReS), a network of family physicians interested in participating in family medicine research with clinical relevance. The 97 who agreed to participate were asked to recruit three consecutive, English-speaking, female patients older than 18 with any family history of breast cancer. Each patient who gave written consent completed a baseline questionnaire in the office and was then given the information aid and a second questionnaire to complete after reviewing the aid at home.

The first questionnaire asked about patient demographics, family history of breast or ovarian cancer, breast screening, breast cancer worry, risk perception, and attitudes toward breast screening, and included the 11-item BCHK. The second questionnaire evaluated satisfaction with the booklet and audiotape using multiple-choice and open-ended questions. A third questionnaire, which repeated the questions about anxiety and risk perception, attitudes to screening, and the BCHK, was mailed 4 weeks after the second questionnaire was returned.

After 4 months, too few patients had been recruited, so we sent a letter to the physicians asking them to recruit up to six patients. The study received ethical approval from the University of Toronto Human Subjects Review Committee.

Data analysis

Based on family history, responding patients were classified at low, moderate, or high risk of hereditary breast cancer (HBC) using previously validated criteria.⁸ χ^2 2 comparisons were used to detect differences between risk groups. McNemar's matched pair test was used for before-after differences in dichotomous outcomes; paired *t* tests were used for continuous outcomes. Significance was set at $P < .05$ (two-tailed).

RESULTS

Recruitment and baseline data

Recruitment took place from February 1999 to May 2000. Of the 97 physicians who agreed to participate, 59 (61%) enrolled a total of 203 patients in the study with a median of three patients (range one to six) per physician. Of the 203 patients, 160 (79%) completed all three questionnaires. There were no significant demographic or family history differences between the women who responded to all three questionnaires and the 21% who did not.

Of the 160 women who completed the family history questions, 39% were classified low risk, 35% moderate risk, and 26% high risk for HBC. Patient demographics (**Table 1**) did not differ significantly across the three risk categories. Patients' self-reported baseline breast screening behaviour is summarized in **Table 2**.

Satisfaction

Study patients were highly satisfied with the booklet and tape; 91% gave the aid an overall rating of excellent or very good (**Table 3**). The low-risk women rated the HBC component of the aid more highly than the higher-risk women did. There were no differences in overall satisfaction between the women who completed only the first two questionnaires and those who completed all three (92% vs 91%, $P = .84$). All but one woman said they would recommend the aid to other women, and 96% thought it should be available in family physicians' offices.

Table 1. Patient demographics: Mean age 45 years, range 20 to 74 years ($N = 203$)	
CHARACTERISTIC	N* (%)[†]
Marital status	
• Single	31 (16)
• Married or common-law	135 (71)
• Separated or divorced	21 (11)
• Widowed	4 (2)
Have children	135 (71)
Highest education	
• Elementary or some high school	16 (8)
• High school	33 (17)
• Some vocational school or college	22 (11)
• Technical or college diploma	41 (22)
• Some university	22 (11)
• University degree	38 (20)
• Postgraduate degree	21 (11)
Religion	
• None	3 (2)
• Protestant	94 (49)
• Catholic	67 (35)
• Other Christian	9 (5)
• Jewish	8 (4)
• Other	11 (6)
Race	
• White	175 (90)
• African-American	2 (2)
• Asian	6 (3)
• Other	10 (5)
Born in Canada	168 (84)
Language spoken at home	
• English	183 (94)

Table 1. Patient demographics: Mean age 45 years, range 20 to 74 years (N = 203)	
CHARACTERISTIC	N* (%)[†]
• English and other	7 (4)
• French	2 (1)
• Other	2 (1)
*Some respondents did not reply to some questions. [†] Percentages are rounded up.	

Table 2. Baseline breast screening behaviours: N = 203.	
BEHAVIOUR	N* (%)[†]
Ever had a mammogram	
• Age 50 or older (n = 60)	59 (98)
• Younger than 50 (n = 127)	64 (50)
Practises breast self-examination	
• Monthly	56 (34)
• Every 2 to 3 months	58 (35)
• Every 4 to 6 months	26 (16)
• Never	27 (16)
Breasts examined by a health professional	
• More than once a year	50 (30)
• Yearly	105 (62)
• Less than once a year	11 (7)
• Never	3 (2)
*Some respondents did not reply to some questions. [†] Percentages are rounded up.	

Table 3. Patients' satisfaction with the information aid by hereditary breast cancer risk level: N = 172.				
	RATED EXCELLENT OR VERY GOOD			
ASPECT OF THE AID	LOW (%)	MODERATE (%)	HIGH (%)	P VALUE
Overall	95	90	87	NS
Ease of use	92	98	87	NS
Design and layout	94	95	92	NS
Simplicity of language	95	93	92	NS
General information about breast cancer	97	95	94	NS
Description of risk factors	92	88	85	NS
How much it increased knowledge of HBC	97	78	72	.001
How well it increased understanding of HBC risk	95	82	81	.034
How well it answered questions about HBC	92	78	77	.051
Explanation of prevention and screening	90	85	87	NS
Presentation of sensitive issues	87	85	83	NS

Table 3. Patients' satisfaction with the information aid by hereditary breast cancer risk level: <i>N</i> = 172.				
	RATED EXCELLENT OR VERY GOOD			
ASPECT OF THE AID	LOW (%)	MODERATE (%)	HIGH (%)	<i>P</i> VALUE
HBC—hereditary breast cancer, NS—not significant.				

At baseline, the percentage of women answering a particular question correctly ranged from 8% to 87%. Following the intervention, there was a highly significant overall improvement in knowledge on all items of the BCHK (**Table 4**). Although baseline knowledge was higher among more educated women ($P = .034$), knowledge increased among all women.

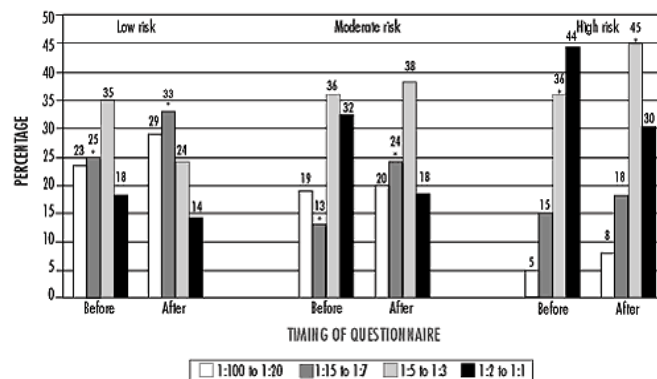
Table 4. Effect of reviewing the information aid on patients' knowledge: <i>N</i> = 160.			
ITEMS	BEFORE (%)	CORRECT RESPONSES AFTER (%)	<i>P</i> VALUE
GENETICS			
Testing for breast cancer gene mutations will tell a woman if she has cancer (F)	35	52	.001
Men cannot inherit breast cancer gene mutations (F)	74	83	.021
A woman whose mother was diagnosed with breast cancer at age 69 is considered at high risk for breast cancer (F)	40	65	<.0001
Ovarian cancer and breast cancer in the same family can be a sign of HBC (T)	74	84	.105
INCIDENCE			
Out of every 100 women diagnosed with breast cancer, 75 are alive and well after 10 years (T)	44	75	<.0001
Stress has been proven to increase the risk of breast cancer (F)	9	42	<.0001
Women older than 50 are more likely to get breast cancer than younger women are (T)	72	78	.001
Over a lifetime, one in nine women will develop breast cancer (T)	56	68	.01
DISEASE PREVENTION AND TREATMENT			
A change in the size or shape of one breast could be a sign of breast cancer (T)	69	81	.005
Chemotherapy is always used in treatment of breast cancer (F)	72	81	.014
Women older than 50 should have mammograms at least every 2 years (T)	87	94	.027
Note: Mean number of correct responses (maximum score = 11) was 6.2 (99% confidence interval 5.9 to 6.6) before and 8.1 (99% confidence interval 7.5 to 8.3) after, $P < .0001$.			

Anxiety and risk perception

Worry about breast cancer did not differ at baseline across the three risk groups and was not affected by use of the aid. The risk of breast cancer for average women was greatly overestimated or underestimated by a substantial proportion of the women; reviewing the aid did little to improve many women's estimation of risk.

On average, patients in all risk groups overestimated their risk at baseline with a trend toward higher average risk perception with increasing risk group. Reviewing the aid substantially reduced the mean risk estimate of low- and moderate-risk groups to a more appropriate level (**Figure 1**); however, there were still women who greatly overestimated or underestimated their risk of developing breast cancer.

Figure 1. Perception of lifetime risk of breast cancer before and after reading information aid: Before-after differences across the four categories are borderline significant ($P = .072$, $.058$, and $.132$ for low-, moderate-, and high-risk categories, respectively), but change in mean lifetime risk estimates is highly significant ($P < .0001$, $= .001$, and $= .003$ for low-, moderate-, and high-risk women, respectively.)



Note: Response categories have been collapsed from 14 to the 4 shown.

* Optimal response category for each risk level.

Breast screening intentions

After reviewing the aid, there was no change in intent to undergo mammography or breast self-examination, but there was a significant increase (from 85% to 96%, $P < .0001$) in intent to undergo clinical breast examination, particularly in the low- and moderate-risk groups.

Physician demographics

The demographic characteristics of the 59 physicians who recruited patients to the study (**Table 5**) were compared with those of the 38 physicians who had agreed to participate but did not enrol patients, with the 308 NaReS physicians who were approached but did not agree to participate, and with the 4682 CFPC members in Ontario. Only two significant differences were found across the four groups. The proportion of female physicians was higher among study participants (55%, 39%, 33%, and 43%, respectively, $P = .001$) and physicians who participated or agreed to participate were more likely to have hospital admitting privileges (83% and 86% vs 66% and 67%, $P = .004$).

Table 5. Characteristics of participating physicians: Mean age was 45 years; 55% were men ($N = 59$).	
CHARACTERISTIC	%*
Practice location	
• Suburban	36
• Urban	36
• Rural	23
• Inner city	3
• Geographically isolated	2
Method of remuneration	
• Fee-for-service	81
• Salary	5
• Other	14
Hospital admitting privileges	

Table 5. Characteristics of participating physicians: *Mean age was 45 years; 55% were men (N = 59).*

CHARACTERISTIC	%*
• <20 h/wk	4
• 20-39 h/wk	38
• 40-59 h/wk	38
• ≥60 h/wk	21
*Percentages are rounded up.	

DISCUSSION

Women with a family history of breast cancer are an ideal target group for an information aid because of the complexity of the information involved, the potential benefits of identifying women at increased risk of cancer, and the potential harm that the misinformation that is prevalent in the community can cause.¹³ We chose a self-administered audiotape and booklet as the format for our information aid based on the results of our focus groups and successful use of this format for women considering hormone replacement therapy¹⁴ or surgical options for breast cancer.¹⁵ There are no specific information aids for average women in the community with a family history of breast cancer, and, specifically, there has been nothing to help these women identify the risk attributable to family history for themselves.

We attribute the high satisfaction with our information aid to the process used to develop it that included focus groups of the target population, input from a multidisciplinary team, pilot testing followed by refinement of the aid, and finally testing in the field. The only area of relative dissatisfaction was that a substantial number of women at highest risk of HBC thought that the amount of information about HBC in the aid was inadequate. This suggests that the aid is achieving its aim in supplying sufficient information to women at low and moderate risk of HBC, while allowing higher-risk women to identify their risk themselves and approach their family physicians for discussion about referral for genetic counseling. In addition to one-on-one counseling, there is abundant information available^{16,17} and under development for these high-risk women. The aid significantly increased knowledge across all risk groups and educational levels. Even after reviewing the aid, however, the widely held misconception that stress definitely causes cancer was retained by more than half the women. Risk perception also remained relatively refractory to change, a phenomenon well described in the literature, even after individual genetic counseling.^{3,18-21}

Limitations

The main limitations of this study were the relatively low rate of participation by the family physicians who had originally indicated interest in the study and the highly selected study population. The participation rate of the physicians in our study is comparable to that reported in other recent NaReS studies and likely reflects shortages of physicians, the lack of financial compensation for participating in studies, and the work involved in the study.

The patient population was overwhelmingly white, Canadian born, English speaking, and generally highly educated. Also, 98% of the women older than 50 had had previous mammograms compared with 79% of all Canadian women over 50,²² the age group for which population screening is recommended in Canada. This is precisely the profile of the women who are already being disproportionately referred to familial cancer clinics.^{23,24} Although physicians were asked to recruit three consecutive women with a family history of breast cancer, it is likely that there was at least subconscious selection bias. To reach a broader group of Canadian women, we have translated the booklet and tape into French and are publicizing the aid to specific groups, such as aboriginal women.

Although a potential limitation of our aid is that it focuses on an area in which new developments are occurring rapidly, the aid deals predominantly with principles that will not quickly become outdated. We have also created an Internet version of the aid that is available through the Canadian Cancer Society (CCS) website in English or French at <http://www.hereditarybreastcancer.cancer.ca> in both audio and read-only versions. This format will be easier to update in the future.

To help family physicians assess higher-risk women identified by the aid, a companion package for physicians has been developed. It includes a family history risk assessment and management algorithm on a two-sided laminated page. In a companion study, these materials and the information aid were evaluated very highly by participating physicians.

The booklet, audiotape, and physician package are currently available free of charge through the CCS Cancer Information Service at 1-888-939-3333. Brief evaluation forms are included with each copy and on the website to enable us to determine whether these materials are now reaching a wider spectrum of Canadian women and physicians, and, if so, whether they are as satisfied with the material as our study participants were.

Conclusion

Our information aid for women with a family history of breast cancer was highly rated by our study patients. It could be a useful tool for educating and reassuring low-risk patients and helping higher-risk patients to identify themselves and receive appropriate management.

References

1. Hoskins KF, Stopfer JE, Calzone KA, Merajver SD, Rebbeck TR, Garber JE, et al. Assessment and counseling for women with a family history of breast cancer: a guide for clinicians. *JAMA* 1995;273:577-85.
2. Evans DG, Blair V, Greenhaigh R, Hopwood P, Howell A. The impact of genetic counselling on risk perception in women with a family history of breast cancer. *Br J Cancer* 1994;70:934-8.
3. Alexander NE, Ross J, Sumner W, Nease RF, Littenberg B. The effect of an educational intervention on the perceived risk of breast cancer. *J Gen Intern Med* 1995;11:92-7.
4. Lerman C, Seay J, Balshem A, Audrain J. Interest in genetic testing among first-degree relatives of breast cancer patients. *Am J Med Genet* 1995;57:385-92.
5. Black WC, Nease RF, Tosteson AN. Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. *J Natl Cancer Inst* 1995;87:720-31.
6. Lovegrove E, Rumsey N, Harcourt D, Cawthorn SJ. Factors implicated in the decision whether or not to join the tamoxifen trial in women at high familial risk of breast cancer. *Psychooncology* 2000;9:193-202.
7. Degner LJ, Martin J, Till J. Communication in cancer: report on the Terry Fox Workshop. *Can Med Assoc J* 1991;144:1417-8.
8. Warner E, Heisey RE, Goel V, Carroll JC, McCready DR. Hereditary breast cancer: risk assessment of patients with a family history of breast cancer. *Can Fam Physician* 1999;45:104-12.
9. Fisher B, Constantino JP, Wickerham DL, Redmond CK, Kavanah M, Cronin WM, et al. Tamoxifen for prevention of breast cancer: report of the National Surgical Adjuvant Breast and Bowel Project P-1 Study. *J Natl Cancer Inst* 1998;90:1371-88.
10. Cummings SR, Eckert S, Krueger KA, Grady D, Powles TJ, Cauley JA, et al. The effect of raloxifene on risk of breast cancer in postmenopausal women: results of the MORE randomized trial. Multiple Outcomes of Raloxifene Evaluation. *JAMA* 1999;281:2189-97.
11. Warner E, Goel V, Ondrusek N, Thiel EC, Lavina H, Lickley A, et al. Pilot study of an information aid for women with a family history of breast cancer. *Health Expect* 1999;2:118-28.
12. Ondrusek NK, Warner E, Goel V. Development of a knowledge scale about breast cancer and heredity (BCHK). *Breast Cancer Res Treat* 1999;53:69-75.
13. Ryan EL, Skinner CS. Risk beliefs and interest in counseling: focus-group interviews among first-degree relatives of breast cancer patients. *J Cancer Educ* 1999;14:99-103.

14. O'Connor AM, Tugwell P, Wells G, Emslie T, Jolly E, Hollingworth G, et al. Randomized trial of a portable, self-administered decision aid for postmenopausal women considering long-term preventive hormone therapy. *Med Decis Making* 1998;18:295-303.
15. Sawka CA, Goel V, Mahut CA, Taylor GA, Thiel EC, O'Connor AM, et al. Development of a patient decision aid for choice of surgical treatment for breast cancer. *Health Expect* 1998;1:23-36.
16. Green MJ, McInerney AM, Biesecker BB, Fost N. Education about genetic testing for breast cancer susceptibility: patient preferences for a computer program or genetic counselor. *Am J Med Genet* 2001;103:24-31.
17. Cull A, Miller H, Porterfield T, Mackay J, Anderson ED, Steel CM, et al. The use of videotaped information in cancer genetic counselling: a randomized evaluation study. *Br J Cancer* 1998;77:830-7.
18. Lerman C, Lustbader E, Rimer B, Daly M, Miller S, Sands C, et al. Effects of individualized breast cancer risk counseling: a randomized trial. *J Natl Cancer Inst* 1995;87:286-92.
19. Lloyd S, Watson M, Waites B, Meyer L, Eeles R, Ebbs S, et al. Familial breast cancer: a controlled study of risk perception, psychological morbidity and health beliefs in women attending for genetic counselling. *Br J Cancer* 1996;74:488-90.
20. Elwood JM. Public health aspects of breast cancer gene testing in Canada. Part 2: selection for and effects of testing. *Chronic Dis Can* 1999;20:14-25.
21. Watson M, Lloyd S, Davidson J, Meyer L, Eeles R, Ebbs S, et al. The impact of genetic counseling on risk perception and mental health in women with a family history of breast cancer. *Br J Cancer* 1999;79: 868-74.
22. Maxwell CJ, Bancej CM, Snider J. Predictors of mammography use among Canadian women aged 50-69; findings from the 1996/97 National Population Health Survey. *Can Med Assoc J* 2001;164:329-34.
23. Meiser B, Butow P, Barratt A, Friedlander M, Kirk J, Gaff C, et al. Breast cancer screening uptake in women at increased risk of developing hereditary breast cancer. *Breast Cancer Res Treat* 2000;59:101-11.
24. Emmons KM, Kalkbrenner KJ, Klar N, Light T, Schneider KA, Garber JE. Behavioral risk factors among women presenting for genetic testing. *Cancer Epidemiol Biomark Prev* 2000;9:89-94.

Handout #7: Adapting the Evaluation Case Study Activity: Worksheet

				MONITORING	OUTCOME EVALUATION
Goals/Objectives	Overall Intervention (General Strategies)	Evaluation Activities (Use examples from Handout #5, Evaluation Methods)	Evaluation Results (Brainstorm what you hope to learn from the evaluation)	Evidence of Activities and Quality (Brainstorm what kinds of materials you will need to carry out the evaluation activity)	Evidence of Results (What kind of results would show that an objective has been met?)
Objective 1: Increase the number of women who receive Pap test screening by 20 percent during the life of the program.	<ul style="list-style-type: none"> • Introductory mailing • Home visits with a video, visual aids and counseling • Help with appointment logistics 				
Objective 2: Learn about the cervical cancer screening behaviors of this group of women.	<ul style="list-style-type: none"> • Introductory mailing • Home visits with a video, visual aids and counseling • Help with appointment logistics 				
Objective 3: Increase the number of women in the program who can state that HPV is linked with cervical cancer by 20 percent.	<ul style="list-style-type: none"> • Introductory mailing • Home visits with a video, visual aids and counseling • Help with appointment logistics 				

Handout #8: Adapting the Evaluation Case Study Activity: Possible Answers

				MONITORING	OUTCOME EVALUATION
Goals/Objectives	Overall Intervention (General Strategies)	Evaluation Activities (Use examples from Handout #5, Evaluation Methods)	Evaluation Results (Brainstorm what you hope to learn from the evaluation)	Evidence of Activities and Quality (Brainstorm what kinds of materials you will need to carry out the evaluation activity)	Evidence of Results (What kind of results would show that an objective has been met?)
Objective 1: Increase the number of women who receive Pap test screening by 20 percent during the life of the program.	<ul style="list-style-type: none"> • Introductory mailing • Home visits with a video, visual aids and counseling • Help with appointment logistics 	<ul style="list-style-type: none"> • Documentation review • Pre and post survey. 	Whether or not intervention increased Pap test screening.	<ul style="list-style-type: none"> • Development of surveys • Staff to review medical records • Consent forms. 	Increased clinic visits.
Objective 2: Learn about the cervical cancer screening behaviors of this group of women.	<ul style="list-style-type: none"> • Introductory mailing • Home visits with a video, visual aids and counseling • Help with appointment logistics 	<ul style="list-style-type: none"> • Interviews • Focus groups • Case studies • Surveys. 	Knowledge, attitudes and opinions about cervical cancer and the Pap test.	<ul style="list-style-type: none"> • Consent forms • Question guides • Survey instruments. 	Revealed knowledge level and attitudes about Pap test screening.

Handout #8: Adapting the Evaluation Case Study Activity: Possible Answers

				MONITORING	OUTCOME EVALUATION
Goals/Objectives	Overall Intervention (General Strategies)	Evaluation Activities (Use examples from Handout #5, Evaluation Methods)	Evaluation Results (Brainstorm what you hope to learn from the evaluation)	Evidence of Activities and Quality (Brainstorm what kinds of materials you will need to carry out the evaluation activity)	Evidence of Results (What kind of results would show that an objective has been met?)
Objective 3: Increase the number of women in the program who can state that HPV is linked with cervical cancer by 20 percent.	<ul style="list-style-type: none"> • Introductory mailing • Home visits with a video, visual aids and counseling • Help with appointment logistics 	<ul style="list-style-type: none"> • Pre and post questionnaires • Pre and post interviews. 	More women understand the link between HPV and cervical cancer.	<ul style="list-style-type: none"> • Questionnaire instruments • Consent forms. 	Increase in women who understand the link between HPV and cervical cancer. Difference between pre and post results.