FEASIBILITY STUDY:
RESEARCH EFFORTS TO IDENTIFY AND REACH PORTUGUESE-SPEAKING WOMEN
WHO ARE UNDERSCREENED FOR CERVICAL CANCER

by

Elizabeth Grace Stevens Rael

A thesis submitted in conformity with the requirements for the Degree of Doctor of Philosophy, Graduate Department of Community Health, in the University of Toronto.

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Feasibility Study:

Research efforts to identify and reach Portuguese-speaking women who are underscreened for cervical cancer

Doctor of Philosophy, 2001

Elizabeth Grace Stevens Rael

Graduate Department of Community Health, University of Toronto

Abstract

The value of secondary prevention of cervical cancer by screening with the Pap test is well-recognized, but women at greatest risk for cervical cancer (older, poorer, not speaking an official language) continue to be least well-screened. This study investigated the use of quantitative and qualitative research to identify and reach Portuguese-speaking women who are underscreened with respect to cervical cancer. Traditional epidemiologic approaches were seriously constrained, but conceptual synthesis using qualitative approaches provided a resolution.

The project was developed, implemented and reviewed, in iterations, with Portuguese-speaking women and those who care for them in Toronto, Ontario. Many approaches to identify and reach underscreened women were considered; two approaches (health events and physicians' offices) were evaluated. Questionnaires, surveys and physicians' logs revealed misclassification of “eligibility for screening”, “interval since last Pap test”, and “intentions regarding Pap tests”. Not all underscreened women identified by their doctors or friends wished to attend health events or have Pap tests. A pilot trial of appointment
scheduling (now versus later) and brochure language (Portuguese versus English and Portuguese) showed that randomization, consent forms and follow-up interviews were largely acceptable to participants, but data validation (requested on follow-up) was not.

Barriers and facilitators of Pap testing were categorized using the PRECEDE (Predisposing, Reinforcing, and Enabling Constructs in Educational / Environmental Diagnosis and Evaluations) model. A theoretical model integrates elements of others, including the Health Belief Model, and social learning theory. This “Two Streams” model explains perceptions of need and value for Pap testing in the context of the test and understandings (including myths) about cancer and health care. This model explains how age, fear, and lack of symptoms impede screening Pap tests. Time, contact and communication are proposed to develop trusting relationships and understandings about health behaviour and health outcomes.

Public health’s role in developing and implementing strategies for improving screening to prevent invasive cervical cancer is affirmed. Recommended strategies, which should contribute to social marketing, include: scheduling appointments for prevention counselling, dispelling myths (e.g., Pap tests are for young and sexually active women) with their complements, and developing narrative or dramatic scenarios to model patient-provider interactions.
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Three remarkable Portuguese-speaking women gave much to sustain me: Margareth Toste, Helena Monteiro, and Oligia Resendes.

Finally, my best friend and devoted husband, the late Barry S Rael, supported me in every aspect of this undertaking, in every way possible.
Dear Dr. Granahan,

I am emailing you to request official copyright clearance to use the PRECEDE-PROCEED model diagram, taken from the second edition of "Health Promotion Planning: An educational and environmental approach" (Green & Kreuter, 1991:24), in my doctoral thesis dissertation. I have been using the model to help sort through the complexities in my collaborative project on developing and pilot-testing invitations of Pap testing for Portuguese-speaking women. Dr. Green has given his permission and recommended I contact the publishers directly, as you may know from his cc'ed email to you of Nov 30, 1998. I am attaching the Bitmap Graphics file which I produced for your review; it recreates the model in electronic form for importing into a figure for my thesis.

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With appreciation for your assistance,

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Chapter 1 Introduction and literature

Cervical cancer is largely preventable through screening with the Pap test, yet not every woman who needs a Pap test has one. This chapter presents what is known about the disease and screening for it, placing these understandings in the context of other health behaviours. Challenges and priorities for research are identified.

1.1 Cervical cancer

1.1.1 Incidence and mortality

The incidence and mortality of uterine cervical cancer varies widely by geographic region, over time, and by population. Throughout the world, incidence rates range widely: lowest rates are found in Israel (3.0 per 100,000) and highest in Trujillo, Peru (54.6 per 100,000) (Zatorński et al., 1996:83). At least since 1970, the incidence and mortality from cervical cancer have declined in Canadian women (Band et al., 1993). In 1970, the incidence and mortality rates, respectively, were 19.4 and 7.3 per 100,000; by 1994, they had decreased to 9.3 and 2.7 (NCIC, 1999:34-5). Cervical cancer rates increase with age. In Ontario, the age-specific incidence peaked within age group 65-69 (30.1 per 100,000 per year, between 1992-1996, corrected for hysterectomy) (Marrett et al., 1999:15). Within the same period, age-specific mortality rates increased steadily with age, to 16.5 per 100,000

1. Rates are provided only for regions with established cancer registries.
2. age-standardized to the 1991 Canadian population.
3. Rates standardized to the Canadian population are higher than those standardized to the world population, because the age distribution of Canada’s population is older than that of the world.
4. Women without a cervix are not at risk for cervical cancer, so rates unadjusted for total hysterectomy, i.e., including removal of the cervix, underestimate true cancer rates. Reported rates of all hysterectomies increase sharply from less than 1% for women below age 35, to approximately 30% for women aged 55 and over; nothing is known about whether these hysterectomies removed the cervix (Snider & Beauvais, 1998). Therefore, cervical cancer incidence and mortality rates adjusted for all hysterectomies overestimate true cervical cancer rates to an unknown extent.
worn per year for women 80 years and older (Marrett et al., 1999:15). Populations with higher cervical cancer incidence may also have higher mortality than expected from the observed incidence, possibly due to later tumour stage at diagnosis (Marrett et al., 1999, Schwarz et al., 1981).

Rates for cervical cancer incidence, like many other diseases, are generally higher among those who are relatively disadvantaged (Marrett et al., 1999) and this trend has persisted over time (e.g., Pukkala & Weiderpass, 1999). Women with cervical cancer are more likely than others to be of lower socioeconomic status, whether measured by education, income, or occupation (reviewed by Brinton, 1993). Risk of cervical cancer is related to sexual activity, whether measured by marital status, age at first birth, number of children, age at initiation of sexual activity, numbers of sexual partners, or partners' number of partners (Brinton, 1993). Sexual activity may have confounded associations of smoking and cervical cancer (Brinton, 1993). Certain strains of the Human Papillomavirus (HPV strains 16 and 18) are considered the cause of cervical cancer; the other risk factors increase the chance of exposure to HPV (Munoz, 1992, IARC, 1995). Diet may be important in cervical cancer prevention and treatment. DeMarco's (1995-6) review indicated folic acid may be important in preventing cervical cancer, particularly for women on the birth control pill. Current human studies focus on suppositories or oral supplements for women with abnormal Pap smears (DeMarco, 1995-6). Finally, not having Pap tests is itself a risk factor for invasive cervical cancer (Carmichael et al., 1984, Clarke et al., 1979, reviewed by Straton, 1994). In most situations, underscreening was not due to lack of contact with the health care system (Macgregor, 1977, Fruchter et al., 1980, Carmichael et al., 1984, Norman et al., 1991).

1.1.2 Cervical cancer screening

Much of the decline in mortality from cervical cancer is credited to screening with the Papanicolaou smear test (Miller et al., 1990, Band et al., 1993). While primary prevention of cervical cancer is not currently a realistic option, the Pap test provides the best opportunity for secondary prevention, or early detection, of cervical cancer (Miller, 1992:1-5). The Pap test or Pap smear is a technically simple, inexpensive test wherein cells are collected from the transition (squamocolumnar) zone of the uterine cervix, and smeared on a cytology slide (Papanicolaou & Trout, 1941). Staining and cytopathology review detects cellular atypia, the precursors of invasive cancer, severe dysplasia and carcinoma in situ, which
correspond to a cervical intra-epithelial neoplasia (CIN) classification III (Richart, 1980). This permits appropriate follow-up and early treatment of neoplastic cells before they invade the basement membrane of the epithelium; this reduces the incidence of and mortality associated with invasive squamous cell lesions (Miller, 1992:7).

In the absence of organized screening programmes, coverage rates¹ are lower (e.g., Bos et al., 1998), and elderly, poor or less well-educated women are least likely to have had adequate or any Pap testing (Clarke et al., 1979, Celentano, 1982, Carmichael et al., 1984, Cohen, 1989, Sweet et al., 1991, Goel, 1994, Snider et al., 1996, reviewed by Norman et al., 1991). In Ontario the percentage of women who reported never having had a Pap smear remained stable between 1985 and 1997, ranging from 12% to 14%² (Snider et al., 1996). Among women aged 18 and over responding to the 1994 National Population Health Survey, 46% reported a Pap test within the previous year, 22% one to three years ago, 15% three or more years ago, and 15% never (Snider et al., 1996). Pap tests reported within the previous year, by age group, were highest (59%) for women aged 25-34, and decreased steadily with age, to 22% for women aged 65 and over. Conversely, for never having had a Pap test, the lowest percentage (8%) was among those aged 35-44; the highest percentages were for women aged 18-24 (31%)³ and 65 and over (28%) (Snider et al., 1996). These rates, not adjusted for reported hysterectomies, may overestimate the extent of underscreening⁴; however, response bias, where underscreened women are not included in surveys, would have the opposite effect. The relationship with age could be a cohort effect, so it is important to understand the factors that influence health behaviours among older, poorer, and less well-educated women (Norman et al., 1991).

1. Coverage rate is the "percentage of women with at least one Pap smear taken in the previous 5 years." Among women aged 35-54, the coverage for women invited for screening was 91% and for those not invited, 68%. (Bos et al., 1998)

2. Survey results for women in Ontario, reporting never having a Pap test: 1985 Health Promotion Survey, 13%; 1990 Health Promotion Survey, 12%; 1994 National Population Health Survey (ages 18+, 2.8% of responses "not stated"), 14%; 1996/97 National Population Health Survey, 12%.

3. Analysis did not take into account whether women in this youngest age group had initiated sexual relations. If they had not, they are not considered at risk for cervical cancer.

4. Adjusting reports of Pap tests for hysterectomies decreases the overall rate of women reporting no Pap test within the prior 3 years, from 32% to 18% (Snider & Beauvais, 1998). It shifts the peaks for adequate Pap testing, by age, upwards: among women aged 45-54 approximately 65% reported Pap tests within the previous year, and 100% within the prior three years (Snider & Beauvais, 1998).
1.2 Models of health and health behaviours

Models have been used to try to explain health, health behaviours in general, and cervical cancer screening in particular. Models of health behaviours (outlined in subsequent sections) have been developed empirically, (i.e., essentially describing patterns of health care utilization) or using theory. Models of health often include measures of health behaviour, and models of both of these can also include sociodemographic and psychosocial or other behavioural factors. The interrelationships between and among these things are complex and not all well understood.

Socioeconomic status is a well-recognized but not necessarily well understood determinant of health. The relationship holds for many measures of morbidity as well as for mortality, and whether socioeconomic status is defined by education, income or job classification (reviewed by Shah, 1994). Researchers continue to investigate possible mechanisms for how lower socioeconomic status is associated with poorer physical and mental health. Possible explanations include artefacts, natural selection, material deprivation, and cultural or behavioural theories (Shah, 1994:11-13). Among the cultural and behavioural explorations are possible mediating roles for social networks or social support (e.g., House, 1994, Stansfeld et al., 1997), and for literacy (Baker et al., 1997). These matters are taken up in the context of Pap testing later in this chapter.

Models to explore or explain Pap test behaviours include the Health Belief Model (Rosenstock, 1966), the PRECEDE-PROCEED model (Green & Kreuter, 1991, defined later), social support and network influences (e.g., Valente, 1995) and health education and communication (Maibach & Holtgrave, 1995). These theoretical approaches are not mutually exclusive. Indeed, the PRECEDE-PROCEED model is comprehensive and flexible enough to incorporate the others.

It is not always clear what theories are being applied in research about Pap tests. Not all research into Pap testing behaviours acknowledges a particular theoretical perspective: some research does not specify any at all. Surveys and interventions directed towards cervical cancer screening sometimes cite theoretical models as relevant to their development, but published accounts of formal theory testing, delineating the links between
propositions, concepts and operationalizations of them are rare. Partitioning the literature and research findings into particular theoretical categories is thus somewhat arbitrary.

More importantly, regardless of what theoretical models are used, the strongest and most consistent predictors of current or future health behaviours seem to be past health behaviours (review and example, Mullen et al., 1987). Such intransigence poses a considerable challenge for researchers who are interested in not only understanding, but also in changing behaviour.

1.2.1 Health and health system utilization

Secondary analysis of health service administrative data has yielded a number of explanatory models of health system utilization (McKinlay, 1972, Andersen & Newman, 1973, Aday & Shortell, 1980, Rosenstock, 1980, Hulka & Wheat, 1985). Andersen and Newman (1973) produced a framework where the determinants of health care utilization include characteristics of the health care system, societal determinants, and individual determinants. Their model emphasizes the preeminent role of the societal determinants of technology and norms. These determine illness definition and treatment and influence both the health service system and individual determinants (Andersen & Newman, 1973:98). Hulka & Wheat (1985) note that cross-sectional associations between health status and health care system utilization limit conclusions about causality and its direction. Taking a conceptual leap, they contend that three concepts (need, enabling and predisposing factors) described as influences on health care utilization in earlier work (beginning with Andersen's, 1986) could all be labelled as need. In their view, use is prompted by perceived need, and perceived need is synonymous with symptoms perceived by either the patient or by the health care provider (Hulka & Wheat, 1985). These models make good use of administrative data, but they are all restricted by it; the problem is particularly serious for preventive care behaviours. Hulka & Wheat (1985) explicitly acknowledged what others must recognize implicitly, that models of health care utilization based on administrative data about symptom treatment cannot, by definition, explain preventive care behaviours.

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1. Andersen & Newman refer to this as a theoretical framework, but distinctions between, and relationships among the abstract and the empirical are not resolved in their formulation.
Other research has shown illiteracy associated with self-reported poor health, but it did not necessarily influence hospitalization or ambulatory care use (Baker et al., 1997).

1.2.2 The health belief model

The Health Belief Model, based on the notion that knowledge, attitudes and beliefs are predictive of health behaviours has been applied to the investigation of health behaviours in general (e.g., Rosenstock, 1966, Becker, 1974, Rosenstock, 1974) and of screening behaviours in particular (e.g., Peters et al., 1989). Rosenstock's original formulation (Rosenstock, 1966) of this model, cited less than his later one (Rosenstock, 1974), seems more complex but provides useful information for a behaviour like Pap testing. The original version grapples more directly with the dynamics of the choice-making process. Rosenstock (1966) describes three concepts relevant in predicting whether a certain behaviour will take place or not.

1. Readiness to act. Readiness to act is the psychological state of readiness to take specific action. It includes perceived susceptibility, which is the sense of vulnerability or susceptibility to a particular health condition, and perceived seriousness, which is the sense of seriousness of contracting the condition (Rosenstock, 1966:99). Perceived seriousness includes the "degree of emotional arousal created by the thought of a disease as well as by kinds of difficulties the individual believes a given health condition will create for him." (Rosenstock, 1966:99, derived from Robbins, 1962).

2. Perceived benefit. Perceived benefit is "the extent to which a particular course of action is believed, on the whole, to be beneficial in reducing the threat." (Rosenstock, 1966:98)

3. Cues to action. Cues to action or instigating events may be internal or external. Internal cues include the perception of bodily states. External cues would include

1. Rosenstock calls the concepts “classes of variables”, but for consistency this term is not used here.

2. This cue to action, perception of bodily state may overlap or elicit the perceived seriousness aspect of readiness to act.
interpersonal or media communications (general or specific to the individual), where the content could include knowing that some one else has become affected (Rosenstock, 1966:101).

A provocative aspect of this model is the relationship between readiness to act and cues to action. Rosenstock posits that the intensity of the cues required to prompt action varies inversely with the level of readiness (Rosenstock, 1966:101). This is not just semantic clarification; it seems to have prescriptive overtones. That is, it suggests that it may be necessary to increase the intensity of cues for those people who are not yet ready to act. If true, this central premise has powerful implications for health education efforts. This premise warrants further examination.

Janz & Becker's (1984) review concluded that perceived barriers and susceptibility were the most important variables in relation to preventive health behaviours. With respect to cervical cancer screening in particular, some findings are quite clear but others are not. In a small survey (n=44) of Inupiat women of Alaska, triggers to action (i.e., invitations to attend for testing) were found to be statistically significant as predictors of Pap testing (Williams, 1986). The barrier of fear of embarrassment is consistently found to be a negative predictor of Pap testing (Lerman et al., 1990, Peters et al., 1989). Even so, Lerman et al. (1990) found some inconsistent results in their study. Three factors were associated with increased numbers of Pap tests, as the model would predict: perceived susceptibility to cervical cancer, the belief in the efficacy of Pap tests, and benefits of screening. In contrast, three factors were statistically significant, but in the opposite direction than predicted by the model. The fear of finding cancer, and advanced age, which are other measures of susceptibility, were associated with less recent testing, and worry about finding cervical cancer was associated with fewer total Pap tests (Lerman et al., 1990). In Australia, a survey before and after a comprehensive intervention revealed no change in knowledge or attitudes, although rates of Pap testing did increase (Shelley et al., 1991). In contrast, in a Vietnamese population, knowledge and attitudes were reported to change but Pap testing adequacy remained unchanged (Jenkins et al., 1999). Inconsistencies such as these are not unique to Pap test behaviours, and have raised questions about the Health Belief Model (Gillam, 1991).
The Health Belief Model has been applied widely in the examination of health behaviours (Janz & Becker, 1984), but not always with success (Gillam, 1991). The Health Belief Model is comprised of some highly abstract concepts which are difficult to define, investigate and apply to policy issues, and it assumes that women make their decisions on strictly rational bases (Gillam, 1991). These criticisms are serious, but they could be applied to many models of health behaviour. Here, though, for the Health Belief Model, the difficulty in operationalizing abstract concepts is readily apparent in the predictor variable “fear of finding cancer” (e.g., Lerman, 1990). This measure, brief as it is, overlaps several concepts within the Health Belief Model as originally articulated (Rosenstock, 1966). It could relate to either aspect of “readiness to act”: it could mean a woman perceives that she is susceptible to cervical cancer, or that getting it is serious. Or, it could refer to an internal cue to action, where she perceives and labels her bodily state as fear. Thus, the measure “fear of finding cancer” could be capturing any or all three of these HBM concepts.

These criticisms are important, but do not necessarily mean the Health Belief Model is unproductive. Rosenstock’s own critique of the model (1966:107-12) identified needs for research in: identifying and understanding cues to action; operationalizing the variables of susceptibility and seriousness; quantifying optimal levels of readiness; assessing reliability of health beliefs; perceived seriousness; understanding the origin and development of health beliefs; and experimenting to test the effect of beliefs and their susceptibility to modification. More importantly, Rosenstock (1966) acknowledged a number of restrictions and assumptions for the Health Belief Model. Certain factors were identified as likely to restrict the universality of the model: it was only relevant for situations of voluntary behaviour; it was likely more relevant to middle than to lower class groups; and it was likely not relevant where health behaviours were developed as early habits (Rosenstock, 1966:107-12). Most importantly, Rosenstock specified that objective characteristics of a situation are less relevant than the individual’s perception of it, and further, that the emotional element was likely more important than the cognitive (Rosenstock, 1966:99).

Any investigation of the Health Belief Model should also consider which of its restrictions and assumptions apply; its apparent failings with respect to Pap test behaviours might be illuminated.

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1. Model restriction due to class was based on understandings about middle classes (compared to lower classes) being more oriented to defer gratification (citing Simmons, 1958) and thus more likely to accept health beliefs conducive to health behaviours (Rosenstock, 1966).
Gillam (1991) concluded that "organizational factors, not women's health beliefs, are the main obstacles to the success of cervical screening." Undoubtedly, organizational factors can preclude Pap testing, if services are neither available nor accessible. Where services are available and funded by a provincial health care system, as they are in Ontario, it is worth considering how perceptions and beliefs, such as those suggested by the Health Belief Model, might influence choices. After all, insisting on the pre-eminent role of subjective perceptions rather than objective circumstances still recognizes what Milburn and MacAskill (1994) refer to as the "contexts and constraints" that are relevant to a woman's choices about Pap testing. Gaining an understanding of women's (health) beliefs may provide important clues to improve how screening for cervical cancer is organized and delivered.
1.2.3 The PRECEDE-PROCEED model

The PRECEDE-PROCEED model (Figure 1) provides a comprehensive framework for health education and program planning (Green & Kreuter, 1991). This model includes "predisposing", "reinforcing" and "enabling" factors, all subsumed within the educational and organizational diagnosis (PRECEDE) as likely to influence behavioural change (Green & Kreuter, 1991:30). Combined with the PROCEED tasks, the model permits systematic development and evaluation of policy and program interventions (Green & Kreuter, 1991).

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1 The acronym PRECEDE-PROCEED refers to "(a) a diagnostic phase called ... Predisposing, Reinforcing, and Enabling Constructs in Educational / Environmental Diagnosis and Evaluations and (b) a developmental stage of health promotion planning that ... implements the implementation and evaluation process,... Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development...." (Green & Kreuter, 1991).
Allen (1992) applied the PRECEDE model explicitly in a qualitative enquiry about Pap testing. She found that limited knowledge of the Pap smear and its preventive role were factors that predisposed women not to participate in screening, while previous negative experiences with the health care system, with providers or with sexual relationships were factors that reinforced non-participation (Allen, 1992).

The findings from other investigations of Pap testing are summarized below using the PRECEDE framework's educational and organizational diagnosis.

1.2.3.1 Predisposing factors

"Predisposing factors include a person's or population's knowledge, attitudes, beliefs, values and perceptions that facilitate or hinder motivation for change" (Green & Kreuter, 1991:28-9) Predisposing factors can include or echo themes of knowledge, attitudes and beliefs, familiar from the Health Belief Model. Predisposing factors can include women's experiences, because they shape their perspectives on life, and may influence responsiveness to invitations for Pap testing.

Some women classed as non-respondents in studies of Pap testing invitations are not or believe themselves not to be at risk (Eardley et al., 1985). When Mandelblatt et al. (1986) invited elderly women patients to have Pap testing, 1/3 of those who agreed were found not to have a cervix. This phenomenon may reveal language or communication barriers, lack of knowledge (of the patients and/or of the care-givers) of prior medical procedures, or women's compliance with authority figures. Whatever the underlying issues, the implication for Pap test interventions is that subjective assessments of risk may not correspond with objective risk. Unfortunately, underscreened women are probably least likely to participate in intervention studies (reviewed by Straton, 1994); these are the women for whom recruitment research per se is the most meaningful.

Culture shapes our perceptions and experience of the world, whether public or private, and of course this includes our understandings of health and disease. Culture may include shared language, shared sets of beliefs, and shared behaviours (Masi et al., 1993a & 1993b, Frank-Stromborg & Olsen, 1993).
Certain types of previous experience that are expected to serve as predisposing factors (in a negative way) are physical or sexual assault. Those who have experienced assault may find the gynecological examination particularly distressing (Allen, 1992). It is hardly surprising that a procedure as intrusive and personal as the pelvic examination would elicit strong feelings, including embarrassment and fear (reviewed by Straton, 1994). These feelings may relate to the internal examination itself and to possible test results. Either may serve as barriers.

1.2.3.2 Enabling factors

"Enabling factors are those skills, resources, or barriers that can help or hinder the desired behavioral changes as well as environmental changes.... [They] include all the factors that make possible a desired change in behavior or in the environment." (Green & Kreuter, 1991:29) Provider characteristics, availability and accessibility of health care services (e.g., language), poverty and invitation strategies are considered enabling factors.

1.2.3.2.1 Provider characteristics

Provider characteristics including gender, training or experience, may dictate the provision of Pap testing. Women with female physicians are less likely to be deficient in Pap tests (Franks & Clancy, 1993). Those who attend gynaecologists are much more likely to have had Pap tests (Celentano, 1982), but gynaecologists may overtest, as Cohen et al. (1992) found in Manitoba. Another prompt for care-givers may be their conviction about the test's efficacy. Goggin (1990) observed that physicians who had found cervical cancer when exposed to a population of mostly unscreened refugee women tended to consistently offer the test to subsequent immigrant women.

1.2.3.2.2 Availability or accessibility of health resources

Availability or accessibility of health resources can refer to the health-care environment, to other environmental influences, and to a person's skills. Eardley et al.'s (1985) review of screening programmes is relevant; important barriers contribute to low response rates for women who most need screening. Location, notification systems, information provided, and language are not always as helpful as they could be (Eardley et al., 1985).
Health care policies and regulations can determine the availability and accessibility of Pap smear services, and Canada's universal health care coverage could be expected to reduce socioeconomic differences in health or preventive care (described earlier in the first pages of the thesis). In the United States, an amendment to the Public Health Act (The Breast and Cervical Cancer Mortality Prevention Act Public Law 101-354) in 1990 dictated that regular cancer screening tests would be provided "for every woman for whom it is deemed appropriate" (U.S. Department of Health and Social Services, 1994:iii). In 1996, though, this meant that poorest Americans would receive screening at no charge, but their treatment was not covered by Medicaid (Miller, 1996). Not unexpectedly, in the United States, data indicate marked differences in cancer rates across populations (Sondik, 1998): differences are apparent for cervical cancer incidence (Sondik, 1998) and prognosis (Press, 1998).

Press (1998) summarizes Haynes' (1996) findings about what contributes to high rates of cancer for African Americans: "poverty, lack of information and limited availability of quality health care". Katz & Hofer (1994) did a comparative analysis of U.S. (National Health Interview Survey) and Ontario (1990 Ontario Health Survey) data to investigate the relative effects of education and income. In both countries, higher income was associated with a greater prevalence of reported Pap test within the past two years, even when the analyses were adjusted for age, education, marital status, and pregnancy history (Katz & Hofer, 1994). That is, despite the differences in health care coverage, the same socioeconomic trends in self-reported Pap tests persist in both Canada and the United States.

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1 Investigations of the relative contribution of socioeconomic status to mortality are complicated when regions have both different policies about access to care and different socioeconomic environments. In Detroit, Michigan, but not in greater metropolitan Toronto, survival is linked to socioeconomic status for many cancers, including cervical cancer (Gorey et al., 1997). For diagnoses of cervical cancer among women residing in areas with the lowest relative income tertile, Toronto compared to Detroit, has a 5-year survival advantage (Survival Rate Ratio = 1.48, 95% confidence interval = 1.25, 1.76). Marked differences in the absolute incomes between Toronto and Detroit may contribute to this difference (Gorey et al., 1997).
1.2.3.2.3 Language: Culture and/or communication

Language is an important predictor of Pap tests (Woloshin et al., 1995, Woloshin et al., 1997, Goel, 1994, Ghazal et al., 1993, Harlan et al., 1991). Woloshin et al. (1995) reviewed how language barriers might restrict communication in medicine in the United States. Unspecified language and cultural barriers were considered important in restricting access to Pap tests (Ghazal et al., 1993, cited by Coyne, 1995:10). Harlan et al. (1991) found that over 11% of the Spanish-speaking women in their study reported that their doctor had not recommended a Pap test; the investigators concluded that "practitioners who do not speak Spanish may not be able to communicate its importance to their Spanish-speaking patients" (Harlan et al., 1991). The 1990 Ontario Health Survey dataset was used to show that language differences are associated with less adequate cancer screening (Goel, 1994, Woloshin et al., 1997). Women who spoke a language at home other than English or French were less likely to report having had a Pap test within 2 years (odds ratio 0.58, 95% confidence interval 0.45 to 0.74, compared to a reference category of one for English speakers) even when adjusted for socioeconomic factors, health care system contact, and measures reflecting culture (Woloshin et al., 1997). The analysis revealed some telling details: language spoken was not a barrier to contact with the health care system; socioeconomic status did not account for the language effect; and cultural measures of "ethnic self-report and immigration status" also did not remove the effect. Woloshin et al. (1997) concluded that the barrier of language in receiving preventive care services was not reflecting cultural differences, it was truly a communication barrier per se. Nevertheless, Woloshin et al. (1997) acknowledge some important caveats to their conclusions: language may reflect degree of acculturation\(^1\), and the most "linguistically isolated households" (i.e., where no-one spoke either English or French, 2.4% of the eligible households) were excluded from the survey. Even with these caveats, it seems clear that information provided in a woman's own language, either directly as a translation or through an interpreter, is more likely to be understood than information provided in a language not her own. If the language is not understood, the information cannot be useful.

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\(^1\) Acculturation may be operationalized in part by language spoken.
1.2.3.2.4 Invitation strategies

There are many ways to invite women to undergo Pap tests: directly (by mail, in person, or by telephone) and indirectly (by media campaigns).

Invitations for Pap tests can be mailed (e.g., Fleischl, 1993, Bowman et al., 1995). A personal letter from the general practitioner was more effective at prompting attendance for cervical cytology screening than one provided by screening program staff (Palm et al., 1993). Letters which indicated a scheduled appointment were more effective than open-ended invitations (Havelock et al., 1988, Roberston et al., 1989, Shroff et al., 1988, Ronco et al., 1994); this was confirmed statistically in controlled trials (Wilson & Lemming, 1987, Pierce et al., 1989, reviewed by Segnan et al., 1998). Finally, a letter that was both from the doctor and that included a prefixed appointment, resulted in statistically significantly higher compliance than letters with just one of those options; the characteristic of the letter coming from the doctor had a larger effect than did the prefixed appointment (Segnan et al., 1998). Where the value of one was for letters from a doctor, with a prefixed appointment, the rate ratio for letters simply from the doctor was 0.85 (with a 95% confidence interval of 0.78-0.93); and the rate ratio for letters simply with a prefixed appointment was 0.63 (95% confidence interval of 0.57-0.69) (Segnan et al., 1998). Evaluation of cervical screening in New Zealand concluded that "a personalized invitation to women from general practices is the most important factor influencing women's participation in cervical screening." (Coyne, 1995:12. citing Fleischl, 1993). In New South Wales, Australia, Bowman et al. (1995) used a randomized trial (n=659) to compare four mail strategies: educational pamphlet; personalized letter for clinic; letter from regular GP; and control (i.e., nothing). Written invitations are understood to be restricted in usefulness to situations where the woman can read the invitation herself or has someone available who does this for her.

Besides written invitations for Pap tests, they can also be made in person (e.g., Ward et al., 1991) or by telephone (Lantz et al., 1995). Provider letters and follow-up calls increased compliance in a population of low-income minority women (Lantz et al., 1995). Short and long verbal invitations for Pap tests provided by physicians were compared in a well-designed, individually randomized study (Ward et al., 1991). Little difference in efficacy between short and long invitations was found, but there were marked inter-physician differences in efficacy (11-94%, Ward et al., 1991). It would be useful to know how these
physicians' approaches differed, and which aspects were most relevant to women's decisions about Pap testing. Such research is difficult to do and to report tactfully, if physicians (or other caregivers) are identifiable. One challenge, then, is to explore what things may trigger or inhibit recruitment, in ways that will not alienate either care providers responsible for offering services, or women who need them.

It is not enough just to establish an organized screening programme, experts around the world have identified some important principles. Programmes must meet the needs of the women for whom they are designed (Eardley et al., 1985). "Promotion and awareness campaigns for breast and cervical cancer screening should target relevant attitudes and beliefs." (Coyne, 1995:13) Health care systems reflect the orientation of their dominant cultures. Thus it is not surprising when programmes designed by dominant or majority populations meet with low acceptance by minority groups (Aspen Reference Group, 1997, Jandt, 1995). Approaches to health promotion for cervical cancer screening programmes may require "operational research to determine the best ways to recruit women": the key parties for developing approaches for health education and health promotion are "women, health care providers, community leaders and those involved in other relevant sectors such as education." The characteristics of the programs need to be focussed on the women ("client-centred") and appropriate to the cultural context ("local cultural setting") (Miller, 1992:25). Mak & Straton (1993) emphasized not just the identity of important individuals but also the characteristics of their interactions and the relationships (summarized by Coyne, 1995:13): "Personal contact, sensitivity to social context, development of trust and the consistency and continuity of service provision have proven effective to overcome barriers to screening." The key challenges for research in these areas include operationalizing each of these features in a way that permits their effects to be disentangled. Even without such rigorous research, it seems obvious that for women who cannot or do not read, personal elements would likely be particularly important.

One area of agreement for women and practitioners is that convenient scheduling of appointments is essential (Eardley et al., 1985, review by Segnan et al., 1998). Invitations should include a specific time and date for a smear, and if it is not convenient, women "should be encouraged to request an alternate" (Miller, 1992:33). Generally, interventions

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1 New Zealand's National Cervical Screening Programme established in 1993 (Fleischl, 1993, cited by Coyne, 1995:11) includes "culturally appropriate educational and resource materials".
offer either immediate or later appointments, presumably depending on the setting and resources available. For opportunistic screening, immediate Pap tests have been recommended, unless a woman is menstruating (Miller, 1992:33). Yet, Milburn & MacAskill (1994) found that even after an organised programme of cervical cancer screening had been introduced in Scotland, women reported offers for screening that were opportunistic, and not necessarily helpful. Women reported that they felt "physically or emotionally unprepared to have a smear there and then", that it could feel like pressure; non-attenders reported using menstruation as an excuse to avoid a Pap test, and they would avoid making or keeping a subsequent appointment (Milburn & MacAskill, 1994:210).

The question of what appointment scheduling strategy is best is particularly salient for jurisdictions which lack an organized screening programme, and situations where women cannot or do not read. In these cases, invitations may be offered opportunistically, when women come in for other health care appointments. Should Pap tests be offered and provided at that same time, or should an appointment be scheduled for a later date? Notwithstanding the problems for immediate appointments reported above, there are good reasons for both options: on one hand there is the convenience of an immediate appointment, that may suit women with busy schedules, and on the other hand, a later appointment may suit women who are inclined to take time to prepare for an internal examination. For caregivers, providing immediate Pap tests has implications for scheduling, personnel and office space. Without research, it is not known whether one of these approaches might be preferable or even essential.

Women over age 65 may be differentially excluded from screening programs (Fletcher, 1990); sometimes medical records are not up-to-date for these women. Similarly, records for inner-city and poorer women, who move more often, may be more out-of-date than those for more affluent women (Fletcher, 1990). Even if minority ethnic women are registered with a GP, details of their addresses may be inaccurate (Luke, 1996).

"Reinforcing factors, the rewards received, and the feedback the learner receives from others following adoption of the behavior, may encourage or discourage continuation of the behavior" (Green & Kreuter, 1991:29). Reinforcing factors "include social support, peer influences, and advice and feedback by health-care providers" as well as "physical consequences of behavior" (Green & Kreuter, 1991:165). The possible influences of social
support and peers are dealt with later, in the section on social support and networks. Here, research on strategies involving health-care providers themselves is presented. When a nurse-initiated reminder system was instituted, it did not have any statistically significant influence on the proportion of women (with intact uteri) who underwent Pap tests (Davidson et al., 1984). This negative result might be explained by at least three things: the flowchart indicating what tests were appropriate was simply placed on the patient's chart, physicians did not receive any training as part of this intervention program, and analysis was simply on the total proportion of eligible women screened. That is, it did not investigate whether there had been a shift in the provision of Pap tests to a more appropriate population (i.e., to underscreened rather than overscreened women) (Davidson et al., 1984). This last point, about the time frame that defines eligibility for Pap tests, is likely the most relevant, because the other three outcome measures were recommended annually for eligible populations, and each of these outcomes showed statistically significant improvements (Davidson et al., 1984). This issue of overscreening showed up again in the randomized controlled trial comparing cancer screening reminders, audit with feedback and control groups (McPhee et al., 1989). There, lack of statistically significant differences in the proportion of women having Pap testing is not simply a consequence of small sample sizes. There are two reasons this trial cannot be considered conclusive. First, the measure used to assess compliance ("performance formula") was based on an aggregate (essentially the proportion of all women screened) in contrast with a measure where the appropriateness of screening was assessed (i.e., eligibility was dependent on each individual's screening status). Second, even before the intervention, annual Pap testing exceeded 100% in two of the three intervention groups (McPhee et al., 1989).

These interventions took place in the context of a trial directed at improving several complementary preventive care procedures. Outside of such interventions or a screening programme, in general practices, women may receive the Pap test opportunistically, as an adjunct to other procedures, e.g., for diagnosis of symptoms. If they do, they may not perceive the test as preventive nor realize the need for further tests (Knopf, 1976).

1 The other three measures were influenza immunizations, breast examinations, and the stool test for occult blood.

2 There were only 20-21 internal medicine residents per group, but this sample size was sufficient to show statistically significant differences in compliance scores (at $p < 0.05$) for reminders for five items (rectal examination, sigmoidoscopy, pelvic examination, breast examination and mammography); and for audit with feedback for two of those (breast examination and mammography).
1.2.4 Social support and networks

Bowling noted in her 1989 review of preventive care behaviours that there had been limited research on how relatives or friends might prompt women to solicit information or health care encounters (Bowling, 1989). Since that time several complementary theoretical perspectives have been used to consider and explore these matters: self-efficacy, social support and social network, and diffusion of innovation.

Social networks and their role in determining health behaviours is an intriguing area of investigation. The domain of social support may be measured in many different ways: in its type, source, quantity or quality, or by measuring the social relationships or social network that produce them (House & Kahn, 1985:86). Suarez et al. (1994) considered social networks among a random selection of older Mexican-American women and found that the number of close friends was the most important predictor of the Pap smear. In a Los Angeles population (which included women of white, black and Latino ethnicity) adherence to recommended follow-up after abnormal Pap smear was found to be related to several aspects of social support (Crane, 1996).

It is not immediately obvious why having more close friends should be associated with having a Pap test (Suarez et al., 1994) unless network measures reflect, among other things, socioeconomic status, the degree of integration into the dominant culture, information exchange among friends, or other personal or community characteristics. Certainly, each of these things could be considered within the diffusion of innovation approach (Valente, 1995). House et al. (1994:90) posit several possible mechanisms, including that "[s]ocial relationships have a predictive, arguably causal association with health in their own right", or they may be not just generally supportive, they "may also regulate or control human thought, feeling or behaviour". In the PRECEDE-PROCEED model, social support and social networks could be considered as reinforcing factors, with potential to influence behaviour fairly directly, or they might also function indirectly through the predisposing factors of knowledge, beliefs, values, attitudes and confidence. It would

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1. The mechanism for network influence would be more obvious for a different reproductive health behaviour, family planning. In Bolivia, personal network exposure did predict use of family planning: the number of children in a family would indicate whether family planning was used or not, and might serve as a cue for conversation (Valente and Saba, 1997).
be useful to know whether social relations and networks are important for underscreened women in Ontario, and if they are, how they influence behaviour.

One way to reach underscreened women is to use social networks or agencies, providing programs or lay health advisors. Where such cancer screening strategies have been evaluated, results have been reported as positive (Mann et al., 1997, Mamon et al., 1991-2). Churches have been recommended (Ransdell, 1995) and used as a source of lay health educators for women with inadequate screening for cervical cancer (Mamon et al., 1991-2).

Churches have been used as the source for Catholic church-based "neighbourhood influencers" using personal invitations and reminder cards for Latinos (Frank-Stromborg et al., 1997) and as a setting for health sessions (e.g., breast health, Erwin et al., 1996, Mann et al., 1997). In Mamon et al.'s (1991-2) study, churches were the source for 144 lay peer educators who were trained to telephone women, discuss any barriers to screening and encourage appointments to be made. Where follow-up was possible, 43% (survey interviews) to 46% (lay peer educators' records) of eligible women were recorded as having made at least one appointment in the two years following intervention.¹

One advantage of church settings is that women attending them may include the older age groups at higher risk for cancer. Mann et al. (1997) involved 3 African-American churches in an intensive health promotion program, and 75% of their population was aged 40 years or more. They began with surveys about screening, and followed up with literature, health fairs, testimonials by cancer survivors, and visits by members of the medical community. Seven months later, on follow-up, they found an impressive 49% (of n=120 originally reported as underscreened) reported appropriate screenings (Mann et al., 1997). In contrast, in Mamon et al.'s study (1991-2), women over age 65 were excluded from the lay peer educator intervention because pilot tests had indicated older women were not as responsive to (telephone calls from) lay peer educators as were younger women.

Lay health workers, beyond church settings, have also been used in efforts to increase cervical cancer screening (Bird et al., 1998, ~Lacey et al., 1989, Navarro et al., 1995). Bird

¹. No information was provided about whether the appointments were kept. Here, "identifying" and "reaching" women were initially done at the same time. Later these tasks were separated.
et al. (1998) reported major effects in behaviour and knowledge using Vietnamese lay health workers in California. These workers provided educational sessions in their neighbours' apartments and exhorted them to have screening (also described in Bird et al., 1998). The lay health worker intervention was done contemporaneously with a media-led campaign, which in itself was not effective in changing behaviour (discussed later) (Jenkins et al., 1999). Navarro et al.'s (1995) study randomized Spanish-speaking "consejeros" to deliver variants of 12 educational interventions for low-income Spanish women (n=512, of which 358, presumably the adults, were included in the Pap test analyses). Pre- and post-intervention levels of lifetime cervical screening were compared: for the intervention group, prevalence increased from 80% to 94%; while in the control group it increased from 80% to 83% (Navarro et al., 1995).

Women who understand the importance of screening may be a potential resource in providing peer support, if they are able to communicate with other underscreened women. They may serve as "informed nuclei": they might induce a "ripple effect" (Wakefield, 1966).

1.2.5 Health education and communication

Witte (1999) summarized the literature on health communication and identified three variables or features of several theoretical models which have emerged as important influences in varied health behaviours. The three "universals" are perceived threat (i.e., personal vulnerability to health threat), perceived efficacy (comprised of self- and response efficacy), and barriers (perceived costs of performing the behaviour). Because these have not been systematically investigated in Pap test intervention studies per se, it would be helpful to have a study design flexible enough to elicit whether any of these factors may have prompted the decision about Pap testing.

Developing information materials appropriate for women with language or literacy limitations is important, but difficult to do well and to evaluate (Aspen Reference Group, 1997, Jandt, 1995). There is no question that language barriers per se need to be

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1. Detailed trial results were not provided, but I calculated that if the groups were of equal size (n = 179), the absolute numbers of underscreened women changed from 35 to 12 in the intervention group (equivalent to 69% "success"), and from 30 to 25 in the control group (equivalent to 17% "success"). The authors plan to validate self-reports. (Navarro et al., 1995)
overcome. Studies of Pap testing invitations for women with minority languages generally provide either unilingual (e.g., Castro et al., 1995) or bilingual (Navarro et al., 1995) materials and/or instruction; they do not assess the relative merits of one over the other. Of course, providing written material assumes that the woman herself, or someone she knows, can read, and can read that particular language. Bilingual materials may provide a relevant vocabulary if she needs or wants to communicate in the majority language. If, however, a woman has limited literacy, the paramount value of written materials may lie in their capacity to prompt interactions with others who can read and who may be better integrated into the preventive care system. For example, English-speaking and -reading daughters of child-bearing age may not just be able to read material for their non-English-speaking mothers, they may also affirm the Pap test as a norm for preventive care.

The Aspen Reference Group (1997) recommends programs "train and use lay bilingual community members in health care settings". Whether this is feasible or not, it presupposes that the appropriate health education messages, in the appropriate language, are known by the providers of health care.

Audiovisual materials about Pap tests have been developed with and for particular underscreened populations, and have been well-received. These include flip-charts for Native Canadians (Deschamps, 1996), videos and personal visits for under-screened Asian women in Leicester, England (McAvoy & Raza, 1991), and a video for Latina mothers in East Los Angeles (Yancey et al., 1995). Production of audiovisual materials is time-consuming and expensive, in part because identifying and pretesting messages is a slow, iterative process (Deschamps, 1996). Though arduous, it is warranted, because language and information must be appropriate (Eardley et al., 1985).

The usefulness of materials provided to underscreened women may be determined not just by the content, but also by the source of the information or the context in which the materials were provided. There are many modes or forms of delivery of health communication messages, and their usefulness may vary depending on the message content and on source and recipient characteristics (Freimuth, ~1997). Source credibility is linked with persuasiveness, and credibility is not necessarily based on just objective characteristics. Instead, credibility reflects "the perceived expertness / competence, trustworthiness, and dynamism / attractiveness of the source of the message. Sources
perceived as more credible are more persuasive." Freimuth (~1997). Persuasiveness may be increased where there is "homophily", when message source and recipient share similar language, values, or characteristics (Freimuth, ~1997b, citing Rogers, 1983). Freimuth (~1997b) cites the Forsyth County Cervical Cancer Screening Project's use of that approach to develop cancer education strategies (Micheliutte et al., 1989).

Another way that health messages may be valuable, beyond the appropriateness of content or providers, is in the interactions they prompt with others (McAvoy & Raza, 1991). Topics in the mass media may prompt discussions about a sensitive topic among friends, or a request for information from someone considered a credible source of information (e.g., reproductive health behaviors of family planning (Valente & Saba, 1997)). Would this also be so for women who are underscreened for cervical cancer here in Ontario? Would they have credible sources within their network, and would they be willing to discuss the matter, much less initiate such a request? If social networks influence health behaviours, it will be important to know how and why they function the way they do, to develop appropriate interventions in these areas.

Mass media has been commended as a valuable tool to communicate education about Pap testing, but well-designed evaluation is limited, and what there is indicates some challenges yet to be resolved (Cochrane Collaboration review by Grilli et al., 1998). Of 17 studies which met the criteria for inclusion in the review, 7 were about cancer, one of which was about cervical screening' (Grilli et al., 1998). That study (Shelley et al., 1991) included a mass media campaign, and concurrent educational intervention for general practitioners and "community level promotional activities". The target group was women aged 50-69 years, with a screening history of a last Pap test ≥2 years. After the campaign, among all women aged 50-69, there was a 32% increase in Pap smears (statistically significantly higher than 2 of the 3 control areas). In the same age group, among women with a screening history of the last Pap smear ≥2 years ago, there was a (statistically significant) 52% increase beyond expected levels. However, these changes were not accompanied by corresponding changes in survey responses about knowledge and attitudes towards Pap

1. Five were on skin cancer and melanoma, and one on colorectal screening.
tests (Shelley et al., 1991). More recently, Jenkins et al. (1999) reported a 24-month media-led campaign, in California for Vietnamese women, about breast and cervical cancer screening. This study used health education messages in electronic, outdoor and print media, including television, videos, newspapers, and material delivered to agencies. At posttest, they found statistically significantly higher results for intervention regions than for control regions. The odds ratio (OR) for having heard of a Pap test were 5.0 (95% C.I. was 3.5-7.2); the OR for planning to have a Pap test was 1.9 (95% C.I. was 1.3-2.7); results were higher but not statistically significant for having had a Pap test (O.R.=1.3, 95% C.I. 1.0, 1.7) (Jenkins et al., 1999). To summarize, then, these two major studies, for particular underscreened populations, had virtually opposite findings: Shelley et al. (1991) found changes in behaviour but not knowledge among Australian women aged 50-69, while Jenkins et al. (1999) found changes in reported knowledge but not behaviour among Vietnamese women in California. These findings suggest at least two interpretations: 1. Some health behaviour models' expectations may not apply to Pap testing, i.e., that knowledge change is required for, and will be followed by, behaviour change; and 2. For Shelley et al.'s study (1991), where mass media had effects on women's behaviour it may have been mediated by the effect on professional caregivers' activities or interactions. If either of these interpretations are true, designing and measuring interventions will require complex designs. The next section pursues the matter of research challenges more fully.

1.3 Research challenges

Intervention research into complex behaviours in uncontrolled settings is difficult, and reviews of studies done on Pap testing consistently grapple with similar issues. A preliminary challenge for such reviews is locating relevant materials. Then, deciding which studies will be included in a review presents a dilemma. On the one hand, including only

1. Indeed, only 20% of 50-69 year old women recalled the commercial (Shelley et al., 1991:270).

2. Resource information about breast and cervical cancer prevention and control has been compiled by the U.S. Centers for Disease Control and Prevention: the Combined Health Information Database (CHID) includes the Cancer Prevention and Control Database (CPCD), and can be searched online (through BRS Online) or on CD-ROM (CDP File), and selected annotations have been published as a monograph (U.S. Department of Health and Social Services, 1994). The CPCD includes: "bibliographic citations and abstracts for journal articles, book chapters, technical reports, proceedings, papers, policy documents, legislation, monographs, unpublished documents, educational materials, and descriptions of cancer prevention programs and risk reduction activities at the National, State, and local levels." (U.S. Department of Health and Social Services, 1994:v)
well-controlled studies with rigorous designs ensures confidence in the findings - but such studies about Pap tests are rare. On the other hand, including studies with less stringent designs may be useful in suggesting possibly fruitful areas, but this presents a problem for interpreting results.1 Nevertheless, such reviews help researchers around the world recognize what the relevant issues are, and how to make sense of complex literatures and disparate methods.2

Coyne et al.'s (1992) review of strategies to provide health education about Pap testing consistently identified barriers to Pap testing, but "failed to distinguish the relative saliency of any one barrier" (Coyne et al., 1992:294). Straton's review (1994) of community-based and media strategies concluded that concerns about earlier programs (Kegeles & Grady, 1982) remain; there is generally insufficient descriptive and evaluative detail to understand or evaluate program components.3 As mentioned earlier, Gillam (1991) concluded that "organizational factors, not women's health beliefs, are the main obstacles to the success of cervical screening." Thurston & Scott's (1995) critical review (for studies of barriers to screening published between 1990-1995) notes serious problems: survey designs, limited theoretical development and consequent different measures of barriers to screening.

Despite these difficulties, and "Regardless of the subject area, systemic barriers appeared

1. Several examples illustrate such difficulties. Various aspects of projects may be reported separately, for example, the media-led program (Jenkins et al., 1998), the lay health workers (Bird et al., 1998) and the physician intervention (Nguyen, 1995) were all directed towards increasing Vietnamese women's understanding and uptake of Pap test in the same region, at the same time. Yet each presented the findings as if they were independent of the other effects. Alternately, a single report may include a comprehensive set of interventions (e.g., Spanish-language media and single visit intervention included results and treatment with colposcopy on the same day) with no way to distinguish among the effects of any particular element of the intervention (Burger, 1995). Early optimistic reports may be displaced by later, more comprehensive ones (e.g., studies with Vietnamese women in California, Davis et al., 1995, McPhee et al., 1989, McPhee et al., 1991, Jenkins et al., 1999). Finally, populations who receive cervical screening interventions may not necessarily be underscreened themselves (e.g., Morgan & Levin, 1995).

2. In addition to the Cochrane Collaboration review that addresses mass media effects on cervical cancer screening (Grilli et al., 1998) there are other Cochrane Collaboration Reviews underway regarding screening in general and breast cancer screening: influencing people's experiences of screening (Bastian et al., 1998); and the effectiveness of strategies for inviting women for breast cancer screening (Bonfill et al., 1998).

3. Indeed, most interventions reported are case studies of varying approaches to service provision, and such designs play a limited role for epidemiologic purposes. For example, community or regional interventions of cervical cancer screening have used media coverage, including radio, television & newspaper (Mitchell et al., 1991, Ward, 1991, Halton Regional Health Department, 1991), telephone, peer recruiters (Mamon et al., 1991-92), and letters (Ward, 1991) or other printed material (WAND, 1992). Generally, such studies suggest an increase in screening due to the intervention, but with no control groups, it is difficult to know whether the effect is real.
to play a more substantial role than individual barriers." (Thurston & Scott, 1995: preface).
Thurston and Scott's definition of systemic barriers is interesting, and telling: it includes poverty, language and ethnicity, attitudes and social support. In contrast, personal barriers includes physicians' lack of training or recommendation, and continuity of care (Thurston & Scott, 1995).

Grilli et al.'s (1998) review of the effect of mass media on various health behaviours concludes that further research in the effects of mass media is needed to address certain issues. The first issue, whether changes are specific or non-specific, requires denominator data including eligibility for Pap tests and screening status. The second issue, about who is affected and how, probably requires different instruments for consumers and health professionals: qualitative data would complement traditional quantitative data. The issues of duration of observed effects and cost-effectiveness require ancillary data for long-term and economic analyses. Let us examine the studies that deal with some of these issues.

The choice of outcome measures for intervention research is an interesting challenge for Pap tests. Interim outcomes, essential to research on smoking cessation or dietary interventions, are widespread, but they are not as useful for a health behaviour like Pap testing, which does not require continuous modification of behaviour for integration into one's lifestyle. Some studies have reported interim measures to describe the development and implementation activities of particular programs (e.g., Navarro et al., 1995), including an extensive and imposing set of measures of process evaluation (e.g., 2,100 interviews by Dignan et al., 1991). Such research may assume that interim measures (e.g., knowledge, attitudes and beliefs) will reflect changes in health behaviours. This assumption would need to be verified. Indeed, a Pap test may be undertaken with little preparation, and a Pap test is an unambiguous and salient outcome. Even so, despite its desirability as an outcome measure, confirmation of a Pap test may not be acceptable or possible in every setting.

1. The issues are: "whether [the] impact of mass media on clinical practice is specific (resulting in more appropriate use of services by patients who can actually benefit from them), or non-specific (resulting in changes in overall rates of use, without affecting the appropriateness of how health services are utilised)].[... ] whether mass media have equivalent effect on consumers and health professionals[... ] duration of observed effects[... and] cost-effectiveness" (Grilli et al., 1998:7).
Identifying underscreened women for recruitment studies is a common challenge where there is no population-based data system. Some areas have data systems that include screening status (e.g., McAvoy & Raza, 1991, Straton's review highlighting Australian studies, 1994). Even so, Mitchell's review (1990) considered the problem of "eligible" women's lack of responsiveness, and concluded that not all studies have been able to differentiate between women who failed to respond because they thought they did not need the test and those eligible who chose not to attend. Where there is no data system to identify underscreened women, there is a fundamental need to determine how to identify and reach these women.

In Ontario, there is no population-based registry of women who are eligible for cervical cancer screening, and thus identifying and recruiting underscreened women remains a major problem (Mai & Brueckner, 1999). Workshops have drawn workers of various disciplines together (NCIC, 1994, NCIC, 1995), literature is being reviewed to identify the characteristics of successful recruitment strategies (Clarke & Majpur, 1997), and an Advisory Group has been convened to provide guidance on devising a project to encourage women at high risk to participate in Pap testing (CCS, 1996, CCS, 1997). As well, the Ontario Cervical Screening Collaborative Group has produced a set of proposals to enhance cervical cancer screening activities in Ontario. One of these is to "develop effective methods to enrol women who are hard to reach through public health units, community agencies, and others" [emphasis mine] (Ontario Cervical Screening Collaborative Group, 1996:43). Thus far, the Ontario Cervical Screening Collaborative Group has concentrated on achieving consensus on terminology for cytopathology, on database development, and on developing and disseminating screening practice guidelines for physicians. These will make important contributions for follow-up and recall of screened women. Also valuable will be their workshops for staff of Public Health Units and others, and funding to evaluate projects "directed at specific target populations" (Clarke, 1996 Nov:15). Without strategies to identify, reach and recruit underscreened women, including unscreened ones, an otherwise perfect screening program would still miss the women who need it most (Schabas, 1999, Mai & Brueckner, 1999).

Researchers, health care providers and members of the general public recognize that "special efforts are required to bring many at-risk women into screening programmes" (Miller, 1992:24). Special efforts are indeed necessary if we wish to include recent (≤10
years) immigrants to Canada, and those who speak neither English nor French, both of which are predictive of never having had a Pap test (Goel, 1994, Woloshin et al., 1997). Naish et al. (1994) used focus groups with six non-English speaking groups in London, England, and recommend the focus group strategy for user consultation regarding screening.

Learning about health problems from community members is not a new idea. Throughout history, public health has concentrated on problems of community life (Rosen, 1993). Notwithstanding the role of politics or philosophies in determining what issues are addressed (Fee, 1993, Morman, 1993), progress in public health has depended on a detailed understanding of the factors associated with health and disease (Rosen, 1993). Using mumps as a historical example, valuable information has been provided as narrative and clinical descriptions of epidemics by Greek and Roman authors such as Hippocrates (e.g., Rosen, 1993), structured field investigation of an outbreak (Wharton et al., 1988) (Tyler & Last, 1992:22-26) or journalist’s reports investigating vaccination failure (Milner, 1988). Whatever their form, these investigations rely not just on passive surveillance but also on active, careful observation of and contributions from informants. The way it is done may be expressed as a philosophy of enquiry (e.g., community-based research, Allman et al., 1997) as an approach to research (e.g., action research, Stringer, 1996), or as a set of procedures and techniques (e.g., grounded theory, Strauss & Corbin, 1990). Forms of gathering data from community members are discussed in more detail later, in the context of defining precisely what this research is and is not. What has changed over time is that methods may now include, as participants or collaborators, people who would previously have been considered research subjects. There are arguments over the relative merits and appropriateness of involving community members to learn about health and illness behaviours (e.g., Syme, 1997, McKeever, 1998), and discussions of the success or usefulness of particular collaborations (Allison & Rootman, 1996, Boutilier et al., 1997); but there is no dispute over the potential value of learning from community members.

Despite their merits, projects carried out in community settings face serious challenges. Coalitions and how they function have been explored from various perspectives: skill development for public health staff (Hall & Best, 1997), logic models to guide the selection of appropriate measures to build self-care and collective capacities and supportive environments (Moyer et al., 1997), characteristics of inter-organizational partnerships and
how they function (Scott & Thurston, 1997, Allison & Rootman, 1996), factors related to coalition effectiveness (Butterfoss et al., 1996) and problems that exist for variants of action research, that engage community members in the health promotion process (Boutilier et al., 1997). The challenges of collaboration are magnified when the project involves not just a health promotion activity but also research on its effectiveness. Allison & Rootman (1996) refer to the "dynamic tension" between the goals of scientific rigor and community participation: here, community refers to non-academic agencies.

In the past century, the methods of various disciplines have been used in concert to understand and address complex disease issues (Dunn & Janes, 1986, Trostle, 1986a). In the past few decades there has been an increase in "interdisciplinary exchange" (Trostle, 1986b:73), with epidemiologists, medical geographers, anthropologists and other social scientists collaborating (Dunn & Janes, 1986, Trostle, 1986b). Syme has developed interventions that involve extensive community interactions; these experiences may have contributed to his identification of the need for innovative designs to help deal with current problems in epidemiology² (Syme, 1997).

Qualitative research methods are important in their own right, and they also make important contributions to quantitative research design, data collection and analysis (Sieber, 1973a). In-depth interviews permit researchers to discover new aspects of a problem and provide important background information which help researchers interpret and understand their findings (Caplovitz, 1983, Green & Caplovitz, 1959). Qualitative methods can contribute to data collection in at least four areas: data collection legitimation, sampling frame formulation, survey instrument development, and return rate improvements (Sieber, 1973b).

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1. Trostle (1986) provides six reasons for the increase in interdisciplinary exchange:
"[1] the growing numbers of international studies in epidemiology [sic]; [2] increasing migration and pace of change of human populations; [3] growing epidemiological and anthropological interest in studies of migrant groups; [4] a resurgence of interest in human behavior as an important etiological variable; [5] uncertainty as to why effective preventive or curative treatments were not being used by more people; and [6] the creations of private and public sources of research funds that both created and responded to these various projects." (Trostle, 1986:73-4)

2. Other contributions (more closely aligned with traditional epidemiology) are improved definitions, measurements and assessments, and creative statistical approaches (Syme, 1997).
To summarize, then, the research challenges are formidable. There is clearly a need to develop effective, easily-implemented strategies to identify, reach and recruit underscreened women to have Pap testing in order to prevent invasive cervical cancer. How does a researcher choose where to begin?

Fortunately there is some consensus about the priorities. The National Cancer Institute Working Group on Behavioral Research on Cancer Prevention and Control (Lerman et al., 1997) identified six priority areas and cross-cutting themes. One of the priority areas was “integrating preventive and early detection services into changing health delivery systems” (Lerman et al., 1997:S5). Their work clearly acknowledges the context of the shift towards managed care, and because of that, the need to "design and test innovative cancer control interventions that can be integrated into health care systems in a cost-effective manner" (Lerman et al., 1997:S5). In addition, cross-cutting themes "relevant to all areas of priority behavioral research... are...: 1. considerations of race, social class, and culture; 2. theory-driven research; 3. multiple-level interventions targeted to multiple risk factors; [and] 4. research settings” (Lerman et al., 1997:S6-7). With respect to cancer screening adherence, the importance of theoretical models was again stressed, and research issues

1. The NCI Working Group on Behavioral Research on Cancer Prevention and Control convened a meeting in 1995 to begin to define research directions for the coming years. In developing recommendations, group members considered the “successes and failures of behavioral research in the past decade, as well as the emerging challenges posed by scientific advances and changes in health care delivery... [and these criteria are]: (1) strength of the scientific evidence, (2) potential for reducing the cancer burden, (3) responsiveness to opportunities arising from advances in basic science and technology, (4) availability of technologies, (5) feasibility of implementation, and (6) achievable and measurable goals and outcomes”. (Lerman et al., 1997:S4)

2. The six research areas identified as most important are: "1. preventing tobacco use among children and teenagers; 2. enhancing risk communication, comprehension, and informed decision-making under uncertainty; 3. integrating preventive and early detection services into changing health delivery systems; 4. improving the outcomes of genetic testing for cancer susceptibility; 5. enhancing survivorship of cancer patients; 6. promoting a healthy diet and physical activity.” (Lerman et al., 1997:S5-6)

3 By research settings, they mean tailoring the design of initiatives to the appropriate settings, depending on how much is known about the issue and the type of study.
were articulated for three levels: outreach\(^1\) (e.g., for patients), inreach\(^2\) (e.g., for providers), and systems and policy\(^3\) (Hiatt, 1997).

Freimuth (1997) recommends that successful communications be tested with and directed to specific audiences, using what we know from models of health behaviours (Freimuth, 1997). Gaining access to underscreened women may permit us to characterize populations most likely to be underscreened, and to recognize factors that may serve as barriers and facilitators to Pap testing (Miller, 1992). Masi (1988) is optimistic about the possibility that beliefs and behaviours are shared among diverse ethnocultural populations. He explains that, although "language, behaviour, concepts, interests, beliefs and values" vary considerably within communities, generalizations about them are necessary and useful to describe communities (Masi, 1988). Further, and more importantly, different ethnocultural groups may share health beliefs and behaviours if they share the same socio-economic characteristics (i.e., education, occupation, access to health opportunities) (Masi, 1988).

This provides a compelling rationale for research on any population which is largely defined by those limiting characteristics of education, occupation or access to health opportunities.

The most useful research, in behavioural science terms, will not simply review and summarize data using a "historically particular" approach, but will continue the analysis to indicate concepts (Lofland & Lofland, 1995:183). Abstraction, that is, constructing "general principles from a set of observations" (Cuba, 1988:35-6), permits transcendence beyond

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1. Outreach includes (emphasis mine): "a continued focus on underserved groups including the socially disadvantaged, race / ethnic minorities, new immigrants, and the elderly; a broader prevention emphasis for outreach research beyond cancer screening (e.g., smoking cessation, hypertension and heart disease, adult immunization, nutrition counseling, and violence prevention (citing Hiatt, 1995); new methodologic approaches to outreach interventions at the community level; behavioral research on screening tests of as yet unproven efficacy (e.g., genetic susceptibility testing); agreement on methodologic issues and outcomes measures that allow comparison of consistent measures across studies." (Hiatt, 1997:S14)

2. Inreach includes: "translational research to explore the behavioural consequences of the introduction and application of genetic susceptibility testing and biomarkers to cancer screening; continued and enhanced use of computer technology to aid providers in delivering cancer screening and other prevention services; studies of the potential negative consequences of screening; study of cross-cultural communications between providers and patients." (Hiatt, 1997:S15)

3. Systems and policy includes: "behavioral science in health services research; health care policy and cancer screening; health care reform and the underserved." (Hiatt, 1997:S14-S16)
the specifics. This can be contrasted with epidemiology's definition of generalizability (also referred to as external validity) that is "only meaningful with regard to a specified external target population." (Last, 1995:171) Respecting these distinctions, a complex public health issue like this provides both an impetus and an opportunity to develop study designs that are rooted in but not constrained by their respective disciplines.

The balance of this dissertation describes such a project, building on the literature and working with community partners to elaborate and amplify research plans. It begins with a set of complementary objectives that guide the entire research agenda.
Chapter 2  Methods and design

2.1  Objectives

This project had both methodologic and substantive objectives:

1. To develop, with community partners representative of a population of underscreened women, a research project to identify and address key issues relevant to promoting adoption of a health behaviour.

2. To study various approaches to identify and reach underscreened women.

3. To undertake a pilot randomized controlled trial of approaches to inviting underscreened women for Pap testing.

4. To synthesize the findings from the collaborative development, the approaches to underscreened women that were identified, and the pilot project, and identify factors that serve as barriers or facilitators of Pap testing in a population of underscreened women.
2.2 Overview

The research project had a hybrid design, incorporating elements of epidemiologic and behavioural sciences research methods and designs. The design, overall, includes three interdependent study elements that contribute to the fourth: the randomized trial of underscreened women (Objective 3), nested within a cross-sectional survey of Portuguese women (contributing to Objective 2), which is further nested within a community-based diagnostic and research development process (Objective 1). The fourth objective included technical summaries and integrations, that, in turn, contributed to the conceptual synthesis of this work.

Both qualitative observation and analysis as well as health promotion program planning and evaluation techniques are used for Objectives 1 and 2; while a standard epidemiologic intervention design is used for Objective 3. For the first objective, two different but complementary strategies were used with various community partners, to identify and address key issues relevant to the adoption of Pap tests. Qualitative observation and analysis (Lofland & Lofland, 1995) was used with the initial group, while the health promotion program planning and evaluation techniques of the PRECEDE-PROCEED model (Green & Kreuter, 1991) were used with groups, such as the community steering group, and with individual key informants. Building on these collaborations, a set of approaches to identify and reach underscreened women were explored for Objective 2: this included cross-sectional survey questionnaires with closed and open-ended questions. The design and evaluation for Objective 3 compares invitations for underscreened women, and can be described from two different perspectives. Health promotion program planning would refer to it as a rigorous type of impact evaluation (Green & Kreuter, 1991:243-5); in epidemiologic terms it is an efficacy trial design using a two-by-two factorial allocation (Fletcher et al., 1988:132, Last, 1995:52). As stated earlier, all study elements contribute in some way to Objective 4, synthesizing the findings to identify factors that serve as barriers or facilitators of Pap testing.

The iterative and interactive processes for this project do not fit neatly within the standard format used to statistically test a formal research hypothesis. Indeed, the elaboration of Objectives 2, 3, and 4, and the selection of methods to address them, were done during or after the initial and steering group processes. Without those processes, there would be no
feasible plans to reach underscreened women (Objective 2), no selection of specific hypotheses about Pap testing invitations and no devising of a trial to test them (Objective 3) and no follow-up strategies (contributing to Objective 4). To reflect the iterative development of this research project, chapters on methods and results for each objective are presented in turn. While this structuring may seem odd, the product or result of process evaluation (Objective 1) could be considered part of the methods section in an epidemiologic feasibility study. Structuring the material in this unusual way is intended to provide "a clear, descriptive picture of the program elements being put in place and what is going on..." (Green & Kreuter, 1991:230)

The sampling strategy for identifying community members (for the diagnostic and research development of Objective 1) began with approaching community agencies to identify convenience samples of key informants (commonly referred to as the snowball process). Some of these contacts resulted in community partnerships for Objective 1; some contributed to the effort to study various approaches to identify and reach underscreened women for Objective 2; some contributed to the planning, implementation or interpretation of the invitation trial for Objective 3; and some contributed to the identification of factors that serve as barriers or facilitators of Pap testing among underscreened women for Objective 4. Some of these contacts contributed in some way to several of these objectives. Interactions with some community members were restricted to a single contact, while with others they extended over the course of the project.

The methods and designs were shaped by a unique constellation of forces and constraints. The balance of this chapter sets the stage for the research by identifying which abstract principles and theoretical notions underlie the choices of methods and design.

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1. This structuring largely reflects the chronology of the project, with the exception of the physicians' office surveys for Objective 2, which were actually carried out after Objective 3's trial.
2.3 Factors shaping the methods and design

Scientific and ethical ideas and practical factors have shaped this work. Scientific ideas here include the scientific and personal tenets or assumptions underlying this research. Ethical considerations underlie these. Practical constraints include the role of this work as a doctoral dissertation research project and the personal and collaborative relationships which built the project. Together, they influence or define all aspects of the research: the subject of investigation, the question of interest, the methods used, and the analyses and interpretations of the data. Most particularly, these factors underlie the choice to use flexible and iterative collaborative processes.

Health education, health promotion, and other research on Pap testing and other health behaviours, seem largely influenced by behaviourism, i.e., "the theory that human behaviour is determined by conditioning rather than [simply] by thoughts or feelings" (Thompson, 1995:116). This perspective assumes that "human behaviour is externally regulated" (Bandura, 1977:6), as opposed to internal "motivational forces in the form of needs, drives, and impulses, frequently operating below the level of consciousness" (Bandura, 1977:2). The PRECEDE-PROCEED model (Green & Kreuter, 1991), and any other theoretical model applied within its framework, permits program planning (and evaluation) using a behaviourist approach. That is, the model contends that it is not only possible to recognize how human behaviour influences health outcomes, but that it is also possible to change social and disease outcomes by designing interventions which can (directly or indirectly) modify those behaviours. This approach is consistent with the traditions of public health, which recognizes "the social context as well as the biological determinants of disease" (Fee, 1993:ix).

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1. As described earlier, the PRECEDE-PROCEED framework assumes that it is possible to "diagnose" situations in epidemiologic (or health) and social (or quality of life) terms, and to understand their antecedent causes or influences, in terms of behavior and environment, education and organization, administration and policy. Focussing on the factors that influence behaviour and lifestyle, the model identifies a set of predisposing, enabling and reinforcing factors.
2.3.1 Science and paradigms

Science has been defined as "a systematic and formulated body of knowledge on a subject" (Thompson, 1995:1235). Some researchers believe that positivist science ensures that truth transcends opinions and personal bias (Carey, 1989:99). Other researchers (e.g., Guba, 1990:17) believe that subjective, human constructions called paradigms (i.e., basic sets of beliefs) guide action. Denzin & Lincoln (1994:99) indicate three elements of paradigms: 1.) epistemology, which asks, How do we know the world?, and which explores the relationship between the inquirer and the known; 2.) ontology, the nature of reality; and 3.) methodology, or how we gain knowledge about the world. Epistemology and ontology are not always explicitly identified: they may be expressed as either the theoretical tenets of the relevant discipline or implied by the methods of enquiry. In addition, the researcher's background may contribute to how the scientific ideas are perceived or understood. It is important to identify explicitly the philosophies, assumptions and values which underlie the disciplines of interest and which relate to this project. Broadly speaking, two disciplines have provided important contributions to research on Pap testing: epidemiology and the behavioural sciences.

2.3.1.1 Epidemiology

Epidemiology is "the study of the distribution and determinants of health related states or events in specified populations, and the application of this study to control of health problems." (Last, 1995:55). Philosophically, epidemiology subscribes to scientific realism, which asserts that science is possible. Epidemiology's assumptions are elaborated as an explicit set of propositions, including Hill's criteria for causation (Hill, 1965) and Evans's postulates (Evans, 1976). Hill's criteria for causation are consistency, strength, specificity, dose-response relationship, temporal relationship¹, biological plausibility, coherence, and experiment (Hill, 1965). These criteria, which permit investigation of diseases other than ones in which a particular agent is responsible for disease, are more widely applicable than Evans's postulates. This set of rules about the purported etiologic agent in population studies includes presence, exclusiveness, isolatability and recoverability. These notions are rooted in earlier microbiologic research on the etiology of disease, recognized as either

¹. Temporal relationship is considered the only essential criterion for causality (Hill, 1965).
Koch's (Stanier et al., 1986:9) or as Henle-Koch's postulates (Last, 1995:75-6). These biomedical approaches have been particularly useful to understand acute and infectious disease processes. For diseases which are chronic or more complex in etiology, traditional epidemiology may simply describe the patterns of correlates. The behaviour related to such diseases or conditions may not be as amenable to the analytic processes of traditional epidemiology.

As researchers recognize the complexities of topics and the constraints on science, it is becoming more common for researchers to combine qualitative and quantitative research methods in studying health (Eakin, 1997, Casebeer & Verhoef, 1997). Epidemiologic and behavioural science share many things, including a dependence on data, an intention to develop, through analysis, coherent explanations for phenomena of interest, and a goal of producing reports of the findings (Strauss & Corbin, 1990:20). They also share a concern about standards of scientific rigour (e.g., Lofland & Lofland, 1995).

2.3.1.2 Behavioural sciences

Behavioural sciences provide a complementary way to investigate health-related behaviours; they are directed "to understand human behaviour" (Eakin, 1997). Both behavioural scientists and epidemiologists develop and apply quantitative methods, but a unique contribution of behavioural sciences as a discipline has been in developing and applying qualitative research approaches.

Although, as a field, qualitative methods are not defined by a unified set of principles (Denzin & Lincoln, 1994c:ix), there are some identifiable themes which contrast with traditional epidemiologic approaches. Denzin & Lincoln (1994b:4) summarize: "Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry." They summarize Becker's (1993) five differences between qualitative and quantitative researchers: uses of positivism, acceptance of postmodern sensibilities, capturing the individual's point of view, examining the constraints of everyday life, and securing rich descriptions (Denzin & Lincoln, 1994b:5-6). Behavioural science enquiries tend to be observational and naturalistic, with an emphasis on the development of theory with elaboration at various levels of abstraction, and include "an ongoing critique of the
politics and methods of positivism." (Denzin & Lincoln, 1994b:5) Instead of quantitative validation techniques, qualitative researchers may strive for triangulation, or using the perspectives of several varieties of data, investigators, theories and methods (Berg, 1989:4-5). Such research encourages an explicit identification of the researcher's biases and assumptions, beginning with a statement about her personal background and experiences relevant to the topic, and how she interacts with the research participants (Hertz, 1997:ix).

2.3.1.3 Researcher's background statement

All research reflects the researcher in some way or another, and qualitative research in particular involves subjective processes, wherein a researcher's positions and interests "are imposed at all stages of the research process" (Hertz, 1997:viii). In the qualitative research tradition, a background statement is provided. This information is intended to identify factors that may have contributed to biases or expectations, because "researchers are acknowledged as active participants in the research process" (Hertz, 1997:viii).

The background information most relevant to the research project relates to my family and educational background, and my experience of the health care system and Pap testing. These may influence my approach to the topic of cancer screening in general and Pap testing in particular.

I am a 44 year old woman of British and French heritage, the fourth of six children of a carpenter father and a homemaker mother. I grew up outside of a small village in southern Ontario, in a neighbourhood that included immigrants from Russia, Portugal, the United States of America, Holland, as well as Prince Edward Island. My parents were devout fundamentalist Protestant Christians whose conservative values meant that we were socially isolated, with limited opportunities for education or professional development. I left home at age eighteen, and worked in a number of jobs, including service, retail and police dispatch, before marriage at age 25. I trained and worked in prosthetic and orthotic techniques, in both a cancer treatment lodge and a rehabilitation centre. One particular interest was in developing strategies to improve patient-caregiver communication around amputation and prostheses, using audiovisual and small-group approaches.
My husband encouraged me to begin undergraduate training, and I entered university at age 28, where I was introduced to various academic disciplines and perspectives by which to understand the world. A summer job in a genetics unit included a prevalence study on Huntington Disease, which introduced me to epidemiologic methods and concerns. During my undergraduate degree, we fostered for some months a teenager who had emigrated from Vietnam, and observed at close hand how difficult integration into Canadian life was for him and his family. Entering graduate school at the University of Toronto in 1989 provided the chance to develop an academic career; Professor Miller provided early mentoring.

My understanding of the health care system is informed by considerable interaction with it. Direct experience occurred in my roles as a patient with injury and illness, as a primary care giver, as an allied health professional in rehabilitation medicine, and as a research assistant in a genetics unit. These experiences of the health care system occurred here in Ontario and in Britain, and involved care systems ranging from emergency to surgical to palliative, from hospital- to home-based. Indirect experience of the health care system has come from friends and neighbours, from art (theatre, books), and from the scientific literature. I know about the challenges of communication between health care providers, patients and their families, the emotional upheavals associated with diagnoses and treatment, and the difficulties these impose on supportive relationships, intellectual pursuits, and work.

Pap testing to screen for cervical cancer has been a routine in my life, although not always a well-understood or pleasant one. My recollection is that for the first few gynecologic examinations at least, I was not aware of which tests were being done, or which one was being done at what time. Descriptions of the procedures were cursory and / or they were confusing, combining the various tests and procedures together into one confusing jumble. Those exams have ranged in quality in terms of comfort and communication: most involved nothing more unpleasant than a cold speculum, but others could only be described as painful. As for the bad experiences, they were due to physician technique; I did not generally offer verbal feedback about my confusion, discomfort or pain. In addition to these problems, I remember the anxiety of not receiving notice of results.

My experience of internal examinations and my recognition that they were not always handled well did have one particular effect on me: during my undergraduate training I
became a gynecology teaching associate at Queen's University. Training for that role included formal introduction to the notion of the gynecologic examination as invasive and as having powerful emotional repercussions for women who had been sexually assaulted, regardless of the origins of that assault. In the training sessions with small groups of medical students, I and a partner introduced the "educational pelvic examination", which included routine screening for infections as well as for cervical cancer. I emphasized both technical proficiency and communication as essentials for a successful and comfortable examination, and was gratified when students demonstrated proficiency (including finding an ovary!) and grace within a single session. That experience served to make me more assertive and communicative about subsequent internal examinations, and since then I generally have not hesitated in providing direction or feedback when necessary to guide or correct the examiner. Nevertheless, even with that level of comfort and self-assurance, I preferred to have gynecologic examinations and procedures with my husband present.

The part-time job teaching medical students in gynecology, and my current project, also open up conversations, and my attitudes undoubtedly reflect this. As a student of human nature, I have found it intriguing that most women use the terms Pap, Pap smear or Pap test to refer to the entire, internal gynecologic examination. It is common for women, especially those near my own age, to respond to my thesis topic by voluntarily describing their own Pap tests with a mild shudder, an amused grimace, and/or a deprecating comment e.g., "salad tongs". It is the rare woman who describes it as a pleasant experience. Nevertheless, in spite of these things, most of these women, who are comfortable discussing the topic, still report going for routine Pap testing, as I do.

My husband's diagnosis with stomach cancer in 1992 and his death in 1996 have undoubtedly influenced my research. Sharing his illness and experiencing widowhood have meant revisiting old memories of fear, abandonment and loss. I recognize how experiences and deep feelings are not always easily shared. I am sensitized, indeed biased, to recognize themes that resonate with my own experience. My losses to an incurable cancer are a powerful motivation to develop strategies to prevent unnecessary morbidity and mortality. Throughout, I have sought therapeutic relationships to sustain me, and intellectual interactions to ensure my work receives the necessary attention and rigour.
2.3.2 Ethical stance and values

Research is influenced not just by scientific notions but also by political, personal or ethical values and contexts. The "aim of epidemiology - to promote, protect, and restore health" (Last, 1995:56) is not value-free. It expresses ideals that are unambiguously interventionist, whose origins may be rooted in moral, ethical or political justifications. In Canada, the idea of focusing on Pap testing was developed over many years; two reports on cervical cancer screening programs identified a set of priorities and concerns. The first, entitled "Cervical Cancer Screening Programs. The Walton Report", was prepared by the Task Force Appointed by the Conference of Deputy Ministers of Health (1976); the second was a Report of a National Workshop on Screening for Cancer of the Cervix (held in 1989, and later published as Miller et al., 1991).

One potential danger is that a researcher who believes that "the ends justify the means" may be insensitive to ethical concerns of the research participants; thus, external review is an important constraint. As a project under the auspices of the University of Toronto, this project has been reviewed and approved by the Human Subject Review Committee. Denzin & Lincoln (1994d:20-2) reviewed ethical positions that qualitative researchers may hold. Sometimes these positions merge: absolutist stance, where research is restricted to the public sphere; deception model, or "investigative voyeurism in the name of science, truth and understanding"; relativist stance, where the agenda is determined by personal biography; and contextualized-consequentialist model (Denzin & Lincoln, 1994d:20-2). This last model's guiding principles seem closest to the ones used in this study: principles of respect, noncoercion, support of democratic values, and a recognition that research affects others, in a way that is consistent with a feminist ethic of collaborative, trusting, nonoppressive relationships. (Denzin & Lincoln 1994d:20-2).

How these principles were applied in concrete or specific terms is evident in later sections of methods and results. Here, to summarize, this project expressed both epidemiologic and qualitative aims and values. The choice of topic, Pap testing and underscreened women, was prompted by the epidemiologic aim to "promote, protect and restore health" (Last, 1995:56). At the same time, the project methods and interactions were guided by principles of collaboration, trust and non-oppressiveness; every effort was made to "respect the
women" and to have partners participate in ways that were comfortable and beneficial for all.

2.3.2.1 Collaboration and representativeness

In this project, the objective of developing a research project with community partners who are representative of a population of underscreened women is an ideal but perhaps unrealistic notion. It is ideal because the more similar the women are to the women of interest to us, i.e., underscreened for cervical cancer, the greater our chances of understanding what the factors are that serve as barriers to their having Pap testing. It is unrealistic because the demographic characteristics associated with underscreening can reasonably be expected to be associated with a disinclination to participate in any research process. That is, women who are older, of lower socioeconomic status, who are less well educated, with a short time since immigration, and a lack of official language (Goel, 1994) would be less likely than other women to participate in any project, much less a research process. And although these measures are unambiguous, they probably reflect many things. They are important as probable indicators of underscreening status, but they also reflect, by definition, a marginalization from many other aspects of Canadian society.

Paradoxically, in developing the project, even if we are not able to include women who are underscreened, we may derive an important benefit by including women who have already adopted Pap testing. All immigrants face certain challenges, which may include language acquisition, acculturation, and disruptions of family hierarchies and roles (Remennick, 1997, Disman, 1997). If people belong to the same cohort, defined by age, gender, and by immigration to Canada from a Portuguese-speaking country, they may have shared a common culture, language, and lifestyle and certain experiences. Immigrants who share origin and host countries may also share the experience of differing patterns of health care service provision as well as different types of relations between health care service providers and consumers. Women who share origins and immigration experiences, screened or unscreened, may also share a base set of values, expectations, perspectives and insights. In addition, and perhaps most importantly, women from the same cohort who have adopted Pap testing may provide valuable insights about the factors that prompted their choice. Understanding what opportunities or invitations women have had, and how they responded to them, may help identify successful strategies. Furthermore, those who
live or work with Portuguese-speaking women may provide valuable perspectives about how these women respond to preventive care services available here in Canada. Thus, collaborations with community partners of differing expertise and experience may provide useful information.
2.3.2.2 Is this project community-based / participatory / action / research?

This project may or may not be considered community-based participatory / action research, depending on the description or definition used. The terms community-based, participatory, and action research have been used in many applications, singly and in combination, and their meanings have elicited considerable discussion and debate. Explicit definitions, below, help identify the characteristics of this collaboration.

In the most general or abstract sense, this project could be considered action research. Allman et al. (1997:21), in one part of their discussion, conceive of community-based research as a philosophy or ideology for inquiry, rather than a particular method, framework or strategy. Stringer (1996:158) summarizes the role of (community-based) action research: "Community-based action research, therefore, is ultimately a search for meaning. It provides a process or a context through which people can collectively clarify their problems and formulate new ways of envisioning their situations." What research would not aspire to this? A historical review of action research finds common themes as far back as Kurt Lewin's 1946 seminal work (Stringer, 1996). Action research projects:

1. are rigorously empirical and reflective (or interpretive);
2. engage people who have traditionally been called "subjects" as active participants in the research process; and
3. result in some practical outcome related to the lives or work of the participants."

Green et al. (1995:43) define participatory research as "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change". A review and set of recommendations for the development of participatory research in Canada (Green et al., 1995) described a working definition, guidelines and a semi-structured instrument that could be used to assess the extent to which a particular research project reflected the definition of participatory research. The six guidelines refer to: 1. participants and the nature of their involvement; 2. origin of the research question; 3. purpose of the research; 4. process and context - methodological implications; 5. opportunities to address the issue of interest; and 6. nature of the research outcomes. The 25 questions within these guidelines provide response categories which span the spectrum of project orientation, from totally community-oriented, to totally researcher oriented (Green et al., 1995:43-50). Again, these notions resonate in
the planned project, and it would be compelling to leave matters there - but that would not be adequate.

This project differs from action research and its variously-labelled relatives in terms of who initiated it and who defined the initial and central question. Allman et al. (1997:25-48) refer to the fundamental premise of community-based research, that it begins where the people and the problems are (Allman et al., 1997:25). This project fulfils that focus, but not that mode of inception. Another way of assessing research projects is in terms of the extent of citizen participation. This can be viewed as a ladder or continuum, with manipulation at one end and citizen control at the opposite end (Arnstein 1970). This project is somewhere in the middle, and Guba's typology is useful to explore it. Guba (1996:iix-xiii) described (and Stringer (1996) exhorted) an ideal for educational research, or what he called human inquiry, as having three characteristics: decentralization, deregulation, and co-operativeness in execution. My work definitely is decentralized, it has considerable co-operativeness in execution, but it is not completely deregulated.

Looking at each of Guba's three ideals (Guba, 1996:iix-xiii) in turn, my work is decentralized because the inquiry is focussed on the local context. Certain aspects of my study might fulfil the second ideal, deregulation, which he describes as a shifting away from the conventional modes of inquiry into physical science, and their reliance on validity, reliability, objectivity, and generalizability. He makes this recommendation in the context of his perspective about social inquiry, where he contends the usual distinction between ontology and epistemology collapse. That is, when the nature of reality is determined in the interaction of the inquirer with reality, the "construct" that results is created - it does not exist as some objective truth. The parts of my project that best correspond to this notion of deregulation are the interactions with the initial planning group of Portuguese women and with the steering group. The selection of hypotheses for Objective 3 depended not simply on what the experts in the literature had determined was important, but also on the perspectives of the women in the initial group. Further, interactions with both groups helped to identify important themes in their lives, and challenges to operationalizing possible hypotheses suggested by the literature. These iterative processes appear to shift the usual direction of research development, i.e., from starting with the theoretical and moving to the operationalization, to beginning with concrete notions of what might be important or what could be done, and seeking to understand what theoretical notions these
might be reflecting. This involuted approach demands flexibility; researchers, and reviewers too, must impose standards on the work, but without distorting either the work or the standards themselves.

Guba’s third ideal, co-operativeness in execution, could be mistaken as true for my study. On the surface, the project is essentially about co-operativeness in both execution and design. The community partners contributed phenomenal amounts to the design and execution of the study; indeed, the project could not exist without them. But Guba’s use of this term is misleading, because he explains that what he really means is that the ideal research into human inquiry has “no functional distinction between the researcher and the researched” (Guba, 1996:x). In this study, I had one explicit role that could not be shared, that is, an obligation to produce a defensible thesis. I identified both the topic of the research and the design of the randomized trial. The community partners did contribute by deciding which questions could be asked and how, and by working out the details of the events and the trial. But despite the efforts to accommodate scientific, ethical, and practical concerns in ways that satisfied the community partners, ultimately the thesis committee and I could and did make certain decisions, e.g., by virtue of having access to the project funds. Thus, although the community partners did actively function as essential partners, they did so in limited ways.

Returning to Green et al.’s (1995) guidelines and using them to do a parallel assessment, this project demonstrates the strongest community orientation in terms of the participants and reliance on their knowledge to learn about the community health issue (guidelines 1 and 4) and the weakest community orientation for the origin of the research question (guideline 2). Green et al. (1995:A-17-22) append instructions for further testing and refining the guidelines; this would be expected to include a weighting strategy that would yield a summary rank for assessing projects. Without those weights and a classification scheme, it is not possible to unambiguously categorize any research project as participatory research or not. This, and the need for broader consensus on the principles are two of the “unresolved limitations” in the knowledge development in health promotion (Green et al., 1995:viii). At this stage, the guidelines provide useful guidance for understanding the features of a particular project, but not for formally judging whether a project qualifies as participatory research.
The decision about what the project should be labelled remains subjective. My inclination is that who defines the research question or area of interest, and who ultimately controls the processes, are the critical matters in whether a project should be labelled as community or researcher based. Thus, this project should not be labelled as participatory action research. This project was functionally based in the community, and it has two important features, i.e., its ethical stance and extensive participation from community partners. Nevertheless, the project remains a traditional academically-directed project.

2.3.3 Practical constraints

This project was restricted in scale and scope by its role as a doctoral thesis research project. Otherwise, it might have tried to address several other issues in women's health that were naturally linked with the topic of cervical cancer prevention. This would have meant including a broader set of outcomes.

The next chapter begins the presentation of detailed research methods and design per se, beginning with the iterative processes of research development with community partners for Objective 1.
Chapter 3  Methods for Objective 1: Project development

Objective 1. To develop, with community partners representative of a population of underscreened women, a research project to identify and address key issues relevant to promoting adoption of a health behaviour.

3.1 Overview

The previous sections presented a general overview of the project design and the factors that shaped this research; this section presents the details of the research development process for Objective 1. Two complementary approaches, a social science and a health promotion program planning perspective, were used to develop a research project to identify issues relevant to Portuguese women’s choices about adopting a health behaviour such as Pap testing. These issues might be of either theoretical or practical importance; and the research project had to be compatible with the sensitivities of the community. Before the meetings with the initial planning group, it was not clear how things might develop, nor what collaborations might be fruitful. And without knowing those things, it was recognized that a research project of any type might not be feasible.

Developing collaborative relationships is in itself an important aspect of feasibility. Working together to achieve a common goal is a challenge even when collaborators share disciplines. Working with people from differing backgrounds holds greater challenges. This is particularly so when the research does not follow a predetermined format. Throughout this research, as conflicts arose, the criteria of science, ethics and practicality were used to make decisions. Details of deliberations and compromises are woven throughout the methods and results, because these choices shaped the project design, what could be studied and how.

The methods for Objective 1 were based on the diagnostic Phases 2 through 5 of the PRECEDE framework (introduced earlier in the section on Models of health and health behaviour, page 10). Phase 2 of that framework, the epidemiologic diagnosis, based on the literature and expert advice from colleagues and clinicians, contributed to the choice of study population. (This material is amplified below in the section "Choosing a group"). Simply put, a pattern of excess mortality and morbidity due to cervical cancer was
suspected to exist for the Portuguese-speaking community in Ontario. This, along with the size and concentration of the population, provided the rationale for choosing this group as the focus of a research project.

Collaboration with community partners, described in detail below, was used to continue with diagnostic Phases 3 through to 5. Phase 3, the diagnosis of women's behavior and lifestyle and the "environmental" factors (described below) likely to influence them, began with reports that Portuguese women seemed reluctant to adopt physician-based preventive care strategies such as Pap testing. Phase 4 is the educational and organizational diagnosis, or identifying the predisposing, reinforcing and enabling factors likely to influence women's behavior either directly or indirectly. Phase 5, the administrative and policy diagnosis shifts the emphasis to understand what existing policies, resources and organizational characteristics are likely to influence the development of a health promotion program to improve Pap testing. Having completed Phase 5 of the PRECEDE\(^1\) framework, the norm is for the research to pivot, and shift to the PROCEED\(^2\) phases, planning and implementing policies or programs that are likely to influence women's choices about Pap tests (Green & Kreuter. 1991:24). In this project, the boundaries between diagnostic and planning phases were sometimes blurred, in that diagnostic information for Phases 3 through 5 sometimes emerged together, along with ideas for implementing and evaluating process and impact, relevant for Phases 6 through 8 respectively.

Two sets of key informants contributed to the development of this research project. The initial planning group was a small group of Portuguese-speaking women. The second set of partnerships was more extensive and more diverse in nature, identity and interaction. This set included institutional and individual partners. Within that larger circle of partnerships were other key informants who contributed to the project. Their affiliation with the project, though limited in terms of duration or intensity, was important to helping understand the complexities of the world faced by Portuguese-speaking women, and in identifying key issues relevant to screening, that might serve as barriers or facilitators of Pap testing. For Objective 1, the methods present the overtures to identify and develop

\(^1\) PRECEDE stands for Predisposing, Reinforcing, and Enabling Constructs in Educational / Environmental Diagnosis and Evaluations (Green & Kreuter, 1991:24).

\(^2\) PROCEED stands for Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development (Green & Kreuter, 1991:24).
potential community partnerships. These resulted in the elaboration of possible approaches for Objective 2 and the invitation trial for Objective 3, as well as the identification of barriers and facilitators to Pap testing for Objective 4.

Although the PRECEDE-PROCEED model provides the framework for the approach, a social science perspective is used here to describe the processes with the initial planning group: the selection of a community with whom to develop the work; data gathering; and data analysis. Dovetailing with that information, and presented within the context of choosing the community, is a section describing the rationale for choosing a population, and why this particular group is important.

3.2 Initial planning group

Choosing an initial planning group to work with depended on both opportunity and rationale. The decision processes for making that choice are described below, and are followed by descriptions of the social relations with and within the group, and then by the details of data gathering, focussing, inscription, analysis, and returning the results for review.

3.2.1 Choosing a group

This project was preceded by a protracted series of efforts to identify a group of women for whom preventive care was recognized as underutilized, and with whom barriers and facilitators of Pap testing might be explored. This included Inuit, native Indians, urban seniors, and Somali, Polish, and French women, in various locations. Discussion and reflection, from 1990 through 1994, with women and / or health care providers of each potential population considered research approaches that might be feasible, useful and acceptable. Other factors, including political priorities and sensitivities, group member identification and accessibility, and the researcher's personal circumstances, also restricted the options. As a consequence, none of the discussions yielded suitable projects.

Eventually, in 1994, a local group of women was identified through a colleague, a physician at a Multicultural Community Health Centre. A health promoter there who worked with the Portuguese community identified Portuguese women from a "Stress Management" group as interested in learning about Pap testing and possible involvement in a research project.
Having entree to an interested group is not sufficient to rationalize any study. The other practical and scientific factors that do provide appropriate justification are characteristics related to the Portuguese population itself: the potential health burden due to its size, the practical relevance of its geographic concentration, and the likelihood that these women are at high risk of cervical cancer.

Portuguese people, whether defined by their language or their origins, are a sizable presence in Toronto. Estimates of the population size vary, depending on the originating agency and the definition of the term: according to the 1986 Census, 113,000 people in Metropolitan Toronto identified themselves as being of Portuguese ethnic origin (Statistics Canada, cited by Kendall, 1992); the Portuguese Consulate-General estimates 150,000 Portuguese immigrants living in Toronto (Consulado-Geral de Portugal, 1994). Census data for 1996 for the Greater Toronto Area (GTA) for those who provided single responses regarding language indicates: Portuguese is the mother tongue for 108,015 people and it is spoken at home by 68,225 people (Toronto Community and Neighbourhood Services, 1998:T7). By either measure, it is the third largest immigrant group in the GTA and Toronto per se, behind the Chinese and Italian communities. The population speaking Portuguese language at home is not just large, it is also concentrated geographically in a dense node in west central Toronto (Appendix 1) (Toronto Community and Neighbourhood Services, 1998).

Information about cervical cancer rates among Portuguese-speaking populations within Canada is not available, but we believe their risk is elevated for two reasons. First, cervical cancer incidence rates in Portuguese-speaking countries are high (Table 1). Second, Portuguese women may have low levels of Pap testing. Clinicians at Access Alliance (a Doctor and health promoter) affirmed anecdotally that Portuguese women are not generally well screened to prevent cervical cancer. And, although the details of the methods are not available, a survey undertaken by the Portuguese Interagency Network found that Portuguese women in Toronto reported low levels of Pap testing: 31% had never had a Pap smear, and only 27% had had a Pap smear in 1989 (Ferreira, 1990). If age-related patterns in screening adequacy from other populations apply here, we can expect that women in older age categories (≥40 years) are less likely to be adequately screened.
Table 1. Cervical cancer incidence and mortality (age-standardized to 100,000 population) in selected regions

<table>
<thead>
<tr>
<th>Rate /100,000</th>
<th>Canada</th>
<th>Ontario</th>
<th>Portugal</th>
<th>Brazil</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence</td>
<td>9.5*</td>
<td>10.0*</td>
<td>17.8**</td>
<td>64.8*** (Belem)</td>
</tr>
<tr>
<td></td>
<td>7.8***</td>
<td>8.4***</td>
<td>(Vila Nova de Gaia)</td>
<td>37.1*** (Goiânia)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>31.2*** (Porto Alegre)</td>
</tr>
<tr>
<td>Mortality</td>
<td>2.6*</td>
<td>2.8*</td>
<td>2.7†</td>
<td>4.7††</td>
</tr>
</tbody>
</table>

* Age standardized to the 1991 Canadian population (which is older than the World Population), adjusted for net census undercoverage (Gaudette et al., 1998:65-6)
** Age standardized to the world population (Parkin et al., 1992)
*** Age standardized to the world population (Parkin et al., 1997)
† 1996 data, standardized to world standard (WHO cancer mortality database*)
†† 1995 data for Brazil South, South-East, and Central West (areas that include Porto Alegre and Goiânia, but not Belem) standardized to world standard (WHO cancer mortality database, 2001)

NOTE: The mortality in Portugal is low compared to incidence reported from one registry in the North of the country. Possible explanations include non-comparability of data from the registry compared to the country as a whole or under-recording of mortality in Portugal. Portugal has a high rate of reporting deaths to uterus unspecified (2.8 per 100,000, standardized to World standard), and the majority of these deaths were probably due to cancer of the cervix.

When both risk and burden are great, the impetus for research increases. Calculations from estimated distributions of the relevant demographic and behavioural characteristics (Appendix 2) yield a conservative estimate of 2,200 women in the top priority group for this study; that is, Portuguese-speaking (at home) women in Toronto, 40 years old or more, who are underscreened for cervical cancer. Therefore, if this group would be interested in participating in the research, they would make an ideal priority group with which to begin to identify and address key issues relevant to promoting adoption of Pap testing.
3.2.2 Social relations

The health promoter who served as initial liaison with the Portuguese women emphasized certain caveats about possible involvement with the women. These women were busy, but they were interested in learning about health issues. As well, they would probably be more comfortable if the sessions were held for them as a group rather than individually, and if the meetings were to address planning for something practical rather, than just reflecting on abstract or theoretical concerns, such as their perceptions and attitudes about Pap testing. Clearly, the form of these meetings would be neither the traditional individual qualitative interview nor the method of the focus group. Our group differed from the standard focus group in many ways, and most clearly in terms of the participants and the activities involved (Green, 1991:74-8). In a standard focus group, participants do not know ahead of time exactly what they will be talking about, they do not know each other, and they are randomly selected from the target group. The activities differ because the norm would be to have at least four groups address the same questions once, and usually the leader would begin by giving out name tags and index cards asking for some basic information and posing some leading questions for participants to write their ideas about the topics to be discussed. The key similarity to a standard focus group was the use of open-ended questions to explore and understand the women's perceptions and attitudes about cervical cancer and Pap testing and what might influence underscreened women's decisions about adopting Pap testing. In a nutshell, the type of interaction specified by the liaison as preferable was one which combined the diagnostic Phases 3, 4, 5 from the PRECEDE framework with the planning Phase 6 from the PROCEED framework.

Qualitative researchers have been advised to think of the relationship with research participants in terms of the roles of guest and host respectively (Disman, 1997). That is, the researcher is the guest of a participating host. Applying this perspective, the researcher needs to be grateful for disclosures made, and respectful of the boundaries of the hospitality. For the researcher, this means behaving conservatively and respectfully, not over-probing in sensitive areas, and not presuming on the intimacy in the relationship, in order to ensure that the relationship can be sustained over time and that the research participant host does not regret having entertained the researcher guest. Thinking of the relationship in this way may seem unusual, but it shares some similarity with how we might broach comparable issues with colleagues, relatives, or neighbours. In my case, although I
tend to speak candidly about Pap testing and other personal matters, I do not generally ask explicit questions of others about these topics unless they make some overture to suggest they would like to discuss it.

The consequence of this deference, in the initial planning sessions, was that there was no formal, direct questioning about the women's demographic characteristics or their experience of Pap testing. I forfeited such enquiries because this made sense in terms of the stated purpose of the meetings, and because it avoided the possibility of embarrassing the women. To identify the sessions as planning sessions but then to focus on individual women's screening status would have been inappropriate, and it might have made them feel uncomfortable or awkward. The liaison and I had each expected that the women might feel shy about revealing various details about their own lives, and my intention was to ensure that each woman could participate in a way that was as comfortable as possible.

The health promoter liaison and I agreed that it was most suitable to hold a brief (1½ hour) introductory meeting in my home, and the women were invited to come with their questions. At the first meeting we introduced ourselves to each other. The women had brought a young woman known to them from their Stress Management group to serve as translator. I spoke slowly in English, enunciating carefully and pausing after every sentence or two to permit her to translate into Portuguese. I provided information about cervical cancer and screening for it with the Pap test, the need to invite underscreened women, and research design issues relevant to this, and answered the women's questions about these and other related matters.

Afterwards, telephone discussions with the health promoter and the natural leader of the group elicited concerns that might restrict the women's participation. These included increasing family responsibilities as the Christmas holidays approached, travelling on the transit system after dark, and a disinclination to go out in Canadian winter weather. Of these, the latter seemed to be the most serious, reminding the women of how much they missed their origins in sunny, mild Portugal and how no matter how long they live in Canada, they never get used to the weather. Nevertheless, the women did consider the topic important, and the natural leader reported back "Everybody says okay". That is, the women agreed to meet once every month or so until Christmastime.
3.2.3 Data gathering

After the introductory session, five more sessions were held with the initial planning group of Portuguese women. Each meeting was attended by five or six Portuguese-speaking women, all but one including the interpreter. The interactions with these women yielded narrative and analytic data.

3.2.3.1 The interpreter

The interpreter was at the time enrolled as a student in Physical Education at the University of Toronto. She knew the women through the Stress Management classes at the Access Alliance Community Health Centre. She had been born in the Azores and had moved to Brazil with her family when she was younger. She still lived at home with her family, who lived a traditional Portuguese family lifestyle, speaking Portuguese at home.

3.2.3.2 Interactions

Some of our interactions were anticipated and due to my deliberate efforts, others were unexpected. From my perspective, our contact was characterized by warmth, mutual respect and good humour. As hostess of the sessions in my home, I served tea, and initially, snacks. As the outsider in their "Stress Management" group, I introduced myself and asked their names. As researcher, I let them know that I was happy to share my knowledge about cervical cancer and that I valued their input as experts in being Portuguese women. When I asked questions, I made an effort to respect their need for privacy, not probing further about personal details if the woman appeared less than completely comfortable. When the women shared a joke among themselves, I asked them to tell me what was funny, and then responded in turn. My willingness to allow topics to remain somewhat impersonal yet to banter with the women when they initiated it meant that the mood remained light and good-natured. The women seemed relaxed and comfortable talking about sensitive issues.

Not all our interactions proceeded as anticipated, and this meant that I had to modify my behaviour and expectations. My initial efforts to elicit information using simple, direct questions did not always elicit simple, direct responses. Instead, as described later in the
methods section on data inscription, my questions prompted several, sometimes simultaneous, narrative tales. In contrast, questions that I had considered more abstract were sometimes answered in literal or practical terms. At times, the mixed style of communication was disconcerting, and I felt lost and confused. When this happened the look on my face showed that I was puzzled. The interpreter would break in with information to help me understand what the women meant. At other times, when the women became caught up in telling stories, the interpreter would indicate, with a few words or a nod, that I should just be patient and listen, that she would explain why this was important later. She summarized the main themes and points of agreement and disagreement, facilitated the discussions, and provided background and context about these women's lives. These contributions, by the interpreter and others, provide "auxiliary conjecture" (Lofland & Lofland, 1995:139), that is, explanations by group members of the phenomena in question. These are incorporated into and supplement the results: analysis and interpretation of issues relevant to underscreened Portuguese women's adopting of Pap testing, practical concerns relevant to inviting these women for Pap testing, and research questions and issues emerging from these initial meetings.

3.2.4 Data focussing

Data focussing requires asking a question about a social science topic (Lofland & Lofland, 1995:149). Subsequent meetings were centred on discussing how to invite underscreened Portuguese women for Pap testing, and on understanding the barriers and facilitators that might serve to influence its adoption. As suggested by the natural leader, an agenda with a set of preliminary questions was used to focus discussions. The interactions were guided by qualitative analytic methods, familiar from grounded theory (Schwandt, 1997:60-1). The approach, which considers the women as the experts, or key informants, involved soliciting their expertise, documenting, and probing in a respectful manner, and analysing the disclosures in a way that recognizes varying levels of abstraction (Glaser & Strauss, 1967, Glaser, 1978, Strauss & Corbin, 1990. Various formulations were posed of the question "How can we invite other women to have Pap tests?", and initial responses were followed up using standard probing techniques. That is, nodding, or prompting with verbal cues such as "Tell me more about that", was used to elicit more information and explore the meanings of responses. This approach respected the women's predilection for developing concrete, specific strategic planning ideas for an intervention, but also explored why these
recommendations were being made, that is, identifying which issues were likely to be relevant in promoting adoption of Pap testing.

The approaches to elicit and analyse the data were both passivist and activist (Lofland & Lofland, 1995:145-6) and correspond to five of the eight propositional forms for qualitative observation and analysis (Lofland & Lofland, 1995:157). Citing Blumer (1969), Lofland & Lofland (1995:45) explain that the passivist perspective views humans as "more or less neutral media through which social forces operate and out of which social forms and organizations are composed". Four of the five propositional forms used correspond to this passivist perspective: structures, processes, causes and consequences. The first two, structures and processes, were applied to consider what Portuguese women's lives are like, i.e., how they are structured and function. Causes and consequences explored, among other things, what factors prompted provision of Pap tests, and with what result.

These passivist perspectives are in contrast with the fifth propositional form, an activist approach, that focused on choices about adopting Pap testing. The activist approach explored human agency (Lofland & Lofland, 1995:157), or the situations facing the women, and the strategies they use to deal with them. The situation aspect does complement the passivist propositions, which simply describe the objective characteristics of the situation of cervical cancer and Pap tests, that women face. The questions of human agency or strategy are intended to deobjectify and demystify social arrangements (Lofland & Lofland, 1995:147,170-2). The activist perspective involves moving deliberately beyond concrete details, to "deciphering and depicting exactly what sort of situation the participants are facing" (Lofland & Lofland, 1995:146). This perspective goes beyond simply describing observable processes, to explore and understand the meaning behind the actions, ideally identifying "collective self-deceptions" and "situationally induced irrationality" (Lofland & Lofland, 1995:171). This process expresses moral aims of social science's questioning mindset: "aims of widening peoples' perceptions of their situations and of enlarging their perceptions of social arrangements [...] [to] open the way to humane social change" (Lofland & Lofland, 1995:171-2). Human agency refers to the strategies women employ regarding cervical cancer, including their choices about the relevant health behaviour, Pap testing. It includes women's objective responses to invitations to have Pap testing, as well as their subjective dealings with their own understandings. Following Lofland & Lofland's (1995) recommendation, the emphasis here was not on psychology, but on recognizing
how social organization might be relevant for Portuguese women as they face choices about Pap testing.

An example may help clarify the differences between psychology and social organization, and between passive and active analyses. When Portuguese women described work and family obligations, this was accepted as a reality. The business of their lives was interpreted not as some psychological rationalization for not having Pap tests; it was accepted, at face value, as likely to restrict a woman going to a doctor without symptoms. Then, these passive descriptions provided a starting focus for the activist perspective, to identify what social constructions they might express. That is, do these obligations provide a context for decisions about self-care? Do they dominate or influence values, expectations, or choices regarding health behaviours? It also means considering other questions, which remain unspoken, such as: How does this relate to what other respondents report? What other pieces of information resonate with this? How is this information important? Why did they choose to describe this, rather than something else? What is not being said here, that might have been expected?

In applying these propositional forms about structures and processes, causes and consequences, and human agency, (Lofland & Lofland, 1995:156-7) there was a desire to include women with diverse experiences. The intention was to understand where women, in a group that was relatively demographically homogeneous, shared similar perspectives, and where they differed. Heterogeneity in understandings and experience of Pap testing included: the first invitation (if any) to Pap testing; the response to any such overture; the experience of having a Pap test and internal examination; and the current levels of screening adequacy. This notion of including women with a spectrum of experience parallels epidemiologists' use of comparison groups, to produce findings that are valid and generalizable.

Therefore, the experiences and understandings of adequately screened women, as well as underscreened ones, were relevant. As stated earlier, though, women were not obliged to identify their Pap testing status and were not asked directly about it, because I wanted to respect their privacy, and I understood that not all of them would be comfortable disclosing such personal details. Nevertheless, they were welcome to attend and listen to those who could discuss these matters openly, and they were welcome to share their own experience.
They could choose to divulge this information directly, to make comments about Portuguese women in general, or even to present information about women they knew.

3.2.5 Data inscription

At our first meeting, we agreed that the most sensible way to document the proceedings was for me to sit at my computer and record as the women talked. At the beginning of each meeting, once we had exchanged preliminary friendly greetings, I began the inscription process for the meeting by typing which women were in attendance. No names or identifying information were to be used in publication, but for clarity, when a particular woman provided a story that was unique to her, I would note her initials in front of it. Typing meant that I could watch the women as they talked, make eye contact when possible, and take notes at the same time. The notes included quotes and observations of postures, gestures, tone, volume, or other indicators of mood or group dynamics. Recorded data thus included both verbal material in the form of questions and responses, as well as participant observation.
3.2.5.1 Advantages of typing

The main advantage of typing was the convenience of using the computer to inscribe the data in the moment. The entire process seemed surprisingly unobtrusive and comfortable for all of us. There were several reasons why it may have worked so well. First, the pace of the discussions was restricted by some women's diffidence in expressing themselves in English and the need to translate everything. Second, translations of the women's responses were not always verbatim; translations sometimes were controlled or prompted by the women, with directive nods or gestures or words, for summaries of the preceding discussions, highlighting key issues or points of agreement or disagreement. These translated comments were remarkably succinct. Occasionally, women other than the translator also contributed summaries in English to write down. Third, the process worked well because the women were comfortable with my interrupting them with questions or requests to repeat pieces that I had missed. Anytime I did not understand what they had said, or had missed something that a number of them were attending to, I asked about what was going on. My use of clarifying questions, essential and natural to qualitative enquiry, did slow the process down even further. All of these things, which slowed the pace, made the typing process easier, and ensured that I was documenting what the women considered important for me to know.

3.2.5.2 Disadvantages of typing

There were some disadvantages of typing during the meetings to produce the data for these initial planning sessions. The most obvious is that it took a lot of effort to keep my attention sharply tuned for the entire meeting time. This technical challenge is not as important as a related disadvantage of typing, that is, an entire step in data generation became invisible. My choices about what data to attend to, what pieces of conversation and disclosure to recognize and record, highlight just how data inscription is a "process of selective attention" (Schwandt 1997:71). Certain things diverted my attention from the typing process, including refilling the women's cups of herbal tea, or even hearing my cat meowing at the window and going to let him in. In those cases, I would choose to do those things when the women were engrossed in their own conversations, or there was a natural pause, and then, if the conversation had moved on when I returned, I would ask what I had missed. Several factors consciously influenced my attending to the women's disclosures,
including language, volume, repetition, emphasis, emotion, body language. This was so particularly when other group members indicated something as important, by speaking more loudly, by repeating words or phrases, by translating key words or phrases themselves or by directing the translator’s attention to a particular disclosure, by nodding in agreement or comprehension of a point made, by "mmm-ing", or by incorporating names of people or places into what seemed to be a continuing narrative about a particular situation. If no translation or clarification was spontaneously offered, I would request one. Other factors, that were not applied consciously, but of which I was aware, include the biases described in the researcher's background statement. Factors that remain unconscious or unrecognized may also have influenced the production of these data.

3.2.5.3 Why not use a tape recorder?

Had we relied on a tape recorder, transcripts would have been difficult, if not impossible, to produce and to follow. Although a tape recorder could have been used to record these sessions, some technical matters would have to have been resolved: finding a convenient spot in my cramped flat to put the tape recorder; locating the microphone so that every woman could be heard distinctly and clearly; and attending to the machine during the meetings. These were hardly insurmountable, but the real problem with tape recording became apparent after the meeting was underway, and the women's enthusiasm surfaced. Once I had completed my introductory remarks, it was not uncommon for two or more women to speak at the same time. At times, the women held entire conversations with each other, and I was strictly an observer, neither a participant nor an interviewer. Add to that the laughter and verbal interjections of the women, and simple tape recordings would have yielded virtually unintelligible raw data. If the transcriber could actually tease apart multiple simultaneous contributions, there would still remain the challenge of reassembling the parallel conversations. This would have been very difficult because, although there was clearly a sense of focus on particular topics, there were neither formal addresses to the chair nor identification nor recognition of who each speaker was. While these unexpected interactions indicate potential problems, the health promoter assured me later that if Portuguese women were talking together and laughing, it meant the meeting had gone well, i.e., the women were interested, and comfortable with me and with the topic at hand.
3.2.5.4 Data transcripts

The transcripts from each meeting were saved on hard disc and diskette and formatted to yield unique identifiers for each line of text. The first page of each transcript included the meeting date and time and the names of the women attending. Subsequent pages were formatted within WordPerfect 6.0 to produce unique identifiers for each line of data. Each page included the date, in the six digit format "year year month month day day", followed by a colon and the page number. Each line was numbered in the left margin. The identifier included the information "meeting date: page number; line number", a complete source citation for any line in the data. These identifiers, though eliminated in the final write-up, provided a reference to the chronology of the information.

3.2.6 Data analysis

Printed and electronic versions of the transcripts were used for review, coding and analysis of the data. Two sets of formatted data were printed out. One set served as the reference document and the other as the working document. As described above, these data included the women’s English quotes and translations / summaries of their Portuguese narratives, as well as my questions and elemental memos about the interactions (as described by Lofland & Lofland, 1995:193-7). The working printout was reviewed for key words and phrases or meaningful narratives that specifically addressed the propositional forms described above, or that generally addressed the topics relevant to the objectives. These sections of text were underlined, and / or the margin was annotated with codes to describe that section. Coded pages were cut apart as necessary into segments, and sorted into topic folders. Folder topic headings were: initial planning methods and results; Portuguese women's situations; knowledge, attitudes and behaviour; barriers & facilitators; intervention ideas; and planning for the intervention. The categories used for codes and topics were neither rigid nor mutually exclusive, they were simply flexible and convenient tools to sort and keep track of the data (Lofland & Lofland 1995:182). Having sorted the data in this way, all the folders were opened and spread out on a large work-surface in preparation for the next step in the analysis.

It is easy to explain the physical sorting processes but difficult to describe the transition to the more abstract part of the analysis; part of the complexity may be apparent in coding
details. Table 2 is included below as an example of the researcher's preliminary and tentative efforts to organize the data, in preparation for and as part of the analysis. It presents topics, codes and elemental memos, and quotes with key words and phrases selected from the Barriers and Facilitators folder; there is considerable overlap in the codes and memos across folders. The quotes here were selected for their shortness and their clarity out of context; the researcher's notes may reflect the context as well. Comparison of these entries with the final analysis would show that the assignment of codes is not rigid; it is flexible and provisional.
Table 2. Codes and elemental memos, and quotes with key words and phrases, from the initial planning sessions with Portuguese-speaking women, concerning barriers and facilitators.

<table>
<thead>
<tr>
<th>Codes and elemental memos (Researcher)</th>
<th>Quotes with key words or phrases (Women)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barrier language</td>
<td>&quot;brochures are only in English&quot;</td>
</tr>
<tr>
<td>Barrier doctors</td>
<td>&quot;some doctors don't suggest it&quot;</td>
</tr>
<tr>
<td>Barrier suspicious of motivation of recommendation for testing when someone is healthy</td>
<td>&quot;They never did it before, why are they gonna do it now? Doctor business?&quot;</td>
</tr>
<tr>
<td>Attitude fear fear of mortality due to cancer</td>
<td>&quot;She has headaches she thinks she has cancer.&quot;</td>
</tr>
<tr>
<td>Perception Social reality? Belief diagnosis=death</td>
<td>&quot;Once it's got you, you're dead, within months... [a very energetic woman] died of cancer... hit on the head... never got better.... went blind and died.&quot;</td>
</tr>
<tr>
<td>Perception Social reality? belief</td>
<td>&quot;died in seven weeks&quot;</td>
</tr>
<tr>
<td>Knowledge fatigue</td>
<td>&quot;neighbour who's 16 years old... fever... tired... little bump on the head... one week... it's too late&quot;</td>
</tr>
<tr>
<td>Barrier? Facilitator? Attitude? Belief? Does this increase fear and sustain state of ignorance?</td>
<td>&quot;negative thoughts. always arguing, irritated, then you can get sick&quot;</td>
</tr>
<tr>
<td>Attitude fear during diagnostic tests Fear isolation from spouse</td>
<td>&quot;&quot;I have lots of pains in my bones... so he make the bone marrow. because the rescue, maybe you have the cancer, the 2 weeks, I don't tell my husband.... I'm already scared, I don't need to make him scared.&quot;</td>
</tr>
<tr>
<td>Diagnosis sadness fear, alone? isolation?</td>
<td>&quot;Right to her face they said that's cancer.... She cried all night. Then they took tests and they removed it and they said it wasn't the dangerous kind of cancer.... It hurt so much... but not cancer.&quot;</td>
</tr>
</tbody>
</table>

N.B. The entries in the right-hand column are short narrative extracts considered understandable out of context; entries in the left-hand column may also reflect the context. The researcher's notes are provisional, and function primarily as tools to manage and organize the data for analysis.
3.2.7 Analysis and interpretation

The next phase of analysis shifted the emphasis from sorting individual pieces to framing the study in generic concepts, seeking patterns within the historic particulars of the data. Lofland & Lofland (1995:164) described three dimensions of the developed treatment in social science framing: elaboration, balance, and interpenetration. Elaboration means identifying major conceptual or analytic subdivisions that would form the basis of the report. The tangible expression of this intangible process began with the production of working diagrams and tables drawn on the front of the folders. These diagrams summarized the contents and possible interrelationships within and among folders. The other two dimensions of a developed treatment, balance and interpenetration, seemed to overlap here: both were directed to making sure that the data and the analyses of them were complementary in quantity and in content. As the diagrams on the folders were prepared, the printed reference document was used as needed to confirm the context of particular pieces of paper. In parallel with this process, the text was reviewed onscreen just for quotes. The most concise and explicit quotes were selected and extracted. These were grouped and compared with the folder categories and their contents, to ensure that the analysis remained focussed on what the women themselves said. These processes of checking back to the full text and to the quotes alone were used to achieve qualitative research's method of constant comparison (Glaser & Strauss, 1967:101-16). Selected extracts to demonstrate this process were included as part of the formal results.

3.2.8 Returning the results for review

My analysis and interpretation of the data was done independently, and then the drafts were returned separately to the translator and the natural leader of the initial planning group. Returning the results to original participants was another step taken to ensure that I had not imposed the findings. I contacted the interpreter and the natural leader of the initial planning group and asked if they were interested in participating in this review process. I summarized the results verbally, and provided drafts of the methods and results sections to the two women. The women were asked to review the results, to decide whether they seemed complete and whether the summaries and interpretations were reasonable. They were encouraged to identify things that were wrong or missing, or that should or could be clarified, corrected or improved. Both women, on opening their file folders, began reading
the results document immediately, with interest and enthusiasm. Their initial assessments were largely positive: the themes seemed complete and prompted a lot of good memories about those meetings and interactions in them.

I encouraged the women, again, to consider what I might have missed or misunderstood, and the women took their folders home to review. Later, we had meetings with two or three of us together, referring back to the transcripts and using a Portuguese-English dictionary as necessary to be sure we understood each other. The women's comments suggested some small but important revisions and one significant addition to this set of results. Inserted at the location the women considered appropriate, and indented to indicate its unique status, that section expresses ideas about communication which the women felt had not been emphasized enough or had not been explained adequately. The women affirmed that this additional material represents no new ideas; it includes what the women had tried to convey in the initial planning meetings, but which the earlier draft had failed to fully capture. Negotiating and discussing these matters at length provided confidence that the results reflected fairly what the women had been trying to convey in the meetings.

Although the formal write-up did not take place until after the health events, the transcripts themselves were reviewed and reflected on, as background for discussions with community contacts. In parallel with, and following the initial meetings with the Portuguese women, more contacts were made with key informants in the community. A set of collaborative working relationships with staff and clients of community agencies serving Portuguese-speaking people culminated in the establishment of a community steering group. This group was at the core of a larger circle of key informants who contributed to the research development process, and the methods to develop those community partnerships are described next.
3.3 Collaboration with the wider community

The initial planning sessions were described using qualitative social science terminology (e.g., Lofland & Lofland, 1995, Glaser & Strauss, 1967:101-16); here, the collaborative processes with the wider community are described primarily using the language familiar from health promotion planning and evaluation (Green & Kreuter, 1991). While the focus of the deliberations was on identifying and addressing key issues relevant to promoting adoption of the health behaviour of Pap tests (corresponding with the PRECEDE diagnostic phases) for this objective the processes of the collaborations are described (using PROCEED) (Green & Kreuter, 1991). The focus here is on the continuing, interactive and iterative process of research development, critical to decisions about feasibility.¹ Later, within Objective 2, the activities associated with the health events are reported using the traditional process evaluation (PROCEED), within Objective 3, the invitation study is reported as a traditional epidemiologic trial, and within Objective 4, the findings of barriers and facilitators from the entire project are presented using the PRECEDE framework (Green & Kreuter, 1991).

The wider community contacts can be separated into two groups, key informants who were on the community steering committee, and others. An important difference between the initial planning group described earlier and these key informants was that this wider community group included not just Portuguese-speaking women themselves, but those who might have some professional or personal contact with them. The designation of key informants as belonging to the community steering group or not is informal and somewhat arbitrary, being defined by contributions to or attendance at the community steering meetings, which culminated in the health events and the invitation trial. Other key informants who were not part of that community steering group provided their guidance independently. They provided their perspectives about issues relevant to developing a research project or to identifying and reaching underscreened women, or about factors that serve as barriers or facilitators of Pap testing.

¹ This decision recognizes the convention of the health promotion program planning and evaluation framework of Green & Kreuter (1991), where the PRECEDE phases occur (not surprisingly) before the PROCEED phases.
3.3.1 Community steering group

Identifying community partners was done in a way compatible with the role of the "outside researcher" (Lofland & Lofland, 1995:37-41). Gaining access to research participants (in this case community collaborators) by negotiation involved connections, providing accounts or explanations of proposed research, sharing knowledge enough to demonstrate competence to do the research, and courtesy. In my case, negotiations were not just to get permission to have access, since the agency might not necessarily have direct links to a group of relevant women. The negotiations also sought referrals to other agencies and individuals with interests, abilities and resources compatible with the project, commonly known as the "snowball" technique. Depending on the role of the contact, or their responsiveness, discussions could also elicit factors surmised by that person to serve as barriers or facilitators of Pap testing in the population of underscreened Portuguese-speaking women.

Each successive encounter built on the preceding ones, and the longer the project went on, the more the same core set of names came up. The broad consensus about which contacts were appropriate was largely affirmed by those individual's interest in the project. "Saturation" was thus achieved from two perspectives: in identifying relevant community members and in their participation. As community members became involved, they also suggested or sought out more contacts from their personal and professional networks. In all of these encounters, courtesy meant that the accounts and knowledge provided began as brief overviews, and the balance of the contact depended on that person's interest and inclination to know more. If initial telephone calls indicated some receptivity, a follow-up interview or presentation would be arranged for either that person alone or for the group represented. In the first meetings with these other contacts, the researcher generally provided information about relative rates of cervical cancer, risk factors for cervical cancer and the role of Pap testing in cervical cancer screening to reduce excess morbidity and mortality. By the end of these, it was generally clear whether the agency or individual was interested in participating, and then discussions would proceed, if they had not already done so, to identifying what type of participation they wanted. Efforts to invite community members to work with us centred around the notion of each partner providing whatever service they were most capable of providing, whatever was easiest for them, or whatever suited them best.
3.3.2 Other key informants

Key informants other than those on the community steering group were identified in the same way described above. They included people who were involved in some way with Portuguese-speaking women, and who may have been in a position to identify issues relevant to these women's choices about health behaviours. These included members or representatives of social support groups or service agencies, including churches, public health agencies, neighbours, colleagues, and physicians serving Portuguese-speaking people.

The results of these collaborations with the wider community are presented using the PRECEDE-PROCEED process evaluation, which describes the inputs, implementation activities, and stakeholder reactions relevant to the development of a research project.

Besides Objective 1's project development, the initial planning group and other community contacts contributed to the other objectives. They suggested approaches to identify and reach underscreened women in Toronto, elaborated more fully within Objective 2. Contacts provided information about measuring impact, i.e., the target behaviour of Pap testing, for Objective 3's trial with underscreened women. Finally, community contacts provided guidance to clarify, correct or confirm the research findings, for Objective 4's synthesis of barriers and facilitators.

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1. Inputs include theoretical and material inputs relevant to this research development project. Implementation activities include the data and events generated. Stakeholder reactions indicate how the intended participants responded to these.

2. At this point, epidemiologists and statisticians may note that impact measures would be labelled in their disciplines as outcome measures, but here, for consistency, the terminology of the PRECEDE-PROCEED model (Green & Kreuter, 1991) is maintained.
Chapter 4 Results for Objective 1: Project development

Objective 1. To develop, with community partners representative of a population of underscreened women, a research project to identify and address key issues relevant to promoting adoption of a health behaviour.

The results of the project development are presented in two sections, corresponding to the small initial planning group and the larger community group which included the steering group and other key informants.

4.1 Initial planning group

4.1.1 The women

These women were all known to each other, having graduated from the Stress Management program at Access Alliance Multicultural Community Health Centre. Excluding the translator, all but one of these women were married. Their Pap testing history was not formally requested, but it seemed as if it was a regular part of their lives. Some of these women had children. All but one of these women held at least one regular job, and all of them had significant family commitments and obligations. They all appeared to be between the ages of 45 and 60. Their clothing and demeanour, other than their language, would not identify them as being members of any particular ethnic or cultural group. Generally, the women wore clothing of conservative cut and colour, often skirts and jackets or sweaters in muted tones and subdued patterns, and often in shades of black, blue or brown. None of these women dressed completely in black, the colour traditionally worn by widows. They generally sat erect, with their hands resting on their laps and their elbows resting closely by their sides. They wore sensible shoes, and often they crossed their ankles and tucked their feet under their chairs. Some of the women had been born on the mainland of Portugal, others were from the Azores, the translator was born in Brazil; all were first generation immigrants.
4.1.2 Representativeness

The women participating in the initial planning group may not be representative of the group of greatest interest for recruitment (i.e., underscreened) in the sense that they were most likely adequately screened to prevent cervical cancer. In terms of demographics, from what was disclosed, it seemed that the women were over 40 years of age (except for the translator), immigrated from a Portuguese-speaking country (the continent and the Azores and/or Brazil), and spoke Portuguese at home. The group included women who differed by marital status, parity, employment, English language facility, literacy, and their use of publicly available resources such as libraries. Their personalities and communication styles differed too, e.g., assertiveness in asking their doctors questions, and the level and type of social interaction they enjoyed. Some of the women talked spontaneously about their own experience about adopting Pap testing. Others did not; it is possible that they had not previously had Pap testing. For the women who did describe it, it seemed as if this took place in Canada long after they were adults ("You're 50, it's time for do it"). These women remembered their introduction to Pap testing.

4.1.3 Analysis and interpretation

4.1.4 Overview

Several overlapping themes emerged in the meetings: time, isolation, communication and, underlying or pervading these, fear. The dominant theme expressed throughout these sessions is: “Portuguese women are terrified of cancer.” This fear seems to be a reasonable consequence of the Portuguese community’s understanding and experience of cancer. Table 3 summarizes the concerns and understandings with respect to cancer screening, symptoms, diagnosis and treatment. The text elaborates on these matters, relevant to promoting adoption of screening behaviour.
Table 3. Concerns and understandings about cancer from initial planning sessions with Portuguese women

<table>
<thead>
<tr>
<th>Aspects</th>
<th>Time</th>
<th>Isolation</th>
<th>Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening tests</td>
<td>My description of a long latency period for cervical cancer provided a meaningful rationale for screening.</td>
<td>Tests with little or confusing information contribute to concern.</td>
<td>Descriptions of screening tests imply detection is intended and anticipated.</td>
</tr>
<tr>
<td>Appearance of symptoms</td>
<td>Symptoms and pain prompt immediate anxiety and fear. Doctors' appointments may be very short.</td>
<td>Symptoms and pain justify seeing a doctor.</td>
<td>Women and their doctors may not have meaningful discussions about their concerns.</td>
</tr>
<tr>
<td>Diagnosis of symptoms</td>
<td>Diagnostic procedures are time-consuming.</td>
<td>Woman kept her fears from her spouse.</td>
<td>Women did not understand the diagnostic procedures.</td>
</tr>
<tr>
<td>Treatment</td>
<td>Aggressive and prompt treatments may take place while a patient deteriorates rapidly.</td>
<td>Being in hospital means being away from family.</td>
<td>Women did not always learn the prognosis for their medical condition.</td>
</tr>
</tbody>
</table>

4.1.4.1 Fear dominates

The Portuguese women expressed how terrifying cancer is for them and how that terror dominates their interpretation of physical symptoms. The women's concerns about the meaning of menopausal hot flashes was explained by the interpreter's interjection, with its concise explanation: "Portuguese women are terrified of cancer." She explained that every time her mother got a head-ache she wondered if it was cancer. Painful symptoms are understood as the threat of cancer. [Referring to Portuguese women in general] "Everything what hurts her, it's cancer, [even if the pain happens to be] in the head, in the ear." And further, "She think all the time that it's about cancer."

Portuguese community members fear cancer because of what they know and because of what they do not know. "Cancer is something that we fear more than any other disease because we don't know about it." The women did know some warning signs of cancer, i.e., "A lump" and "If you're too tired all the time." Yet, even from our first session together, it was clear that there was much that they did not know. The women were interested and pleased to learn a number of things: cancer cells are distinguishable from healthy cells microscopically and biochemically; cancers are characterized by unrestrained growth,
which nevertheless takes time to develop; and that cancer is many diseases, and different cancers have different natural histories, risk factors and prognoses. And yet, what the Portuguese women do know of cancer is not optimistic. Many of the women told stories with a tragic theme: friends’, neighbours’ or relatives’ lives ended abruptly following a cancer diagnosis. Diagnoses within the Portuguese community, occurring at a late stage when treatment is ineffectual, may contribute to Portuguese women’s equating a cancer diagnosis with a quick death. On prompting, the women did acknowledge that they had heard of some people who had survived following cancer diagnosis. “She knows someone that had breast cancer and she’s still alive. That’s sixteen years ago.” The response of another woman to this story was: “Sixteen years is a long time.” This discussion also evoked stories of tumours that turned out not to be malignant. Nevertheless their fear of cancer remained. One of the women summarized the tragic stories of people they knew who had gotten cancer, and this was translated word for word as “Once it’s got you, you’re dead, within months.”

4.1.4.2 Time

Various themes related to time were reflected explicitly and implicitly in the interactions with the women, and are apparent throughout other sections. As described earlier, family and work responsibilities limit the amount of time available to the women for self-care. Descriptions of the flurry of hospital procedures associated with cancer diagnosis and treatment seemed in contrast with the orderliness that seemed to mark their work and domestic routines. Women’s orientation to think about and plan for the future was apparent, and in their minds it provided a sensible context for adopting healthy behaviours. In addition, having learned briefly about the natural history of cervical cancer (in our first session together), the slow development of this cancer was received with optimism.

4.1.4.3 Isolation

Compounding the fear that grips the Portuguese woman facing the prospect of cancer is that she remains isolated in her fear. One woman described how frightened she was when she had a set of diagnostic tests done. The interpreter clarified “But you didn’t tell your husband.” She responded, with laughter, “I’m already scared, I don’t need to make him scared.” A Portuguese woman sets her family obligations and responsibilities ahead of her
own needs. In a discussion following the question "What is it like to be a Portuguese woman?", the first response was "The house, the home, that's what I think about. [pause] It's like a family."

Another woman interpreted "To be Portuguese means having to take care of your parents, it's expected of you, it's also expected of you to hold on to your kids until they're married...." This discussion was notable in that it evoked a calm, pensive, and tranquil mood, with less talking all together. Then, a final phrase summarized a Portuguese woman's responsibilities: "What a family means." A traditional Portuguese woman, whose first responsibility is the family, and not herself, means that she is likely to remain silent about her own fears. She faces her crises on her own.

Women's limited exposure to information about preventive care behaviours and the difficulty in communicating may produce some suspicion about what has prompted the suggestion of Pap testing and what purpose it will serve. "They never did it before, why are they gonna do it now? Doctor business?" i.e., Is this just extra business for the doctor? Similarly, on another occasion, a discussion of various women's perspectives on Pap testing prompted this summary:

[She] says people say "why do the Pap test?", explaining the basis for the scepticism: "Why do the test if half the time they do the tests they won't find anything and they have to open you up to find anything?" (and the implication is they can't do anything for you anyway).

Besides these explicit quotes, stories that women told about their friends' and relatives' experience of cancer indicated that they were familiar with extensive diagnostic procedures and surgical interventions, which were not necessarily helpful.

Going to the doctor for preventive care when someone is healthy was contrasted with the traditional Portuguese approach "Old people say: if you're sick, you go to the doctor, if you have symptoms like bleeding, headaches, vomiting in the morning." A Pap test when someone was asymptomatic did not make sense to everyone: "Lot of people know about the Pap test, some people say I got nothing wrong, why I got the Pap test?" The idea of going to a doctor for a Pap test was reported to be perceived as sensible if a woman had symptoms, but not necessarily if she was asymptomatic.
4.1.4.4 Communication

The theme of communication was interwoven through many of the topic discussions. The women realized how their limited English language facility restricts their capacity to communicate with English-speaking health care professionals and others. This was apparent in several ways: by the reluctance of some who were unsure of their English to use it; and by their stated desire to hear me speak English (slowly) and then hear it translated, so they could learn how to talk about these things.

With such significant barriers, it seemed surprising and somewhat contradictory to learn how easily some of the women had been prompted to adopt Pap testing themselves. Several women told similar stories of their physician having initiated the procedure. One woman described, with assistance from her friends, how her doctor had suggested it. "The doctor tell me 'Well, you're 50, it's time for do the Pap test.'" and "She's had 3 tests, and each time, the doctor reminded her ... 'it's time for do it'". Although the women acknowledged that they had many sources of information about health care, including friends and relatives, they did not describe spontaneous discussions about Pap tests: "She says her daughter never talks about it." A number of women contrasted the openness of Canadian society with their experience back in Portugal, where "intimate" topics, including pregnancy might not have been spoken about openly in a family. Despite the lack of communication about preventive care, there was agreement about the salience of a doctor's role. If the doctor advised a woman to have any test, she would probably do it. Even so, in their experience, and that of other women with whom they had discussed this topic, (i.e., after they had begun attending the sessions in my home) the women were not convinced that all doctors advocated for Pap tests: "We're saying that some doctors don't suggest it."

4.1.4.5 Planning intervention messages

These meetings were identified as "planning sessions", and although no formal plans for interventions were developed at these meetings, the women were clear about the importance of providing the right messages to women. In considering factors that might help women who needed them choose to have Pap tests, the women's suggestions indicated that the Pap test must be perceived as a normal behaviour, and that it must be
seen as safe and comfortable. One dilemma that emerged is when the concept of cancer prevention can suitably be raised. The women were explicit in advising not to put the words cancer prevention on the flyer, i.e., "it's too frightening". But that was one of the things they did want to talk about in the group. They agreed that in meetings people are there to learn, so it would be fine to raise the issue then. In response, to clarify, I asked: "So what should we tell women to help them decide to have a Pap test?" They replied; "It's an important question." "It's every year, it's a healthy test." When I asked "If you were unsure about going for a Pap smear, what would help you to decide to go?" one woman responded, as the others laughed in agreement: "Take them by the ear" [making the motion of pulling someone along to the location for Pap testing] The notion that it might be appropriate to compel Portuguese women to have Pap testing seemed logical to them, when they accepted the premise: "It's necessary to do it, she [a woman] always heard about it, it's part of life,..." Information and invitation messages about Pap tests could reasonably be provided either through the physician, or in group meetings.

Discussion with the natural leader and the translator for verification and clarification resulted in the addition of the next section. The natural leader and the translator eventually disclosed that the initial group discussions had touched on some of the complexities, confusions and challenges of communication about Pap testing, that I had either not fully recognized or had not adequately expressed. If all those original women had the opportunity to review the results, they were expected to recognize these points as small but important omissions. The points elaborated below, in italics, are thus also results; they tangibly demonstrate this iteration of the collaboration.

Three things emphasized about Pap test communications were: the role of Pap tests for asymptomatic women; the importance of women learning about cancer per se; and the expectation that some women will refuse invitations.

1. The women in the original group recognized that not every woman has the opportunity to talk about these things with people who are trusted and

1. The process of providing drafts of these results was reassuring and enlightening. I had invited them to identify anything I had missed, and took notes of their clarifications and amplifications. I drafted the section with the three points about communication and then edited it with the natural leader, line by line, word by word.
knowledgeable, whether daughters, friends, or doctors. Older Portuguese women might never bring up the subject on their own initiative, if they have no problems, that is, symptoms, so the issue would never be raised. And communication was considered essential if women are to understand that Pap testing is something that a healthy woman does, even when she has no symptoms.

2. The main reason the women had come to the first meeting was because it gave them the chance to ask questions about cancer. Two important questions were "What causes cancer?" and "What can be done to prevent or cure cancer?" Neither I, nor any scientists, knew all the answers to these questions [e.g., distinguishing between causes and risk factors, and recognizing that different cancers are different]. Even so, being able to talk about these things was interesting and important to these women. So, discussions with underscreened women might need to involve more information than just about Pap testing.

3. Communication would be important to help underscreened women to adopt Pap testing. But the women did not know exactly how to convey the importance of Pap tests, to convince underscreened women to have them. One thing underscreened women would need to know was the correct timing and interval to have a Pap test. As well, good communication would include explanations of what was involved and what the Pap test was for. Other than that, they did not know what format or content of the information would motivate underscreened women to participate. However, even if the communication was appropriate, some women would still not want it, and would refuse to have it.

4.1.4.6 Learning sessions

Learning about preventive care was considered important for Portuguese women. It seemed obvious to them that other Portuguese women would be as interested in learning about Pap testing as they had been at our first meeting. My question about what had prompted them to attend our meetings elicited several responses:

"Because it's never late for learning."

"We like know about the things, maybe some times coming."

"So you're healthy now, but later on you never know."
"Now you are healthy and you want to stay healthy."
"You want to stay prepared for the future."

I clarified "Is it natural for a Portuguese woman to think about the future?" and the women emphatically responded "YES." Learning about preventive care, and taking responsibility for their own well-being, was justified in the context of being able to continue to care for their families. This provided a rationale for them and those they knew to attend sessions or activities in which information on preventive care behaviours would be provided. For the women, keeping healthy was essential to permit them to fulfil their many roles and responsibilities.

4.1.4.7 Group setting

The notion of setting an intervention in the context of a group activity seemed natural and sensible to these women. These women generally met on the corner of my street and then arrived together as a group. When I noticed this, and asked what this meant, whether it meant they were nervous about our meeting (as I had been), they laughed and explained that no, it was just what they liked, what they preferred to do. Community interaction is an important part of their lives.

"A Portuguese woman is involved in other activities, not just work and sleep. Yesterday, the exercise class."
"Work, together, the church, a lot of Portuguese women go to the clubs. Lots of Portuguese clubs. Dancing and dinner and talking, That's very nice. Different traditions, meet some people and talk at different times of the year."
"The Portuguese community involves more in the church as well as in the community."

When I asked "Why do they go to church and to the clubs?", the response was "Change the mind, meet so many people, talk to friends you never talk for a year, if you go away, meet some people, different routine." The women did acknowledge that not every Portuguese woman is involved in the community, and that some maintain fairly isolated lives. "Lots of people like community, lots close the door." Even so, the women felt that group sessions were a good idea. "Better to learn about it in a group. Not so shy. Group is nice. It's better, yeah." Groups may provide a safe and comfortable setting for women to consider adopting preventive care behaviours.
4.1.5 Intervention ideas

In addition to the idea of setting an intervention in a group context, where women could learn about preventive care, other factors emerged as potentially relevant to an invitation study. The women seemed comfortable with the notion of interventions, and research on them. Indeed, they picked up the notion of intervention almost too quickly. At our first meeting, they responded to the information about sexual activity as a risk factor for cervical cancer by challenging the translator in Portuguese until she began blushing. When I asked for an explanation, the women told me "We want to be sure she's getting the test." As the meetings progressed, they reported having talked with other women about their own participation in our sessions, and having explained to their friends and acquaintances the importance of Pap tests. Their enthusiasm for sharing their knowledge with others was matched by their interest in learning about my training, skills, and doctoral work. My explanations about types and purposes of research designs that we might consider using for an intervention were readily accepted. Even the notion of using a randomized trial seemed sensible. They appreciated the importance of comparing different types of invitations, which the interpreter interpreted concisely as "com Lottario" (i.e., like Lottario). These women impressed me with their spontaneous acceptance of the importance of reaching underscreened women and of carrying out scientific studies on the relative efficacy of various approaches.

Other unexpected barriers to successfully reaching and inviting underscreened women were scheduling and misleading wording about the sessions. As mentioned in the methods section, the women admitted to an aversion to going out in Canada's bad winter weather. When we talked about staging a health event, the idea of scheduling it for good weather seemed obvious to the women. One key word also turned out to be important. In one variant of my question, I asked about factors that might help Portuguese women choose to have cervical cancer screening. They reacted negatively. Having confirmed that the women recognized the value of Pap testing, it took some time and effort to clarify that the problem was with the term "cancer screening". Screening implied detection of cancer, and since this was equated with death, the notion of screening was considered likely to be a deterrent against participation by Portuguese women. Set in the context of our discussions, this admonition referred explicitly to advance publicity for events, and not to discussions that would take place there.
The women recommended reaching out to women in various settings, using a variety of media, to disseminate information about Pap testing in general or our intervention in particular. The women recommended handing out brochures or flyers at settings as diverse as malls, festivals, and churches. This method was familiar to them and seemed viable despite concerns of limited literacy. The women recommended involving credible colleagues. They suggested the Access Alliance health promoter and priests, although they acknowledged that some of the churches were in decline and women in need of Pap testing might not attend. Other media suggested were radio, community television, videos and Portuguese newspapers. These ideas were explored as part of Objective 2, and helped shape the strategies used.

As for providing Pap testing itself, the initial suggestions were to provide clinics and suitable health care providers. Free clinics were suggested "like they have for hernias". Given the women's busy schedules, an immediate appointment might provide a good opportunity for a busy woman to agree to a Pap test. On the other hand, the women recognized that Portuguese women would want to be clean for a physical examination, so they might not agree to an immediate appointment if they had not bathed just beforehand. This thought prompted me to elaborate a research question about whether appointment scheduling made any difference to women's choices about having a Pap test. The idea of having Portuguese-speaking doctors at such a clinic was not suggested by the women, but when I asked about that, they considered it a good idea. Physician gender was raised by the women as important, but it is worth noting that not every woman was convinced that a female provider would be necessary. One reticent woman made a point to speak to me to explain that while having a female provider was essential for some women, it was not critical for her.

The challenge of communicating with women who spoke and understood only limited English led to the elaboration of additional research questions. At the first meeting, the women had expressed their preference for having me speak slowly in English, and hearing the translation into Portuguese, rather than having me provide information in Portuguese alone. They may have been shy to expose their limited English language proficiency, but spoke about this bilingual strategy optimistically. It gave them a chance to learn English words that they could use, e.g., in talking with their doctors, something they valued but found difficult to make time for. It also meant that they could teach me some Portuguese,
and indeed, one of the quietest women handed me a tiny piece of paper with a list of Portuguese words and their English translations. Their preference for the use of both languages (and the women did indeed switch back and forth between them) suggested to me that a bilingual brochure might be more valuable than a unilingual Portuguese one. This notion seemed relevant in both practical terms and in theoretical terms. From a practical perspective, a bilingual brochure is twice as long as a unilingual one and therefore costs a bit more to produce. From a theoretical perspective, including English in written brochures about Pap testing might facilitate more discussions, influencing the decisions women make about Pap tests. Reviewing these experiences in the months following our meetings, these concerns seemed amenable to further investigation, using a randomized trial design to investigate the utility of providing brochures in both languages, and exploring a mechanism by which this might influence long-term decisions about Pap testing.

4.1.6 Reflecting on the sessions

An intangible but remarkable aspect of our interactions was the level and type of disclosures that the women made - disclosures whose meaning I did not always understand. In trying to understand what the women had told me and how it related to my efforts, I sought guidance from others. An experienced researcher encouraged me to relax and encourage the women's use of narratives (Corcoran, 1994). Her suggestion to ask "What does it mean to be a Portuguese woman?" proved fruitful. A rhetorician (Boyd, 1995) consulted after the set of meetings had been completed, prompted me to consider how my demeanour provided a respectful environment in which the women could make a meaningful contribution to the work. Her point was the women had probably recognized what had not been explicitly articulated: that it was not a question of what we were there for, but for whom. The natural leader, an active member of the group, told me later about her memory of the first time we met: "You talked slowly and smiled a lot."

The next sections describe the process of research development as it continued with the community partners.
4.2 Community steering group and other key informants

This section presents the results of the research development process with the community steering group and other key informants. The implementation activities are presented first, in chronological order. The other two categories of the process evaluation, stakeholder reactions and personnel inputs, overlap with the implementation activities and with each other. That is because the people involved in development were often the ones doing the work. Their input included helping to plan and carry out the health events, and identifying key issues relevant to promoting adoption of a health behaviour. A key feature here is the section about conflict in the collaborative processes, and how it was resolved.

4.2.1 Implementation activities

The main implementation activities in developing the research project were personal contacts initiated by the researcher and meetings held with community-based key informants. Over 100 agencies and individuals from the wider community were contacted, most of them by telephone or in conference settings. Meetings were held with anyone interested in learning more about the study, in identifying key issues relevant to Pap testing, in providing information about possible approaches to identify and reach underscreened women, or in participating actively as part of the community steering group. Roles played by informants who were part of the community steering group are presented later in this section, as part of stakeholder reactions. Meetings and sessions held to develop the research project are included in Table 4, which indicates the timing, location and activity. Both abstract and concrete matters were dealt with in meetings of several types: professional workshops which addressed issues of underscreening or reaching minority populations; Community Steering Group meetings and training sessions; and interviews with key informants who provided expertise on clinical, cultural or technical matters. The Community Steering Group, formally established by the end of the second year, continued to identify contacts and resources relevant to developing a research project, and to identify issues relevant to Pap testing. Some of these are presented below, and some as part of Objectives 2 and 4. The most practical manifestation of the group's work was preparing and presenting health events, towards the end of the third year. This was determined to be an appropriate and acceptable activity to identify and reach underscreened women, in order to invite them for Pap tests. Planning for the health event included organizing meetings
with the community partners, training sessions held for Health Event Representatives, and site visits before the events. Details of the activities involved in the health events and for the trial are presented as part of the methods for Objective 2 and 3 respectively. By year four, activities in seeking possible institutional partnerships and/or settings to reach underscreened women resolved into the development of doctors’ surveys.

Table 4. Meetings with community partners for research development: Timing, location, and activities

<table>
<thead>
<tr>
<th>Study Year</th>
<th>Month</th>
<th>Meeting location</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>First Canadian Portuguese Club</td>
<td>Presentation to Portuguese Interagency Network, Elderly Committee</td>
</tr>
<tr>
<td>1</td>
<td>8</td>
<td>NCIC Workshop, Halifax, NS</td>
<td>Workshop on Behavioural Science Applications in Cancer Prevention, National Cancer Institute of Canada (NCIC)</td>
</tr>
<tr>
<td>2</td>
<td>5,6</td>
<td>Parkdale Community Health Centre</td>
<td>Presentations to health promoters &amp; clinical team</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
<td>Immigrant Women’s Health Centre (IWHC)</td>
<td>Presentation; discussion of their role providing clinical service &amp; health outreach to 6 communities; worksites; English as a Second Language classes; health fairs</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
<td>Immigrant Women’s Health Centre</td>
<td>Discussion of barriers and facilitators reaching women; Their experience with health event fora = marketplace, with “passports” for data</td>
</tr>
<tr>
<td>2</td>
<td>11</td>
<td>University of Toronto, Department of Preventive Medicine &amp; Biostatistics</td>
<td>Meeting of academic and community people, formal establishment of Community Steering Group (CSG)</td>
</tr>
<tr>
<td>2</td>
<td>12</td>
<td>onsite visit</td>
<td>Observed IWHC’s lunchtime presentation about women’s health, spoke with staff nurse</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>NCIC Workshop Vancouver BC</td>
<td>Workshop Theme: Reaching the underserved with cervical and breast cancer screening programs</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>HealthWatch</td>
<td>CSG Planning, discussions of roles, secretariat</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>Promoting Women’s Health Conference</td>
<td>Discussions with Women’s Health Event Co-ordinator &amp; Ontario Coalition of Agencies Serving Immigrants staff</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>HealthWatch</td>
<td>Program opportunities; contacts who could serve as Health Outreach Volunteers; discussion with hospital housekeeping staff</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>Doctors Hospital</td>
<td>Discussion of possible roles: Administrative resident &amp; Director of Community Outreach, St Michael’s Hospital</td>
</tr>
</tbody>
</table>

1. Over the course of this project, the Department of Preventive Medicine and Biostatistics merged with the Department of Behavioural Sciences. It is now the Department of Public Health Sciences.

2. Healthwatch was a women’s health clinic at Women’s College Hospital.
<table>
<thead>
<tr>
<th>Study Year</th>
<th>Month</th>
<th>Meeting location</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>5</td>
<td>Maternal Infant &amp; Reproductive Health Research Unit (MIRU)</td>
<td>CSG, Health event planning</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>Trinity Bellwoods Community Centre</td>
<td>Presentation to 14-20 women at PW55+ (Portuguese Women 55 Plus)</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>Festivale St. Antone</td>
<td>Attempted handout of posters</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>Doctors Hospital</td>
<td>Community Steering Group meeting</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>Qualitatives Conference, Ontario Institute for Studies in Education</td>
<td>Interdisciplinary perspectives: Barriers to research with minority populations</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>Centre for Health Promotion</td>
<td>CSG: Planning training for Health Event Representatives: Event location, timing &amp; resources</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>Doctors Hospital</td>
<td>Training session I for Health Event Representatives</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>YMCA/YWCA</td>
<td>Site visit</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>Davenport-Perth Community (Health) Centre (D-P CHC)</td>
<td>Site visit</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>Doctors Hospital</td>
<td>Training session II for Health Event Representatives</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>YMCA/YWCA</td>
<td>Health event 1</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
<td>D-P CHC</td>
<td>Health event 2</td>
</tr>
<tr>
<td>3</td>
<td>9</td>
<td>D-P CHC</td>
<td>Health event 3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>The Toronto Hospital (TTH)</td>
<td>Discussion regarding institutions and affiliates as sources of underscreened women</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>TTH Family &amp; Community Medicine</td>
<td>Discussions of project design, sampling, data</td>
</tr>
<tr>
<td>4</td>
<td>8</td>
<td>TTH Family &amp; Community Medicine</td>
<td>Approval processes initiated</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>College Street</td>
<td>Doctors' walk-about survey begins</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>TTH Family &amp; Community Medicine</td>
<td>Approval processes completed, TTH Doctors'survey begins</td>
</tr>
</tbody>
</table>

N.B. A few of the meetings for the Community Steering Group are included on this table to illustrate the partners and various locations where they took place.

Workshops and conferences provided resource material and contacts. Conference packages included relevant literature. Presentations and conversations during and after conferences were candid and revealing. Insightful researchers and clinicians emphasized some clear themes: an awareness of and appreciation for the difficulties of research or
evaluation in the area of cancer screening; and for Pap testing, the challenges in identifying underscreened women, in reaching the underserved, in providing suitable programming, and in establishing a centralized registry of screening activity.

At the meetings for the Community Steering Group, introductions were made, the project was described, and we affirmed the importance of partners participating in ways that they wanted. As discussions and meetings with community partners proceeded, meetings were arranged with some of them and with academics based at the University of Toronto. Besides formal meetings, individual telephone calls were provided by the health event coordinator and myself, to ensure those who could not attend every session were up to date. Before meetings with the entire Community Steering Group, discussions with potential community partners explored possible areas of collaboration. They identified their agency catchment areas, priority populations and services, agency history, shifts in priorities and provision of services, provider roles and experience with Portuguese-speaking women, involvement in outreach services in community settings, and data collected by their agency. In the meetings, partners identified their links with agencies and individuals that would be relevant for this project, and undertook to pursue those to make sure the project could move ahead. This included links with physicians, administrators, hospitals, specific churches or church organizations (e.g., Portuguese Pastoral Council). They identified what they could and would provide as resources in holding the health event. This included materials for display and distribution available through their employer or other contacts, including posters, brochures, and hospitalities. Considerable time was spent on detailed problem-solving, planning the details of implementation, and developing, pre-testing the questionnaire and reviewing its administration.

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1. On the other hand, some key people involved with provincial and national efforts had different ideas about what the key issues were: i.e., young women should be the focus of recruitment efforts, because they contribute such a large burden of precursor lesions; elderly and poor women do not go to their doctors; and, a population registry would solve the recruitment problem by permitting the use of written personalized letters to invite underscreened women to have Pap tests.
4.2.2 Stakeholder reactions & inputs

The implementation activities were carried out by agencies who supported or participated in the project, and thus also measure resources expended and stakeholder reaction. Here the evaluation of the process is considered from both a concrete perspective (i.e., who provided what) and an abstract one (i.e., motivations to participate and conflicts and their resolution).

4.2.2.1 Inputs: Resources

Resources include funds, personnel, and space allocated or expended. One of the most obvious resources was myself, the researcher, who received a Steve Fonyo studentship from the National Cancer Institute of Canada. This financial support (~$19,000 per annum for four years) helped to ensure, with additional private support, that this project could be done on a full-time basis. The former Department of Preventive Medicine and Biostatistics provided early development support in the form of subsidies on travel, photocopying, and long distance telephone bills. The Maternal, Infant and Reproductive Health Research Unit (MIRU) provided $5,000 seed money and access to consultants for developing the research plans. The money went to honoraria for the health event co-ordinator and representatives and photocopying and incidental expenses for health events. The consultations provided by MIRU included the randomization strategy and data base management. Space allocated for the project included my personal work space at home and the office space provided at MIRU at the Centre for Research in Women's Health.

Resource: Questions from the National Population Health Survey (Statistics Canada, 1996) and the Census (Statistics Canada, 1988) were used to develop the questionnaire for the health events. The Portuguese version of the National Population Health Survey was provided by Statistics Canada (~1994).

1. Other measures of stakeholder reactions are the baseline measures characterizing the women who responded to the planned activities (a process measure). This includes age, language and screening status of the population who attended the health event for Objective 2, and the response rate of eligible women to the invitation trial for Objective 3 (an impact measure). Each of these are relevant in some way to the feasibility assessment of the research project.
4.2.2.2 Motivations to participate (or not)

Many people who participated saw a natural link between their agency's mandate and the project objectives, which had been clearly described as being directed to understanding and addressing the needs of underscreened women. Particular individuals within these agencies were familiar with Portuguese women, their lives and challenges, and were aware of how difficult it was to get them to participate in medically-based preventive care strategies. Some of the partners spontaneously indicated that they had been prompted to participate by concerns for underscreened Portuguese-speaking women, who were recognized as isolated and having many needs.

Notwithstanding personal motivations, an agency's participation was contingent on compatibility between their mandate and the goals of the research project. Of the possible collaborating organizations, not every community agency or individual elected to participate actively in the project. Among those who declined, explicit reasons were often provided. Representatives often spontaneously indicated that their inability to participate did not necessarily reflect their own interest or inclination; most indicated a lack of fit between the goals of their agency and the research project. Whether that lack of fit was because their emphasis was on clinical practice or social service, the effect was the same: they did not anticipate being able to contribute significantly to the project. Even among agencies with compatible mandates, it was the norm to hear an individual report that she was very busy and had recently taken on new or more job duties and/or obligations. It was also the norm to hear that the agency was facing further major transitions in governance or structure, and that any participation would only be on a short-term basis, with no commitment to future involvement. Thus participation in the steering committee was flexible, to say the least.

Another reason that individuals gave to explain their reluctance to participate had to do with the fact that it was a student research project. Reluctance here seemed to relate to the experience of having been overwhelmed by other research obligations, e.g., repeated requests from the University for supervised placements for student practica. Occasionally, provided along with explanations of factors limiting participation, were concerns about the scientific merit of the work, e.g., suggesting it was inadequate unless it directly applied the Health Belief Model, or describing it as just a student project. Most people who declined to participate did commend the project, and gave suggestions about people to talk to or
factors that might play important roles in women's choices about adopting a health
behaviour.

In certain situations, the motivations for participation were apparent or disclosed readily.
The YMCA had programs available that were not well attended by Portuguese adults. The
children were already coming, but the adults didn't seem to be too involved. The YMCA
staff indicated that they wanted the Portuguese women to feel comfortable there, and they
provided refreshments for the health event, as well as a complimentary pass for a
subsequent visit. The Davenport-Perth Community Health Centre had tried,
unsuccessfully, to get more of the Portuguese people in the immediate vicinity to visit and
become familiar with the facilities and services available there. An important priority for the
Immigrant Women's Health Centre (IWHC) was to ensure that immigrant women had
access to information and services necessary for their sexual and reproductive health
concerns. A government subsidized agency, IWHC could justify providing counselling in
the context of women making their health-care decisions autonomously, without feeling
pressured by their partners, family members, or employers. The Toronto Hospital,
Department of Family and Community Medicine, recognized that participating in a project
with community participation would be perceived as valuable.

Lastly, Doctor's Hospital\(^1\) provided ambulatory care for minority populations. Their slogan
"A hospital that speaks your language" indicated awareness of the need to provide services
that were sensitive to language and culture. Staff in some chronic care programs (e.g.,
diabetes management) understood the inclinations and dispositions of Portuguese clients;
some staff were Portuguese themselves. Each of these agencies participated in providing
inputs in terms of personnel and/or other resources.

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1. During the course of the project, hospital mergers meant that the Doctors' Hospital site was closed.
4.2.2.3 Areas of agreement: Key issues relevant to promoting adoption of a health behaviour

There was broad consensus about what the key issues were likely to be. There were, however, differences in perspectives about how to address the issues relevant to promoting adoption of Pap tests. Let us begin with the areas of agreement.

Overtures to identify community partners almost invariably prompted that person to contribute his or her perspective about Portuguese women not getting Pap testing or other preventive care. Even when the issues about Pap testing were initially unfamiliar, once preliminary information1 was presented, respondents generally had something to contribute. Sometimes people asked for further information, and explanations were provided (e.g., referring to factors related to women, their culture, their caregivers, and the system). If it had not already been offered, this served to elicit feedback from the respondents about their understanding of Portuguese women and their perspectives or experience of the health care system. Their perspectives generally reflected the agency's mandate or role. For example, the cultural and social service agencies tended to identify cultural factors that might have been operating, while clinical service agencies identified limitations in terms of care providers' gender or approach. Most of the contributions affirmed or echoed issues raised in the literature or the initial groups. Here, the emphases included the importance of: identifying how the study would help the community and particular agencies; ensuring the cooperation of priests in order to reach any church attenders (a "captive audience"); identifying myths and how these might restrict seniors from coming for Pap tests; ensuring any invitation included education, which could be provided in a group setting; providing information that was of interest, and in ways that were culturally appropriate (including BSE workshop, menopause, stress management); having experienced, gentle, female personnel as providers of Pap tests; and ensuring women are informed of Pap test results and their meaning. One theme area not in the literature was the practice characteristics of physicians serving Portuguese-speaking women, particularly in terms of appointment scheduling and Portuguese language availability. These matters prompted further

1. In particular, people responded on hearing concerns that Portuguese-speaking women may be at increased risk of cervical cancer if there are high rates in originating countries and if women are not adequately screened with Pap tests.
investigation with family physicians and general practitioners serving in areas with high density of Portuguese populations (Objective 2).

4.2.2.4 Areas of conflict: Operationalizing the research

Controversies emerged in unexpected areas, sometimes with unexpected intensity. Two major areas of conflict were: the feasibility of operationalizing a particular hypothesis and the appropriateness of particular questions for the Women's Health Questionnaire survey. These conflicts and their resolution reveal some of the values underlying the collaborative research process.

One issue under consideration related to the sources of health care information and their relative influence. The women in the initial planning sessions had described many different sources of health information. The health education literature suggests that people of various cultures and educational backgrounds likely respond differently to sources of health information, depending on whether they are authority figures or peers. This seemed to provide an operationalizable hypothesis, wherein underscreened women could be randomized to receive an invitation to Pap testing from either a health care professional or from a peer, a lay Portuguese woman - but the members of the community steering group objected to this as not making any sense. Eventually I ascertained the reason for this. To underscreened Portuguese women, any individual to whom they were sent for their invitation would be considered to hold some unique status and authority, whether they were formally qualified or not.

In devising the Health Event Questionnaire, there was considerable discussion but one point of agreement was that we would restrict its length. The single page questionnaire would be administered in person by an interviewer as women arrived at the health event. The choices about which questions would be included generated considerable discussion and some conflict. The most contentious by far was the age question, which many of the community partners considered a personal question, one that had potential to alienate the women. In this case, both science and ethics "won" in the compromise agreed on: the question was permitted on the questionnaire, but an introductory paragraph encouraged women to decline to answer if they wanted to. On the other hand, the community members wanted to include a question about country of origin, because they saw that as being a
useful tool for describing and reporting possible differences in risk or response back to the communities. This was considered by one physician to be motivated by political concern, but within the community steering group, it generated no controversy whatsoever. The question was included.

Certain questions on the Health Event Questionnaire were not acceptable to members of the community steering group. Questions about attending the dentist were considered unhelpful because traditional Portuguese women do not attend dentists for preventive care and they would be confused by the inclusion of a question about this in the context of women's health. Level of education was considered an inappropriate question to raise, as women over 40 who had immigrated from Portugal were unlikely to have had the opportunity for much schooling when they were growing up. Back in Portugal, this would have been normal, but here in Canada, the lack of education was considered embarrassing. The possibility of trying to characterize the underscreened with respect to literacy levels, either in Portuguese or in English, never even made it to large group discussions, because informants in small group discussions were adamant that this was likely to be a significant issue for the underscreened population. Raising that issue, either by asking directly, or by requiring the women to answer the questionnaires themselves, would have caused awkwardness and embarrassment for the women of greatest interest to our project. Including any question about education was expected to reduce the response rates for underscreened women; it would definitely have decreased the acceptability of the research for our community partners.

One question that was considered unnecessary by the members of the community steering group was an indicator of whether a woman had attended a previous health event. I attempted to negotiate its inclusion by emphasizing its role and importance. The argument held no sway, and was countered with the directive to search on matching birthdates to determine whether a woman had attended previously. I made that compromise because these women were going to administer the questionnaire, and if they objected to its inclusion they could choose to ignore it or not participate at all.

Documentation was one area of persistent difficulty within this collaborative project, and it prompted some negative reactions from stakeholders. One member of the planning committee, unable to attend all meetings, indicated that more written material, including
detailed minutes of meetings would have been useful, as would more reminders and agendas faxed out ahead of our meetings. In contrast with this reaction was the complaint from another participant that she could not "get into" the material provided, e.g., agenda, protocol. This was understood to mean that either there was too much material, or that it was inaccessible or irrelevant to the agency's mandate, or that this participant may have had other obligations which limited meeting preparation time available. As it was, details of discussions about project development and implementation were recorded directly as edits on drafts of instruments or in summary notes, and other participants kept their own notes about their responsibilities and tasks. Individual meetings by telephone or in person were used to clarify or resolve ongoing decisions about the work. It was clear that every partner on this project had numerous obligations, and that this did influence the type and amount of documentation that could be produced or reviewed. Despite these problems, a core of committed community partners provided input to the project.

One final, unexpected development occurred in the decision about what incentive should be provided to women attending the health event. Everyone agreed that all women attending, and not just underscreened ones, should receive some small tangible acknowledgement of our appreciation for their attending. Initially, the community members and the researcher considered subway tokens or tickets as an appropriate transportation incentive. Then, a visitor suggested the idea of something from The Body Shop, and offered to investigate the possibility of whether a reasonably priced item might be available. When she brought back a sample of a small package of cellophane-wrapped bath beads, the Health Event Representatives unanimously preferred it to the transportation incentive. They felt that the women would be unlikely to buy this for themselves, and as such it made a good gift. The transportation incentive, though recognized as useful in other settings, had lost its lustre. One comment that was translated was that if women really wanted to attend, they would find a way to get there.

To recapitulate Objective 1's methods and results, two different but complementary approaches were used to develop the research project with community partners. Work with the initial planning group involved qualitative observation and analysis, while with the community steering group and other key informants, a health promotion program planning and evaluation approach was used. The contacts and meetings with the groups contributed to the planning and implementation of the health events, one approach to identify and reach
underscreened women, for Objective 2. Key informants provided guidance about additional possible approaches to identify and reach underscreened women, which culminated in surveys of physicians' offices. The group collaborations also contributed to the elaboration of the hypotheses and operational guidance for the randomized trial to invite underscreened women for Pap testing, for Objective 3. The next sections shift from the interactions and processes of establishing partnerships, to consider specific strategies to identify, reach and recruit underscreened women.
Chapter 5  Methods for Objective 2: Approaches to identify and reach underscreened women

Objective 2.  To study various approaches to identify and reach underscreened women

A diverse set of possible approaches to identify and reach underscreened women were considered, and two approaches that seemed appropriate and amenable to feasibility evaluation were attempted. Key informants, including those formally included in either the initial planning group or the community steering group, and those less formally involved, contributed ideas about who and where underscreened Portuguese-speaking women were, and how they might be reached successfully. Informants helped identify the pros and cons of each approach, drawing on relevant experience with the Portuguese-speaking community. Approaches considered appropriate and doable were health events and physicians' offices; these efforts contributed some quantitative data. The balance of this chapter presents details of the choices in methods and design for this objective, beginning with terms and definitions.

5.1  Terms and definitions

The terms "identify", "reach", and "underscreened women" have many possible interpretations, and must be clarified. Identifying underscreened women was interpreted in the sense of yielding the data necessary for descriptive epidemiology of Pap test behaviours among Portuguese-speaking women. Descriptive epidemiology is clearly and objectively defined, that is, to observe or confirm "general observations concerning the relationship of [Pap test behaviour] to basic characteristics such as age, sex, race, occupation, and social class... [and] geographic location" (Last, 1995:56). In contrast, reaching underscreened women could have many meanings: literal, figurative, or functional. In its literal sense, reaching underscreened women could mean either simply achieving physical proximity to women in need of Pap tests to prevent invasive cervical cancer, or being able to communicate with them in a language they understood (in this case Portuguese). The figurative sense of reaching would mean communicating successfully, where the interaction is able to convey concepts and ideas that are appropriate and meaningful, i.e., where recipients "get it". Lastly, to reach underscreened women could
mean to have an impact on their function or behaviour, or as the Concise Oxford Dictionary puts it. "to succeed in influencing or having the required effect on" (Thompson, 1995:1141). This functional definition could mean that underscreened women consent to provide data for the descriptive epidemiology, that they participate in an intervention trial, that they accept an offer of Pap tests, or that they adopt Pap testing as part of their repertoire of preventive care behaviours. For the purposes of this feasibility study, each of the definitions of "reach" was considered in exploring the capacity and limitations of a particular approach. In the context of descriptive epidemiology, the term "underscreened women" implies that the population in the study should, ideally, represent all underscreened Portuguese-speaking women, in a defined geographic area, in this case the City of Toronto. Thus, one of the intentions relevant to feasibility was to understand how the underscreened women who could be identified and reached likely differed from those who could not.

Given the first objective of collaboration with community partners, operationalizing Objective 2 meant being open to their guidance. In fact, community-based partners advised about not only what data could be collected, but also what data should be collected. Partners whose roles included advocacy for Portuguese-speaking women had understandings and recommendations that were prompted not just by scientific or practical concerns, but also by ethical ones. As well, because the research project had not been initiated by partners, they had to be sure their contributions fit within their own agency’s priorities. Ultimately, the partners had the power to define, determine or restrict access to women and to data. Community partners thus had the capacity to influence the research in profound ways.

Earlier, the scientific, practical and ethical factors which shaped the project were elaborated; here, for the objective of studying various approaches to identify and reach underscreened women, these factors were manifest as general concerns and specific questions. These concerns and questions were used to consider, in turn, the merits and disadvantages of possible approaches. Important scientific and practical considerations were: How well would the sampling frame identify and reach the population of interest? How large a sample could be included? What data would be available using a given approach? How well would these data identify and characterize the underscreened women of interest? After considering the scientific merits of the approach, practical things were considered. Was such an approach technically possible? What factors would restrict such an approach, or what were the prerequisites to using such an approach? A key question
for each possible approach was "How would the data be collected?" Also considered were accessibility, resources, preparation required, skills or services available, and the complexity of collecting data. Finally, each approach was considered for its possible intrusiveness and acceptability for Portuguese women. Assessing the cultural or social appropriateness of particular approaches was not a straightforward task; probing was used to explore or explain responses. When informants provided negative feedback about a particular approach, we sought to determine whether particular aspects of the approach were particularly problematic, and whether some variant or compromise might modify the reaction.

Interactions with community contacts regarding approaches and criteria by which they should be assessed were structured informally. None of the key informants had carried out systematic intervention research into Pap tests for Portuguese-speaking women, but some were Portuguese-speaking, and some worked with or knew these women. Without direct evidence, some extrapolation was necessary. Together and on my own, approaches and entire scenarios were imagined, to predict how variations might influence responses. These strategies suggested likely sources of bias and error.

Approaches to identify and reach underscreened women are interdependent, because unless we know who and where the underscreened women are, it is impossible to reach them. Providing any intervention (Objective 3) was contingent on identifying and reaching them, and on understanding the factors that serve as barriers or facilitators of Pap testing (Objective 4). Bearing this in mind, the details of data collection, presented next, are relevant to both Objectives 2 and 4; they also provide the context for Objective 3's randomized trial.
5.2 Designs and data

Processes to collect data for Objectives 2 and 4 were carried out at the same time, building on the community contacts developed through Objective 1’s research development. Telephone contacts followed a semi-structured format. I identified myself as the researcher, described the study and the reasons for the call, i.e., to identify possible community partners and to identify factors that served as barriers or facilitators of Pap testing. As well, any source of referral to that person was cited. Notes on the telephone and personal contacts were made, and included the date, contact details, and summaries or quotes about discussion topics and decisions. Alongside these details of the process, items for further discussion, clarification, reflection, follow-up, or other matters, were added. Sometimes these analytic memos or notes took the form of drawings or summaries. Results were organized as summary tables and narratives of what was known about the pros and cons of various approaches.

Ultimately, formal data collection was done in two settings, women’s health events, and physicians’ offices. These provided quantitative and qualitative data for research Objectives 2, 3, and 4.

5.2.1 Health events

Health promotion planning and epidemiologic methods were used to summarize and describe the health events.\(^1\) The PRECEDE categories for process evaluation, i.e., inputs, implementation activities and stakeholder reactions, (Green & Kreuter, 1991:228-31) were used to describe (narratively) the processes involved in planning and implementing the health events. In this case, stakeholder reactions also included some descriptive epidemiology, using demographic and health behaviour variables approved by the community partners.

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\(^1\) As mentioned elsewhere, terminology varies by discipline: epidemiologists could consider process evaluation as "methods". Here, the health promotion planning convention was used as the general organizing structure and epidemiologic terms were applied to specific analyses where appropriate. The "findings" (as social scientists would call them) were labelled with the epidemiologically conventional term "results".
The epidemiologic assessment of the health events included a one-page questionnaire, developed with community partners, to characterize attenders (Appendix 3, Form WHEQ). Questions were modelled after those in the National Population Health Survey (Statistics Canada, 1996); where possible, using the available Portuguese translation (Statistics Canada, −1994). Demographic variables included birthplace, birthdate, immigration date, number of children, and language spoken at home. Multiple-choice questions asked about general health and preventive care behaviours including smoking, blood pressure, physician breast examination, and Pap tests. The questionnaire was produced with English on one side and Portuguese on the other.

Data from each of the forms were entered using the Microsoft Access® 97 database program (Microsoft Corporation, 1996) using the pre-coded numbered response categories, and narrative extracts. Data were reviewed on-screen to resolve possible duplicate entries (especially for health event attenders) and to calculate variables necessary for analysis (e.g., using birthdate to calculate age; using wedding date or year to calculate years married). These processes were assisted by sorting and viewing the data on-screen, printing it out as necessary, and referring back to hand notations on the original data collection forms.

Export files from Access were produced in DBase IV format, which were in turn imported into SAS® (Statistical Analysis System, SAS Institute, 1996). SAS® procedures were used to create files and summarize the distributions of variables amenable to quantitative analysis. Categorical variables were described using frequency distributions; ordinal or continuous variables with univariate distributions (e.g., mean, standard deviation). Responses of underscreened and adequately screened women were compared using bivariate analyses. Information about what had prompted women to attend the event was collected from participants in Objective 3’s trial (follow-up questionnaires described later, Appendix 4, Form FQ). Open-ended questions were reviewed and responses were grouped into categories and summarized in the text.
5.2.2 Physicians' offices

As described earlier, doctors' offices were expected to be important for several reasons. The women in the initial planning group had talked about Portuguese women's responsiveness to directives from their doctors. Key informants associated with both the initial planning and the community steering groups had said that many Portuguese women "used" doctors on College Street, and City of Toronto mapping of Census information revealed a corresponding marked population concentration along the west central region of the city (Appendix 1). The decision was made to explore whether doctors' offices, defined by location, did indeed serve significant numbers of Portuguese-speaking women. If this were true, it would provide a useful sampling frame for this research and for possible future interventions.

5.2.2.1 Contact efforts to reach doctors

Efforts to reach physicians' offices were summarized. The number of contacts I initiated were summarized according to whether they took place by telephone, fax, mail, in person, or via a designated administrator. Similarly, the types of contacts initiated by physicians were summarized. Responses for part-time or occasional physicians who shared offices with a "main" physician were not included - the sampling frame of "office" denotes a practice for a full-time physician, with a receptionist.

5.2.2.2 Doctors' office surveys

For the physicians' surveys, pre-coded questionnaires were developed and used to collect data in two sampling frames, one strictly geographic and the second community-based hospital affiliates within a particular geographic region. The first sampling frame was six blocks of College Street in Toronto, west from Bathurst Street to Grace Street. This area, just west of the downtown region, had been described by informants as "medical alley". The researcher visited any office with a sign for Family Physician or a General Practitioner, and those lacking any indication of another specialty. After waiting for the receptionist to tend to all the patients and phone calls, I introduced myself to the receptionist as a university researcher, doing a survey on preventive care services for Portuguese-speaking women on the "College Street corridor". If the doctor was not available, the receptionist
was asked if she would be willing to provide the answers to a brief questionnaire (Appendix 5, Form DO) about practice characteristics: Portuguese language spoken; appointment scheduling (walk-in or by appointment); whether Pap tests were referred out or were done by the physician. Receptionists were asked about barriers or facilitators if they had responded to any of the topics; all physicians met with were asked if they had a sense of what might be important as barriers and facilitators.

The second sampling frame for doctors was community-based Family Physicians affiliated with a teaching hospital. Two single-page letters were faxed, mailed, or hand-delivered, using the contact information provided by the Physician-in-Chief. Two letters were sent at the same time. The first letter, written with and signed by the Physician-in-Chief and myself, provided an introduction (Appendix 6a, Form DCL). The second described the rationale for the project and solicited the involvement of physicians who served Portuguese-speaking women (Appendix 6b, Form DP). Physicians could respond by telephone, mail or fax. Those who did serve Portuguese-speaking women were asked the same set of questions posed in the walk-around survey of doctors’ offices (Appendix 5). Options introduced by that one-page questionnaire included: providing their ideas about factors that served as barriers or facilitators of Pap testing, completing a log of patients (described below), or indicating an interest in participating in some possible future research (such as a randomized trial). The two sampling frames for physicians’ offices did overlap, so some offices were introduced to the project in two ways, first orally via the initial office visits, and then in writing by hand delivery of the letters. Any physicians hand delivered their material received an entire set of documents, including the log, all at the same time.

5.2.2.3 Logs

Physicians whose practices were estimated to have more than 5% of their clientele as Portuguese-speaking were invited to complete a log for the next ten Portuguese-speaking women who visited their offices. The covering letter (Form WCL) and log (Form PL) are provided in Appendix 7. The first page of the log (Appendix 7b) included columns for birthplace, age, residence (i.e., first 3 digits of the postal code, known as the Forward Sortation Area code), the estimated date of her last Pap test, as well as the physician’s classification of whether the woman was eligible and due for a Pap test. Explanations for
"eligibility"¹ and "due"² were provided on the form. The second page of the log included space for comments about barriers and facilitators influencing this woman's choices. At the physician's discretion, forms could be completed by the receptionist. Completed logs (with data for 10 women or as few as visited within one week) could be faxed or mailed back or I could be called to pick them up. Quantitative and qualitative data were organized and summarized using the same methods described for the health events.

1. "Eligible: i.e. Has she ever had sexual relations and does she have an intact cervix?"

2. "Due: e.g., If she had two baseline Pap tests one year apart that were both normal, was her last Pap test ≥3 years ago?"
Chapter 6  Results for Objective 2: Approaches to identify and reach underscreened women

Objective 2.  To study various approaches to identify and reach underscreened women.

This chapter begins by outlining the possible approaches to identify and reach underscreened women, and the pros and cons of each. Then the results are documented for the two approaches investigated, i.e., health events and doctors' offices.

6.1 Pros and cons of possible approaches

Approaches included here, to identify and reach underscreened women, were suggested by the literature, by community contacts made during Objective 1’s collaborative research development processes and later throughout the research project, or by other personal or professional experience, acquaintances, or enquiries. Strategies, corresponding to the PRECEDE-PROCEED model’s categories (Green & Kreuter, 1991:153), mostly involved: direct communication with women (to influence predisposing factors, i.e., their knowledge, beliefs, values, attitudes or confidence); and indirect communication (to strengthen reinforcing factors, i.e., family, peers, teachers, employers, health providers, community leaders or decision makers). The Portuguese women’s community is reported to have a history of community organization, one way to strengthen enabling factors. Other ways are political interventions and training (other than through direct communication) but these "enabling-strengthening" strategies were not considered as feasible for investigation, given the duration of the research project and its emphasis on adoption of Pap test behaviours. Within these constraints, any approach which seemed, at face value, to provide either a setting or an opportunity to identify and reach underscreened Portuguese-speaking women was included.

Agencies or individuals had used many approaches themselves, as part of needs assessment, or as part of outreach strategies. Two approaches, videotapes at home, and men, were suggested by work into Pap tests with other populations, and neither had been tried at all with Portuguese-speaking groups. Social service and public health agency contacts had used strategies to publicize regular programming activities, or to present
health education or health promotion information. Other contacts had been recipients of the needs assessment or outreach strategies. Agency contacts often shared their experiences readily and with candour, summarizing their own experience with pithy phrases (e.g., "It was a waste of time") and often spontaneously identified the characteristics of women who might be reached by a particular approach. Contacts sometimes gave emphatic assessments of the merit (e.g., "It's not going to work", "That's a waste of time") or appropriateness (e.g., "You can't do that") for some approaches suggested.

After this section, Table 5 presents the approaches considered to identify and reach underscreened women. Before dealing with individual items, there are some general points to mention. Some things are common to several approaches; for example, written materials would be included as part of any mailing, but they could also be provided as part of a door-to-door campaign or in a physician's office. Similarly, pros and cons are shared across the strategies. The results can be summarized simply: identifying and reaching Portuguese-speaking underscreened women is likely to be difficult. The most optimistic assessments cited the desirability of interactive and/or social opportunities, and the important role that physicians play.

Two inter-related problems were considered likely to restrict any effort to identify and reach underscreened Portuguese-speaking women: (1) Collecting valid, quantitative data directly from Portuguese-speaking women is probably impossible; and (2) Factors that render the underscreened women identifiable, in terms of locating and contacting them, are likely to also function as barriers to reaching them with health education or research. To elaborate, the main advantages, or "pros", are that the Portuguese-speaking population of interest may be reasonably well defined by objective characteristics such as language, residence, employment or social and cultural activities, and they seem interested in discussing preventive care issues with their physicians and other allied health professionals known to them, or with friends or family members they know and trust. The main disadvantages, or cons, have to do with the isolation associated with sustaining their language, culture and heritage in their adopted country after immigration. Immigrants likely to do this would be those who had not received much education in their home country, who may not have been professionally trained. Not only would these immigrants have serious limitations in English language skills, and in literacy in any language, they would also be distrustful of "officials", or others not known to them, who ask personal questions. And since Pap testing is not
something that would readily be spoken about in Portuguese society, questions about it, if understood at all, might well be considered rude. So, even if a researcher were fluent in Portuguese, getting demographic (or other) information necessary to describe patterns of underscreening would be very hard if she was not already known to the underscreened women. Indeed, the chances of a researcher even identifying a Portuguese-speaking woman as underscreened in any private encounter would be difficult. Underscreened women are not likely to be literate or numerate in Portuguese either, but they are probably ashamed of this and are unlikely to acknowledge it. So any approach that requires a woman to provide a written response is unlikely to succeed. Nor do these women readily sign documents. These problems were expected to be particularly troublesome for any functional definition of reaching which involves the provision of consent, for example, for the purposes of any research intervention.

One marked theme was that, in the absence of opportunities to base interventions in physicians' offices, providing some kind of informational and social event as a setting for any research study would help ensure that the women were comfortable and responsive to personal questions. The women were understood to enjoy interactive experiences, such as being weighed, or having their blood pressure taken, and especially having the opportunity to ask questions about topics of concern to them. Portuguese women were considered to be interested in learning, having demonstrated interest and enthusiasm to learn about nutrition, stress management, fitness, sexual communication, and, most especially, menopause. Underscreened women were expected to be least responsive of all women to any overture, so the most promising options would take advantage of people and agencies already a part of their social networks. Contacts stressed the importance of using existing links to provide a credible entrée for the project. Women's health events were planned and formal evaluation strategies were devised, to examine how useful this approach might be to identify and reach underscreened women. Results are presented in the second half of this chapter.

Community contacts had experience with the provision of Pap tests, and/or experience with the Portuguese-speaking (generally Portuguese) population; these are summarized in text. Possible approaches and their pros and cons follows in table format (Table 5, page 112).

1. The pronoun "she", to indicate a female researcher, is used advisedly. This project did not investigate whether a male researcher would be appropriate.
After that, the results for the approaches with health events and physicians' offices are presented.

6.1.1 Experience with / understandings about Pap tests per se

Many of the service providers contacted do offer Pap tests, whether under a specific agency mandate of women's reproductive health or as part of routine preventive care practices. Some of these efforts involve specific outreach interventions, using walk-in or mobile clinics and/or worksite-based education and service. Documentation for these efforts is understood to be minimal and it was not available for this research project. Data may include the number of women who attend presentations, and possibly the number of women who undergo particular screening procedures such as a Pap test or breast examination. Data on the characteristics of service or program recipients are not collected, so agencies cannot produce rates of uptake for underscreened women. Although the agencies are considered by other community contacts to provide unparalleled services to underserved populations, the effectiveness and/or efficacy of their approaches remain unknown. It may be feasible to provide services in this way, but without relevant data, there can be no direct, quantitative assessment of whether they can identify or reach underscreened women. Even so, our process evaluation of the health events, later in this chapter, could be considered an indirect assessment of the agencies' ability to reach underscreened women. That is because the agency designates helped plan both the format and content for the health events, and some of them participated by giving seminars at the events.

As described earlier, community partners told us that many Portuguese-speaking women came to a particular street in the city for their medical care, to the extent that a short section was referred to as "medical alley". This section of College Street in Toronto is part of "Little Italy"; it is a bustling "main street" area, surrounded by established, residential neighbourhoods. It is well-served by streetcars, linking the downtown core to the east with residential, industrial and park regions to the west. The street includes a mix of low-rise residential and commercial properties. There are medical office buildings, a multi-cultural community health centre, other social service agencies, as well as many restaurants, retail and service businesses. If the community partners were correct, and practices within a defined geographic region did indeed serve significant numbers of Portuguese-speaking
women, this might provide a convenient and efficient sampling frame. This could be important to refine efforts to identify and reach underscreened women.

Contacts familiar with service provision on the street described practice characteristics that could influence the availability, accessibility or acceptability of Pap tests. Availability and accessibility of health care service provision correspond to enabling factors of the PRECEDE-PROCEED model. Contacts alerted us to one supposedly "common" practice characteristic, that appointments were not scheduled in advance. Because Pap tests take time, and require a prepared examination table and materials, it was hypothesized that physicians with "walk-in" practices would be less likely to provide Pap tests than offices where appointments were scheduled in advance. Accessibility could also be reflected by the hours the practice was open, particularly whether evening or weekend hours were available. Linguistic access, for Portuguese-speaking women, would also be enhanced if Portuguese was spoken by practice staff. Acceptability was anticipated because of the consistent reports about the perceived appropriateness of doctors as sources of information about preventive care. In addition, gender of the physician was included as a characteristic of interest. It was decided that a walk-around survey was the most efficient design. The personal contact could facilitate response for this study, and might serve as an overture to future efforts regarding preventive care.

Medical offices may be part of private or group practices. Physicians reported that electronic databases in some offices could be used to identify underscreened women and to produce either office-based prompts for providers and/or reminders for women. These systems may also be flexible enough to permit input of additional demographic characteristics, such as country of origin or language spoken at home; summary reports could characterize the rates of uptake to identify characteristics of underscreened women. Although no opportunities to assess feasibility were available, database entry, programming and analyses certainly have the technical capacity to make an important contribution to the effort to identify underscreened women who attend physicians' offices.

6.1.2 Experience with approaches to reach Portuguese-speaking women

Community partners told about their experiences with and expectations regarding door-to-door or telephone contacts, and invariably discouraged such options. They emphasized
that such efforts to identify or reach underscreened women in this way were likely unhelpful because older, Portuguese-speaking women do not generally respond to strangers at the door or over the telephone. Community workers responded to the notion of mailed surveys with body language and facial gestures, including head-shaking and eye-rolling, that conveyed a combination of amusement and/or consternation; the incongruity of such an idea was absolutely clear. In contrast, clinic- or worksite-based overtures to identify and reach underscreened women made a lot of sense to our contacts. Contacts were consistent in reporting that many older Portuguese-speaking women were employed in manual work such as cleaning, service or processing, or as babysitters. Small worksites would be difficult to identify and provide programming, but the agency staff knew worksites with large numbers of Portuguese-speaking women. These included factories, the service industry and food processing plants. In the experience of the staff, these employers were not neutral to efforts to provide health education to employees - either they were responsive or they were resistant. Site visits to recommended workplaces confirmed this; university-based researchers provided no additional allure for resistant employers. The explanation provided by contacts was that employers did not trust the presence of health educators because their presence or instruction might disrupt employment schedules, practices or norms.

Three other approaches on the list were considered infeasible primarily because of sociocultural issues: men, schools and dentists. Men were ruled out not just because presenting health responsibilities as a man's role would be unusual for the traditional culture, but there was some antagonism towards particular Portuguese men's interest in the women's activities and discussions. Grade schools were not used, although they might have reached some underscreened women, because Pap tests and gynecologic examinations are considered intimate topics, inappropriate for discussions between parents and their school children. Dentists were ruled out because it was reported that traditional Portuguese did not routinely go to them for preventive care.

Portuguese festivals, churches, and written notices posted in public places such as grocery stores or pharmacies, were included as part of the strategies to disseminate information, against the advice of community contacts. There was consensus that underscreened women were likely to frequent these settings, but community contacts were clear that the festival setting was not conducive to health or self-care messages. When a booth at a
major Portuguese cultural festival (i.e., Festivale St. Antone) was tried, older adult Portuguese women veered away from the booth or withdrew when offered literature. It was clear that no interviews could have been carried out with women in this setting. Some contacts thought that smaller festivals, which were somewhat more subdued, with less loud music and drinking, might warrant consideration as a place to present a skit.

The second approach that was pursued despite the disinclinations of the community partners, involved churches and priests. Religion was recognized as important in the lives of some underscreened women, especially the most isolated and traditional ones. Certain priests were considered progressive, and possibly supportive of efforts to improve women's health. Yet our contacts told us that even these priests might be unresponsive to requests by any researcher, and especially one external to the community. On this topic, there was something unusual about the advice of the community contacts. That is, it was either vague or else explicit, negative and emotionally-charged. So, any community collaborators who had good relations with church contacts were encouraged to follow up on them to explore opportunities. In addition, guided by the community contacts, I contacted particular priests who might be vocal or public in their response to any project. I let them know of the work, asked for feedback on promotional material, and solicited their support or local endorsement for the work. Telephone conversations with these priests seemed congenial and ostensibly positive, but did not yield any further opportunities for access. As mentioned, some informants were convinced that women in churches might be among the least well-screened. So health events in church basements could have been an excellent way to reach underscreened women of that particular congregation or denomination. In the end, however, no opportunities emerged, and instead churches were incorporated as part of the strategy to invite underscreened women, through the personal efforts of the health event representatives and as a place to distribute flyers after church services. The Health Event Co-ordinator reported that when she went to distribute flyers at responsive churches, women exiting the mass tended to avoid her. More women were willing to accept a flyer from her mother, who was handing out flyers with her. So although churches and priests hold potential for identifying and reaching underscreened women, no opportunities could be developed during the course of this project.

1. Younger people, and in particular, children, did enter the booth; they read the posters and collected brochures or souvenirs.
Finally, written notices were considered unlikely to be useful in independently eliciting any response from Portuguese-speaking women. It was expected that Portuguese women would notice a poster directed to their community, and it was anticipated to increase their general awareness of the project. Nevertheless, it was considered unlikely to be helpful on its own for three reasons. First, not all the women were literate. Second, I was not well-known in the community. And third, it was not considered part of traditional Portuguese women’s behavioural repertoire to respond to a public notice by telephoning for either information or reservations for an event. Despite these community concerns, a poster was produced to advertise a training opportunity. It was reviewed and translated by a well-known Portuguese service agency, and the result was commended by a number of other contacts as being clear and appealing. The agency offered to serve as secretariat for the project; none of the community partners was surprised when the posting of the notice yielded not a single telephone call.

Media options, especially television, were recommended by many Portuguese-speaking contacts but it was premature to include them in this feasibility study. Portuguese newspapers exist, and they seem to be appreciated and widely read. Yet agencies reported that ads or articles in them did not work, that is, they had not seemed to elicit any response in the way of uptake of programs for Portuguese-speaking people. In contrast, it was clear that Portuguese-speaking women who talked to us liked watching television. They had enjoyed seeing Portuguese physicians or health promoters making television presentations about particular health topics in the past, and would like to see them again. In addition, media stations serving Portuguese-speaking populations were expected to be interested in supporting some form of outreach. Before embarking on a full-scale project, we wanted first to develop and test messages on a small scale, to be sure they were appropriate, acceptable and useful in increasing Pap testing. This would be the first step to producing messages suitable for public broadcast; premature or inappropriate mass media messages could have long-term, negative effects for the population of interest, for professionals in health or social agencies, and for researchers. Once the appropriate message content was determined, the next challenge, in the context of research on a minority population would be to design and test a media broadcast intervention. Here again, collecting information about recipients and what they had gained or understood from a particular intervention would require ancillary data collection. Two possible study designs were: before and after sampling surveys to identify or characterize the recipients; and a
detailed population-based cytology registry to determine whether the broadcast improved screening among Portuguese-speaking women who needed it. Given these constraints, it did not make sense to pursue media options.

Interactive computer technology is available, and two different possibilities were explored. A pharmaceutical agency with interactive kiosk technology might have been interested in augmenting their program with information about cervical cancer screening. Particular pharmacies might be selected in areas that corresponded with the geographic regions in which Portuguese-speaking women live. Problems with this option were that the material would have remained text-based: users in pharmacies were recognized as generally being younger and literate. The second option, a more visual program on moles (a collaboration between a medical artist and a dermatologist) was available. A Portuguese version of the program was reported to have been well-received by a young focus group. These opportunities seemed to hold some promise for identifying or reaching underscreened women, but they shared a common limitation that would restrict their utility for any research project: the capacity for reporting user information and/or capturing response remained under development. Without those capabilities, underscreened Portuguese-speaking women might use the computers, might gain new knowledge, and might decide to have a Pap test, but no-one would know, because the systems could not extract user data in a format suitable for research.
Table 5. Approaches considered to identify and reach underscreened Portuguese-speaking women, and their pros and cons.

* Denotes approaches which were seriously considered, ** denotes ones which could be assessed with quantitative data.

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| Mail       | • Defined population is available, i.e., Portuguese directory, with listings of traditional Portuguese names.  
             • Postal code maps are defined geographically.                                                | • Limited literacy may be associated with non-response or with proxy responses, if children answer on behalf of their parents. |
| Telephone  | • Sampling could be based on the first 3 digits of phone numbers or the Portuguese telephone directory.  
             • Initiating telephone contact in this way is relatively non-intrusive and non-coercive; respondents may decline fairly easily. 
             • Telephoning is cost-efficient; Portuguese-speaking respondents could be identified by a Portuguese speaking interviewer. | • Directory-based strategy excludes those with non-published telephone numbers.  
             • Random digit dialing strategy excludes those without telephones.  
             • Mistrust of strangers may cause high refusal rate.  
             • Discussing Pap testing may be embarrassing if others can overhear the conversation, so women who are underscreened may not self-identify. |
| Door-to-door| • High density "node" in distribution of the Portuguese-speaking population provides a convenient geographic sampling frame.  
             • Face to face contact provides possibility of classifying those who decline by sex and age groupings. | • Mistrust of strangers may lead to non-response.  
             • Intimacy of topic may preclude discussion.  
             • Lack of knowledge may yield screening classification error.  
             • Embarrassment about possible deficiencies in behaviour or intentions may prompt social desirability bias. |
| Written materials** | • Written materials ensure message consistency.  
             • Written materials can be reviewed in private or with friends or health care professionals.  
             • Costs for production and reproduction are minimal.  
             • Materials can include both visual images and text. | • Literacy may restrict the use of any text-based brochures.  
             • Lack of familiarity with English language may preclude use of material written in English.  
             • Production of suitable materials in Portuguese or with visuals takes considerable time and effort. |
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| Videotape at home | • Private viewing of a videotape in the home may be appropriate and comfortable for some women.  
• Fixed content in a video can ensure that every woman has access to the same information. | • Producing the appropriate videotape would be challenging.  
• Data collection about women's screening status is unaddressed by this approach.  
• Expense: access to or ownership of a video cassette recorder (VCR) would be necessary to view the video. |
| Visual mass media | • A good mass media campaign may be effective in raising public awareness of the issues.  
• Portuguese women are reported to watch television, especially the Latin American soap operas.  
• An effective campaign mobilizes and focusses professional commitment to improving levels of screening; complementary messages could be provided to physicians' offices. | • Exposure and impact are difficult to measure.  
• Increases in screening may be general, neither specific nor appropriate.  
• Costs of developing, producing and distributing information using mass media are significant.  
• Public campaigns may raise fears of general population or alienate partners (e.g., discussing sexual risk factors). |
| Theatre* | • Skills on drinking and driving have been well-received in shopping malls.  
• Theatre provides a powerful medium for addressing and disseminating sensitive issues; it may be perceived as less threatening than a didactic presentation.  
• Skillful dramatization of real-life stories, using symbols and imagery, permits difficult or sensitive topics to be dealt with in meaningful ways. | • Developing scripts that are powerful and accurate but handle the topic sensitively takes considerable time, effort and collaboration between and among community members and playwright.  
• Defining the recipient population may be difficult if the play is presented in a public area.  
• Actors face serious constraints on their scheduling and availability due to their personal and professional obligations. |
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<td>Interactive computer</td>
<td>- Impersonality of computer interaction may elicit accurate reporting about risk factors and screening status.</td>
<td>- Interaction with computer may be unlikely for populations who have never used one; even progressive women would need a personal introduction to the computer before using it.</td>
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<td>kiosk at pharmacy*</td>
<td>- Women can choose to view material relevant to their interest level and depending on the time available, and this can all be tracked electronically.</td>
<td>- Limitations in data management and reporting capacities currently restrict analyses possible.</td>
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<td>- Drug stores may want to include information relevant to their customers for little or no cost to the provider.</td>
<td>- Concepts relevant to reaching and identifying underscreened women may be difficult to convey using graphics necessary for a non-literate population.</td>
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<td>Mobile units*</td>
<td>- There are 2 mobile health vans which deliver health services to underserved regions in the city and to worksites.</td>
<td>- Existing vans have restricted catchment areas.</td>
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<td>- Mobile units can go to public spaces where underscreened women are understood to go.</td>
<td>- The appearance or physical condition of a mobile van may deter women (e.g., rusty exterior).</td>
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<td>- Follow-up may depend on multiple visits.</td>
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<td>- Entering a van in a public or work space for an intimate health concern may feel uncomfortable.</td>
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<td>Grocery stores or</td>
<td>- Grocery shopping is one activity that even very isolated Portuguese women may participate in.</td>
<td>- Women who are shopping may be pressed for time and therefore may not stop.</td>
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<td>malls*</td>
<td>- Some malls have store-front health services which make a logical link for a project about underscreened women.</td>
<td>- Independent grocery stores used by underscreened Portuguese women may seem an inappropriate forum for serious topics.</td>
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<td>Church*</td>
<td>- Churches remain one of the activities that some isolated, underscreened women participate in.</td>
<td>- Churches' influence &amp; attendance may be dwindling.</td>
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<td>- Women's sexual health may be an unwelcome topic; controversy and misogyny would increase discomfort.</td>
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<td>- Participation could be observed by others.</td>
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<td>Worksites*</td>
<td>Some women with limited English language and literacy do work outside the home in factories or processing plants which are known to community partners.</td>
<td>Portuguese-speaking women may work in decentralized settings: cleaning private homes, businesses or offices. Facilities oriented to preventive care may already provide a nurse on-site, so women are adequately screened; other facilities may prohibit anything that disrupts production.</td>
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<td>Immigration and settlement services, including English as a Second Language (ESL) classes*</td>
<td>The immigrant population attending ESL classes may be eager to integrate and to learn about services, including preventive health care services available in their new country.</td>
<td>Cutbacks in spending have reduced programs &amp; services. The male is more likely to attend language classes. Clients may have pressing immigration concerns which take precedence over preventive care. Agencies and programs may be restricted in their ability to incorporate these matters.</td>
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<td>Grade school</td>
<td>The population reached through schools' catchment areas would correspond with geographic boundaries. Schools are perceived as credible by some. Children may already translate for their non English-speaking parents.</td>
<td>Discussions initiated by children about intimate topics may contribute negatively to family dynamics, e.g., by disrupting established power roles. Getting wide-scale support during transition of amalgamation would be difficult.</td>
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<td>Social or cultural clubs**</td>
<td>Community and women's groups exist and are valued as sources of information about self-care, and as opportunities for social interaction and support.</td>
<td>The social nature and time constraints may restrict discussion. Women's responses may be influenced by group dynamics. The most isolated women do not attend women's groups.</td>
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| Community (Health) Centres** | - Some are located in areas of concentrated Portuguese populations, with geographically defined catchment areas.  
                           | - Portuguese women who are illegal visitors to Canada may use these services. | - Attracting nearby Portuguese populations to visit and use community centres is not always productive.  
                           |                                                                       | - Centres may be at capacity, unable to accept new clients.  
                           |                                                                       | - Other health care or population priorities may compete. |
| Men                      | - Husbands may recognize that their sexual behaviour may elevate their wives' risk of cervical cancer.  
                           |                                                                       | - Sexual repression may restrict communication between husbands and their wives or other sexual partners.  
                           | - Motivated partners may influence acceptance and promote adoption of a new health behaviour.  
                           |                                                                       | - Having the male initiate responsibility for the health of his partner may conflict with cultural values and norms.  
                           | - Men may drive their wives to certain appointments, improving attendance.  
                           |                                                                       | - Discussion of sexual risk factors may disrupt marital norms, and provoke painful or unwelcome disclosures.  
                           | - Men who accompany their wives to appointments could accompany them for the gynecologic examination.  
                           |                                                                       | - Widows, still eligible for Pap tests, would be excluded from this approach. |
| Women**                  | - Screened women know underscreened ones.  
                           |                                                                       | - Population is difficult to identify and reach directly.  
                           | - Friends and family members are traditional sources of information about health, and may be considered credible sources of information about preventive care.  
                           |                                                                       | - Intimate topics were not talked about in the past or back in Portugal.  
<pre><code>                       | - Underscreened women may divulge their screening status to someone they know and trust. |
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| Doctors' offices*              | • Underscreened women may visit doctors' offices when they visit for other health needs.  
• Physicians are trusted and respected as appropriate sources of information for preventive care  
• Offices with electronic patient records could include screening details to identify eligible women, and contact information by which to reach them.  
• Necessary follow-up or treatment could be coordinated through family physician's offices.  
• Portuguese-speaking women attend physicians in a particular area, simplifying contacts.  | • Women may feel some coercion to participate or to have a Pap test.  
• Physicians who had not previously provided preventive care may raise women's suspicions about their motives for doing so now.  
• Participation of physicians in any research project would be biased by practice characteristics, i.e., adherence to screening guidelines, provision of routine Pap tests.  
• Physicians serving Portuguese-speaking women may provide care on a walk-in basis; doing Pap tests immediately might lengthen office waiting times. |
| Dentists                       | • Dentists' professional status would be recognized.                  | • First generation Portuguese people purportedly do not routinely go to the dentist. |
| Portuguese festivals or events*| • These annual festivals are enjoyed and well-attended by the Portuguese population. | • The mood at these events is "festive". Portuguese women may be reluctant to identify themselves as underscreened or to respond to any overtures in these settings. |
| Public Health Units*           | • Public Health Units are located in areas where Portuguese-speaking women live. | • Public Health Units have urgent priorities that may preclude their participation in programs to increase cervical cancer screening. |
| Women's events**               | • Health events are enjoyed and appreciated.                         | • Selection bias for attenders is likely.                             |
6.2 Approaches tried

The two approaches considered feasible for pursuit, then, were health events, and surveys of doctors' offices, and both were attempted and evaluated. The health event approach incorporated several elements: training lay Portuguese-speaking women as health event representatives, developing a flyer to advertise the events, and distributing it widely, including community and social service agency workers. All activities were ultimately directed towards identifying women who were likely to be underscreened and inviting them to attend the health event. Two community agencies had been trying to encourage the Portuguese people in their neighbourhoods to participate in their programs, and were eager to collaborate by providing a location and supporting staff. The next section evaluates the pilot test of the processes of planning and carrying out these health events.

6.2.1 Health events

Meetings held with community contacts, presented as part of the results for Objective 1, provide the background for who was involved, and in what way. The process evaluation for the health events is organized using the PRECEDE framework categories of inputs, implementation activities, and stakeholder reactions (Green & Kreuter, 1991:230). There is some overlap: event descriptions of women who attended the health events (which could be considered a measure of implementation) are included later as a description of program recipients (as part of stakeholders' reactions).

6.2.1.1 Inputs

Inputs include personnel and resources provided in support of the health events.

6.2.1.1.1 Personnel

Community collaborators contributed one important principle, i.e., that the women themselves should enjoy their participation, in whatever form and at whatever level they chose. I extended that principle to the community partners themselves. As a project that relied on volunteerism, this seemed a constructive approach. For the most part, this meant
that partners who did get involved were enthusiastic, creative, and responsible in choosing and carrying out tasks and responsibilities.

One key person for the health event project was the Health Event Co-ordinator. She performed a number of tasks:

- identified, recruited, developed roles for and trained and supervised women to serve as Health Event Representatives (HER’s);
- refined the strategies for reaching women underscreened for cervical cancer;
- facilitated two formal training sessions for the group;
- provided follow-up individualized instruction for the HER’s;
- distributed flyers to agencies serving Portuguese clienteles;
- finalized arrangements with health presenters;
- participated in Community Steering Committee meetings;
- provided consultation privately regarding aspects of Portuguese culture relevant to study elements;
- assisted in translation and pre-testing of questionnaires;
- participated in and assisted in supervising the provision of the invitations in the randomized intervention trial.

Health Event Representatives were women known to the Health Event Co-ordinator through her work as an English as a Second Language (ESL) instructor and social worker. Training is described below. Health Event Representatives invited women they knew through their employment, neighbourhoods, families, churches or other social or cultural groups.

### 6.2.1.2 Resources

The hosting hospital provided refreshments and a set of "conference-type freebies" (i.e., tote bag, pen, paper, folder with brochures). The hosting hospital also sponsored the participation of a woman who had worked as a delivery nurse, to provide translation services for women with the health care provider. HealthWatch underwrote the costs of a physician’s services, and the Community Health Centre provided a health practitioner. Host agencies provided reception staff, rooms, and in one case, refreshments. Agencies involved in the Community Steering Group provided delegates for plenary sessions, and to
assist in reception, greeting and administering baseline health event questionnaires. The Body Shop provided gifts of wrapped bath beads at minimal cost.

6.2.1.2 Implementation activities

Implementation activities for health events include media\(^1\) distributed or broadcast, organizational activities, events sponsored, and the methods of data collection.

6.2.1.2.1 Media broadcast or distributed

Publicity efforts describe implementation; the primary media used to attract women to the health events were flyers and personal contacts. One poster that had been used to encourage women to register for an earlier information session had been a dismal failure.\(^2\) The Health Event Co-ordinator considered this response reasonable, given the characteristics and skills of the women we were trying to reach. Even if they could read, they did not usually place telephone calls; they would be unlikely to initiate contacts with anyone beyond their existing networks. The Health Event Co-ordinator characterised the situation seriously: “These women have no power”.

Given that experience, the flyers used to promote the health event did not require any pre-registration, e.g., by telephone call-back. The bilingual content of the flyers included what we considered, from our training sessions with the health event representatives, essential to inform women about the health events and to encourage them to attend. The flyers were legal size (8½” x 14”) printed on regular weight, attractively coloured paper. Flyers were double-sided, with information in Portuguese accompanied by diagrams on one side, and complementary English information on the other (Appendix 12). Flyers were provided to the health event representatives, who distributed them widely. They posted them or displayed them in public, around their neighbourhoods and in places and services they used: laundromats, churches, libraries, community health centres, community centres,

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1. Here, media is used as a noun.

2. As described earlier, although its content had been developed with and translated by the Portuguese Interagency Network, and that agency had served as a secretariat to receive telephone calls from women who spoke Portuguese, and the poster had been circulated to and posted by agencies on their distribution list, not a single telephone call was elicited.
libraries, grocery stores. The flyer served not just as publicity, but also as a tool to focus conversations inviting women to the health events. In their training sessions, the Health Event Representatives had identified the women that they planned to approach from among their friends, neighbours, relatives, workmates or other personal contacts. In addition, flyers were provided to agencies contacted as part of the research development process, and to the Portuguese print and television media, to invite them to cover the health events. Flyers were also provided to workers in health and social service agencies for distribution to their clients, either individually or as part of support groups.

6.2.1.2 Organizational activities

Health Event Representatives received training in two evening sessions at Doctors Hospital and individual follow-up with the Health Event Co-ordinator. The first meeting was held in the Boardroom of the hospital, the second in the auditorium; an agenda outlines the activities (Table 6).

Table 6. Agenda for first training meeting for Health Event Representatives

<table>
<thead>
<tr>
<th>Agenda</th>
<th>Host hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome</td>
<td>Health Event Co-ordinator</td>
</tr>
<tr>
<td>Introduction</td>
<td></td>
</tr>
<tr>
<td>Project background and challenges</td>
<td></td>
</tr>
<tr>
<td>Pap testing</td>
<td>Researcher</td>
</tr>
<tr>
<td>Planned health events</td>
<td>Health Event Coordinator</td>
</tr>
<tr>
<td>Need for their help to invite women</td>
<td>Health Event Coordinator</td>
</tr>
<tr>
<td>Mock invitation to health event</td>
<td>Health Event Co-ordinator &amp; Researcher</td>
</tr>
<tr>
<td>Snack &amp; break</td>
<td></td>
</tr>
<tr>
<td>Thinking and paper work to identify those whom they plan to invite</td>
<td>Women</td>
</tr>
<tr>
<td>Break apart sessions and role playing</td>
<td>Women in pairs</td>
</tr>
<tr>
<td>Problem resolving</td>
<td>Health Event Co-ordinator</td>
</tr>
<tr>
<td>Farewell and blessing</td>
<td>Co-ordinator &amp; researcher</td>
</tr>
</tbody>
</table>

At the second training meeting, Health Event Representatives reflected on how things had gone in identifying and reaching the intended women. Several women discussed among themselves, and reported with dismay that they had discovered that women who needed it
most (i.e., who acknowledged themselves to be underscreened) did not want to come. The women asked clarifying questions about who exactly was to be invited to the event; for example, the event was not restricted to women over forty, was it? Using a problem-solving approach, the co-ordinator reviewed principles, e.g., that every woman was welcome, but we especially wanted underscreened women (who might be over forty) and that women were to be encouraged (rather than coerced) to come. After that, the representatives worked in pairs to try out the draft Health Event Questionnaire. This served as background that representatives could then include in describing the activities planned for the events. It also helped the co-ordinator confirm whether any of the women might be able to serve as interviewers at the time of the event or later. As the women paired off, the co-ordinator explained quietly to me that several of the women were not literate, even in Portuguese, so pairing off (under her guidance) ensured no-one would be embarrassed by having to disclose this in my presence.

6.2.1.2.3 Events held

Three health events were held on Sunday afternoons in the fall of 1996, the first at a YWCA and the second and third at a Community Health Centre which was also a Community Centre. These were located on streetcar and/or bus routes. Before the health events, a site visit was done with members of the Community Steering Group. Introductions were made, a tour was done to ensure familiarity with the site, and a meeting was held to work out the final logistics, including room locations and set-up information.

A sample agenda for the health events is provided in Table 7, including the script for the introductory presentation about Pap testing. The short message (English text provided below) was considered suitably optimistic and sufficiently detailed, but not overly complicated, for an introductory presentation. It included information about: the research project: about the increasing risk of cervical cancer with increasing age; the opportunity for prevention afforded by the long natural history of the disease; and the Pap test's role in detecting cells before cancer becomes invasive.
Table 7. Agenda for health events

<table>
<thead>
<tr>
<th>Agenda</th>
<th>HEQ questionnaire &amp; gift</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual welcome &amp; registration</td>
<td>Health Event Co-ordinator</td>
</tr>
<tr>
<td>Introductions and acknowledgements</td>
<td>Host agency</td>
</tr>
<tr>
<td>Welcome</td>
<td>Researcher &amp; translator</td>
</tr>
<tr>
<td>Presentation about Pap testing</td>
<td></td>
</tr>
</tbody>
</table>

*My name is Elizabeth Rael. I am studying how to help women prevent cervical cancer. As women get older, they are at greater risk of developing cervical and other cancers. There is good news. Cervical cancer usually takes many years to develop and it can be prevented. This is done with a Pap test, which can detect unusual cells before they become invasive. This research study is interested in how different invitations and appointment schedules affect Portuguese-speaking women's decisions about Pap testing. If you decide to participate, you will be randomly allocated to colours that link to different types of invitations and appointments. There is no obligation for you to respond. The results of this project will be used to make recommendations about how to invite other women in need of screening to prevent cervical cancer. I hope that, if you have not had a recent Pap test [and are therefore eligible for the research], that you will help us in this important project.*

<table>
<thead>
<tr>
<th>General health presentation</th>
<th>Community presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Snacks</td>
<td></td>
</tr>
<tr>
<td>Breakout sessions</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adequately screened women</th>
<th>Eligible women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group &quot;Breakout&quot; sessions (concurrent or sequential)</td>
<td>Small group sessions . . . Researcher &amp; translator</td>
</tr>
<tr>
<td>Women's health &amp; preventive care</td>
<td>Pap test project introduction</td>
</tr>
<tr>
<td>Nutrition</td>
<td>Research Agreement Form</td>
</tr>
<tr>
<td>Sexual health &amp; communication</td>
<td>Randomization of consenting women</td>
</tr>
<tr>
<td></td>
<td>Invitation</td>
</tr>
<tr>
<td></td>
<td>Health Event Representative</td>
</tr>
<tr>
<td></td>
<td>Appointment for Allocated women</td>
</tr>
<tr>
<td></td>
<td>Join adequately screened women for breakout sessions remaining</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal farewells</th>
</tr>
</thead>
</table>

There was one downside to relying on volunteers: commitments were not always fulfilled. Partners whose professional and personal responsibilities shifted over the course of the project also shifted (or were shifted) in their capacity to fulfil their intentions. In extreme cases, some relinquished responsibilities outright, e.g., not attending health events at which they were expected. Others had to substitute or cover for these women. Unfortunately, replacements were not familiar with the plans, and last-minute glitches had to be dealt with promptly. Fortunately, the adaptability, experience, and good humour of the health event
co-ordinator, researcher, host agency delegates and presenters meant that programs proceeded smoothly and women attending did not seem aware of our difficulties.

6.2.1.2.4 Data collected

Each woman attending a health event was encouraged to register on entrance by completing a "Health Event Quiz" (Appendix 3, Form WHEQ). This one-page, anonymous baseline questionnaire was administered by a Portuguese-speaking woman. It addressed demographic, cultural and behavioural factors relevant to the risk of cervical cancer incidence, and other health promoting behaviours. These include general health, birthdate, education, language spoken at home, parity, age at first birth, interval since last Pap test, and other selected questions from Canada's Health Promotion Survey (Statistics Canada, 1996, Statistics Canada, 1994). Completed forms were reviewed and the resulting data entered into a computer and summarized using procedures described earlier. These data also serve to describe the program recipients, that is, the women attending the health event, as an indicator of the stakeholder reactions below.

6.2.1.3 Stakeholder reactions

The inputs section identified tangible evidence of response and commitment to the project, i.e., personnel and resources. Here, additional descriptions of the reactions and responses of stakeholders include those of collaborators and program recipients.

6.2.1.3.1 Collaborators

Stakeholders include a subset of agencies and individuals contacted, i.e., the ones who did participate actively in the development or implementation of the health events. Delegates of agencies which hosted the health events, and some presenters, indicated that they were pleased at the turnout of women. In the year after the health events, one of the agencies launched a program for Portuguese-speaking senior women. This group continues to meet on a weekly basis.
6.2.1.3.2 Program recipients

Stakeholder reactions for Health Event Representatives and for women attending included observations made at the health events, data from questionnaires, from follow-up interviews with trial participants, and feedback gained on returning to community partners.

Most women seemed to arrive at the health events in pairs or small groups, and sat in clusters with their relatives and/or friends. Women were welcomed individually at a reception desk with a small gift of a cellophane package of multi-coloured bath beads, and were invited to participate in the anonymous Health Event Quiz. The plenary sessions began with the Health Event Co-ordinator making a joke that she hoped that the women would understand her because she spoke only Brazilian - it seemed that everyone laughed, every time. Throughout the session, women seemed to visibly enjoy themselves, often with easy laughter, smiles and banter amongst themselves. Some of the women responded to the presentation by asking questions of the presenter, others commented quietly to each other.

A few women (exact number not known) indicated to interviewers that they did not wish to answer the quiz, explaining that they had already attended a previous health event and completed a questionnaire. Where questionnaires were provided, every question was answered. There were varying formats for responses: for how old a woman was; when she was first married; and when she first came to Canada. A few women proudly filled out the health event questionnaire themselves; two young women filled out the English side. The responses to the Health Event Quiz were used to characterize the population attending.

The demographic and screening status characteristics of women attending the health events are summarized in Table 8, overall and by each health event. Fifty-five of the women attending (83.3%) were over age forty. Sixty-four (98.5%) spoke Portuguese at home; seven of these spoke both Portuguese and English at home. Nineteen women (28.8%) were considered underscreened based on the most recent Pap test ≥3 years ago or never. One of these women had not initiated sexual activity (so was ineligible for Pap

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1 That is, some women provided their age at the time of the event, some women provided partial dates (e.g., month and year), while some provided exact dates. As described in the methods, usable variables were created by programming and, where necessary, by hand-reconciliation.
tests and therefore not underscreened); one did not speak Portuguese at home (so was ineligible for the trial), and three were repeat attenders. Eleven of the fourteen women (78.6%) eligible for the invitation trial agreed to participate in it.

Table 8. Number of women (percent) attending health events in terms of characteristics relevant to underscreened population

<table>
<thead>
<tr>
<th>Item Description</th>
<th>Event 1 n (%)</th>
<th>Event 2 n (%)</th>
<th>Event 3 n (%)</th>
<th>TOTAL n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women attending</td>
<td>40 (100.0)</td>
<td>7 (100.0)</td>
<td>19 (100.0)</td>
<td>66 (100.0)</td>
</tr>
<tr>
<td>Age ≥40 years</td>
<td>32 (80.0)</td>
<td>5 (71.4)</td>
<td>18 (94.7)</td>
<td>55 (83.3)</td>
</tr>
<tr>
<td>Speak Portuguese at home</td>
<td>39 (97.5)</td>
<td>7 (100.0)</td>
<td>19 (100.0)</td>
<td>65 (98.5)</td>
</tr>
<tr>
<td>Last Pap test ≤3 years ago, or never, or not sure</td>
<td>11 (27.5)</td>
<td>4 (57.1)</td>
<td>4 (21.1)</td>
<td>19 (28.8)</td>
</tr>
<tr>
<td>Underscreened for cervical cancer*</td>
<td>10 (25.0)</td>
<td>4 (57.1)</td>
<td>4 (21.1)</td>
<td>18 (27.2)</td>
</tr>
<tr>
<td>Eligible for trial**</td>
<td>9 (22.5)</td>
<td>4 (57.1)</td>
<td>1 (5.3)</td>
<td>14 (19.7)</td>
</tr>
<tr>
<td>Agreed to participate in the trial***</td>
<td>6 (15.0)</td>
<td>4 (57.1)</td>
<td>1 (5.3)</td>
<td>11 (16.7)</td>
</tr>
</tbody>
</table>

N.B. *Italics* indicate a single variable. Shaded rows represent subsets of observations. In this table, all percentages are based on column totals.

* Categorization for screening adequacy: ≥3 year interval since the last Pap test AND having initiated sexual relations.

** Excluded are a non-Portuguese-speaking woman (n=1), and repeat attenders (n=3).

*** Besides these, three additional women participated in the trial.¹

Of the sixty-six women who attended health events and completed questionnaires, twelve (18.2%) were excluded from comparisons between well-defined groups of adequately and inadequately screened women. Eliminated were the repeat attenders (n=10), one woman who had not yet initiated sexual relations, and one who did not speak Portuguese at home, leaving fifty-four individuals who were truly eligible for Pap tests and who spoke Portuguese at home. There were differences in demographic characteristics (Table 9) but not in health behaviours other than Pap tests (Table 10). Compared to adequately screened women, underscreened women had more children (3.6 versus 2.6), were older (55.0 versus 51.1

¹ One of the women eligible for the trial did not come to the small-group session nor return her consent form to indicate that she was declining to participate. Two eligible women attended the sessions but declined to participate. Yet three additional women, who had been identified on the Health Event Quiz as being adequately screened, also attended the small group sessions and did participate in the trial. On follow-up, one said she "had never done it", one explained a history of medical care and that she had not had a Pap test for 2 years (she was a health event representative), and one had "done this type of test years ago".
years), and married at an older age (26.3 versus 21.7 years). The two groups were similar in the number of years married (28.3 versus 29.9) and in the number of years since immigration to Canada (20.0 versus 21.1 years).

Table 9. Comparison of demographic characteristics for underscreened and adequately screened women attending health events: Means and standard deviations (s.d.) for continuous and interval variables

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Underscreened mean ± s.d. (n)</th>
<th>Adequately screened mean ± s.d. (n)</th>
<th>All screened mean ± s.d. (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>55.0 ± 13.8 (14)</td>
<td>51.1 ± 13.2 (40)</td>
<td>52.1 ± 13.4 (54)</td>
</tr>
<tr>
<td>Age married (years)*</td>
<td>26.3 ± 11.0 (14)</td>
<td>21.7 ± 22.9 (39)</td>
<td>22.9 ± 6.8 (53)</td>
</tr>
<tr>
<td>Years married*</td>
<td>28.3 ± 9.3 (14)</td>
<td>29.9 ± 11.8 (39)</td>
<td>29.5 ± 11.1 (53)</td>
</tr>
<tr>
<td>Number of children</td>
<td>3.6 ± 1.5 (14)</td>
<td>2.6 ± 2.1 (40)</td>
<td>2.9 ± 2.0 (54)</td>
</tr>
<tr>
<td>Years since immigration*</td>
<td>20.0 ± 11.0 (14)</td>
<td>21.1 ± 9.5 (39)</td>
<td>20.8 ± 9.8 (53)</td>
</tr>
</tbody>
</table>

* One unmarried woman, born in Canada, was excluded from these analyses.
Table 10. Comparison of reported health behaviours for underscreened and adequately screened women attending health events: Frequency distributions for categorical variables

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Underscreened</th>
<th>Adequately screened</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>General health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>0</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>(10.0)</td>
<td>(7.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>3 (21.4)</td>
<td>2 (5.0)</td>
<td>5</td>
</tr>
<tr>
<td>(9.3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>4 (28.6)</td>
<td>10 (25.0)</td>
<td>14</td>
</tr>
<tr>
<td>(25.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>6 (42.9)</td>
<td>19 (47.5)</td>
<td>25</td>
</tr>
<tr>
<td>(46.3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>1 (7.1)</td>
<td>5 (12.5)</td>
<td>6</td>
</tr>
<tr>
<td>(11.1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood pressure ever taken</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14 (100.0)</td>
<td>40 (100.0)</td>
<td>54</td>
</tr>
<tr>
<td>(100.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoke cigarettes now</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily or occasionally</td>
<td>2 (14.3)</td>
<td>1 (2.5)</td>
<td>3</td>
</tr>
<tr>
<td>(5.6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>12 (85.7)</td>
<td>39 (97.5)</td>
<td>51</td>
</tr>
<tr>
<td>(94.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breasts ever examined by Dr.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>12 (85.7)</td>
<td>36 (90.0)</td>
<td>48</td>
</tr>
<tr>
<td>(88.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2 (14.3)</td>
<td>4 (10.0)</td>
<td>6</td>
</tr>
<tr>
<td>(11.1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pap smear test</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;6 months ago</td>
<td>*</td>
<td>15 (37.5)</td>
<td>15</td>
</tr>
<tr>
<td>(27.8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 months to &lt; 1 year ago</td>
<td>*</td>
<td>11 (27.5)</td>
<td>11</td>
</tr>
<tr>
<td>(20.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 year to &lt;3 years ago</td>
<td>*</td>
<td>14 (35.0)</td>
<td>14</td>
</tr>
<tr>
<td>(25.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 years to &lt;5 years ago</td>
<td>7 (50.0)</td>
<td>*</td>
<td>7</td>
</tr>
<tr>
<td>(13.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥5 years ago</td>
<td>3 (21.4)</td>
<td>*</td>
<td>3</td>
</tr>
<tr>
<td>(5.6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never or not sure</td>
<td>4 (28.6)</td>
<td>*</td>
<td>4</td>
</tr>
<tr>
<td>(7.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>14 (100.0)</td>
<td>40 (100.0)</td>
<td>54</td>
</tr>
<tr>
<td>(100.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* By definition of screening status, there are no women in this category.

Feedback about the health event was also provided by trial participants, collected in follow-up telephone interviews (and described further in Objective 3). When telephoned, all women reached immediately and warmly recalled the health event, the researcher and the research assistant. One woman responded to a probe about whether the location was convenient for her, and the research assistant’s notes provide the response: “She said it was quite simple to get there. She was familiar with the area. It is accessible [by public transit] and a good centre to have meetings. However as we know she reminded us that it is not a centre that is frequently used by the Portuguese community, but she suggests it is a
good place to have these meetings in the future." One woman specifically mentioned enjoying the nutrition session. Another described her response simply: "Overall [I] liked the day."

The follow-up interviews with trial participants also provided stakeholder reactions about what had prompted them to attend. Of the fourteen women who participated in the trial, eleven (79%) indicated that they had been invited, by one or more of: a women's group, a friend or a relative. Of those eleven women, five said they had been invited by or came with a friend and/or relative. Nine of the fourteen (64%) women said they were interested in women's health meetings or events. Five of the fourteen (36%) women indicated gynecologic problems had prompted them to come to the event, participate in the research, or have a Pap test. Four women described overt gynecologic problems: one described having had "runnings" in the past and pain after sex now; another had a long-standing infection; two had previously had surgery. Of these, one said the surgery had removed abnormal, but not cancerous, cells on her ovaries, and fibrocysts. The other surgical procedure was described as her "tubes were cleaned and the tumour removed". A fifth woman described an inflammation that prevented her from having a Pap test; it was not clear whether she knew about this beforehand. The woman with the long-standing gynecologic infection also reported other medical problems, including arthritis, osteoporosis, diabetes and cholesterol. These reactions indicate that the prompts to attending included symptoms as well as what had been intended. The implications of these choices are explored later in the theoretical model, contrasting perceptions about the role of the Pap test women as a screening tool or as a diagnostic test. At meetings which took place after the health events, women who had come to the health event seemed happy to identify themselves to the researcher, to talk about what they had learned in the health event and also what they knew of others who had participated. Their reactions indicated that the health events had been well-received by those attending.
6.2.2 Doctors' offices

Doctors' offices provided both surveys and logs of Portuguese-speaking women attending their offices. Contact efforts to gather the data precede the results of the physicians' office survey and the physicians' office logs.

6.2.2.1 Contact efforts

Of the 145 offices in the combined sampling frame (The Toronto Hospital Department of Family and Community Medicine or located within the six blocks on the College Street corridor), 12 (8.3%) were excluded because they did not provide general or family practice; specialties included rehabilitation clinic, pediatrician, cardiologist, psychiatrist. Five (3.4%) physicians' practices were confirmed as closed or moved. Of the 128 offices remaining, contacts were completed with 106 (82.8%), of which two declined to participate in the survey. The 104 offices remaining provided some kind of response to the survey through either the receptionist, the physician or both. Of these, 44 (42.3%) offices reported that greater than 5% of their clientele was Portuguese-speaking, and were included in the survey of practice characteristics.

Efforts to reach physicians' offices, and contacts initiated by them in response are summarized in Table 11. These figures are conservative, because several efforts, e.g., visits to closed offices, might be made on a single day, yet this could count as only one contact. Of the 125 visits, 93 (74.4%) were to offices ultimately included in the study; this largely reflects the fact that 30 of those 44 offices (75.0%) were included in the original six block sample on College Street (see also Table 12). Of the 108 fax attempts, 18 (16.7%) offices provided faxed returns, many with a hand-note indicating that they had no Portuguese-speaking clients.
Table 11. Contact efforts for doctors' offices

<table>
<thead>
<tr>
<th>Description</th>
<th>Physicians included</th>
<th>Entire sample</th>
<th>Not another specialty</th>
<th>Responsive</th>
<th>Clientele ≥5% Portuguese</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of physicians (observations)</td>
<td>145</td>
<td>133</td>
<td>106</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>Researcher initiated contacts</td>
<td>TELEPHONE</td>
<td>134</td>
<td>131</td>
<td>119</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>VISITS</td>
<td>125</td>
<td>118</td>
<td>111</td>
<td>93</td>
</tr>
<tr>
<td></td>
<td>FAX</td>
<td>108</td>
<td>102</td>
<td>83</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>DESIGNATED ADMINISTRATOR</td>
<td>36</td>
<td>36</td>
<td>28</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>MAIL</td>
<td>15</td>
<td>14</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Total contacts initiated by researcher</td>
<td>418</td>
<td>401</td>
<td>349</td>
<td>186</td>
<td></td>
</tr>
<tr>
<td>Contacts initiated by Drs.' office</td>
<td>FAX ONLY</td>
<td>18</td>
<td>18</td>
<td>18</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>FAX &amp; LOG</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>FAX &amp; TELEPHONE</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>LOG ONLY</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>MAIL ONLY</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>TELEPHONE ONLY</td>
<td>10</td>
<td>9</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>TELEPHONE &amp; LOG</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Total offices initiating contact</td>
<td>48</td>
<td>47</td>
<td>47</td>
<td>15</td>
<td></td>
</tr>
</tbody>
</table>

* "Not another specialty" means that there was no indication (e.g., from a sign or a receptionist's advice) that the physician had a specialty other than general practice or family physician.

6.2.2.2 Doctors' office surveys

Table 12 summarizes the results of the survey of physicians' offices, including a number of factors considered relevant to access: gender, language, appointment scheduling and practice hours, and provision of Pap tests. Receptionists, all of whom were female, on learning the nature of the research, or hearing the question about whether Portuguese was spoken in the practice, often spontaneously identified themselves as Portuguese. Six (13.6%) of the practices were headed by a female physician. Half of the practices reported that both the physician and the receptionist spoke at least some Portuguese, and in an additional 17 (36.6%) of practices, one or the other spoke it. Eight practices reported that clinic hours included some weekday evening beyond 6 p.m.; practices do stay open beyond posted hours to see patients. Almost sixty percent of the offices scheduled regular or intermittent Saturday morning openings; others provided doctors on call. Data on reported office hours should be viewed with caution because posted hours were not always
confirmed by open doors within those times. Half of the offices reported scheduling of appointments in advance, the other half that clinics were operated on a walk-in or mixed basis.

Table 12. Survey of physicians' offices

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of physicians' offices in study</td>
<td>44</td>
<td>(100.0)</td>
</tr>
<tr>
<td>Sample</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College St (6 blocks)</td>
<td>20</td>
<td>(45.5)</td>
</tr>
<tr>
<td>Both College St &amp; TTH</td>
<td>10</td>
<td>(22.7)</td>
</tr>
<tr>
<td>TTH</td>
<td>14</td>
<td>(31.8)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>(13.6)</td>
</tr>
<tr>
<td>Male</td>
<td>38</td>
<td>(38.6)</td>
</tr>
<tr>
<td>Portuguese language spoken</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receptionist or physician</td>
<td>17</td>
<td>(38.6)</td>
</tr>
<tr>
<td>Both receptionist and physician</td>
<td>22</td>
<td>(50.0)</td>
</tr>
<tr>
<td>Neither receptionist nor physician</td>
<td>5</td>
<td>(11.4)</td>
</tr>
<tr>
<td>Visit scheduling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appointment (i.e. ≥80% of visits)</td>
<td>22</td>
<td>(50.0)</td>
</tr>
<tr>
<td>Walk-in or mixed</td>
<td>22</td>
<td>(50.0)</td>
</tr>
<tr>
<td>Office hours</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekday evening beyond 6 p.m.</td>
<td>8</td>
<td>(18.2)</td>
</tr>
<tr>
<td>Saturdays (sometime between 7:30 a.m. - 3:30 p.m.)</td>
<td>26</td>
<td>(59.1)</td>
</tr>
<tr>
<td>Provision of Pap tests (n=42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor does Pap tests</td>
<td>23</td>
<td>(54.8)</td>
</tr>
<tr>
<td>Doctor does Pap tests &amp; refers women for them</td>
<td>10</td>
<td>(23.8)</td>
</tr>
<tr>
<td>Doctor refers women for Pap tests</td>
<td>9</td>
<td>(21.4)</td>
</tr>
<tr>
<td>Doctor interested in research</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11</td>
<td>(25.0)</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>(11.4)</td>
</tr>
<tr>
<td>Maybe / not sure</td>
<td>20</td>
<td>(45.5)</td>
</tr>
<tr>
<td>Not asked</td>
<td>8</td>
<td>(18.2)</td>
</tr>
</tbody>
</table>

N.B. Where necessary, categories were collapsed to yield minimum cell size of 5.

Not all offices provided Pap tests: nine offices (21.4%) responded that they referred women to other doctors for Pap tests. Options described included: giving a woman a Pap test if she asked for it, referring women if they needed Pap tests (i.e., specifying if they had vaginal bleeding or symptoms), working collaboratively with female care providers; women
explaining in response to a doctor's enquiry that they already went to a gynecologist; offering Pap tests in accordance with guidelines; giving Pap tests as part of annual check-ups; difficulties in referring healthy women to gynecologists for Pap tests.

Some receptionists provided detail about how they (with the doctor) encouraged women to have Pap tests, describing a pro-active approach using phrases like -"We really press them". They described their own extensive efforts to establish rapport with Portuguese-speaking women, to identify and address any barriers of reluctance, or to follow-up with telephone calls for any missed appointments and providing test results, and reassurance as necessary. A few spoke about how women were often reluctant to have a Pap test, especially a first one, and how they (i.e., the receptionists) responded, using sentences like -"I don't like them either, but you'll be glad you did it." One spoke about referring to menopause as "the second age" and how referring to it in this way seemed useful to prompt women approaching or experiencing menopause to have Pap tests. The receptionists also elaborated on why age was a barrier to women having Pap tests. Receptionists explained that for women who were widowed, or no longer having sexual relations, the idea of a gynecological examination made little sense. For these women, in the absence of symptoms, a Pap test did not seem useful or sensible.

Physicians ranged in responses about whether there were barriers to Portuguese-speaking women having Pap tests. Some physicians compared Portuguese-speaking women's willingness to have Pap tests with other less-willing immigrant groups. Either spontaneously, or on questioning to clarify, it was the norm to hear that older women were unlikely to accept Pap tests. Barriers to Pap tests identified by doctors included: lack of knowledge about health, including parents' cause of death, and religiosity. One physician referred to the difficulty in trying to motivate underscreened women to have Pap tests. A range of responses about what would prompt a woman to have a Pap test included symptoms, to having the doctor "tell" her. Physicians most willing to discuss this matter were convinced that there remains a group of underscreened women in the community.

A key question, the proportion of women patients who receive regular Pap testing, could not be answered with this survey instrument. Invariably, regardless of whether a receptionist or a doctor was asked it, the question elicited hesitations (silent or verbal, e.g., "Hm, let me think"), qualifications (e.g., "I'm not sure,..." ), an explanation that the practice included
many older women who might not be eligible, or, simply, a statement that this question could not be answered without reviewing the practice records. Some practices reported using electronic records which would be amenable to tracking the screening status of their patients, but no such data were available to the researcher. Indeed, one physician mentioned that their practice should start to note when offers of Pap tests are made and refused. When respondents did provide an answer, it may not have been accurate. In one case, for a doctor's office that was reputed not to provide Pap tests unless specifically requested by a woman, the response was that every woman in the practice was routinely screened. Another doctor, when contacted again, raised the concern that an earlier estimate may have been overly optimistic, because some women in the practice who had been invited to have Pap tests might not have returned to the office for their expected appointment. In one office coverage estimates differed for the receptionist and the physician. These things suggest that the data are neither valid nor reliable. Without these data, it is not possible to estimate the proportion of women routinely screened per practice, or to explore possible correlations between coverage and any other factors.

As indicated earlier, some receptionists displayed considerable interest in and enthusiasm for the topic of the study, but this enthusiasm did not necessarily manifest itself as participation in the study. On hearing the survey topic "preventive care services for Portuguese-speaking women, in the College corridor", some spontaneously identified themselves as Portuguese, and warmly pointed out that this was a very important topic. Practices that were not asked that they would be interested in any future study had either already indicated lack of interest and/or lack of time to complete the questionnaire. Of those asked directly (n=36), only 11 (25%) of the practices indicated that they would be interested in any future study. Practices that indicated any possible interest were invited to contribute logs to provide some quantitative data about the screening status of women attending the practices.
6.2.2.3 Logs

Logs were returned by 14 physicians, providing 111 observations for Portuguese-speaking women visiting doctors' offices during a one-week period. Two additional physicians had indicated an intention to fill out the log and would return it if they had any entries. Returns for two physicians were hand-noted to indicate there were no Portuguese-speaking women that week, so they contributed zero observations. One physician contributed two observations, one contributed nine, and ten contributed 10 observations each. Table 13 summarizes the age, birthplace and Pap test screening status information of these women. The mean age of the women was 46.7 ± 14.3 years. Forty-two women (37.8%) were reported as having Pap tests ≤3 years ago, unknown, or never. Nine women were excluded from subsequent comparisons of underscreened versus adequately screened women because they were ineligible or their screening status could not be classified: five women had had hysterectomies, two women saw other doctors for their Pap tests, and two women were reported as new patients within the past six months.
Table 13. Characteristics of Portuguese-speaking women visiting doctors' offices

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>All n (% of total)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age groups</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;40 years</td>
<td>47 (42.3)</td>
</tr>
<tr>
<td>≥40 years</td>
<td>64 (57.7)</td>
</tr>
<tr>
<td><strong>Birthplace</strong></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>6 (5.4)</td>
</tr>
<tr>
<td>Portugal (unspecified)</td>
<td>58 (52.3)</td>
</tr>
<tr>
<td>Portugal (islands)</td>
<td>32 (28.8)</td>
</tr>
<tr>
<td>Portugal (continent)</td>
<td>9 (8.1)</td>
</tr>
<tr>
<td>other</td>
<td>6 (5.4)</td>
</tr>
<tr>
<td><strong>Pap smear test</strong></td>
<td></td>
</tr>
<tr>
<td>That day*</td>
<td>7 (6.3)</td>
</tr>
<tr>
<td>&lt;6 months ago</td>
<td>13 (11.7)</td>
</tr>
<tr>
<td>6 months to &lt;1 year ago</td>
<td>23 (20.7)</td>
</tr>
<tr>
<td>1 year to &lt;2 years ago</td>
<td>16 (14.4)</td>
</tr>
<tr>
<td>2 years to &lt;3 years ago</td>
<td>10 (9.0)</td>
</tr>
<tr>
<td>3 years to &lt;5 years ago</td>
<td>6 (5.4)</td>
</tr>
<tr>
<td>≥5 years ago</td>
<td>13 (11.7)</td>
</tr>
<tr>
<td>Never or unknown**</td>
<td>23 (20.7)</td>
</tr>
<tr>
<td><strong>Pap test status</strong></td>
<td></td>
</tr>
<tr>
<td>Adequately screened (last Pap &lt;3 years ago)</td>
<td>69 (62.2)</td>
</tr>
<tr>
<td>Underscreened (last Pap test ≥3 years ago)</td>
<td>33 (29.7)</td>
</tr>
<tr>
<td>Excluded from subsequent screening comparisons**</td>
<td>9 (8.1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>111 (100.0)</td>
</tr>
</tbody>
</table>

* If additional information about the prior Pap test was provided, that interval was used for this table. See also Table 15.

** Of the 9 women excluded from subsequent screening comparisons, 5 had had hysterectomies; 2 saw an obstetrician/gynecologist; and 2 were new patients. Of these women, dates of most recent Pap tests were reported and were ≥3 years.
Table 14 compares the characteristics of underscreened and adequately screened Portuguese-speaking women reported on physicians' logs. Underscreened women were older (mean and standard deviation of 52.2 ± 15.0 years) than adequately screened women (43.0 ± 12.7 years). As the age group increased, the proportion of women who were underscreened increased, from 17.8% for those under 40 years, to 58.8% for those over 60 years. Almost ninety percent of the women (90/102) had Portugal reported as birthplace; 40 of these women provided enough detail to identify origins as the islands (of the Azores, or Madeira) or the continent.

Table 14. Comparison of underscreened and adequately screened Portuguese-speaking women reported on doctors' office logs

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Underscreened</th>
<th>Adequately screened</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (row %)</td>
<td>n (row %)</td>
<td>n (column %)</td>
</tr>
<tr>
<td>Age groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 40 years</td>
<td>8 (17.8)</td>
<td>37 (82.2)</td>
<td>45 (44.1)</td>
</tr>
<tr>
<td>40 - 49 years</td>
<td>7 (35.0)</td>
<td>13 (65.0)</td>
<td>20 (19.6)</td>
</tr>
<tr>
<td>50 - 59 years</td>
<td>8 (40.0)</td>
<td>12 (60.0)</td>
<td>20 (19.6)</td>
</tr>
<tr>
<td>60 years</td>
<td>10 (58.8)</td>
<td>7 (41.2)</td>
<td>17 (16.7)</td>
</tr>
<tr>
<td>Birthplace</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Portugal (unspecified)</td>
<td>11 (22.0)</td>
<td>39 (78.0)</td>
<td>50 (49.0)</td>
</tr>
<tr>
<td>Portugal (islands)</td>
<td>16 (51.6)</td>
<td>15 (48.4)</td>
<td>31 (30.4)</td>
</tr>
<tr>
<td>Portugal (continent)</td>
<td>4 (44.4)</td>
<td>5 (55.6)</td>
<td>9 (8.8)</td>
</tr>
<tr>
<td>Canada &amp; other</td>
<td>2 (16.7)</td>
<td>10 (83.3)</td>
<td>12 (11.8)</td>
</tr>
<tr>
<td>Total</td>
<td>33 (100.0)</td>
<td>69 (100.0)</td>
<td>102 (100.0)</td>
</tr>
</tbody>
</table>

NOTE: Table 13 includes all 111 women on the logs; the notes at the bottom of that table explain exclusions from this table.
Table 15 summarizes activity and attitudes or reactions in hand notations on the logs of Portuguese-speaking women visiting their doctors’ offices. Among underscreened women, notes suggest some type of discussion took place with 18 women (54.5%) resulting in an appointment, a Pap test, a referral or rejection. For an additional 7 women (21.2%) notes indicated that the woman did not have sexual relations or symptoms, or neither. Among adequately screened women, 10 women (14.5%) were noted as having Pap tests on that day.

Table 15. Activity, attitudes and reactions noted on doctors’ office logs regarding underscreened and adequately screened Portuguese-speaking women

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Underscreened n (%)</th>
<th>Adequately screened n (%)</th>
<th>All n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointment</td>
<td>6 (18.2)</td>
<td>6 (8.7)</td>
<td>12 (11.8)</td>
</tr>
<tr>
<td>Pap test done that day</td>
<td>1 (3.0)</td>
<td>10 (14.5)</td>
<td>11 (10.8)</td>
</tr>
<tr>
<td>No sexual relations / symptoms</td>
<td>7 (21.2)</td>
<td>1 (1.4)</td>
<td>8 (7.8)</td>
</tr>
<tr>
<td>Referral, reluctant or refuses</td>
<td>4 (12.1)</td>
<td>1 (1.4)</td>
<td>5 (4.9)</td>
</tr>
<tr>
<td>No activity mentioned</td>
<td>15 (45.5)</td>
<td>51 (73.9)</td>
<td>66 (64.7)</td>
</tr>
<tr>
<td>Total</td>
<td>33 (100.0)</td>
<td>69 (100.0)</td>
<td>102 (100.0)</td>
</tr>
</tbody>
</table>

Responses to the log (verbal and written) affirmed that, even for physicians, difficulties in classifying women with respect to their Pap test screening status persist. Explanations for this include: patient age distributions vary among practices; some women report attending a gynecologist so the doctor may not track their Pap tests; widows were considered ineligible and so was a woman who was not due for a Pap test; and women leave practices without telling the doctor they are doing so. Doctors recognized how difficult it was to estimate numbers or proportions that would be underscreened, without using formal chart review or an electronic database.

In summary, for the objective of investigating approaches to identify and reach underscreened women, the qualitative and quantitative data largely affirmed each other. Underscreened women could be identified to us or their doctors, but with a certain degree of misclassification. Literally, they could be reached through either health events or their physicians. These approaches were also likely to be more useful than others to reach
women in a figurative and functional sense. These approaches would take advantage of women's predilections for Portuguese stories and for group activities, and / or emphasize a preventive care role for the physician. Although health events were well-received by agencies serving the Portuguese community, the effort expended to plan and implement them was extensive, and the turn-out small. In contrast, some physicians with Portuguese-speaking clientele did not provide Pap tests; and some women chose not to have Pap tests. Physicians affirmed that electronic systems to monitor the Pap test screening intervals would be necessary to accurately determine screening adequacy levels.
Chapter 7 Methods for Objective 3: Randomized trial

Objective 3. To undertake a pilot randomized controlled trial of approaches to inviting underscreened women for Pap testing.

This chapter begins with the randomized trial design details, including inclusion criteria, randomization, sample size and follow-up strategy. Then the outcomes of interest for the appointment and brochure language trials are presented, with the rationales for the choices. Finally, the qualitative and quantitative data and processes contributing to verification and validation of the outcomes and to the identification of barriers and facilitators are outlined.

7.1 Design

Overview: As described in the preceding chapter, the randomized trial took place in the setting of Women's Health Events (part of Objective 2). That aspect of the design is considered a co-intervention. At the health events, women eligible to participate in the invitation study were identified by trained volunteers on the basis of key questions on the Women's Health Event Questionnaire. Eligible women were handed the Research Agreement Form (that had been stapled to the questionnaire) and told they would be receiving a special presentation after the introductory session. When the plenary session was over, eligible women were directed to a group presentation by myself and a translator. They were formally asked to participate in the research project invitation study. Women who agreed to participate completed the Research Agreement Form (Appendix 8, Form RAF) with the assistance of the translator, and were then randomly assigned to one of the four intervention groups.

1. Co-intervention refers to "the application of additional diagnostic or therapeutic procedures to members of either or both the experimental and the control groups" (Last, 1995:32) or to "therapies other than those given as part of the experiment that affect the outcome of interest." (Streiner et al., 1989:41). Fletcher et al. (1988:145) stipulate that co-intervention occurs after randomization, but the health event is here considered a co-intervention to the trial because it is considered to be therapeutic, and it truly threatens the validity of conclusions about effects, that might incorrectly be attributed to what happens in the trial itself, e.g., response rates likely reflect the experience of the entire health event, not just the trial itself.
7.1.1 Inclusion criteria

The ideal inclusion criteria for participation in this screening intervention study would have been: Portuguese-speaking woman; no previous complete hysterectomy or treatment for cervical cancer or its precursors; no gynecologic symptoms; having been sexually active at some point; and under-screened (i.e., no Pap test within the last 3 years, or only one Pap test ever, ≥1 year ago). Eligibility assessment in this study was based primarily on speaking Portuguese language at home and two questions about Pap testing (from Form WHEQ): *Have you ever had a Pap smear test?* (variable ACC-Q20, response categories Yes, No, Don't know); and *When was the last time?* (variable ACC-Q22, response categories Less than 6 months ago; 6 months to less than 1 year ago; 1 year to less than 3 years ago; 3 years to less than 5 years ago; 5 or more years ago). Whether a woman had any history of cervical cancer, pre-existing gynecologic symptoms, and whether she had initiated sexual relations: these issues were all considered by the Steering Committee to be unsuitable for a baseline questionnaire. However, the "*When were you first married?*" question (variable DEM-2) did not provide a response for single women, and assistants were to direct any women who had never been married to see me. When this happened, I explicitly identified the inclusion criteria regarding having initiated sexual activity, and asked whether she was eligible according to this criterion.

7.1.2 Randomization strategy

The randomization strategy for each health event was a 2 by 2 factorial design, comparing two variants each for appointment scheduling and for brochure language (Table 16). The allocation strategy needed to be easy for Health Event Representatives to use, and difficult for me to accidentally unblind myself to the randomization. These constraints were identified to the biostatistician at the Maternal and Infant Health Reproductive Unit (at the Centre for Research in Women's Health). She prepared and provided all materials in advance, using allocation to the four cells based on a simple randomization process, computer-generated. Materials for each health event were provided in a large sealed envelope; the colours and randomization processes were separate and different for each health event. A large sealed envelope was opened at the beginning of each of the invitation sessions. The envelope contained: a set of prepared materials for the researcher and a smaller sealed envelope with the allocation colour decoding information for the
Health Event Representatives. The prepared materials for the researcher included, stapled together, a colour naming sheet and randomized colour allocation sheets. The colour naming sheet (different for each health event) had four named boxes filled in with the appropriate colour; this was provided to help the researcher select the appropriate colour marker to note the Women’s Research Agreement Form (variable ALL-1, Allocation). The colour allocation sheets were in the form of a table with sequential numbers (integers 1-84) down the left-hand column. The middle column was for the participating woman’s identification number (from her Women’s Health Event Questionnaire) when she agreed to randomization. The right-hand column indicated what colour (in words) the woman was allocated. No information about what each colour meant was available to me or to the research assistant providing the explanations for the consent processes. The allocation colour decoding information, in a sealed manila envelope, was given to each Health Event Representative; I did not see the decoding sheet and so did not know what each colour represented in terms of allocation cell. Rehearsals were done ahead of time.

The allocation took place in a small group setting, after the translator and I read the Research Agreement Form aloud and asked whether the women had any questions. As the women agreed to participate and the forms were completed and signed, the bottom section of the form was also completed. This included the date, ID Code and the variable CAP-1, Choice about whether to participate or not, where 1 equaled “Chooses to participate (fill in the form above)” and 2. Prefers not to participate at this time. At the same time, I copied the colour of the allocation (using coloured markers) onto the woman’s Research Agreement Form and her identification number onto the colour allocation sheet (for tracking purposes). These processes, with randomization and colours different for each event, permitted me to remain blinded to group identity until at least after the women had received their appointments.

Research participants, with completed Research Agreement Forms, were directed individually to Portuguese-speaking volunteers. The Health Event Representative referred to the decoding page for that day (in a sealed envelope). Four coloured boxes on the page had the group allocation colours named, with the indicated invitation and brochure to
provide.¹ The Health Event Representative proffered the appropriate invitation (appointment now or later) and brochure(s) (Appendix 9). The verbal invitation included a short educational information component (read from the written brochure) and the offer of an appointment.

The bottom of the Research Agreement Form also included a data collection instrument to record the group allocation (ALL-1), the name of the woman offering the invitation (IP-1), whether 1 or 2 brochures were provided (BL-1), the appointment date offered (APO-1), and the woman's response to the appointment offer (APR-1). This form was later checked against the allocation sheet to verify that the brochure and appointment schedulings matched.

Table 16. Factorial design for participant allocation for Pap testing invitations

<table>
<thead>
<tr>
<th>Pap test appointment scheduled for</th>
<th>Information brochure</th>
<th>Appointment scheduling trial - Compare woman's response to invitation for row totals:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 language: Portuguese</td>
<td>2 languages: Portuguese &amp; English</td>
</tr>
<tr>
<td>Present</td>
<td>A</td>
<td>B</td>
</tr>
<tr>
<td>Later</td>
<td>C</td>
<td>D</td>
</tr>
<tr>
<td>Brochure language trial will compare intention to have Pap tests in future for column totals:</td>
<td>A+C</td>
<td>B+D</td>
</tr>
</tbody>
</table>

7.1.3 Sample size

The sample size of 20 women per cell (80 in total) initially proposed for the trial was chosen primarily by pragmatic considerations. Power calculations indicated restrictions with only 40 women exposed to each intervention arm. Calculations, based on tables for the two-sample test of binomial proportions, reveal an alpha of 0.05 (two-sided) and beta value of 0.65, with anticipated proportions of respondents deciding to have Pap testing of 0.5 and 0.1. The colour decoding sheet provided all four colours and the appropriate instructions. For Event #1, the first box, coloured in green, was labelled:

GROUP GREEN Give Brochure 1 (Portuguese)
Offer appointment NOW

¹. The colour decoding sheet provided all four colours and the appropriate instructions.
0.25 (Fleiss, 1973). As already indicated sufficient eligible women to reach the proposed sample size did not attend the health events; however, pilot studies serve to evaluate feasibility and are not expected to be definitive in themselves.

7.1.4 Follow-up

Follow-up of women was done by telephone interviews planned for one month and three months after the intervention (Appendix 4, Form FQ). A scripted text on the questionnaire form included: an identification of the caller; a recollection of the date and place of the health event the woman attended; and closed-ended and open-ended questions about the woman's decision about Pap testing. These included: whether she had a Pap test and if so, when; whether the material was discussed with anyone else, and if so, the identity and gender of that person and the language of that (those) interaction(s). Open-ended questions also asked about what influenced the woman's choices (details later, in the barriers and facilitators section).
7.2 Outcomes

In intervention research about approaches to inviting underscreened women to have Pap tests, it is important to know women's responses to the interventions. Pap tests, the ultimate goal of this intervention research, are of course of primary concern. Other outcomes are also valuable in research directed to developing strategies for behaviour change. As presented early in the literature review, theoretical models such as the transtheoretical model (Prochaska & DiClemente, 1986) proposes a sequence of intention and behaviour. These models are also valuable in practical terms, to contribute to improvements in screening.

Immediate or intermediate outcomes are valuable because they provide the opportunity to investigate the mechanisms of behaviour change over time, and they contribute to the capacity to plan and evaluate programs. And, as suggested earlier, depending on one's discipline, these interim responses may be considered process outcomes. As indicated in the literature review, though, research on Pap testing behaviour has not previously been undertaken from the perspective of stages of change (Prochaska & DiClemente, 1986); the discussion considers, in some depth, the phenomenon of adoption of Pap testing and proposes sequences of understandings and interactions relevant to this.

Immediate outcomes in the appointment trial were women's responses to the appointment offered them, assessed in both quantitative and qualitative terms. Initial reactions provide a proximate indicator of whether the approach is likely to be useful, and this indicator may be readily available, in a timely manner. This is important for research purposes and for application in any organized approach to screening. In either research or practice settings, making the effort to note a woman's immediate response could provide an opportunity for clarification, particularly where women decline the offer of an appointment. Might an open-ended approach provide a qualitative strategy to elaborate any outstanding barriers? It does seek underscreened women's understandings and concerns. If it is feasible, this simple, friendly overture may afford the chance to determine how easily barriers might be redressed, and whether certain additional facilitators might assist a woman to choose the preventive care option under consideration. Whether it elicits the right kind of information, it does send a message that the person asking the question actually cares about what the woman thinks. The research work here unequivocally affirms this stance.
Immediate and intermediate outcomes are of particular interest in feasibility research. Assessing women’s immediate responses to the offer an appointment for Pap tests may provide data that can be assessed for how well they predict subsequent behaviours. Feasibility assessment thus includes validation of the measures and a consideration of what and how they contribute to understanding the phenomenon of interest. In other words, might these immediate and intermediate outcomes substitute for the confirmed Pap tests, and how or what do they add to our understanding as measured by the quantitative outcome of the confirmed Pap test? Findings were presented in two ways: outcomes and analyses were provided explicitly in the results, and qualitative learnings were incorporated into the synthesis of barriers and facilitators. Intermediate outcomes are also important when the outcome of ultimate interest will take place at some point in the future. In the case of the brochure trial, the adoption of Pap tests is a future outcome and the trial was not intended to follow up women over many years. Measuring intention, or decision about having Pap tests in the future, provided an intermediate outcome of considerable practical and theoretical interest.

The primary analysis for the invitation study was to have been formal statistical testing for each aspect of the trial. Two statistical null hypotheses were to be tested, comparing the alternates using a binomial test of proportions:

1. The response to the invitation (accept or decline) does not differ whether a woman is offered an appointment for an immediate Pap test or is offered an appointment for later. This analysis would compare outcomes for the rows of Table 16 (i.e., Now, cells A+B, versus Later, cells C+D) in a two-sided test.

2. The report of intention to adopt Pap testing does not differ whether a woman receives one brochure (Portuguese) or two (Portuguese and English). This analysis would compare columns for Table 16 (i.e., One language cells A+C versus two languages cells B+D). A one-sided test would be used, anticipating that if a difference did exist, two brochures would be better than one.
7.3 Validation and verification processes

7.3.1 Validation for the appointment trial

The validation component was intended to investigate relationships among the immediate, intermediate and validated outcomes. First, a woman's initial response on having been offered the appointment (immediate outcome, Form RAF, item APR-1), was to be compared with her reports, on follow-up, of whether she had a Pap test at or since the health event (intermediate outcome, Form FQ#, question 3b). Then, initial response to the appointment offer, and report of a Pap test were to be compared with the gold standard, the confirmed Pap test (validated outcome, as confirmed by the physician's office).

The inter-relationships among these outcomes could be investigated with a complete set of positive and negative predictive values and sensitivity and specificity (i.e., Table 17a, 17b, & 17c) (Fletcher et al., 1988:42-75). Positive predictive values for two of these comparisons, denoted by arrows (→) in the following schema, were of greatest interest.

**Schema for calculating positive predictive values**

Woman accepts appointment for Pap test

\[ \downarrow \]

(Table 17a)

Woman reports, on follow-up, having had a Pap test at or since the health event

\[ \downarrow \]

(Table 17c)

Pap test is confirmed by physician's office
Table 17a. Validation strategy: Woman's initial response to appointment (immediate outcome) compared to later report of a Pap test (intermediate outcome)

<table>
<thead>
<tr>
<th>Response to appointment (Form RAF, APR1)</th>
<th>Woman reports having had Pap test (FQ#-3b)</th>
<th>Predictive Values (PV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accept</td>
<td>Yes: a, No: b</td>
<td>Positive Predictive Value = $a / (a + b)$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative Predictive Value = $c / (c + d)$</td>
</tr>
</tbody>
</table>

Response to appointment compared to report of having had a Pap test at or since the health event (FQ#-3b)

| Sensitivity = $a / (a + c)$ | Specificity = $d / (b + d)$ |

Table 17b. Validation strategy: Response to appointment for a Pap test (immediate outcome) compared to physician's records (ultimate outcome)

<table>
<thead>
<tr>
<th>Pap test confirmed on physician's records</th>
<th>Predictive Values (PV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes: e, No: f</td>
<td>Predictive Value Positive = $d / (e + f)$</td>
</tr>
<tr>
<td></td>
<td>Predictive Value Negative = $h / (g + h)$</td>
</tr>
</tbody>
</table>

| Sensitivity = $e / (e + g)$ | Specificity = $h / (f + h)$ |

Table 17c. Validation strategy: Woman's report of having had a Pap test (intermediate outcome) compared to physician's records (ultimate outcome)

<table>
<thead>
<tr>
<th>Pap test confirmed on physician's records</th>
<th>Predictive Values (PV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes: j, No: k</td>
<td>Positive Predictive Value = $j / (j + k)$</td>
</tr>
<tr>
<td></td>
<td>Negative Predictive Value = $m / (l + m)$</td>
</tr>
</tbody>
</table>

| Sensitivity = $j / (j + l)$ | Specificity = $m / (k + m)$ |
7.3.2 Investigating assumptions

In this study, the assumption was that negative responses did not warrant validation efforts. That is, it was assumed that a woman who declined an appointment, would be unlikely to later have a Pap test. Similarly, a report of not having had a Pap test was assumed not to need validation. These assumptions were examined, applying available data using the schema below.

**SCHEMA TO INVESTIGATE ASSUMPTIONS ABOUT REPORTS & DECISIONS**

- Woman accepts appointment for Pap test
  - Woman reports, on follow-up, having had a Pap test at or since the health event
  - Woman reports intention to have Pap tests in the future

The results for this approach were sketched as a set of line tracings for individual women in the trial. This approach also permitted the identification of shifts in responses over time.

7.3.3 Mechanisms to adoption

For the brochure languages trial the study was designed to permit consideration of two pathways that might influence a woman to adopt and continue with Pap testing. Data to explore these mechanisms were collected on the follow-up questionnaires (Appendix 4), which asked whether the material was discussed with anyone else, the role or relationship (health care professional, family or friend) and gender of that person, and the language of the interaction.

The first hypothesis was that women who received two brochures (Portuguese and English) would report a greater number of subsequent conversations about Pap testing than women who received only a Portuguese brochure. The expectation here was that having two brochures could prompt discussion with someone who reads English, who may be better integrated into preventive care practices of the dominant culture, and who may thus function as an advocate for Pap tests. The second hypothesis was that the number of discussions about Pap testing would be related to the intention to have Pap testing in the future.
Each of these two postulated steps of this mechanism were to have been evaluated using the appropriate statistical test (Glantz, 1987). The two main hypotheses for testing would be based on interval data and so would use the Mann-Whitney rank-sum test (Glantz, 1987):

1. The number of people with whom Pap testing was discussed, comparing those who had been given two brochures versus those who had been given one brochure; and
2. The number of reported conversations, comparing those who intended to continue with Pap testing versus those who do not.

In addition, for these same two comparison groups, distributions of nominal data (role, gender, language of conversations) would be tested using chi-square analysis of contingency tables (Glantz, 1987).

Secondary analyses were planned to contribute to the considerations of trial generalizability: differences between those who chose to participate in the trial and those who declined; and the adequacy of randomization. Because so few women were involved, cells had values less than 5, and so statistical testing (even with Fisher's exact test) was not appropriate.

7.3.4 Using qualitative and quantitative data together

Qualitative responses and interpretations of them were considered alongside the quantitative assessments. Community partners identified difficulties in classification. A set of tables was created to contrast the categorization of outcomes using quantitative and qualitative data.
7.4 Barriers and facilitators

Barriers and facilitators were identified using the qualitative data available through the follow-up questionnaires. The questions under consideration included:

FQ#-3c What made you decide to have the Pap test?
FQ#-3d What would help you decide to have a Pap test in the future?
FQ#-4x Are there any other things that you would like the researcher to know about your reaction to the invitation, to the Pap test, to the research project, or to the health event?

In addition to these open-ended questions, notes were made of any comments made during the follow-up interviews.
Chapter 8 Results for Objective 3: Randomized trial

Objective 3. To undertake a pilot randomized controlled trial of approaches to inviting underscreened women for Pap testing.

This section presents results for the randomized controlled trial, having earlier compared the characteristics of eligible and ineligible women attending the health events (as part of Objective 2). Here, results include: the flowchart of study participants; trial outcomes and verification and validation of them; and barriers and facilitators of Pap testing reported by trial participants. Throughout, the emphasis is on using available data to inform the understanding of women’s choices about Pap tests.

8.1 Randomization and eligibility

Figure 2. Flowchart of trial participants: Allocation to interventions for Appointments (Now versus Later) and Brochures (Portuguese versus Portuguese & English)
Figure 2 shows the flowchart of randomization of the trial participants. Of the sixteen women who brought Research Agreement Forms to the small-group presentation about the trial, fourteen agreed to participate, and two declined and walked away. On this flowchart, the allocation to appointment and language appears alphabetic; in reality the allocation for both trials, as described in the methods, was simultaneous. For the appointment trials, seven women were allocated to receive an appointment “now”, i.e., at the health event, and seven to receive one later. For the brochure trial, eight women were allocated to receive the Portuguese brochure and six to receive both Portuguese and English versions.

Comparing this flowchart to the health event results suggests an apparent discrepancy between eligibility for the randomized trial and participation in it. That is, while fourteen women had originally been identified as underscreened on the Women’s Health Event Questionnaire, sixteen attended the small group presentation and fourteen participated in the trial. The resolution lies in the following additional information: one of the women who was eligible did not attend the small group session, and an additional three women not originally identified as underscreened on their Women’s Health Event Questionnaires did show up at the small group sessions and were included in the trial.

The colour coded allocation strategy was reported to be easy for the Health Event Representatives to understand and apply, and it was successful in keeping the researcher and assistant blinded to the randomization until women received their invitations. Not all variables were completed as expected, with certain forms missing information or having it entered in the wrong place, including the name of the Health Event Representative. Two forms missing the appointment allocation were deemed, on review of the comments to have received the correct one (e.g., for a woman randomized to receive an immediate appointment, the form was noted “cannot do it today”). Two forms were missing the number of brochures received, and it was not possible to determine which the woman had received. One error was a brochure number that did not match what had been allocated. Later, on reviewing the completed forms with the research assistant, the idea was raised that rewording certain variables or re-ordering the items would have made the form clearer.

In addition, one woman who had declined a later appointment, and who was deemed by the Health Event Representatives as eager to see the female provider available at the health
event, was allowed to see the provider after the session had finished that day. Her initial allocation for the later appointment and original response to it had been recorded.¹

¹ This decision, to allow someone to see the care provider if there was an opening, had been taken after reviewing the first health event, where one Spanish woman, not eligible for the study, had been turned away from any opportunity to have a Pap test, completely.
8.2 Trial outcomes

The quantitative results of Objective 2's randomized trials are presented separately for each trial: Table 18, Appointment trial; and Table 19, Language trial. Overall, of the fourteen women who participated in the trial, seven accepted or had their appointment booked at the time the invitation was provided (Appointment response, APR-1). Overall, ten of the fourteen women reported an intention to have Pap tests in the future (FQ#-5a, Do you expect to have Pap testing in the future?).

**Appointment trial, comparing now versus later**: Of the seven women allocated an immediate appointment, three accepted, two declined, and for two women the appointment response (item APR-1) was not noted. Of the seven women allocated a later appointment, four accepted or booked an appointment, two declined, and one woman’s response was not noted.

Table 18. Appointment trial outcomes: Woman’s response to offer of appointment (Form RAF, item APR-1)

<table>
<thead>
<tr>
<th>Appointment</th>
<th>Appointment Response</th>
<th>Appointment totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Accepted / booked</td>
<td>Declined</td>
</tr>
<tr>
<td>Now</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Later</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>
Brochure language trial, comparing Portuguese only versus Portuguese & English:
Table 19 provides the brochure language trial summary. Five of the eight women who had received a brochure with Portuguese only, and five of the six who had received brochures in both Portuguese and English, reported that they expected to have Pap tests in the future.

Table 19. Brochure language trial in terms of reported intention to adopt Pap testing (i.e., expecting to have it in the future)

<table>
<thead>
<tr>
<th>Brochure</th>
<th>Intention to have Pap test</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>1. Portuguese</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>2. Portuguese &amp; English</td>
<td>5</td>
<td>0</td>
</tr>
</tbody>
</table>
8.3 Validation and verification processes

8.3.1 Validation for the appointment trial

Validation results compare the woman’s reports of having had a Pap test with information from the “gold standard”, the medical records.1 The results for the quantitative validation processes begin with Table 20a, comparing women’s immediate response to the appointment allocation, to her later report of whether she had a Pap test at or since the health event. Three women whose appointment responses were unknown were excluded from these analyses.

Table 20a. Validation strategy: Woman’s response to appointment compared to later report of a Pap test

<table>
<thead>
<tr>
<th>Response to appointment (Form RAF, APR-1)</th>
<th>Woman reports having had Pap test (FQ#-3b)</th>
<th>Predictive Values (PV)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Accept</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Decline</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Positive Predictive Value = \( \frac{4}{7} = 59\% \)
Negative Predictive Value = \( \frac{2}{4} = 50\% \)

Sensitivity = \( \frac{4}{6} = 67\% \)
Specificity = \( \frac{2}{5} = 40\% \)

Two additional assessments were to be done in the same manner. Comparing the immediate outcome to the future outcome, i.e., the response to the offer of an appointment (Form RAF, question APR-1) was to have been compared to the gold standard of Pap tests confirmed by the woman’s physician’s office (Table 20b)². The retrospective reports of whether a Pap test had been done (at or since the health event, FQ#-3b), compared to physicians’ reports (Table 20c).

---

1. Validation techniques in clinical settings, applied to diagnostic or screening tests, compare the test performance to the actual presence of a disease or condition.

2. The confirmed test for one woman who had declined an appointment was the result of the test being done later that day of the health event.
Table 20b. Validation strategy: Response to appointment for a Pap test compared to physician’s records

<table>
<thead>
<tr>
<th>Woman’s response to invitation (Form RAF, item APR-1)</th>
<th>Pap test confirmed on physician’s records</th>
<th>Predictive Values (PV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accept</td>
<td>Yes: 1</td>
<td>No: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Predictive Value Negative = h / g + h</td>
</tr>
<tr>
<td>Decline</td>
<td>1</td>
<td>h</td>
</tr>
</tbody>
</table>

Sensitivity and specificity of response to appointment, measured against gold standard of physician’s records

<table>
<thead>
<tr>
<th>Sensitivity</th>
<th>Specificity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity = ½ = 50%</td>
<td>Specificity = h / f + h</td>
</tr>
</tbody>
</table>

Table 20c. Validation strategy: Woman’s report of having had a Pap test compared to physician’s records

<table>
<thead>
<tr>
<th>Woman’s report of having had Pap test (FQ#-3b)</th>
<th>Pap test confirmed</th>
<th>Predictive Values (PV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes: 2</td>
<td>No: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative Predictive Value = not calculated</td>
</tr>
<tr>
<td>No</td>
<td>not requested</td>
<td></td>
</tr>
</tbody>
</table>

Sensitivity and specificity of report of having had Pap test, measured against gold standard of physician’s records

<table>
<thead>
<tr>
<th>Sensitivity</th>
<th>Specificity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity = not calculable</td>
<td>Specificity = not calculable</td>
</tr>
</tbody>
</table>

From these tables, it is clear that the quantitative validation effort was compromised. The qualitative data elaborate the problem. The request for validation, posed after the woman reported having had a Pap test, raised a number of negative responses: explanations were that the results were normal (n=2) or the test had been done at the doctor’s office (n=3). Some understood the researcher already had access to the relevant data. One woman refused validation by stating her doctor might get upset. These responses were interpreted by the research assistant to indicate either that the women did not fully understand the intention of the validation process, the nature of the research process, or they perceived the intention to validate as inappropriate. With only three women providing permission for test results to be validated, and only two records being located, the estimates are unreliable.
Even if all women had agreed to validation, only Positive Predictive Values were to have been calculated, because if a woman reported that she had not had a Pap test, this was assumed to be true and no validation would have been attempted. The line tracing that follows provides a different perspective on the data, relevant to these expectations.

8.3.2 Investigating assumptions

As stated above, women were not expected to make a negative initial response and then report a positive intermediate outcome or validated outcome. These assumptions were challenged when results were reviewed using available data to summarize the temporal shifts in individual women’s responses and reports.
Response to appointment | Report of having had Pap test at or since the health event | Intention to have Pap tests in future

1026 | 1001 | Yes
2013 | 1035 | Uncertain or unknown
2002 | 3003 | No
2016 | 1025 | 1043 | 1006 | 1004 | 3040 | 1022 | 2011

Figure 3. Line tracing of trial participants' responses to three outcomes of interest: Immediate response to offer of appointment, report of Pap test at or since the health event, and intention to have Pap tests in the future.

Figure 3 presents a line tracing of the responses of individual women in the trial, using three outcomes across the temporal range, from the immediate response to offer of appointment, to the report of Pap test at or since the health event, to the intention to have Pap tests in the future. Among the three eight possible outcome options for the three outcome measures, every possible combination was represented. This is evidence against the original assumption, that negative intentions are unlikely to shift to positive responses later.
8.3.3 Mechanisms to adoption

The possible mechanisms of adoption of Pap tests, relevant to the brochure trial, could not be quantitatively investigated due to the small numbers in the trial. Even so, the data on the follow-up questionnaires were used to produce a set of barriers and facilitators, later in this chapter.

8.3.4 Using qualitative and quantitative data together

With incomplete data for the immediate outcome for the appointment trial, and limited external quantitative data to validate the Pap tests, other quantitative and qualitative data were used to maximal capacity.

Having recognized that the immediate outcome of women's response to the appointment had not been completed in 3 cases, an alternate question was considered to corroborate the results. The results for that question FQ#-3a "Did you decide to have a Pap test?" (Yes, No, Undecided) indicated that every woman but one had decided to have a Pap test. Further, review of the hand notations on the research agreement form and the transcripts of the follow-up surveys indicated that this reported "decision" did not necessarily correspond with women's qualitative descriptions about what had actually taken place. Thus, this question did not contribute meaningfully to understanding women's responses to the offer of an appointment.

Follow-up questionnaires with the trial participants provided additional qualitative data, elaborating on women's reports of having had the Pap test (FQ#-3b) and of intending to have it in the future (FQ#-5a) (Yes, No, Uncertain). These outcomes were used as the row and column headings for Table 21. Entries for each women include trial allocation as well as an identification code (to permit tracking among text and tables). Allocation indicates the details of whether she was randomized to receive one (Portuguese) brochure or two (Portuguese and English) brochures, and, whether the appointment offered was for Now (N) or Later (L). The brief narrative extracts here are a "capsule" explanation for her behaviour and intentions.
Table 21. Summary of trial outcomes (whether the woman reports having had the Pap test at or since the health event, and whether she intends to have it in the future) indicating identification code, allocation (1 or 2 brochures, appointment Now or Later), and narrative extracts from follow-up interviews.

<table>
<thead>
<tr>
<th>HAD A PAP TEST AT OR SINCE THE HEALTH EVENT</th>
<th>INTENDS TO HAVE IT IN FUTURE (ADOPTION)</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Yes</td>
<td>n=8</td>
<td>n=0</td>
</tr>
<tr>
<td>1001 2L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1004 1L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1025 1N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1026 1N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1035 2L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1043 2N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2013 1N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3040 2L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>n=2</td>
<td>n=1</td>
</tr>
<tr>
<td>1006 1L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002 1L</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>n=10</td>
<td></td>
</tr>
</tbody>
</table>

* These women were not identified as underscreened by the eligibility questions on the Women's Health Event Questionnaire.
The narrative transcripts provided a more complex perspective on the outcomes of interest. On discussing results with a community partner, the problem of possible misclassification about future intentions (presented earlier in Table 19) was emphasized. On reviewing narrative transcripts, the partner noted the classification of one woman's intention to have a Pap test with concern. Reading the narrative led her to believe that the woman was expressing a "hidden no". Her understanding of a Portuguese woman's reference, description of an appointment as tentative or flexible, any indication of ambivalence (e.g., by referring to her age) or any mention of barriers, such as fear or shyness, meant that the woman was not intending to keep the appointment at all. What I had considered a strategy to ensure that she could carry out her intentions, in the community partners' experience was understood as reluctance or lack of intention to carry through with the behaviour. This was considered a polite way of expressing things.

A reclassification scenario was devised to consider how these interpretations might modify the "results". Table 22 provides narrative capsules of each woman's experience. It also reclassifies women regarding intention to have it in the future, from what the quantitative results alone had indicated, to using the qualitative data for any evidence of a "hidden no". That is, if the narrative text expressed anything other than an explicit and unambiguous intention to have Pap tests in the future, whether by hesitation, ambiguity, or suggestion of potential difficulties that might impede a woman, her response was down-graded. Seven women were reclassified based on such data: compared to the initial classification (Table 5) six "moved over" to the right hand column and one (2011) was shifted from uncertain to a definite no.

1. Two types of quantitative comparisons could be used to investigate classification of intention. The first would compare the researcher and a community partner's independent assessments of the narrative and quantitative data for each woman. Each assessor would classify each woman's "intention to have or continue with Pap tests in the future" (i.e., using a binary classification of "will" or "will not"). A Kappa statistic could be calculated to compare the responses between the two "assessors" (Rosner, 1986). This statistic accommodates agreement expected by chance and provides what Rosner calls "a quantitative measure of reproducibility" (Rosner, 1986: 424). The Kappa statistic would indicate the extent of concordance between the two assessors. The second approach would compare each woman's initial classification with her actual behaviour one to three years later. Predictive values would be calculated, with larger predictive values considered superior. Neither of these options was feasible.
## Table 22. Reclassification scenario: Intention to have Pap tests using qualitative data

<table>
<thead>
<tr>
<th>HAD A PAP TEST AT OR SINCE THE HEALTH EVENT</th>
<th>INTENDS TO HAVE IT IN FUTURE (ADOPTION)</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>YES (n=3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1004 1L (does test every year, never given an app't, ended up doing test at doctor's);</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1025* 1N (porque nunca tinha feito, she never had done it before);</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2013 1N (it was necessary - learning is important for prevention-abnormal cells - will continue to do the test always);</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NO (n=0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>n=5</td>
</tr>
<tr>
<td></td>
<td>1001 2L C (FQ3: The specialist gave her medication but she did not get better - still in the same condition. Wants to go to another specialist. Will continue to do the test. She has not yet told her doctor about the test but will tell him. Concerned if she should bring her husband. Felt sick, important test for women);</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1026 1N (FQ3 - re validation: results were fine / normal so there is no need to do anything else. She was going to be over 60 years old the next month.)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1035 2L (was planning to have this test done, knows that women should have this test, she is extremely shy and does not feel comfortable talking about it with doctor, feels it's important, In my age it's good to do this test)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1043* 2N U (complicated medical history, friends feel they are too old for this test, without a doubt I will continue to do the test in the future, we must take care of ourselves and our bodies);</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3040* 2L C (my Dr is a man, Dr that day was a woman - test normal);</td>
<td></td>
</tr>
</tbody>
</table>

n=8
<table>
<thead>
<tr>
<th>HAD A PAP TEST AT OR SINCE THE HEALTH EVENT</th>
<th>INTENDS TO HAVE IT IN FUTURE (ADOPTION)</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>YES (n=0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NO (n=2)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2011 2N (went to Dr but not to do this test, I know this is carelessness, I am a very scared person, have desire, lack courage - if I don't feel the pain I don't find it necessary to go)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2016 1L (clinic called to change appointment - not important because of age)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1006 1L (embarrassed in front of doctor, daughter also uncomfortable going to doctor, afraid of doing a checkup)</td>
<td>n=4</td>
</tr>
<tr>
<td></td>
<td>1022 2N (illegal rep)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2002 1L (FQ1. She finds herself old to be doing this test. FQ3: Although she had an appointment set up she did not do the test.)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3003 1N (infection for 27 years so test couldn't be done, interviewer notes woman is not clear re Pap test)</td>
<td></td>
</tr>
</tbody>
</table>

* identified as adequately screened on WHEQ

C = Confirmed (i.e., The woman had given authorization for validation; physician records for this patient confirmed the reported Pap test.)

U = Unconfirmed (i.e., The woman had given authorization for validation; records for this patient could not be located at her doctor's office.)

Underlined identification codes indicate no change in the classification.

FQ1 = Followup Questionnaire 1          FQ3 = Followup Questionnaire 3
In summary, the quantitative trial results in themselves present paradoxes of feasibility and certainty. Participation and question response rates, both important measures of feasibility, were reasonable, while the overall numbers who attended the health events were inadequate. That is, eleven of the fourteen women originally identified as eligible participated in the trial; the co-intervention of the health events attracted the right kind of women (i.e., Portuguese-speaking, over age 40); these women answered the questions asked of them. In contrast, the small numbers of women (n=54 unique women) who attended the health events meant a severely restricted trial. Further, the strategy chosen for validation of reports with medical records, i.e., where authorization was requested after the report of outcomes and intentions, did not make sense or was otherwise considered unsuitable by the women.

The other paradox was that using several quantitative measures as well as qualitative data revealed considerable uncertainty in the categorization of outcome. These were not apparent in any single quantitative outcome. Analyses confirmed how sensitive the findings were to the definition chosen and to the interpretation of the results.

In contrast to these ambiguities, the appointment and language trials yielded meaningful and straightforward findings about barriers and facilitators of Pap tests.

1. Appointments: There were pros and cons for both immediate and later appointments. Immediate appointments eliminated, for women attending the health events, the barrier of location, and having the female care provider in evidence was a prompt to stay for a test. However, a barrier with an immediate appointment was that a woman was not able to stay. Barriers for later appointments included scheduling glitches, and difficulty in finding the (different) location.

2. Brochures: Women brought the health event flyer with them to the trial. Women in the trial invariably described having put their invitation brochure away; other women in women's groups requested or described using the brochure to show their doctors.
8.4 Barriers and facilitators

Qualitative data, collected at the time of the trial and on follow-up, contributed additional information about the barriers and facilitators of Pap tests. Of the ten women who indicated an intention to have Pap tests in the future, five used phrases which included the words "important", "necessary" or "must". Conversely, among other women, one indicated that it was not important because of her age, and another that if she had no pain she did not find it necessary to go. These two reports indicate a confusion about what screening is for, and who is eligible for it; they contributed to the development of the set of myths in the discussion. Another facilitator, of timing or appropriateness, was evident in reports that one woman had never done it before, another had not done it in years. Two women reported specific factors that prompted their having had a Pap test: one woman felt sick and another reported that she participated because the doctor that day was a woman.

Barriers to Pap tests were explicitly identified by seven women in the trial. These included the presence of infection or inflammation (n=2), shyness or embarrassment (n=2), being "a very scared person" (n=1), clinic difficulties in rescheduling (n=2), getting lost trying to find the office for the Pap test (n=1), and no health care coverage for a woman in Canada illegally (n=1). Two women reported more than one barrier. Two other women reported having had a Pap test despite their barriers of shyness and not having been given an appointment.
Chapter 9 Methods for Objective 4: Barriers and facilitators

Objective 4. To synthesize the findings from the collaborative development, the approaches to underscreened women that were identified, and the pilot project, and identify factors that serve as barriers or facilitators of Pap testing in a population of underscreened women.

All of the study elements and data sources described previously helped to identify factors likely to serve as barriers or facilitators of Pap testing in underscreened Portuguese-speaking women. As described earlier, this moved beyond the passivist approach of simply reporting concrete or objective details, to the activist strategy of behavioural sciences. This was intended to “decipher” and “depict” the situation these women were facing (Lofland & Lofland, 1995:146). The goal was to identify “collective self-deceptions” and “situationally induced irrationality” (Lofland & Lofland, 1995:171).

The material was synthesized using four complementary approaches: 1) a figure of the specific steps in the adoption of Pap tests; 2) a summary of reported barriers and facilitators, organized using the PRECEDE framework (Green & Kreuter, 1991); 3) the "self-deceptions", embodied as a set of myths identified over the course of the study; and 4) an examination of the representativeness of the study participants. Finally, emerging results were returned to the community to explore and clarify emerging or outstanding issues. The methods for each of these approaches are described below.

9.1 Steps in the process of adoption of Pap tests

First, qualitative data describing factors reported as influencing choices about Pap tests were reviewed and assembled into a "flowchart" figure of when the factor appeared to be functioning. This strategy shows the process of adoption of Pap testing as a process set in time (corresponding to Lofland & Lofland, 1995:199).
9.2 PRECEDE-PROCEED framework

Findings were organized using three phases from the PRECEDE model (Green & Kreuter, 1991:24, 230) to investigate Portuguese-speaking women's choices about Pap tests:

Phase 3. the behavioral and environmental diagnosis; Phase 4. the educational and organizational diagnosis to identify the factors which may influence them; and Phase 5. the administrative and policy diagnoses relevant to health promotion in these matters. For Phase 3, behavior, lifestyle and "environment" here refer specifically to Portuguese-speaking women, with respect to the health behaviour of screening for cervical cancer. In the context of the PRECEDE model, "environment" means external, potentially modifiable factors, i.e., those that "can be modified to support the behavior, health, or quality of life of that person or others affected by that person's actions" (Green & Kreuter, 1991:28) Phase 4 differentiates three categories for the educational and organizational diagnosis, i.e., predisposing, enabling and reinforcing, corresponding to the "types of interventions available in health education and health promotion." (Green & Kreuter, 1991) Reinforcing factors can be either positive or negative. The available interventions are: for predisposing factors, direct communications to the population of interest; for enabling factors, community organization, political interventions and training; and for reinforcing factors, indirect communications through others who provide it (Green & Kreuter, 1991:165). Phase 5, the administrative diagnosis, refers to "an analysis of the policies, resources, and circumstances prevailing in the organizational situation that could facilitate or hinder the development of the health promotion program" (Green & Kreuter, 1991:189).

Using the PRECEDE-PROCEED framework anticipates that the results may be relevant to health care and social service clinicians who provide care for Portuguese-speaking women and to those who develop policy and programs for them, but for this study, factors did not

1. As described earlier, Phase 2 (epidemiological diagnosis) corresponds nominally and functionally with the tradition of descriptive epidemiology, characterizing "the existing distribution of variables" (Last, 1995:46).

2. As presented earlier, "Predisposing factors are those antecedents to behavior that provide the rationale or motivation for the behavior. Enabling factors are the antecedents to behavior that enable a motivation to be realized. Reinforcing factors are factors subsequent to a behavior that provide the continuing reward or incentive for the behavior and contribute to its persistence or repetition." (Green & Kreuter, 1991:151)
necessarily have to be modifiable to be included. These data were grouped using the categories of the PRECEDE framework and the sources which reported them.

Besides sources described earlier, additional information regarding provincial legislation and policies relevant to preventive care was obtained from sources at or affiliated with the provincial Ministry of Health and Long-Term Care and with local public health units.

9.3 Myths

The presence and importance of myths was identified early in the study. Some of the myths were explicitly articulated by respondents, others represent distillations of the perceptions, attitudes or understandings of the issues around cancer and the provision of health care, including screening.

9.4 Representativeness

Characteristics of study participants were considered with respect to how well they represented the population of greatest interest i.e., Portuguese-speaking women who were underscreened with respect to cervical cancer. It was not possible to compare the screening adequacy of the study population (attending health events and physicians' offices) with the Portuguese-speaking population in Toronto. In the Ontario Health Survey (1996/1997), data on language spoken at home were collected, but the small sample of Portuguese-speaking women precluded analysis. Prevalence of underscreening was summarized by age group, comparing Portuguese-speaking women attending health events, Portuguese-speaking women reported on the physicians' logs and respondents from the National Population Health Survey (Lee et al., 1998).

1. In fact, factors under consideration seem closer to the epidemiologic definition of "environment": "all that which is external to the human host.... physical, biological, social, cultural, etc., any or all of which can influence [the] health status of populations." (Last, 1995:53).

2. There were 59 Portuguese-speaking women aged 41 years old or more who responded to the survey in Ontario. of whom 19 were in Toronto (Paul, 1998).
9.5 Returning results to the community

As the thesis results were being written up¹, representatives of community agencies were contacted by telephone to advise on the progress and to solicit their preferences about form and content for returning results to the community. This led to a number of meetings, described using simple narrative form. Points of clarification were incorporated into relevant sections of the thesis. Suggestions about ways to communicate findings and program development were noted and used to develop ideas for future intervention research.

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¹. Indeed, some results of these iterations were presented in earlier chapters, i.e., the initial planning group's review of communication issues.
Chapter 10 Results for Objective 4: Barriers and facilitators

Objective 4. To synthesize the findings from the collaborative development, the approaches to underscreened women that were identified, and the pilot project, and identify factors that serve as barriers or facilitators of Pap testing in a population of underscreened women.

The synthesis of findings about barriers and facilitators includes: a figure of steps on the pathway to adoption of Pap tests; the PRECEDE framework, the set of myths relevant to cervical cancer and screening for it; a consideration of the representativeness of study participants; and a description of the final iteration of the project with community partners.

10.1 Steps on the pathway to adoption of Pap test (as reported by women attending health events)

Figure 4. Barriers and facilitators along the path to Pap tests
Figure 4 shows barriers and facilitators along the path to Pap tests, as reported by women attending the health events. Barriers, on the left, are outlined by ovals; they reflect themes of fear, time, isolation and communication. Facilitators, on the right, are outlined by rounded boxes; they reflect themes of communication and/or company. The choices facing underscreened women are represented as nodes along the path. The choices on the right side of the figure represent actions along the path to Pap tests, in the context of the health event where the trial took place. The bottom set of options, indicating future intentions, is indicated with a broken line.

There are more facilitators than barriers, reflecting the data available and the participants in the study. More data were available on women who chose to do something than on those who declined; the women who responded positively (i.e., choosing Pap tests) were more amenable to follow-up than those who declined or walked away. In addition, as the trial results showed, when data on both were available, those who "did" something tended to describe things directly and in terms of their understandings of the role or purpose of the test, identifying explicit or discrete or objective influences. Those who "did not" do something gave more complicated or diffuse or personal explanations, describing confluent factors that served as barriers that prevented them from taking the action. Facilitators were identified by those who did, while barriers were identified by those who did not.

The diagram (Figure 4) summarizes what trial participants reported about what had prompted them to come to the health event, participate in the research, or have a Pap test. It was not always easy to distinguish among these things. Several things were mentioned, including wanting to learn about health, or being invited by a friend, relative, or as part of a group. Although the participation in the research and having a Pap test were, from a researcher’s perspective, discrete, recognizable steps, distinguishing what had prompted women to participate in the research was not clearly distinguishable from what had prompted them to have a Pap test. Both were reportedly prompted by being aware of the importance of the Pap test to stay healthy. In addition, receiving a firm appointment at a convenient time and location, and knowing that the health care provider was a "lady doctor" or a trained professional were cited as important. Having found out their test results seemed meaningful and relevant to expectations about continuing with Pap tests in the future.
Being "too old" was given as an explanation for not participating in the research or not continuing with Pap tests, while being scared or embarrassed was reported by others as a reason for not having the Pap test at all. Obligations and responsibilities, and chronic family or health conditions meant that some women could not attend their scheduled appointments.
10.2 PRECEDE-PROCEED framework

This section summarizes and collates material about barriers and facilitators of Pap tests from all phases of the project, from research development through returning results to the community. "Diagnoses" are organized as barriers and facilitators of Pap testing, using the PRECEDE-PROCEED framework for health promotion program planning and evaluation (Green & Kreuter, 1991). Factors could be included even if they were not necessarily amenable to change, or if nothing was known about whether they could be changed. For Pap testing, this meant identifying any recognizable "risk" factors (e.g., whether social, demographic and cultural) and any factors that might be contributing to them (i.e., whether individual or not). The material is presented in 3 tables, one for each phase: behavior and environment (Phase 3); education and organization (Phase 4); and administration and policy (Phase 5). Within each of the categories, entries are grouped, with barriers to Pap testing (-) preceding facilitators (+); in some cases a single item serves as both.

Tables 23A, B, & C summarize the barriers and facilitators of Pap testing reported by study participants. Study participants are here summarized within six groups: the Initial Planning Group; the Community Steering Group, which included Health Event Representatives and the organizers of the health events: Trial Participants; and three sets of key informants. Physicians involved in this study were mostly family doctors, most of whom responded to the survey. Other physicians included a psychiatrist and a gynecologist with experience with the Portuguese community. For this study, the term "Other Clinicians" refers to any provider of health or social services other than a medical doctor. "Other Portuguese" refers to Portuguese-speaking people not included in any other category; it includes those met during the development phase or in returning results to community members. Although different groups reported things from different perspectives, sometimes emphasizing different aspects of the same thing, there was considerable consensus about how certain barriers and facilitators likely influenced or determined women's Pap test behaviour.
10.2.1 Phase 3. Behavioural and environmental diagnosis

The behavioural, lifestyle or environmental factors identified explicitly as barriers to Pap tests are identified in Table 23A. Trial participants reported that they did not ask for Pap tests, and the Initial Planning Group and other Portuguese people consulted in the course of this project reported that women go to doctors for treatment of symptoms rather than for preventive care. The planning groups reported that Portuguese women were busy, generally working long hours, sometimes in several jobs, and their many responsibilities meant limited opportunity for self-care. Women’s own needs would come after the needs of their families. Illegal visitors (e.g., staying with their relatives to look after sick children) were reported as generally having no medical coverage, and therefore being unlikely to seek self-care for anything other than urgent needs.
Table 23A.  Behavioral and environmental diagnosis: Barriers (-) and facilitators (+) of Pap testing

Phase 3 of the PRECEDE framework for health promotion program planning (Green & Kreuter, 1991)

<table>
<thead>
<tr>
<th>BARRIER (-) OR FACILITATOR (+)</th>
<th>IPG</th>
<th>CSG</th>
<th>TP</th>
<th>KI: DR</th>
<th>KI: OC</th>
<th>KI: OP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BEHAVIOUR AND LIFESTYLE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women don't ask for Pap tests</td>
<td>-</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women go to doctors with acute and chronic symptoms, not for preventive care</td>
<td>-</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td><strong>ENVIRONMENTAL</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women are very busy, often with several jobs &amp; responsibilities</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women in Canada illegally do not have health care coverage</td>
<td>-</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>
10.2.2 Phase 4. Educational and organizational diagnosis

The majority of reported barriers and facilitators of Pap testing were categorized as educational or organizational (Table 23B).

Predisposing factors are those attributed to the women themselves. "Predisposing factors are those antecedents to behavior that provide the rationale or motivation for the behavior." (Green & Kreuter, 1991:151) Lack of knowledge about preventive care options, including Pap testing, was widely recognized. Values and attitudes were also cited as likely to influence women's choices about Pap tests, but they were not always specified, nor was their mechanism generally identified. Religiosity, fear, passivity, and shyness, were considered likely to serve as barriers to Pap tests; these were not reported as mutually exclusive. Limitations in language, literacy and education were acknowledged as important barriers to women having Pap tests. Sometimes these factors were linked explicitly with women not asking for Pap tests; more often no details of how they served as barriers were provided. Portuguese women who attend health education sessions were reported to be oriented to think about preventive care behaviours and receptive to guidance about these matters. They reported, about themselves, that they think about the future and they want to stay healthy. Yet women raised in traditional Portuguese cultures may not attend such activities. They are shy, not used to talking openly about health or intimate matters.

Enabling and reinforcing factors overlapped. "Enabling factors are the antecedents to behavior that enable a motivation to be realized." (Green & Kreuter, 1991:151) Enabling factors are grouped within the categories of availability and accessibility of health care. In this study, there was marked consensus about the role physicians play in initiating Pap tests for asymptomatic women, especially for immigrant women who do not realize that preventive care is part of a doctor's role. In contrast, some respondents (including Portuguese women themselves) expected women who wanted preventive care tests to have to take the responsibility to ask their physicians to provide them. Representatives (but not all members) of most groups reported that doctors should recommend women have the Pap test and/or other tests to stay healthy. Doctors were understood to have important and well-recognized roles in recommending and providing the Pap test, but it was reported that not all doctors examine their patients, or provide Pap tests themselves, or explain that the Pap test is necessary. Further, many women reported that their doctor did not allow
enough time to answer questions or explain things to them, and some confirmed that their
doctor did not recommend Pap tests. The women in this study contrasted the notion of the
doctor's time constraints with their own inclinations to discuss their health concerns. Some
doctors reported that they offered women a Pap test [only] if they needed it, specifying, if
they have bleeding or other symptoms.

Reinforcing factors were not as clearly characterized as were predisposing and enabling
factors. Reinforcing factors are those "subsequent to a behavior that provide the continuing
reward or incentive for the behavior and contribute to its persistence or repetition." (Green
& Kreuter, 1991:151). Obligations were expected to function in a negative way; these could
deflect a woman's time and energy away from her own self. Alternately, a supportive
husband might drive his wife to her appointments. Friends and relatives (here also
considered as peers) might also encourage a woman to learn about health, either directly or
in the context of a women's support group. Here the emphasis would initially be on
identifying and addressing any long-standing or acute symptoms. This role, of encouraging
women to deal with their health problems, is contrasted with encouragement for preventive
care. Notions of preventive care seemed appropriate only after other immediate or long-
standing health and family concerns were addressed.
Table 23B  Educational and organizational diagnosis: Barriers (-) and facilitators (+) of Pap testing.
Phase 4 of the PRECEDE-PROCEED framework for health promotion program planning and evaluation (Green & Kreuter, 1991)

<table>
<thead>
<tr>
<th>BARRIER (-) OR FACILITATOR (+)</th>
<th>IPG</th>
<th>CSG</th>
<th>TP</th>
<th>KI: DR</th>
<th>KI: OC</th>
<th>KI: OP</th>
</tr>
</thead>
<tbody>
<tr>
<td>PREDISPOSING FACTORS (WOMEN'S CHARACTERISTICS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge: Not knowing about the Pap test (as a preventive care behaviour)</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Values: Religiosity</td>
<td>-</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Fear</td>
<td>-</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Passivity</td>
<td>-</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Shyness</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Some women prefer women doctors</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Women think the family doctor should recommend tests to stay healthy</td>
<td>+</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Portuguese women respect their doctors</td>
<td>+</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Portuguese women think about the future and plan for it</td>
<td>+</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Women want to stay healthy</td>
<td>+</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes: Fear</td>
<td>+</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**LEGEND**

**IPG**  Initial Planning Group
**CSG**  Community Steering Group, including Health Event Representatives
**TP**  Trial Participants

**KI: DR**  Key informants: physicians
**KI: OC**  Key informants: Other Clinicians
**KI: OP**  Key informants: Other Portuguese
<table>
<thead>
<tr>
<th>BARRIER (-) OR FACILITATOR (+)</th>
<th>IPG</th>
<th>CSG</th>
<th>TP</th>
<th>KI: Dr</th>
<th>KI: OC</th>
<th>KI: OP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ENABLING FACTORS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Availability of health resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some doctors do not ask women to have Pap tests</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some doctors do not do Pap tests; they may refer women to specialists or female Drs.</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Some doctors don't touch their patients</td>
<td>-</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Some doctors advise women to have the Pap test</td>
<td>+</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Accessibility of health resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employers' policies regarding provision of preventive care services or time off for it</td>
<td>+/-</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Misunderstandings, myths or lack of knowledge influence provision or response to health care services</td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Health-related skill: Some Portuguese women like to learn</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>REINFORCING FACTORS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family: Obligations &amp; responsibilities</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Family: Husband might drive or go with woman to Pap test appointment</td>
<td>+</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Peers: Invite &amp; accompany women to support groups, befriend others</td>
<td>+</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>

**LEDEND**

- **IPG**: Initial Planning Group
- **CSG**: Community Steering Group, including Health Event Representatives
- **TP**: Trial Participants
- **KI: Dr**: Key informants: physicians
- **KI: OC**: Key informants: Other Clinicians
- **KI: OP**: Key informants: Other Portuguese
10.2.3 Phase 5. Administrative and policy diagnosis

Administrative and policy diagnosis describes the situation and opportunities for health promotion at the time of the study. It includes the health education efforts in place, as well as rules governing the provision of service. Table 23C presents the factors reported by study participants.

10.2.3.1 Health education

Currently, few health education brochures were reported to be available in the Portuguese language. Two exceptions were the booklet about women’s health (Immigrant Women’s Health Centre, ~1994, first published 1981) and the Pap test brochure (adapted by Maniezzo, 1995). Repeating the ideas from earlier sections, health education opportunities identified as most likely to be beneficial would be those that did not rely on printed material, and which incorporated narrative and/or interactive approaches. The two options identified were television or interactive group presentations.

10.2.3.2 Policy, regulation and organization: reported by study participants

Policy, regulation and organization define or set the context for the provision of health care. Most reports in this study described the limitations in time or money which constrained the delivery of Pap tests or discussions about them, i.e., physician’s busy schedules or the physician payment system. Toronto Department of Public Health staff described three specific preventive care activities relevant to cervical cancer: clinics for sexually transmitted diseases; referring women to social service agencies; and the production of the “Series of Ethnocultural and Health Profiles of Communities in Toronto”, including one for the Portuguese Canadian community (Kendall, 1992). In addition to these reports, Board of Health posters were observed in the waiting rooms of two physicians’ offices: brightly

1. The complete Series of Ethnocultural and Health Profiles of Communities in Toronto includes: #1. Native Canadian; #2. Chinese; #3. Italian Canadian; #4. Greek Canadian; #5. Caribbean; #6. Sri Lankan Tamil; #7. Portuguese Canadian; #8. Spanish-speaking. All were produced by the City of Toronto Department of Public Health, Health Promotion and Advocacy Section, under the auspices of PRW Kendall, Medical Officer of Health. Profiles #1-6 were published in 1989, #7-8 were published in 1992.

2. This booklet includes a listing of 13 agencies that offer health-related services in Portuguese.
coloured "sunflower" posters referred, in English, to Pap tests. One physician, previously active with the Portuguese community, pointed out fee provisions for preventive counselling. Details about these, and other aspects of policy, regulation and organization are outlined in the text following Table 23C.
Table 23C. Administrative and policy diagnosis: Barriers (-) and facilitators (+) of Pap testing 
Phase 5 of the PRECEDE-PROCEED framework for health promotion program planning and evaluation (Green & Kreuter, 1991)

<table>
<thead>
<tr>
<th>BARRIER (-) OR FACILITATOR (+)</th>
<th>IPG</th>
<th>CSG</th>
<th>TP</th>
<th>KI: Dr</th>
<th>KI: OC</th>
<th>KI: OP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PHASE 5. ADMINISTRATIVE AND POLICY DIAGNOSIS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HEALTH EDUCATION</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most brochures are only in English</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Women watch television and have seen health promoter &amp; doctors on TV</td>
<td>+</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>POLICY, REGULATION &amp; ORGANIZATION</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctors are busy so visits can be rushed</td>
<td>-</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Some female gynecologists are too busy to be referred healthy patients</td>
<td>-</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fees for doing Pap tests are minimal</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>No fee is provided for women without health care coverage</td>
<td>-</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preventive counselling is a service covered by health care plans</td>
<td>+</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

--- LEGEND ---

<table>
<thead>
<tr>
<th>IPG</th>
<th>Initial Planning Group</th>
<th>KI: Dr</th>
<th>Key informants: physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSG</td>
<td>Community Steering Group, including Health Event Representatives</td>
<td>KI: OC</td>
<td>Key Informants: Other Clinicians</td>
</tr>
<tr>
<td>TP</td>
<td>Trial Participants</td>
<td>KI: OP</td>
<td>Key Informants: Other Portuguese</td>
</tr>
</tbody>
</table>
10.2.3.3    Policy, regulation and organization: Ministry of Health and Long-Term Care documents

This section goes beyond what was reported by study participants, identifying the policy, regulation and organization relevant to the provision of Pap tests. These are outlined in Ontario’s Ministry of Health and Long-Term Care documents. These administrative and policy factors are facilitators of Pap tests: they either compel or encourage the provision of Pap tests and/or related services.

10.2.3.3.1    Policy

The provincial government in Ontario has passed legislation affirming a role for boards of health to contribute to screening and other efforts to reduce morbidity and mortality due to cervical cancer. The Health Protection and Promotion Act (Revised Statutes of Ontario) (Ontario government, 1998 Jul:5-6, Chapter H7) identifies the duties of the board of health (Section 4) and their mandatory health programs and services (Section 5). Part II, Health Programs and Services (Section 4) begins: "Every board of health, (a) shall superintend, provide or ensure the provision of the health programs and services required by this Act and the regulations to the persons who reside in the health unit served by the board". Section 5 then describes the areas for the mandatory health programs and services that "every board of health shall superintend, provide or ensure the provision of health programs and services": [These include] [Paragraph 4] "Family health, including i. counselling services,.... iii. health services to... the elderly,.... v. Screening programs to reduce the morbidity and mortality of disease,... [Paragraph 4.1] Collection and analysis of epidemiological data" (Ontario Government, 1998, Chapter H7: Section 5). While boards of health are not required to provide the services, they must superintend or ensure their provision. Operational details of these legislated requirements are outlined below, in the second half of the Regulation section.
10.2.3.3.2 Regulation

In Ontario, the regulation of Pap tests extends not just to the clinical provision of care, but also to preventive counseling and to the reduction of barriers to care. All of these are regulated by the provincial Ministry of Health (now known as the Ministry of Health and Long-Term Care). There are regulations regarding Pap tests in two settings: physician services and boards of health.

**Ministry of Health [and Long-Term Care] Physician Services:** The fees for Papanicolaou Smears and related procedures are provided in a Schedule Of Benefits for Physician Services (Gynaecology) (Ministry of Health SOB, 1998). The fee for either an initial or a follow-up Papanicolaou Smear is the same, $4.10; if a Pap smear is performed in the context of other services, the physician receives no additional fee for providing it.

The Schedule Of Benefits also provides for individual counseling about preventive care "scheduled prior to the time the service is rendered". Such a visit must be:

"dedicated solely to an educational dialogue between the patient and a physician. This service is provided for the purpose of developing an awareness of the patient's problems or situation and of modalities for prevention and/or treatment, and to provide advice and information in respect of diagnosis, treatment, health maintenance and prevention." ³ (Ministry of Health 1998: SOB Preamble Section 7, Other terms and definitions 5.c.i., claim code K013, K033)

---


2. "The Papanicolaou smear is included in the consultation, repeat consultation, general or specific assessment (or re-assessment), annual health or routine post-natal visit when a pelvic examination is a normal part of the foregoing services." (Ministry of Health, 1998 SOB Gynaecology:1).

3 The description for procedure code K013, K033, individual counseling, continues: "Advice provided to a patient that would ordinarily constitute part of a consultation, assessment or other treatment, is included as a common or constituent element of such other service, and does not constitute counselling in this context. [new paragraph] "The counselling must have been scheduled prior to the time the service is rendered." (Ministry of Health 1998: SOB Preamble Section 7, Other terms and definitions 5.c.i., page 5 of 6). In addition, "the minimum time period for ... all forms of counselling (to be claimed as such) is 20 minutes of appropriate therapy." (Ministry of Health 1998: SOB Preamble Section 7, Other terms and definitions 1., page 5 of 6)
Boards of health: In Ontario, the Minister of Health (1998:3) affirmed the Health Protection and Promotion Act (Part II, described above) as the basis for providing or ensuring overall "General Standards" for public health and "Program Standards" specific to cervical cancer screening. The General Standards state the goal "to ensure that all Ontarians have access to public health programs" and the objective "to reduce educational, social and environmental barriers to accessing mandatory public health programs" (Minister of Health, 1998:11). Barriers to access are specified in a footnote, and include: "literacy level, language, culture, geography, social factors, education, economic circumstance..." (Minister of Health, 1998:11). Addressing the barriers may require adjusting existing programs, promoting accessibility and developing special programs including special educational materials, tailored service delivery and active outreach." (Minister of Health, 1998:11). The board of health is directed to "establish ongoing community processes to identify needs, recommend approaches and monitor progress toward achieving access to the mandatory public health programs and services." (Minister of Health, 1998:11) These General Standards affirm that boards of health are to play active roles in ensuring that Mandatory Programs reach those who need them most.

Two programs relevant to cervical cancer screening are Early Detection of Cancer and Sexual Health. The Program Standards for Early Detection of Cancer specify the goal "To reduce mortality from breast cancer and cervical cancer by increasing early detection" (Minister of Health, 1998:29). Two of the four objectives are directed to breast screening and two to cervical cancer screening: (their) Objective 3 is "To reduce the mortality from

1. The Requirements and Standards for the General Standard of Equal Access include:
   "1. The board of health shall provide mandatory public health programs and services, whenever practical and appropriate, which are accessible to people in special groups for whom barriers exist. [The footnote here specifies "Barriers can include, but are not limited to: literacy level, language, culture, geography, social factors, education, economic circumstance, and mental and physical ability."] Broadening access may require adjusting existing programs, promoting accessibility and developing special programs including special educational materials, tailored service delivery and active outreach.
   "2. When planning to use facilities and sites for mandatory public health programs, the board of health shall select those which are barrier-free and have suitable access for special groups.
   "3. The board of health shall establish ongoing community processes to identify needs, recommend approaches and monitor progress toward achieving access to the mandatory public health programs and services." (Minister of Health, 1998:11)

2. The Public Health Branch Early Detection of Cancer Program is undergoing Technical Review, so goals, objectives, requirements and standards may change. (January 2001)

3. The Reproductive Health program included within the Mandatory Health Programs and Services Guidelines focuses strictly on pregnancies (Minister of Health, 1998:39).
cervical cancer by 50 per cent by the year 2005”; (their) Objective 4 is "To increase the proportion of women screened according to the guidelines of the Ontario Cervical Screening Collaborative Group to 85 per cent and to increase the proportion of ever-screened to 95 per cent by the year 2010." (Minister of Health, 1998:29). The stipulated Requirements and Standards for Early Detection of Cancer include "2. The board of health shall work with community groups, women and health professionals to coordinate services, identify gaps and barriers to screening, and develop and implement strategies to increase recruitment for cervical cancer screening, particularly those in hard-to-reach groups.” (Minister of Health, 1998:29). Clinical service requirements are covered within the Sexual Health Program'; Requirements and Standards are extensive.  

Implementation of these provincial regulations is organized at the local level by boards of health. Compliance with the requirements and standards of the Mandatory Program Services and Guidelines is monitored by the Ministry of Health and Long-Term Care; results are not available to the public.

1. The Sexual Health Program has the goal “To promote healthy sexuality” and the objective "3. To increase the awareness and knowledge about personal responsibility and life skills required to deal with sexual relationships and behaviours including the impact of alcohol and other drugs.” (Minister of Health, 1998:37).

2. Requirements and Standards for Sexual Health include [emphasis mine]: 

"2. The board of health shall provide clinical services, at a minimum of four hours per week per 150,000 or less population, and such additional services as are required to meet local needs. Activities associated with these clinical services shall include as a minimum:

a. client's health assessment;...

b. preventive counselling and screening for cancers of the cervix and additional physical and laboratory examinations as appropriate;...

c. education and counselling on reproductive and sexual health choices, with appropriate client referral to: smoking cessation programs, nutrition counselling, assertiveness training groups, alcohol and drug abuse programs and other health and social service agencies and groups;...

d. development of a management plan appropriate to client needs, including discharge planning and referral where necessary to health care and/or social agencies.

"3. The board of health shall work with coalitions/networks of community groups and health and social services partners to coordinate and address gaps in sexual health programs in the community.” (Minister of Health, 1998:38)
10.2.3.3 Organization

Public health in Ontario is organized and delivered at the local level, but standards and requirements are set and monitored at the provincial level. Local boards of health must ensure mandatory health programs and services are delivered. Boards of health and medical officers of health may request assistance from the Ministry of Health and Long-Term Care if a problem is beyond their jurisdiction or capacity. The Public Health Branch provides technical and scientific expertise to enable boards of health to fulfil their obligations.

In implementing their goals and objectives, boards of health are called on to:

"develop their programs and services within the context of the community as a whole, .... create and deliver public health programs in partnership with other sectors, agencies and volunteer community groups / coalitions. They will provide leadership in identifying issues and developing services, integrating those services with other services in the community and advocating for those which fall outside their mandate." (Minister of Health, 1997:6)

Although not necessarily required to provide a program or service directly, they must ensure that it is available and accessible (Minister of Health, 1998:6).

The Mandatory Health Programs and Services Guidelines (Minister of Health, 1998) include four standards pertinent to the topic of underscreening. The two relevant general standards are Program Planning and Evaluation and Equal Access, and the two relevant program standards are Chronic Diseases and Injuries (i.e., Early Detection of Cancer) and Family Health (i.e., Sexual Health). Extracts (Appendix 11) provide the relevant general and program standards; each includes goals, objectives, requirements and standards.

Public health program standards for the early detection of cancer include clear objectives, i.e., reducing mortality from cervical cancer by 50 per cent by the year 2005, and increasing the proportion of adequately and ever-screened women to 85 and 95 per cent respectively by the year 2010 (Minister of Health, 1998:29). Requirements and standards for this program state:

1. "The general standards are directed toward achievement of all health goals by outlining considerations or activities to be undertaken in the planning and delivery of all programs and services." (Minister of Health, 1998:37)
"The board of health shall work with community groups, women and health professionals to coordinate services, identify gaps and barriers to screening, and develop and implement strategies to increase recruitment for cervical cancer screening, particularly those in hard-to-reach groups" (Minister of Health, 1998:29)

This provides a rationale and a challenging directive for public health practitioners to work with others. Table 24 summarizes Public Health Mandatory Health Programs and Guidelines pertinent to this study's methods and findings. There is considerable overlap here; program planning and evaluation and equal access are general standards that complement each other and apply to every program standard.
Table 24. Public Health Mandatory Programs & Standards (Minister of Health, 1998) pertinent to this study

<table>
<thead>
<tr>
<th>GENERAL OR PROGRAM STANDARD</th>
<th>Aspect of the study [Relevant requirement or standard ]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective</td>
<td></td>
</tr>
</tbody>
</table>

**EQUAL ACCESS**

To reduce educational, social and environmental barriers* to accessing mandatory public health programs.

*Barriers can include, but are not limited to: literacy level, language, culture, geography, social factors, education, economic circumstance, and mental and physical ability

- Brochures in Portuguese and English were used to help women get to the right location. [1,2]
- Women wanted to show brochures to their doctors to prompt discussion and provision of Pap tests. [2,3]
- The walk-around survey of physicians’ offices identified where Portuguese was spoken (and identified that receptionists served as translators and providers of information). [1,3]
- Group sessions, simultaneously translated into Portuguese, were socially acceptable, and did not require English language or literacy skills. [1, 2, 3]
- Health events held at familiar locations, on public transit, were appreciated [2].
- Traditional, socially isolated women did not generally attend health events or women’s groups. [2]
- Community input identified issues of acceptability and accessibility. [2, 3]
<table>
<thead>
<tr>
<th>General or Program Standard Objective</th>
<th>Aspect of the study [Relevant requirement or standard ]</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program Planning and Evaluation</strong></td>
<td></td>
</tr>
</tbody>
</table>
| 1. To ensure that programs and services are based on community health status information. | • Interviewer-administered baseline surveys of women at health events had high response rate and completeness. [1, 2a, 2e]  
• Community partners identified that physicians in a particular geographic region served Portuguese women. [1] The walk-around survey confirmed that Portuguese-speaking women did attend these offices. [2a, 2e, 4],  
• Physicians' logs confirmed anecdotes and health event questionnaire reports that Portuguese-speaking women remain underscreened (and these probably represent the tip of the iceberg) [2e, 4]. |
| 2. To ensure program development and design is based on evidence of effectiveness and efficiency. | • Collaboration of researcher and practitioners was possible [5].  
• Community partners' predictions about utility of various strategies (e.g., festivals) were largely confirmed. [4]  
• Useful, innovative approaches (e.g., bath beads, walk-around survey) were sometimes relatively simple and required few resources. [5a]  
• Evaluation using a randomized trial was acceptable; validation requested on follow up was not helpful.[5a]  
• Education of practitioners providing care to women with language or literacy barriers may be enhanced by including receptionists. [5c, 6] |
<table>
<thead>
<tr>
<th>GENERAL OR PROGRAM STANDARD</th>
<th>Aspect of the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eearly Detection of Cancer</td>
<td>• The understanding that Pap tests are part of a health care practice’s preventive</td>
</tr>
<tr>
<td></td>
<td>orientation must be clearly and consistently communicated to women, particularly</td>
</tr>
<tr>
<td></td>
<td>those who are more familiar with the medical system’s diagnostic and treatment</td>
</tr>
<tr>
<td></td>
<td>functions. [2]</td>
</tr>
<tr>
<td>Sexual Health</td>
<td>• Women who are underscreened with respect to cervical cancer may require additional</td>
</tr>
<tr>
<td></td>
<td>preventive counselling, and appropriate referral to other health care or social</td>
</tr>
<tr>
<td></td>
<td>service agencies and women’s groups. [2c, 2f, 2h]</td>
</tr>
</tbody>
</table>

**Objective**

3. To reduce the mortality from cervical cancer by 50 per cent by the year 2005.

4. To increase the proportion of women screened according to the guidelines of the Ontario Cervical Screening Collaborative Group to 85 per cent and to increase the proportion of ever-screened to 95 per cent by the year 2010.
10.3 Myths

A set of myths was identified (Table 25), encapsulating ideas which, when applied to cervical cancer and screening for it, are presumed to serve as barriers to the adoption of Pap tests for screening purposes. It was not possible to ascertain the prevalence of these myths. Indeed, as described in the methods, these understandings were not always explicitly identified—they were sometimes only implicitly recognizable. In the discussion, these myths are presented with their complements, the fuller and more correct understanding. There, myths are incorporated in a model that postulates mechanisms for how they would function as barriers to Pap tests.

Table 25. Myths

<table>
<thead>
<tr>
<th>Myth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pap tests are intended to detect cervical cancer.</td>
</tr>
<tr>
<td>If a person gets cancer they will die.</td>
</tr>
<tr>
<td>Some women are too old for Pap tests.</td>
</tr>
<tr>
<td>Pap tests are for women who are sexually active.</td>
</tr>
<tr>
<td>Cancer can develop suddenly.</td>
</tr>
<tr>
<td>Pain means cancer or some other dangerous condition.</td>
</tr>
<tr>
<td>Growths or lumps mean cancer.</td>
</tr>
<tr>
<td>A diagnosis of cancer means being in hospital and/or having treatments with serious side effects.</td>
</tr>
</tbody>
</table>

One physician referred explicitly to the Pap test, in English, as a "cancer test". (1999 Mar 30).

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1. The word myth has several definitions. Here, the term myth is used primarily in the sense of "a widely held but false notion" and, to a lesser extent, "a traditional narrative usually involving supernatural or imaginary persons and often embodying popular ideas on natural or social phenomena etc." (Thompson, 1995:900). Stories heard in this study were generally about other Portuguese people known by the respondent.
10.4 Representativeness

To thoroughly evaluate representativeness of study participants, demographic and behavioural data would be needed for every study participant and for the target population - these data are not available. What is clear is that Portuguese-speaking women involved in this study (with the exception of those recorded in physicians' logs) in many ways represent elites within the community. Professional women (e.g., those affiliated with health care and social service agencies) are elite because they are educated; other women who responded (e.g., those involved in the initial and community planning, as Health Event Representatives for the health events) were elite (in a restricted sense of the word) because they were successfully connected with established social service agencies. Women attending the health events and participating in the trial did include other "less connected" women, but women who dressed in the traditional black (e.g., widows, and other mourning women) were not generally involved (although they may have been included if they visited their physicians). These women, who are understood to maintain traditional cultural values, including church attendance, were expected by key informants to include a significant proportion of underscreened, at risk women.

Despite the data limitations, two important aspects of representativeness were evident; women of particular interest for this feasibility study were Portuguese-speaking women, underscreened with respect to cervical cancer. There is no question that the majority of the respondents were Portuguese-speaking, and some of them almost exclusively so. The prevalence of underscreening, among the Portuguese-speaking women reached by the two approaches, is compared in Table 26. The age distribution of women attending the health events was older than that of women attending physicians. The sample size for the physicians' logs was 102, compared to 54 for the health events, and the overall rate of underscreening was slightly higher in the sample from those logs. Limited sample sizes preclude 10-year age groupings and comparisons with national estimates (Lee et al., 1998). Overall, the prevalence of underscreening (26% at health events and 32% on physicians' logs) is similar to the estimate obtained in the National Population Health Survey population (25%) (Lee et al., 1998).
Table 26. Prevalence of underscreening: Percent of women reporting Pap test ≥3 years ago by age group, comparing data from this study's health events and physicians' logs with the National Population Health Survey (Lee et al., 1998)

<table>
<thead>
<tr>
<th>Age group (years)</th>
<th>Health events % underscreened (n)</th>
<th>Physicians' logs % underscreened (n)</th>
<th>National Population Health Survey* % underscreened</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 40</td>
<td>18.2 (22)</td>
<td>17.8 (45)</td>
<td></td>
</tr>
<tr>
<td>40 - 49</td>
<td>35.0 (20)</td>
<td>35.0 (20)</td>
<td>23.1</td>
</tr>
<tr>
<td>50 - 59</td>
<td>35.3 (17)</td>
<td>40.0 (20)</td>
<td>31.7</td>
</tr>
<tr>
<td>60 - 69</td>
<td>26.7 (15)</td>
<td>58.8 (17)</td>
<td>41.3</td>
</tr>
<tr>
<td>70 +</td>
<td>26.7 (15)</td>
<td>58.8 (17)</td>
<td>69.9</td>
</tr>
<tr>
<td>TOTAL</td>
<td>25.9 (54)</td>
<td>32.3 (102)</td>
<td>25.0*</td>
</tr>
</tbody>
</table>

* Overall for women aged 18-69 (Lee et al., 1998)
10.5 Returning results

In the final iteration of this thesis, meetings with delegates of community agencies yielded feedback about the project. Clarifications of findings from the initial planning sessions were already presented as part of Objective 1. Here, feedback about unexpected findings, resources desired, and ideas about how to convey results are provided. In the course of these interactions, community partners also reflected on the phenomena of interest, and contributed ideas for interventions to address barriers and facilitators.

10.5.1 Unexpected findings clarified

When data for health event attenders were reviewed, the age at marriage seemed high, and the number of children low: these characteristics suggested that an elite, high socioeconomic status group had attended the health events. This did not seem to correspond with what community partners had insisted, i.e., that most women attending the events had limited education and literacy. Independent Portuguese community members at hand resolved the confusion. In Portugal, it had been the norm for women to live at home until they married, often in their mid- to late twenties. Patterns of parity differed markedly, between the mainland and particular islands. Women from the continent would normally have only two or three children, while women in certain remote, isolated communities, especially those on certain islands, were understood to have a dozen or more children. Nevertheless, when women aged 40 or over were growing up, education beyond grade eight, particularly for girls, would have been the exception, available only for well-off families in major cities. These explanations diminished concern about possible lack of demographic representativeness of health event attenders.

Another discrepancy emerged as results for Objective 1's initial planning sessions were compared with Objective 3's follow-up interviews of trial participants, and this was reviewed with the primary research assistant. With the initial planning group, fear was identified as characterizing Portuguese women's attitudes to cancer and screening for it. Yet, later, fear was mentioned only a few times, referring to women who were too frightened to have Pap tests. Women in the trial did refer to the importance of the Pap test as a reason for choosing to have it. Two options were considered: the finding was an artefact due to social desirability bias, presumably echoing phrases we had used; or the observation was valid.
The first option could have been likely if phrases with the word important had been used repeatedly in various interactions with the women in the trial, for example, in unscripted introductions at the health events by the health event co-ordinator, in small group sessions, or by health event representatives as they invited women to the events. Yet neither the script of the short presentation about Pap tests (for the health event plenary sessions) nor the text of the Research Agreement Form had included the phrase "It's important". The second option was considered more likely by the woman who had worked as research assistant on the project since 1994, both as translator in the original group and as interviewer in the randomized trial. The phrase Fear, replaced by "It's important" seemed to summarize an apparent difference in sentiments and attitudes.

In considering how or why fear might have been replaced by notions of importance of Pap tests, the research assistant proposed that it may have been not just what was said, but who was involved and what this represented, that conveyed the idea of the importance of the Pap test. Reflecting back to the moments after the Research Agreement Forms were signed, as the women waited to be randomized or to receive their invitation for Pap testing, she recalled that she had continued to sit with them, and, that, when not verifying allocations or resolving confusing points with the inviter, I would also join them. As they waited, the women had chatted quietly with each other and with the research assistant in Portuguese. One of the things they asked was if I was a physician. The assistant had explained that I was not: I was a researcher from the University, involved in Community Health. Their body language (e.g., smiling, nodding their heads approvingly) and their verbal responses indicated how pleased, impressed and reassured the women were. The assistant interpreted the women's reactions as indicating that if the university was doing research on this matter, then it must be important. And as delegates from the university, researching a health issue, we helped them to feel as if they were "in arm's reach" of the health care system.

Two further discussions with community collaborators elaborated on mechanisms by which a supportive presence might function. One woman, a former labour support nurse, had presented at the health events and had attended women having Pap tests. The phrase "in arm's reach" prompted her to describe how, in her job as health promoter at a Community Health Centre, she sometimes assists with patients who are anxious about undergoing a gynecologic examination. Standing beside them and holding these women's hands, she
coaches them on breathing to help them relax during the internal examination. This provides both physical presence and emotional support to frightened women who would otherwise not want to undergo the procedure. Lastly, a third community partner reviewed my binders with printouts of electronic databases and tabular or statistical summaries of them, including results of the health event questionnaires, and narrative excerpts from follow-up interviews with trial participants. One of the pages of narrative transcript included a trial participant’s description of a whole series of problems, including getting lost on the way to her appointment. This situation seemed familiar to this woman, who also worked with Portuguese-speaking women and had noted that their limitations in literacy and lack of English language skills meant that if they got lost they could not even ask for directions. The common thread linking these interactions was how the physical presence of a credible and/or supportive woman might help underscreened (or even, perhaps, unscreened) Portuguese-speaking women accept, attend or undergo screening Pap tests. A trusted, supportive presence could be expected to provide relevant information, guidance and feedback to a woman who would otherwise be unable to undergo behaviours that would be difficult for her to do on her own.

10.5.2 Providing resources to the community partners

Community partners who participated actively on the project were asked to identify resources that might be useful for them. Several referred to limited resources for professional development, and challenges in networking and locating speakers for their women’s groups. Email contact information, e.g., for CERIS (the Joint Centre of Excellence for Research on Immigration and Settlement) was forwarded to those interested. Another assistance was to identify individuals and/or agencies who could provide speakers for Portuguese-speaking women’s groups, including some suggestions and contact information contributed by Public Health Sciences faculty. In addition, I participated in two women’s groups, including one at the Community Centre where two of the original health events had been held. Planning for those involved several discussions about health promotion program planning and delivery (described throughout this section). In addition to the agency representatives, several other Portuguese-speaking women who had participated in the project, i.e., as Health Event Representatives, or as members of the initial planning group, or as research assistants, appreciated learning about public or university-based seminars, although only English-speaking women benefitted from these. References (for
admission to a university program and for a job) based on the work done in the study were provided for two of these women. Drafts of papers for academic coursework were reviewed, and relevant scientific and statistical methods were discussed.

**10.5.3 Format and content preferences and difficulties**

As the research project drew to a close, community members, including those affiliated with collaborating agencies, were asked for their suggestions about what structure and presentation of the research results would best meet the needs of their own agency or clients. Three social/health service agency partners provided explicit ideas about what they wanted, in terms of content or format that would be most useful. These same women also spontaneously suggested how they might implement the ideas suggested by the research project, to address the barriers and enhance the facilitators.

Simple intervention ideas were immediately and spontaneously proposed by the collaborators, to modify their own care strategies. One suggested providing physical contact (i.e., while translating on behalf of the woman, holding her hand during the examination); the other, contingent on resource availability, proposed developing a program to provide a companion to accompany a woman to her appointment. Specific suggestions were complemented by general comments in many spontaneous discussions, with neighbours and women at support group meetings that emerged as a consequence of the discussions with the agency delegates (described further below). Two agency partners explained that, while they were interested in seeing the results, they did not wish or were unable to provide any guidance about presenting them or recommendations about them at the time.

Community members provided some clear directives about what format and content of results would be most useful to them, their community or to their agency. There was no interest in seeing statistical testing, although simple summary tables, for example, of the numbers of women attending health events, were considered sensible. One suggestion, to simplify the work involved in preparing a report of results for the community was to select key tables and results from the thesis, and provide an executive summary of the main findings. That summary should be translated into Portuguese, and as an excerpt for wider circulation, would probably suffice for most women. Women who wanted additional
information (i.e., from the community report) were expected to read or understand English on their own, or to know someone (e.g., within the community agencies) who did. Content of interest was identified: barriers and facilitators reported by trial participants; narratives about women's situations; and a list of clear recommendations emerging from the research.

As for conveying results to trial participants, a simple letter was recommended, with no numbers at all (draft is in Appendix 10), accompanied by the myths (or a subset of them). The myths were considered to reflect what many people really believed or understood; including them and the complementary "fuller truths" was considered an acceptable and helpful way to convey the results and guard against any misinterpretation.

One woman, who had been a co-presenter at the health events, explained the powerful roles of "Portuguese" stories. Three aspects were described. First, any news item which featured someone with a Portuguese name, say, a driver whose load had fallen from his truck, would yield considerable discussion and interest. Second, Portuguese women circulated and "learned" from stories of experiences of other Portuguese women in the community. As a labour and delivery nurse educator, this contact regularly heard a terrifying story (about a complication from epidural anaesthetic) from Portuguese-speaking women who were pregnant. Although the complication was rare, the story of one Portuguese woman's tragedy was well-known, and influenced the pregnant women's attitudes about epidurals. Third, other important stories in Portuguese-speaking women's lives were fictional ones, on Portuguese or Spanish-language soap operas. This contact explained that Brazil produces soap operas which are exported throughout the world and dubbed into many different languages. Characters and plot developments from these soap operas served as the topic of regular, lively discussions among Portuguese women working at factories and plants. These television dramas were understood to hold considerable appeal for a large audience of working women, including those who were not literate.

Presentations to groups led by community partners revealed a number of challenges for presenting research results and for developing interventions. A wide range in literacy and numeracy within and between groups influenced how different women interpreted information presented to them. One of the groups had identified Pap tests and cervical cancer as one of their top priorities for discussion. When I presented overheads on incidence and mortality rates for cervical cancer, comparing Canada, Portugal and Brazil, the concept of a rate seemed new to many of the women. They confused the rates with
counts of diagnoses and deaths. One woman, seeming to speak for a number of others, reminded me that Brazil had a huge population, and this likely accounted for the difference. Yet, in another group, when the same material was presented, it was better understood. In that group, when the risk factors for cervical cancer were presented, one woman noted that the factor of early age at first birth, associated with increased risk of cervical cancer, was the opposite for breast cancer! Differences in knowledge and comprehension may have been related to the length of time the women in the group had been meeting. Groups established more recently may not yet have presented and discussed certain kinds of ideas. Similarly, women new to a group might have missed earlier presentations about risk factors and rates.

Another hurdle in presenting information was concepts that could elicit discomfort or bad feelings. One partner, a leader of a Portuguese women's group, was interested in my considerations of the health belief model. Together, we explored motivations for preventive care behaviour, and how high susceptibility can lead to fear which "paralyzes" the women's choices about health behaviours. She agreed that it would be good to present this to her group and ask if this was real for them. As she saw it, presenting a rational model for health care decision-making might make it easier for women to think about their situations and about adopting a health behaviour; yet, when she saw the cartoon pictures drawn to convey the health beliefs, she was disconcerted. In particular, she found one picture - of a woman imagining herself in a hospital bed - too realistic and frightening. She did not want to use this in an initial presentation because the image might have a negative influence: it might reinforce, rather than dispel, an irrational (in her view) belief that the prognosis for cancer is bad.

Presentations to women's groups were also difficult in terms of the amount of time available and the ideas that needed to be communicated. The group meetings attended, whether weekly or monthly, are scheduled to take up to two hours, and invariably the women seem to be planning or organizing other activities, such as rehearsing songs for Christmas or International Women's Day. So presentations were scheduled for an hour or less. But all material was presented in both English and Portuguese, and I spoke English slowly, choosing short, simple sentences, so this meant presentations were planned with about 20 minutes worth of material. Preparing presentations in both Portuguese and English also took additional time in advance, to consult with co-presenters. In person, on the telephone,
and via email, we worked together to review the material, and to confirm which translated words or phrases were most appropriate for the overheads. The co-presenters did simultaneous translations, which took time and effort to ensure that everyone understood things. Again, during and after the presentations, translations were provided whenever the women asked questions.

These question-and-answer sessions were a valued and important part of the group interactions. Some women wanted to discuss their current health problems (e.g., fibroids, abdominal pain) and the investigations they were undergoing. These women were worried that they had cancer and the doctor had missed it or was hiding it from them. One of these women had undergone a number of examinations and tests for her abdominal pain, and each time the doctor assured her the results were normal. But she was still having pain, and, worried about her family history of gastrointestinal cancer, thought something had been overlooked. Community contacts told me that these types of questions and situations were common: some women clearly did not know, understand or believe explanations they had been given about health conditions or diagnostic procedures. Community contacts found that women’s lack of knowledge also extended to treatment options or prognoses. One co-presenter explained that virtually every presentation she gave ended this same way, and invariably the women asking the questions were worried. Invariably we (as presenters) provided factual information at our disposal (e.g., fibroids are not cancer) and encouraged the women either to return to their own physicians to explain what they were really worried about, or if they were not able to talk openly with their own doctor, to choose another one.

In preparing and co-presenting, or in discussing research results, community contacts emphasized explicitly the powerful role of language for women as they faced choices about health behaviours. Leaders encouraged women in the groups to ask questions in both English and Portuguese, to practice their English language skills. Some women were reluctant to speak English in front of me, even though their peers and the leaders encouraged them to try. When those women did overcome their shyness, their vocabulary and comprehension were greater than their diffidence would suggest. One community contact wanted to help women develop written contracts about cultivating health
behaviours¹, and in her mind, the health behaviour with the greatest value for Portuguese-speaking women was speaking English. Speaking English meant that women could communicate independently and privately with their health care providers, without having to rely on others. It meant they could ask questions and discuss their concerns. While the women's groups provided valuable opportunities to talk with their peers about their everyday "stresses and problems", speaking English meant that they could get expert advice if and when they wanted it.

Some of the women attending these group sessions had attended health events and had either participated in the trial themselves or knew other women who had; they provided further anecdotal feedback about the responses of underscreened women after the trial was over. Each of the women who had attended a health event seemed pleased to see the researcher again, and referred to their own or a friend or relative's good experience there. One described how a session about breast cancer had helped a trial participant realize that she should also see her doctor about an inverted nipple; that woman ended up having surgery for breast cancer, and was undergoing chemotherapy. The woman reporting the story was grateful that this woman had found her tumour "in time". Another woman, who had been a health event representative, described how one woman had participated in the trial, had done the Pap test, but was unlikely to have another because she had "many problems, ... family problems, ... health problems". The woman was not able to come to a women's group: she had arthritis, diabetes, an unsupportive spouse.² These situations were very difficult, she explained, but maybe long-term, consistent support could help. "All we can do is be friendly [sic] them....". Other contacts affirmed that underscreened women they knew would be unlikely to attend health events, and some were adamant in rejecting Pap tests. Thus, although participation in the health event and randomized trial were understood to have been positive experiences, the perception was that not all underscreened women could be reached or recruited by this approach, if at all.

This chapter presented the results of the synthesis for Objective 4, considering first particular steps on the path to adoption of Pap tests, then, in turn, the abstract and practical

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¹. The contract could specify what agency assistance would be most helpful for each woman to achieve her desired behaviour.

². I asked what could be done for a woman in that situation, and she shook her head sadly, in concern.
factors that are understood to define the context and provision of the Pap test. Representativeness of, and interactions with community partners, were described to emphasize how their pragmatic understandings prompted both theoretical elaborations and the practical research and intervention ideas. These are elaborated more fully in the next chapter, the discussion.
Chapter 11 Discussion

11.1 Summary of key findings and themes

This feasibility project can be summarized with a set of four inter-related and overlapping questions and their responses. These are organized to reflect the key findings and themes for the project's four objectives. Following these questions, a table summarizes the feasibility of each of the objectives and the study elements contributing to them.

Question 1) Was it feasible to develop a research project collaboratively with community partners?
Answer 1) Yes. It was not easy but it was valuable.

Collaboration with community partners, using an iterative research design, was possible, and provided valuable information about Portuguese-speaking women and the adoption of Pap testing. Collaboration made it possible for the intervention study to proceed, and it optimized the value of the quantitative data that could be collected. On the other hand, it took considerable time to develop the necessary connections and relationships, to establish the work's priority, and to provide information and resources back to community collaborators. Adapting qualitative and quantitative approaches to the task was critical to the project's success. It required researcher flexibility to accommodate the iterations that clarified phenomena, anecdotes, narratives, and other findings.

A diverse set of respondents included health care and social service agency personnel, and interested lay Portuguese-speaking women. All project participants were collaborators in one sense or another. They provided explanations of immigrant Portuguese-speaking women's cultural understandings, in the context of those women's experience and/or expectations of the health care system and of cancer itself. Respondents identified, explained or addressed research issues, especially: barriers that prevent access to the "denominator" population, necessary to document the prevalence of underscreening; difficulties in classification regarding eligibility and/or screening status; and the meaning of reported intentions about health behaviour.

There were some problems that could not be resolved in spite of our collaborative approach. Determining the status of a woman with respect to cervical screening, i.e.,
identifying a woman as underscreened, could not always be done. Without access to medical records, true screening status was sometimes ascertained only after an intervention which included education. Even then, the possibility of error remained. Despite these difficulties, community guidance in restricting the enquiry (in focus, content, and length), and in devising approaches and formats conducive to participation, is believed to have contributed to high levels of acceptance and response to the research processes, both by underscreened women and by health care providers.

Although procedures to validate reported Pap tests were not wholly satisfactory, other traditional epidemiologic procedures were successfully implemented. These included: randomization at the individual level; the use of written research agreement forms; and a prospective design with follow-up interviews.

Thus feasibility can be summarized: collaboration afforded access and the opportunity to collect and understand limited but valuable data. The collaborative and iterative processes meant the research could surmount some serious constraints imposed by differences in language, literacy, and culture.
Questions 2) Are there underscreened women in this community? Can underscreened women be identified and reached?

Answers 2) Yes. Some can probably be identified and reached.

There are indeed Portuguese-speaking women in Toronto who remain underscreened with respect to cervical cancer. Lay Portuguese women and their social and health service providers reported anecdotally that they knew of underscreened women. Baseline survey results collected at health events indicated that 26% of women attending the health event (n=54) had not had Pap tests for 3 years or more. Similarly, one-week logs completed by physicians (n=14) who provided Pap tests for Portuguese-speaking women indicated that 32% of these women were underscreened. In both venues, some women had never had a Pap test. There was no evidence to suggest that underscreened women did not attend family doctors. It was reported that such women might choose to attend doctors who did not offer Pap tests for routine preventive care, and our survey investigated and confirmed that such practices exist. Some underscreened women (an unknown number) were reported to have refused or to have been unable to attend health events or women's groups, owing to family and/or medical "stresses and problems".

Identifying underscreened women in this study was equivalent to having reached them in literal terms, either directly or indirectly. Literally, the women who were identified at health events or doctor’s offices were physically proximate to either the researcher or the health care provider; but identifying the women was not necessarily a direct result of our own efforts. The majority of women attending the health events had actually been invited or accompanied by women they knew. That is, they were identifiable to us because they had already been reached (in whatever sense) by someone they knew and trusted.

In contrast, screening and diagnostic roles of the Pap test seem to have been confused by lay women and by their health care providers, even when definitions were provided. Seven of the 33 underscreened women (21%) were noted as having no symptoms and/or no sexual relations. Also troubling were anecdotal reports (from receptionists, community service providers, women and even doctors themselves) that some doctors do not provide Pap tests themselves. Our survey confirmed such practices exist. Two offices explicitly indicated that they did not provide or offer Pap tests at all, and twenty-one percent of the others (9 of 42 offices) reported that they only refer women for Pap tests. Further, practices
that did not participate are expected to be less likely than participating practices to offer screening Pap tests. Underscreened patients in these practices are likely to be particularly difficult to identify or reach in any sense of the word.

Reaching underscreened women in figurative and functional terms was even harder than reaching them literally. Furthermore, distinguishing whether women had been reached literally, figuratively or functionally, was sometimes impossible. Even so, our intervention seemed successful in figuratively reaching some underscreened women at the health events. Five of the seven women (of the fourteen in the trial) who spontaneously raised the issue of importance affirmed that the Pap test was indeed important, or necessary, to stay healthy. This recognition was explained as due to the researcher's presence, which was understood to indicate that the topic and Portuguese women were both important to the university medical research community. For the functional understanding of reaching underscreened women, we turn to Question 3.
Question 3) Can underscreened women be recruited to Pap tests?
Answer 3) Possibly.

In functional terms, underscreened women were successfully reached in that most (eleven of the fourteen originally identified as eligible) participated in the research trial and nine of the fourteen who ultimately did participate in the trial\(^1\) (64%) reported that they intended to have Pap tests in the future. As presented in the results, though, screening adequacy was overestimated and intentions overstated the adoption of Pap tests. Some of the women at the health events had pre-existing gynecologic symptoms; some came to the event with the intention of having a Pap test. Even so, for some women, reducing barriers to Pap tests and providing facilitators seemed enough to prompt a Pap test, e.g., having a female health care provider, and offering an appointment at a convenient time and place.

Reports from physicians' logs indicated that twenty-one percent of women (7 of 33) identified as underscreened accepted an appointment for a Pap test, and twelve percent refused outright (4 of 33). Physicians were consistently reported as credible sources of information about health care, including preventive care. There was a significant clustering of these physicians serving Portuguese-speaking women along the College Street corridor, near downtown Toronto. Of the practices serving Portuguese-speaking women, some physicians and secretaries and/or receptionists did indicate an interest in learning more about this matter. These practices may provide an opportunity to develop and test strategies to recruit underscreened women.

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1. As explained previously, three women participated in the trial, even though their responses on the baseline questionnaire indicated a Pap test within the past 3 years.
Question 4) What are the barriers and facilitators to Pap tests?

Answer 4) I think the biggest barriers and facilitators are not logistic, they are conceptual, and these are shared by women and their health care providers. Facilitators are things that help women recognize both a need for preventive care and the corresponding value for the Pap test. Barriers in our study were the concerns women carried with them. The conceptual barriers and facilitators were formulated as a theoretical model, provisionally entitled “Two Streams” (Figure 5, page 245). The model proposes that women's understandings and choices about Pap tests are largely determined by their understanding of its purpose and roles. The dual roles of the Pap test, for diagnosing symptoms and for screening to prevent symptomatic disease, are confused and confusing. The model integrates ideas from a number of theoretical models of health behaviours, and elaborates them using this project’s understandings of the process of adoption of Pap tests.

In the model, women with gynecologic symptoms may comply with referrals or directives to have Pap tests for diagnostic purposes. Symptoms need to be diagnosed, so the Pap test has a value. In the absence of symptoms, though, the need and value for a Pap test are not as obvious. What is necessary is both a perceived need for preventive care and, to complement it, a perceived value for the Pap test as a meaningful strategy to prevent the development of invasive cervical cancer. Such a context for screening, or secondary prevention, stands in marked contrast to the cultural experience for those whose experience (e.g., in their country of origin) of health care was a system oriented to response to (acute and/or chronic) symptoms. In this culture delayed cancer diagnoses and poor prognoses are well-known, and may underlie or contribute to "myths". Myths represent incomplete knowledge or understandings about cancer, cancer screening, and health care providers. Although not typically identified by respondents as barriers per se, myths are hypothesized nonetheless to serve as barriers, by affirming the incorrect notion that increased age and/or lack of sexual activity render a woman ineligible for screening, or by conveying pessimistic expectations, i.e., that a screening test is intended to detect cancer, and that cancer is likely to be lethal. Table 27 provides the set of myths identified earlier, but here they are juxtaposed with their complementary, fuller understandings.
<table>
<thead>
<tr>
<th>Myth</th>
<th>More complete understanding</th>
</tr>
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<tbody>
<tr>
<td>Pap tests are intended to detect cervical cancer.</td>
<td>Screening Pap tests are intended to prevent invasive cervical cancer. The Pap test can detect unusual cells, which may be precursors to cancer, so they can be treated or removed. This is called secondary prevention of cervical cancer.</td>
</tr>
<tr>
<td>If a person gets cancer they will die.</td>
<td>Some cancers can be cured or prevented. Detection of cancer at early stages means the best chance of cure.</td>
</tr>
<tr>
<td>Some women are too old for Pap tests.</td>
<td>There is no upper age limit to begin Pap tests. If a woman has been adequately screened throughout her life, the age limit to stop Pap tests is 70.</td>
</tr>
<tr>
<td>Pap tests are for women who are sexually active.</td>
<td>Pap tests are for women who have ever been sexually active.</td>
</tr>
<tr>
<td>Cancer can develop suddenly.</td>
<td>Different types of cancers grow at different rates. Most cervical cancers can take 10-15 years to develop.</td>
</tr>
<tr>
<td>Pain means cancer or some other dangerous condition.</td>
<td>Pain can mean many things - not all of them are dangerous.</td>
</tr>
<tr>
<td>Growths or lumps mean cancer.</td>
<td>Some growths are not cancerous. Growths that are not malignant are called benign. Benign means they are not dangerous, for example, cysts or fibroids. They may still cause pain.</td>
</tr>
<tr>
<td>A diagnosis of cancer means being in hospital and/or having treatments with serious side effects.</td>
<td>Different cancers have different treatments and different chances of cure.</td>
</tr>
</tbody>
</table>
Presenting the myths with their fuller understandings is intended to achieve several things: to echo inadequate understandings held by physicians and women, or incomplete communication conveyed by practitioners, and simultaneously clarify what the more complete information is and how easily it could be conveyed. The purpose or context for the Pap test does not seem to always be fully conveyed by practitioners, nor recognized by the women. Portuguese-speaking women involved in this project reported a predilection to think about the future and to want to look after themselves. Yet the culture of preventive care and early medical treatment does not seem to have been inferred by these immigrant women’s experiences of Canada’s health care system. Women who do understand it had been introduced to it by health care providers and their receptionists who explicitly endorsed and provided preventive care. If the preventive role for the Pap test is not completely or consistently articulated by medical practices, by social service agencies, and by public health agencies, the diagnostic role is likely to be uppermost in women’s minds.

The results of this research suggest to me (and are implied by the model) that underscreened, asymptomatic women may undergo Pap tests if they are recommended to do so, persistently, and consistently, by health care personnel whom they trust. This may require considerable investment of time, contact and communication, until it is appropriated as part of these women’s culture. The solution would be having the physician’s office recognized as a source of routine preventive care. This would mean that everyone (health care providers and their patients) understands the function of the doctor’s office in providing “healthy tests” for healthy women.

For women facing barriers of language, literacy, or fear or embarrassment, Portuguese-speaking and/or female supportive contacts (whether personal or professional) who initiate and provide consistent and clear follow-up were widely reported to facilitate attendance for a scheduled appointment. Comfortable, supportive networks of women, whether formal (groups) or informal (friends or relatives) may play a valuable role in helping otherwise isolated women learn about healthy choices. They may affirm the importance of healthy behaviours by talking about and/or modelling them. As a forum for skill development, women’s agencies or support groups may also encourage women to practice speaking English and to ask questions. These may contribute to self-confidence and self-efficacy, both of which are likely necessary to adopt Pap tests and other health behaviours.
Some women reported embarrassment about going to a male doctor, and for them having a female provider was helpful. On the other hand, receptionists for physicians (of either gender) reported their capacity to influence women to choose to have a Pap test. Their communication includes linguistic, semantic, and supportive elements that seem to have the capacity to “reach” women. Receptionists affirm a practice’s commitment to preventive care: by speaking a woman’s language, by conveying clearly the importance of an appointment for a Pap test for that particular woman, e.g., especially at menopause, “the second age”; by acknowledging their own distaste for the examination and its necessity nonetheless; by using humour judiciously to provide accurate but unthreatening descriptions of gynecologic procedures or treatments; by following up assiduously to reschedule any missed appointment; and after the test, by calling the woman back to report her results. In terms of appointment scheduling, it seemed that immediate appointments might be acceptable, but perhaps only if the woman had been prepared in advance to expect the invitation: otherwise, making a firm appointment for a convenient time and location was valuable. Significant efforts are necessary to overcome unscreened women’s reluctance to undergo an initial Pap test: some women seem responsive to simple, direct overtures and recommendations about the need for preventive care; some are not.

Further research, investigating the prevalence of myths or their contributions to underscreening, is likely to be difficult if not impossible using traditional epidemiological approaches. Determining whether trusting and communicative relationships can influence immigrant women to adopt new, healthy behaviours may also be beyond their scope. An ideal approach would combine the flexibility associated with behavioural science, the pragmatism associated with program planning and evaluation, and the statistical rigour associated with epidemiology. One fertile area for research would explore the role and usefulness of dramatic or narrative presentations, compared with traditional didactic ones.

Table 28 summarizes the feasibility of the thesis, organized by objective and the elements contributing to each. The utility, complexity and resources required are categorized in relative terms as low, medium, and high. Here, utility refers to how this item contributed to the intended objective. Complexity summarizes the intellectual and technical difficulties associated with each element. Resources refers to time, personnel and supplies. Finally, the right-hand column presents key findings that complicate judgments about feasibility. The paradox is that study elements labeled as low utility for one objective might
nonetheless contribute to others. This seemingly contradictory situation is resolved only by recognizing that the four objectives of this thesis are interdependent.

Overall, this project concludes by suggesting that future efforts to identify and address underscreening may best be served within the context of a comprehensive, integrated program of care. Such a program would begin by providing services to address women's immediate symptoms or concerns. Once these initial problems were dealt with, the system would provide or refer women to services for preventive care and well-being. In an integrated program of care, health care, public health and social agencies and providers are truly complementary. If the model is correct, their capacity to improve health is likely to be enhanced by collaborative working relationships among agencies and providers. Yet again, the interdependence of their roles and functions echoes the research challenge encountered in this work.
Table 28. Feasibility Summary: Utility, complexity and resources for study objectives and elements.

<table>
<thead>
<tr>
<th>Objective Study component</th>
<th>Utility</th>
<th>Complexity</th>
<th>Resources</th>
<th>Challenge / Limitation / Assessment in the context of the other objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Iterative Project Development</td>
<td>High</td>
<td>Medium</td>
<td>High</td>
<td>This work permitted other activities that required community participation.</td>
</tr>
<tr>
<td>Initial planning group</td>
<td>Medium</td>
<td>Low</td>
<td>Low</td>
<td>Sessions in the researcher's home yielded information and credibility, but women were not fully characterized in this small group setting.</td>
</tr>
<tr>
<td>Community Steering Group</td>
<td>High</td>
<td>Medium</td>
<td>High</td>
<td>Many agencies approached did not participate, but those that eventually did served and knew Portuguese-speaking women.</td>
</tr>
<tr>
<td>2. Approaches to Identify &amp; Reach Underscreened Women</td>
<td>High</td>
<td>Low</td>
<td>Medium</td>
<td>Community partners' advice proved useful.</td>
</tr>
<tr>
<td>Churches</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
<td>Political / social situation meant this approach was not helpful, but never-screened women, otherwise isolated, were reported to attend church.</td>
</tr>
<tr>
<td>Festivals</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
<td>Women were reluctant to accept brochures, but many Portuguese attend and enjoy these celebrations.</td>
</tr>
<tr>
<td>Written materials</td>
<td>Low</td>
<td>Medium</td>
<td>Low</td>
<td>Women did not refer to invitation materials after their appointment, but bilingual flyers were used for location information or to raise topics with physicians.</td>
</tr>
<tr>
<td>Women's groups</td>
<td>Medium</td>
<td>Medium</td>
<td>Medium</td>
<td>This approach clarified concepts, built researcher credibility and community interest in the topic. Underscreened women did attend, but attenders were elite in having supportive social interaction, and the time to attend it. Isolated women or those with many responsibilities did not routinely attend.</td>
</tr>
<tr>
<td>Objective Study component</td>
<td>Utility</td>
<td>Complexity</td>
<td>Resources</td>
<td>Challenge / Limitation / Assessment in the context of the other objectives</td>
</tr>
<tr>
<td>---------------------------</td>
<td>---------</td>
<td>------------</td>
<td>-----------</td>
<td>---------------------------------------------------------------------</td>
</tr>
<tr>
<td>Health event</td>
<td>Medium</td>
<td>Medium</td>
<td>High</td>
<td>Interactive, group activities provided a desired forum, and underscreened women did attend and complete a survey. Attendance was not high (n=66), and no traditional women “in black” attended.</td>
</tr>
<tr>
<td>Physicians’ survey:</td>
<td>Medium</td>
<td>Low</td>
<td>Medium</td>
<td>Receptionists knew the patients and the issues, and some doctors and receptionists spoke Portuguese.</td>
</tr>
<tr>
<td>walk-around</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physicians’ survey:</td>
<td>Low</td>
<td>Low</td>
<td>Medium</td>
<td>Existing database permitted easy communication with geographically-defined population of family practitioners, but few reported Portuguese-speaking patients.</td>
</tr>
<tr>
<td>Community-based family physicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physicians’ logs</td>
<td>High</td>
<td>Low</td>
<td>Medium</td>
<td>There were underscreened women in these practices (33/111). Yet even participating providers misclassified eligibility for screening, and offices that did not offer routine screening Pap tests did not participate.</td>
</tr>
<tr>
<td>3. Randomized trial</td>
<td>High</td>
<td>Medium</td>
<td>Low</td>
<td>Selecting questions that could be operationalized was difficult but precluded useless designs.</td>
</tr>
<tr>
<td>Co-intervention (health event setting)</td>
<td>Medium</td>
<td>Medium</td>
<td>High</td>
<td>The health event and researcher participation seemed to enhance research acceptability, but it is difficult to standardize health events that are intended to be interactive.</td>
</tr>
<tr>
<td>Consent process</td>
<td>High</td>
<td>Low</td>
<td>Low</td>
<td>Small group, mutual agreement process seemed to enhance recognition of importance of topic, but the merits of this approach could not be tested.</td>
</tr>
<tr>
<td>Randomization</td>
<td>High</td>
<td>High</td>
<td>Low</td>
<td>Scientific rationale was readily accepted. The trial compared only options that were equally reasonable (i.e., now vs later).</td>
</tr>
<tr>
<td>Objective</td>
<td>Study component</td>
<td>Utility</td>
<td>Complexity</td>
<td>Resources</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------------</td>
<td>---------</td>
<td>------------</td>
<td>-----------</td>
</tr>
<tr>
<td></td>
<td>Validation with</td>
<td>Medium</td>
<td>Medium</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>medical reports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Followup telephone</td>
<td>High</td>
<td>Medium</td>
<td>Medium</td>
</tr>
<tr>
<td></td>
<td>survey</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Review of results</td>
<td>High</td>
<td>Low</td>
<td>Medium</td>
</tr>
<tr>
<td></td>
<td>with community</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>partners</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Synthesis &amp;</td>
<td>High</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>integration</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The synthesis for objective four was complex and took a long time, but it was useful because it provided raw material for the elaboration of a conceptual model. The challenge was to distill the material down to the final key themes and relationships, while integrating ideas from other models of health behaviour. Yet the result, a simple model, may permit the work to be appreciated beyond an academic setting.

The balance of this chapter now discusses the study, one objective at a time. It begins at the beginning, with the collaborative research process.
11.2 Detailed discussion of each objective

11.2.1 Objective 1. Collaborative research process

Collaboration, particularly successive iterations with community partners, influenced this project's methods, results and interpretation; paradoxically, it was both a limitation and a major strength for the study. With all the participants, the researcher exerted an effect, whether recognized or not, influencing the types and levels of disclosures, whether by prompts, tone or pacing. By not raising certain topics, implicit boundaries regarding sensitive topics were sustained. The researcher's limited ability to communicate in Portuguese and her lack of understanding of the culture restricted what she could learn. An important influence itself, the university affiliation of the researcher conveyed a clear message to Portuguese-speaking women: underscreened women warrant attention and Pap tests. With the Portuguese-speaking women, most things were translated, and nuances were not always recognized or understood. Even so, having to rely on independent, explicit interpretation did provide some surprising and powerful learnings in this study.

Participation was a two-way street. It included what the researcher learned from the respondents, and what the respondents learned from the researcher. There was a clear bias in participation, and participants have been described in some general and restricted ways. Ultimately non-participants cannot truly be characterized.

The flexibility and adaptation inherent in the iterative approach produced a unique set of methods, results, and interpretations of them. The iterative approach was fraught with uncertainty. This, combined with the small number of respondents for the quantitative aspects of the study, could have combined to produce a project that was fatally flawed. It did not, because of: caution in interpreting findings; acknowledgement of discrepancies and limitations; consistency of key themes; and their compatibility with and contribution to other theoretical and practical findings. All of these provide assurance that the findings, essentially hypothesized relationships, merit consideration for policy development and program planning, as well as research to implement and evaluate their impact.
This section discusses how the collaboration with community partners worked, and how this influenced the study. The collaboration worked because there were common goals and values, complementary roles, and compromises based on respect, pragmatism and good humour.

11.2.1.1 Shared goals and values

This collaborative process worked well because everyone involved shared an interest in seeing the needs of underscreened Portuguese-speaking women identified or addressed. Even though a set of specific "rules" for the project was not produced as a separate document, guidelines were regularly articulated. Two things were paramount. First, the notions of respect and enjoyment or comfort were made explicit. Second, the focus of identifying and addressing issues relevant to women who were underscreened for cervical cancer was clear and sustained. These things defined the scope and activities for the trial, and affirmed respect for each other's expertise and contributions. Active collaborators had limited time and many obligations; there was a pervasive sense of altruism. At the same time, pragmatism meant consensus was achieved in a timely manner.

Probing on sensitive issues was restricted. We never intended to aggressively explore intimate issues, such as inappropriate physician behaviours or unpleasant sexual encounters, even though they might be relevant to understandings or choices about gynecologic examinations. These matters did not generally emerge spontaneously, although our community contacts were prepared to refer if necessary. Most of the interactions with lay Portuguese women, other than the follow-ups with the women in the randomized trial, were in group settings. While there were a few times when women did talk about sex and sexual communication (and sometimes they joked about it) women did not typically disclose explicit details of personal trauma in English, and certainly not in the context of direct enquiry. Perhaps they shared these things privately with their friends, but they did not routinely share these matters with the researcher, for instance, by requesting they be translated. We expected clear boundaries around such disclosures, and respected women's privacy. Similarly, physicians who acknowledged not providing routine screening with Pap tests were not asked to explain why this was so. Such matters, important though they are, lie beyond the scope of this project.
Without diminishing the positive aspects of the collaboration, community members' participation may have been prompted in part by motivations unrelated to the project goals. For example, it was recognized that planning meetings in the home of the researcher provided something of value to the women, that is, information about women's health. They could be with their friends, and they could exchange their knowledge with someone at the university. Similarly, a set of community partners described a certain cachet in being able to refer to a University affiliation. These "self-interests" were not a problem in the collaboration processes, because they did not conflict with the project goals or values.

11.2.1.2 Complementary roles

Complementary roles enhanced the university-community collaboration. This project was distinguished by considerable input from lay Portuguese-speaking women, in the initial planning group, as health event representatives, as trial participants and as groups to whom "results" were presented. These people included underscreened women, as well as others who had undergone their first Pap test with their family doctor after they had immigrated to Canada. Other community-based informants included social and health service providers, such as health promoters and physicians, who provided care to Portuguese-speaking and other women. Having multiple perspectives from a diverse set of community partners meant that a range of understandings and interpretations were available. These helped us recognize and understand the complexities facing underscreened women.

Participants, mostly volunteers, decided how and at what level they would participate. As described, from the beginning, efforts were made to engage people in ways that were comfortable, meaningful and ideally enjoyable for them. Although this tack proved troublesome and perhaps offensive to some contacts, it was good for many. Letting people know that we wanted them to participate in whatever way was easiest for them, was often met with candour and clarity about what they would like. This "tell us what you'd like to do" approach also seemed to elicit generosity and unleash creativity. On the other hand, it increased the complexity of the project, as the research methods were frequently reviewed, modified, or updated. This inconvenience was more than compensated for by the richness of the contributions. Most of the people involved in this project did not routinely do
research, and instead were experienced in and oriented to education or service delivery. It was thus generally easy to defer to their judgments about the best way to go about things.

Representativeness of the community partners and research participants is critical, but it was impossible to fully engage underscreened women in the development and the intervention research per se. The factors that influence screening behaviour are undoubtedly also related to the inclination or ability to participate in research or planning processes. If the reports of the women who did participate are true, those women they knew who need Pap testing may not be integrated into Canadian culture, nor participate in other self-care activities. In contrast, the women in the initial planning sessions, who participated in Stress Management classes at a Community Health Centre, were integrated enough to socialize and had family situations supportive of this. These women, although not necessarily underscreened and therefore not strictly representative, could and did contribute their own understandings of what it meant to be Portuguese-speaking women. Screened women, including those in the initial planning group, health event representatives and other key informants also knew mothers, aunts, friends, and neighbours who were not adequately screened. Their contributions were valuable because of their experience, their understanding of others, and their willingness and ability to communicate what they knew. Representativeness at every stage or in every component of the study was not possible, but the screened women were likely once underscreened.¹ Their understandings of adoption are examined more fully later, and are a considerable strength of this work.

11.2.1.3 Conflict and compromise

The collaboration, though distinguished positively by shared goals and values and by complementary roles, was not without challenge. There were conflicts among the ethical, practical and scientific factors throughout the research project, and compromises influenced the development of the methods for each of the objectives. Conflicts were described throughout the methods and results, where they yielded important compromises about operationalizing hypotheses and approaches to identify and reach underscreened women. Other more diffuse conflict existed too. Allison & Rootman (1996) referred to the "dynamic

¹ Recall that the adequately screened women (n=40) at the health events had a mean age of 51.1 ± 13.2 years, with 21.1 ± 9.5 years since immigration (n=39). In contrast, underscreened women were aged 55.0 ± 13.8 years, with 20.0 ± 11.0 (n= 14).
tension" between community participation and academic rigour in health promotion research; this dynamic tension could apply to interpersonal as well as objective aspects of the collaboration. In some cases, competing obligations could have contributed to tension, and with those agencies doors were closed after preliminary discussions. Among the collaborators and community contacts, tensions seemed related to power, or when expectations were not met.

Power struggles may have been behind some awkward or slightly fractious interactions. There appeared to be two forms of power conflict in this collaboration: education versus influence, and clinical relevance versus research merit. If this project had been devised as "community-based / participatory / action" research these matters may have manifested themselves differently, or with different consequences. Instead, this project was not democratic: it had to proceed according to the requirements of a doctoral dissertation. Patience and flexibility in planning were necessary to maintain a meaningful collaboration; intellectual agility and responsive but unambiguous guidance from the thesis committee assured the research could continue. Partners did not generally provide theory relevant to their practices or recommendations, so the researcher had to discern areas of congruence among theory, ethical stance, and practicality.

There were also some difficulties in documentation for the project. Some community partners said they wanted more documentation, but did not always read what they had been given. Producing documents for various community interactions was time-consuming, but useful in developing clear articulations of the issues. We had to constantly adjust to shifts in community members' availability, obligations, and job descriptions. Partners' training and level of commitment varied. It was not possible to document the private interactions in the health event co-ordinator's work to identify and train Health Event Representatives. Their interactions were documented primarily as the two formal training sessions.

The shared goals and values and the complementary roles that marked our collaboration have some similarities with other researchers' descriptions of collaborative relationships. Our experience can be compared with Kegler et al.'s (1998) findings in their study of coalitions between and among agencies. There, successful coalitions were marked by good communication and skilled members, and high levels of member participation. More
staff time and more complex structures were associated with greater resource mobilization.

In our study, goals and values shared by members of a university and a Portuguese-speaking community in the same city functionally defined the coalition.

The term "community capacity" (Goodman et al., 1998), used to characterize communities, is also useful here to explain the contributions of the community to the collaborative processes. Here, the community referred to is specifically the Toronto Portuguese-speaking community. Community capacity assessment dimensions include: participation and leadership, skills, resources, social and interorganizational networks, sense of community, understanding of community history, community power, community values and critical reflection (Goodman et al., 1998). In the Portuguese-speaking community, there are a number of sources of strong leadership, not all of whom see eye-to-eye (Brazao, 1998, Landsberg, 1998). Participants in this project had many skills, although not necessarily advanced academic or professional credentials, and many had demonstrated their sense of community by participation in other projects that benefitted the Portuguese-speaking community, and indeed, Portuguese women. Throughout their short history in Canada, Portuguese immigrants have committed resources to establish and sustain agencies to benefit others in their community. As a consequence, there is an established, albeit small, set of social and interorganizational networks. No community is static, and recent changes within the Portuguese community reflect and influence their sense of community, understanding of community history, and community values. Critical reflection, about the roles of men and women and the role of the church, has been accompanied by shifts in community power (Brazao, 1998, Landsberg, 1998). Undoubtedly, shifts in community leadership will influence future collaborations.

Lastly, our situation, where shared goals and values, complementary roles and respect for each other made the collaboration work well, can be contrasted with other situations. Such compatibility may not exist in all community-research collaborations. Although there is no published information about the processes and factors involved in other attempted collaborations between academics and the Portuguese-speaking community, stories exist. One such "collaboration", a needs assessment, was reported to have had a happy outcome: the funding agency simply gave the money and the responsibility for the project to the community group; the group did the project independently and reported back on their findings. Allman et al. (1997:30) refer to the participatory nature of community-based HIV
prevention research as "a change that is not always easy to accommodate". Researchers are unlikely to publish details of incompatibilities, but the problems are real, and they can jeopardize both the research process and its outcomes.

Research collaboration may also be difficult to achieve in remote or disadvantaged communities where there is a history of problems with researchers. Native Canadian communities provide an example of this: when research is proposed, it is routine to hear the reaction that they are "researched to death". It requires considerable time and effort both to establish credibility and to comply with codes of research ethics (Tri-Council Guidelines on Research, 1998). Notwithstanding shared goals and values and the existence of skills which are complementary, collaborative research (or indeed any research) may be difficult to launch and sustain.

Although this research is structured with four discrete objectives, the development of the work, its implementation and interpretation, were all interwoven and interdependent. The iterative nature of this project meant that its form or structure was somewhat unpredictable, although not to the same extent as other possible forms of collaboration, such as participatory research and community empowerment (Travers, 1997). What remained at the core, though, was the focus on understanding what factors contributed to underscreening, and what might contribute to improving the situation. This clarity and consistency ensured that the feasibility study itself could be completed, and produced research that might not be achievable any other way.
11.2.2 Objective 2: Identify and reach underscreened women

The discussion for Objective 2, to study various approaches to identify and reach underscreened women, is organized according to what was feasible and what was not.

11.2.2.1 What was feasible

Of the possible approaches to identify and reach underscreened women that were considered, health events and a walk-around survey of physician’s offices were explored in this feasibility project.

The walk-around survey confirmed the geographic concentration of physician’s offices, along College Street, providing care to Portuguese-speaking women. Receptionists in those offices appear, along with their physicians, to have some potential to influence women’s choices about preventive care. They also serve as gate-keepers in physicians’ offices, functioning as mediators of both research and screening processes.

The health events were seriously limited by small numbers of women attending them, yet the study was successful in at least five ways. One, it did attract women who matched the priority for demographic characteristics, i.e., over 40 years of age, and speaking Portuguese at home. Two, most of the women identified as underscreened chose to participate in the randomized trial. Three, a majority of the women who participated in the trial did choose to have a Pap test. Four, followup interviews with trial participants provided data on a range of factors that served as barriers or facilitators of Pap testing. Five, women reported how much they liked the health event and being part of the trial. These things suggest that we had probably done something right.

Identifying women as underscreened was difficult using only self-report. Even so, one surprising finding was the ability, ease and willingness of Health Event Representatives to determine whether women they knew were underscreened. Health Event Representatives wanted to raise the matter when they invited women to come to the health event. They wanted their friends, relatives, or workmates to know the "real" purpose of the health events. And this was so, even though it was acknowledged not to be a usual topic for discussion. This is in marked contrast with Mamon et al.’s study (1991-2) which found that
lay health workers were less comfortable and capable of identifying underscreened women than they were of providing information to women already identified as underscreened. The difference is that in our study Health Event Representatives approached women they knew. They could select whom they approached and how, whereas in Mamon et al.'s study (1991-2) the workers telephoned women assigned to them. One benefit of our approach was that it could include women living in households without a telephone (cf. Mamon et al., 1991:29). In Mamon et al.'s study, the workers shared certain demographic characteristics (i.e. black, inner-city) with the respondents, but they were not part of the same social network.

Our approach, with health events and women to represent them, had two major limitations: the population exposed to the peers or to the posters is not defined by objective criteria, such as geography or type of establishment, e.g., beauty parlour, and the number and type of interactions remains unknown. If the project were set in a workplace or a health care practice, this would provide a more clearly defined sample. Also, if all the Health Event Representatives were literate, they might have been able to document their interactions or record some basic demographic characteristics of the women they contacted (e.g., using a simple table format comparable to the physicians' logs). As it was, they reported their experiences and concerns verbally during training sessions. Had all the health event representatives been literate, they might have known relatively fewer illiterate, underscreened women.

In our study, we were able to ask women about their screening status in a short personal interview at the beginning of the health event. Interviewers noted that not every woman knew what a Pap test was. At its most extreme, a woman may have had a Pap test but not realize it. How can this be? Of course, she is probably aware that she had some kind of gynecologic examination. But if she has not received and understood an explanation of exactly what test she has had done, or what it is for, she may not realize exactly what procedures were done. Language barriers could explain this: no-one can be expected to understand an explanation if it is provided in a language they do not understand. Even if a translator is available, limited time may restrict the explanation that a woman receives. It was not unusual to learn that health care providers lack the time to provide full or specific information about what services are being offered or provided. If a woman is anxious, e.g., with gynecologic symptoms or abdominal pain, she may not remember the details of what
she is told. If a woman has had a hysterectomy or other surgical intervention, she may not
know whether she has a uterine cervix.

Setting an intervention in a place with access to health care records would solve many but
not all of the concerns about identifying screening status. We learned of three possible
problems: women may go to more than one doctor, they may change physicians, and
records may not always be correct or complete for other reasons. In our immigrant
population, we learned of inconsistencies in health card numbers, birthdates and even
names. Even so, health care staff who have access to a woman’s records, who know the
definition of screening adequacy, and who have a good rapport with Portuguese women,
may stand the best chance to classify women’s screening status correctly.

As for reaching underscreened women in a way that fostered responsiveness to an
invitation to a Pap test, the health events were well-received by some women. Women who
came to the health event reported that they came because relatives, friends, or leaders of
their women’s groups invited them. Using Bandura’s framework of sources of efficacy
expectations; the women were verbally persuaded to come, induced by suggestions or
exhortations from sources close to them (Bandura, 1977:82). Having come to the event,
efficacy expectations about having a Pap test might be surmised to have influenced women
as “vicarious experience”, because the underscreened women were aware that the other
women there had already had Pap tests (live or symbolic modelling, Bandura, 1977:80).
Health Event Representatives found that not all underscreened women wanted to come;
women who were believed to need it the most, were reported to be least interested in
coming to the event.
11.2.2.2 What was not feasible

We (members of the project) were not able to identify and reach underscreened women directly through their churches, as our contacts had predicted. We persisted, because we had been told that some church-going Portuguese-speaking women were underscreened. Further, there were enthusiastic reports of an important role for churches in increasing cancer screening among Spanish-speaking (Frank-Stromborg et al., 1997) and Black women (Mamon et al., 1991, Erwin et al., 1996, Mann et al., 1997).

The nature of our research project and the nature of Portuguese-speaking, and particularly Portuguese, women probably contributed to differences between this and other successful church-based projects. But first, publication bias should be acknowledged. Efforts that failed to solicit churches as collaborators or sources of underscreened women are unlikely to have resulted in publications describing the venture. In our project, although we provided a women's health event, our emphasis was focused on Pap testing, with an explicit offer to have one, and research about this matter. Some churches that participated in screening interventions had established priorities for health education or promotion projects, that could include mental, physical, social, and spiritual dimensions. The Witness Project™ was perceived as a ministry of the church, and was intended as such, recognizing that "religious and medical beliefs are often united" for African American women (Erwin et al., 1996:214). Although the project was based on presentations of breast cancer survivors, it capitalized on existing beliefs about God's will, rather than trying to change them (Erwin et al., 1996, Erwin et al., 1992). That project, in rural east Arkansas churches, had a relevant population, with 75% aged 40 years or more. They found a statistically significant increase in self-reported mammography, and breast self-examination overall and among women over age 40 (Erwin et al., 1996). Mamon et al. (1991) also had good reason to use churches, because they had done a needs assessment of their inner-city population, among women aged 18-64, of whom the majority were Black (Mamon et al., 1991:26). Their project dealt with cervical cancer screening, and an initial needs assessment showed that "66% of inadequately screened women reported belonging to a church" (Mamon et al., 1991:26). Fifteen of the 17 agencies involved in their subsequent educational intervention were churches; previous experience with providing health outreach programs may have contributed to many churches' responsiveness to this opportunity (Mamon et al., 1991:25). Some difficulties with this approach were identified: women aged 65 or older had been
found to be less responsive to peer intervention so were excluded from the study; and
volunteer lay peer educators from the seventeen churches (who followed up on women for
two years) did have a 62% attrition rate among their 144 volunteers between year one and
two of their study (Mamon et al., 1991-2). These difficulties are not unique to the church
setting, but the church setting does not necessarily resolve them.

I would have liked having churches as active collaborators, to assist in developing the
research project, to study approaches to reaching underscreened women, or in planning for
and providing health events. As it was, church representatives played valuable but limited
roles, permitting us to hand out posters, reviewing promotional material, and reflecting on
the characteristics of the Portuguese-speaking community.

Other factors related to cultural characteristics of the Portuguese community and their
churches may have contributed to differences in our experience and that described in
church-based interventions. The Portuguese community may not share the same cultural
values as Black or Hispanic communities, particularly with respect to issues of intimacy,
and to the acute sensitivity of disclosures related to sexual activity (Scorsone, 1998). The
Portuguese community has been described, by one health care worker experienced in
working with it, as sexually repressive (Hansen, 1998). This, combined with the possible
moral/ethical overlay, regarding, for example, the risk factor of numbers of sexual partners,
raises the uncomfortable issue of whether it is appropriate or acceptable to discuss
"private" matters in a public place (Scorsone, 1998). Political storms within the Roman
Catholic churches in Toronto were associated with one priest, whose views on women were
infamous (Brazao, 1998, Landsberg, 1998). This situation, widely recognized in the
Portuguese community and eventually publicized in the local press, could have made even
sympathetic priests reluctant to participate. Although our efforts with churches were not
particularly fruitful, times change; opportunities for working together may emerge over time
or in different communities.

1. They were assumed to be addressed by provider intervention.

2. This attrition occurred even though they had modified their original study design from the pilot when
they realized that identifying and recruiting women were two different kinds of tasks and required two
different kinds of skills. The lay health educators, after 2 hours of training, had initially tried to do the
telephone survey to identify the women, but later they were restricted to intervening with women already
identified (Mamon et al., 1991:29).
The women who participated in our planning, implementation and attending the health events were not "women in black". That is, they were not traditional women who dressed in black after mourning a husband or relative's death. Women in black are still seen in the study area, shopping or going to church, but no estimates of the size of the population are available. The women who did attend the health events understood what it means to be a Portuguese woman: to live, to work, to care for others. They also recognized that socialization patterns differed, that women who were unaware of Pap testing may well be the ones who were generally isolated.

To summarize the understandings that emerged out of the work for the second objective, what was learned from studying approaches to identify and reach underscreened women, can be expressed as a restatement of the first objective. That is, promoting adoption of Pap tests is contingent on "identifying" women's screening status with certainty, and "reaching" them by being physically proximate, and by providing a compelling rationale to participate in screening Pap tests.
11.2.3 Objective 3: Randomized trial

The research methods of the trial, other than data validation, were largely acceptable to the women, and useful to identify and address some key issues relevant to adoption of a health behaviour. The most remarkable features of the randomized trial were the high participation rate of eligible women for the trial, and the large proportion which reported a Pap test following intervention. Discussed in detail below, these findings are probably due to the health event co-intervention, built into the design of the trial.

11.2.3.1 Appointment scheduling

The appointment trial was too small to determine the relative merit of scheduling women to receive immediate versus later appointments. Four of the six women who were allocated for a later appointment reported having had a Pap test. Two of these women reported a scheduling problem and then having had the test at their doctors, rather than at the appointment location recommended.

11.2.3.2 Language

The two-by-two factorial design of this study meant the women in the appointment trial also participated in the language trial, and here again, the trial was too small to determine a difference between the treatment arms. It had been expected that providing two brochures (in Portuguese and English) would be preferable to providing only one brochure (in Portuguese). Although the small sample size meant that we could not distinguish any relative merit between these options, we did learn from the follow-up interviews that brochures did not seem to have been actively referred to after the day of the health event. Instead, women consistently "put them away". The brochures may not have been referred to because the women had received many other brochures at the same time, at other sessions of the health event. Would we recommend going for written material? Absolutely not. After all, our verbal invitations were "read out" from the Portuguese brochure to the women. They provided a clear, consistent message about the role of the test. And women got to keep their own copy, which they could use to find out about the meanings of test results. For women with literacy limitations, though, referring to written brochures (in whatever language) may simply not be a part of their repertoire. Even so, written
information seemed important in at least two other ways. First, women had referred to the map on the flyers which invited women, and certainly social service staff referred to or provided the flyers to inform the women they knew. Second, outside of the trial, at the meetings with women's groups, some women who had never had Pap tests seemed to want written material: either asking us to write down the words "Pap test", or requesting a brochure to take to their doctor.

Although the language trial per se was not particularly informative, and did not permit the originally planned investigation of communication mechanisms, other parts of the study affirmed how powerful words and language can be. Choosing appropriate language was more than simply translating short, uncomplicated sentences. At a conference on health education, Freimuth (1997a) the Director of Communication Services at the U.S. Centers for Disease Control, emphasized that "hard to reach" is the label we apply to the population, when we do not know what we are doing. Reaching the Portuguese-speaking women effectively meant understanding what issues and concepts were important to them, and why. We learned that particular words or phrases, such as "cancer screening", served as barriers in themselves.

Finally (and perhaps obviously) communication involves far more than just language and statements of fact or exposition. In this study, much seems to have been conveyed by my presence as a professional researcher, and by the personal attentiveness, warmth and good humour of those involved with the women in the project. Any attempt to recruit women might well be influenced by considerations such as these.

11.2.3.3 Strengths and limitations of the trial

The randomized trial has strengths and limitations in the three categories identified by Cook & Campbell (1979): "(1) the definition of the disorder or phenomenon of interest, (2) the selection of the subjects, ...[and](3) the design or execution of the study itself".

11.2.3.3.1 Definition of the phenomenon of interest

Our operational definition of eligibility for the intervention study was based simply on reported Pap test screening status. First, women with gynecologic symptoms were neither
identified nor excluded from the intervention study in advance. On the follow-up questionnaires, it became apparent that some of the women were going to receive some kind of treatment, and it seemed some may have had existing discharge or other symptoms (including pain). Therefore, these women’s tests could not be considered as true screening tests. Second, women did not always know whether they were eligible for a Pap test. Our community contacts had told us, and we observed in sessions with women’s groups, that women with hysterectomies did not always know the details of their procedure. Further, women who understood themselves to be "too old" seemed to believe themselves to be no longer eligible for routine Pap tests. Third, some women just did not seem to know what a Pap test was, or if or when they had had one. This may help explain why three women, who indicated recent Pap tests on the questionnaire, subsequently attended the small group session announced after a short presentation about Pap tests in the plenary session. These problems in determining eligibility contributed to the development of the theoretical model.

11.2.3.3.2 Selection of the subjects

The women who chose to attend the health events and/or participate in the study may differ from the general population of underscreened (Portuguese) women eligible for screening. Self-selection occurred in terms of coming to the event and participating in the trial. Women attending the health events had been in Canada for many years, and were generally comfortable in the social setting chosen. As organizers, we were acutely aware that we did not see the "women in black" that we had anticipated as a relevant population for our study.

It was not possible to quantify the existence or extent of bias between eligible women who participated and those who declined to participate at various steps of the intervention.

1. Secondary prevention by screening is intended to detect asymptomatic disease (Fletcher et al., 1988:158, Miller, 2000). Fletcher et al. (1988:159) contrast mass screening with case finding, "when clinicians search for disease with screening tests among their own patients who are consulting them for unrelated symptoms". They distinguish between case finding and mass screening in terms of the responsibility taken by the clinician for follow-up and treatment: the doctor would take that responsibility, mass screening would not.

2. Recall that the questionnaires were administered in person, in Portuguese, so language literacy or comprehension (i.e., Portuguese versus English) were not the issue here.
Fortunately, some of the women who declined told us why: they were too old. But these women had heard the plenary introduction, which emphasized that Pap tests were intended for older women, at higher risk of cervical cancer. Discussions with receptionists and other community contacts explained that being too old could mean a woman was no longer sexually active, or was post-menopausal and without gynecologic symptoms. These ideas were keys to recognizing the strong undercurrent of misunderstandings that serve as barriers to screening.
11.2.3.3.3 Design or execution of the study

The study design and execution did not resolve problems in defining underscreened women. Most salient of the design features was the co-intervention of setting the invitation trial in a health event. The other study design and execution limitations are: contamination, and unexpected difficulties on the questionnaires, including validation. These are examined in some detail here, as they have both practical implications and theoretical relevance.

11.2.3.3.3.1 Co-intervention

The health event was, by definition, a trial co-intervention. The right setting may have overshadowed any effect of the particular invitation received. Women's adoption of Pap testing as a consequence of the health event experience could be considered evidence in support of the success of having an integrated set of experiences and information that all leads to one purpose, that is, preventive care.1 "The more pervasive the stimulus inducements, the greater the likelihood that learned innovations will be tried." (Bandura, 1977:51) Underscreened women may also have realized that their friends had already adopted Pap testing, because only certain women, a minority, were invited to the special group to learn about Pap testing. This might have indicated to underscreened women how widely diffused the "innovation" of Pap tests was in their network (cf. Valente & Saba, 1997). Attending the health event, learning about the study and agreeing to participate in it were non-obligating steps to find out what they might be missing.

One other aspect of cointervention was that we focussed on the women, not just on Pap testing. We respected them. It may be that the women ended up perceiving the test as important, because the entire event and trial were aiming to help them understand that they were valued and we considered them important. While the sessions presented information on preventive care opportunities, they also encouraged women to ask questions about health-related issues, both in the health event and with their own physicians.

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1. Alternately, as described earlier, some may have been worried about symptoms and seeking alternate care provision.
11.2.3.3.2 Contamination

In a randomized trial, contamination is the "inadvertent application of the experimental procedure to members of the control group, or inadvertent failure to apply the procedure to members of the experimental group." (Last, 1995:36). This seems to have happened only once when a woman initially assigned a later appointment was "fitted in" to an appointment that day. In this case, the woman's response to the allocated appointment had already been recorded.

11.2.3.3.3 Questionnaire and measures

There were some problems in the questionnaires and measures used: for tracking repeat attenders and characterizing health event representatives; for names and dates; and for measuring and categorizing trial participants' intentions and decisions about Pap tests.

The Women's Health Event Questionnaire (WHEQ form) did not have a question that identified women who had previously attended another health event and/or who were Health Event Representatives, and this had consequences for the analyses. In the planning meetings, the researcher had made a case to collect data on these possibilities, but one member of the steering committee persuaded the others that any skilled researcher could easily determine duplicate attenders simply by matching duplicate birthdays. The researcher's concern about the chances of shared birthdates held no sway. The matter was further complicated by error in reporting or recording birthdates, and by women's reluctance to complete a second questionnaire on their second visit. Reconciling the forms that were completed, even with hand review, proved difficult. In addition, the absence of a question to identify if a woman was a Health Event Representative was not resolved by the request that representatives sign in the researcher's logbook. This was trickier to carry out than anticipated because a woman arriving at a health event could go to one of several desks for her welcome and questionnaire, while there was only one desk with a logbook. Any woman unfamiliar with logbooks (which the health event representatives had signed at their training sessions) might have been confused or concerned by the need to sign in. Hand notes on some forms did indicate that the woman was a health representative, or had helped invite other women. The bottom line, though, is that without a form for each Health
Event Representative, the WHEQ could not be used as a tool to formally characterize those women.

We had used drafts of the form as part of a partnered exercise in our second training session. We anticipated that this would help women describe the health events and study to their friends, and allow us to observe the women discreetly to identify those best suited to serve as interviewers. Not all the women were literate, but nevertheless they seemed pleased to be able to take their own questionnaires home (plus a blank one) to show their friends. Were I to do this project again, I would try to find an acceptable way to keep copies of the completed forms. Data from them could have been used to characterize and identify the Health Event Representatives and compare them with other women attending.

There were some problems related to dates and names. Differences of up to several weeks in reported birthdates were explained by a community contact as common for women, born in small communities, where a birth certificate would be issued with the baptismal date, rather than the birthdate. But one woman in the trial, who did agree to validation, reported a birthdate that differed by several months from the one noted on her Health Event Questionnaire. On discovering the discrepancy, she was telephoned to confirm which was true, and this seemed to resolve the problem. Yet, not this one, but the birthdate initially provided, turned out to be the one recorded on her family doctor's electronic records. To further complicate matters, the woman had also provided two different health card numbers. Even with only fourteen women in the trial, two women shared first and last names. Fortunately they had also spontaneously provided their middle names. In any future work, I would request complete names and a contact person.

The form for collection of baseline questionnaire data at the Women’s Health Event (Form WHEQ) had an administrative section for eligibility that did not work well. Responses to the administrative section at the bottom of the WHEQ form did not correspond well with women’s answers to the eligibility questions about Pap tests. Two possible reasons were identified. “Flow” instructions, to indicate criteria for eligibility, were provided separately (verbally and written). The other possibility is confusion about terminology, where “eligible” may have been interpreted as meaning a desire to learn more about the study.

1. This was in part due to space limitations and in part anticipating that some of the women would fill out their own questionnaires.
This difficulty in screening status assessment was resolved by basing eligibility on the Pap test recency questions.

Our trial's measure of intention "decided to have a Pap test" in response to the invitation, was not useful as an indicator of performance in the short term. Thirteen of the fourteen women in the trial indicated that they had decided to have a Pap test, but only nine of those women actually reported having had one; this corresponds to a positive predictive value of only 0.69. This is consistent with Mandelblatt et al.'s (1993) finding that the intention to continue with Pap tests may not necessarily predict subsequent behaviour. So what does "decided to have a Pap test" mean to the Portuguese-speaking women in our randomized trial? As a question, it had face validity. In the follow-up interviews, women answered this question without hesitation. But intention, i.e., "decided to have a Pap test" was not a good indicator of whether a woman actually had a Pap test. Deciding to have a Pap test is clearly an important step. But it is not the same as going for a test or actually receiving it. It does not seem to function as a direct and immediate precursor to having a Pap test.

The Theory of Reasoned Action proposes intention as the best predictor of action (Ajzen, 1985, Ajzen & Fishbein, 1980, Ajzen & Madden 1986). In this study measuring decisions and intentions was not clear-cut, perhaps in part because the researcher was not familiar with Portuguese manners. If a woman reported that she had "decided to have a Pap test", one or more residual barriers could still prevent her from going or getting it. Even when the appointment was for the same day, there were time conflicts. When the appointment was for another day and location, a woman got lost and could not find it. Other women, who went to their appointments, reported not having had a test that day because gynecologic infections prevented the taking of a smear. In these cases, there seem to be many intermediate steps between intention and completion of the action. Alternately, a woman could learn about and have a Pap test right away (e.g., in a doctor's office), and this might be considered a compression in time interval between intention and action.

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1. Recall from the results, the possible outcome measures were: a woman's response to offer of an appointment for a Pap test (an explicit appointment either for now or scheduled for later); her reported decision about the offer of a Pap test at the intervention (provided retrospectively); and her intention to have Pap tests in the future.
A favourable disposition towards preventive care and/or Pap tests was undoubtedly a good thing, because an intention not to have Pap tests seemed to be accurate. Negative intentions were held by women who decided not to have a Pap test, and by those who declined to participate in the trial. Other women, not dealt with directly by the researcher, were reported by Health Event Representatives to have refused to come to the health events, even though they were underscreened. Others were described by their peers or care providers as adamant in their refusal to have Pap tests, e.g., "She's not gonna go". These latter women were regularly receiving health care, some for chronic problems which included arthritis and diabetes. One woman was described as having deliberately chosen to go to a doctor who was reputed not to offer routine Pap tests. The body language and tone of these reports was powerful: the choice was deliberate. It was disconcerting that these women could not be fully characterized: they could not be identified, nor could they be reached directly by the researcher.

The outcome measure of women's reported Pap tests within three months of the intervention was not amenable to validation using our strategy with physicians' records. After the follow-up interviews, requesting validation of Pap tests was only meaningful with women who reported having had a Pap test. Some of these women thought that we already had access to the details of their test results. Others seemed uncomfortable with the idea of our contacting their physicians; one woman said her doctor would not like it. The research assistant was confident that these women had actually had Pap tests; women did not hesitate to tell her that they had not kept their appointment. Introducing validation earlier might have been useful, but it could have had other effects, including alienating, offending or confusing the women. An early request for validation might have biased the women to questions on follow-up interviews, or, in the extreme, prompted them to decline to participate at all. On the other hand, requesting the validation later meant forfeiting some access. Validating reported Pap tests by comparing women's reports with physician's records was an unresolved problem for this study.

Lastly, the measure "intention to have a Pap test in the future" seemed to provide considerable optimism about future uptake of Pap testing, until the potential for misclassification was disclosed, i.e., the "hidden no". The community contact identified this as a cultural phenomenon among the Portuguese women she worked with. The hidden no began with "yes" and was followed by, e.g., information about the possibility of having to
reschedule the appointment. In this care provider's experience, Portuguese women would telephone only to cancel, not to reschedule appointments. This information was another key, this one an indicator of an important cultural misunderstanding that the researcher brought to the work.

Together, the classification problems, the self-selection, and the limitations in women's knowledge were substantive points that were incorporated into the theoretical model. Lack of awareness or understanding about what Pap tests are, what they are for, and who should get them, all served as barriers to Pap tests for screening purposes. Yet, if these problems coexist beyond the study population, they mean that identifying and reaching underscreened women is, in and of itself, a key issue for promoting adoption of Pap tests.
11.2.4 Objective 4. Barriers and facilitators

The results for Objective 4 presented three summaries of the barriers and facilitators: steps on the pathway to adoption for women in the trial; the diagnoses of the PRECEDE framework, and the myths. Key themes regarding barriers and facilitators that emerged in the trial were compared and contrasted with those that emerged with the health care providers and others in the study. A pivotal step, shifting the work from the empirical to the conceptual, was to recognize ambiguous or incongruous findings and then juxtapose them with a rational counterpart or logical explanation (Table 29). This presentation both highlights the paradoxical findings, and offers resolutions for them.

The ambiguities or incongruities in barriers and facilitators seemed to represent fundamental confusions about the roles and functions of the Pap test, whether diagnostic or screening. The conceptual model was developed to display and disentangle these confusions, presenting two divergent roles for Pap testing. The model was also intended to convey two conceptual facilitators of screening Pap tests for eligible women. That is, eligibility for screening, and importance, were elaborated as the companion concepts of “perceived need” and “perceived value”. The Two Streams Model proposes these understandings to be fundamental facilitators of Pap tests.
Table 29. Barriers and facilitators: Pivotal recognitions in the development of the conceptual model

<table>
<thead>
<tr>
<th>Ambiguous or incongruous barrier or facilitator</th>
<th>Confusion or question raised by the results</th>
<th>Contrasting finding or complementary rational explanation</th>
<th>Resolution proposed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Health care providers spoke about women’s knowledge or lack of understanding about the Pap test as a barrier to screening.</td>
<td>Exactly what knowledge or understanding is relevant as a facilitator of screening?</td>
<td>Women in the trial retrospectively explained their participation by referring to the Pap test as important or not.</td>
<td>Recognizing the Pap test as having a role in preventive care is crucial to facilitate screening.</td>
</tr>
<tr>
<td>2a. Underscreened women at the health event spoke about being too old as a reason not to participate in the trial or have a Pap test.</td>
<td>The information at the health event emphasized that the Pap test was for women who were old. What didn’t these women understand?</td>
<td>When receptionists and physicians referred to the notion of older women, they occasionally juxtaposed it with the information that some women were no longer sexually active.</td>
<td>Old is a euphemism for no longer being sexually active. It is interpreted by women and doctors as meaning that a woman is no longer at risk of cervical cancer. If a woman is not at risk of cervical cancer, there is no need for preventive care.</td>
</tr>
<tr>
<td>2b. The note “widow” accompanied the designation of ineligible for Pap tests (on a physician’s log).</td>
<td>The definition of eligible had been provided. What didn’t the doctor understand?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3a. Both women and care providers described symptoms as a reason to have Pap tests, and conversely, that the absence of symptoms was a reason not to have it.</td>
<td>Why, given the perceptions about age and symptoms, should menopause be perceived as an appropriate time to begin screening?</td>
<td>Women in the initial planning group explained that women interpreted sudden physiological changes, such as headaches or hot flashes, as indicators of serious underlying physical problems, especially cancer.</td>
<td>Menopausal women willing to have Pap tests might consider this part of the diagnostic procedure for their menopausal symptoms.</td>
</tr>
<tr>
<td>3b. Health care providers reported that menopause could facilitate an unscreened woman’s invitation for a Pap test.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
11.2.4.1 The Two Streams Integrated Model of Pap tests

The Two Streams conceptual model (Figure 5) is considered an integrated or integrating model for two reasons. First, it integrates practical findings from the Portuguese Pap test project with abstract ideas, including those from several theoretical models. Second, the model implies that the adoption of a health behaviour such as Pap testing is enhanced as women are integrated into a health care system that is oriented to provide and promote preventive care.

In this model a woman's perception of Pap testing is determined by whether she has symptoms or not, by her expectations of what kinds of service are provided by health care personnel and by her understandings about cancer and screening for it.
Figure 5. The "Two Streams" Model
11.2.4.1.1  Context for the Pap test influences perceptions

If a woman has gynecologic symptoms such as abdominal pain, bleeding, or some other vaginal discharge, the doctor is likely to recommend a Pap test as part of the gynecologic examination for a diagnostic work-up. In the situation where a woman has gynecologic symptoms, she is not actually eligible for a screening test, and any Pap test she undergoes (with or without treatment) is categorized as diagnostic. On the other hand, if the woman is asymptomatic, either the doctor or the woman may initiate the idea of having a Pap test. If the doctor introduces the Pap test in the context of a visit for some other chronic or emergency care, it is considered "opportunistic" screening. Yet either of these circumstances (unless a woman has symptoms of cervical cancer1) would constitute secondary prevention of cervical cancer, that is, detecting and treating precursor cells before they become invasive. Thus the purpose or immediate context of the Pap test defines it as diagnostic or screening. What is remarkable is that this distinction is relevant not only to researchers but also to women themselves. In this study, walk-in clinics for Portuguese-speaking women were common, consistent with the reports that "People generally wait until they exhibit symptoms before going to the doctor." (Kendall, 1992:10) Underscreened women were reported to question why they should have a Pap test when they did not have any symptoms, indicating that they perceive the test as diagnostic. If Pap tests are provided opportunistically, outside of a screening programme, as an adjunct to other procedures, women may not perceive the test as preventive nor realize the need for further tests (Knopf, 1976).2 There may also be discordance between physicians' and their patients' understandings about what the Pap test is for.

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1. If a woman's symptoms are associated with cervical cancer itself, this suggests more advanced disease. At that stage, any "prevention" would be tertiary (Last, 1995:130).

2. A decade later she and colleagues devised a set of pathways to depict how women came to have Pap tests in the absence of an organized screening program in Britain (Hobbs et al., 1987). Primary pathways are those in which the interaction about Pap tests is the prime purpose of interaction with a health care provider; it is active if the woman requests the test and reactive if she receives an invitation to have it. Secondary pathways refers to having the test as part of another procedure, and it can be either active or passive. This set of pathways was developed as part of the rationale for a comprehensive system of cervical screening; it is compatible with this study's model.
11.2.4.1.2 Understandings from others affect expectations

Social learning theory explains how women's cognitive understandings and emotional expectations of Pap tests may be influenced by other, even unrelated experiences. According to this theory, a woman's response to the offer of a Pap test could be conditioned by contingent or correlated experiences, which create expectations (Bandura, 1977:59-61). Social learning theory describes social processes that influence choices about behaviour; expectancy learning and efficacy expectations (contributing to self-regulatory processes) are all considered relevant to women's perceptions about the Pap test (Bandura, 1977:12).

Symbolic and vicarious expectancy learning are considered antecedent determinants of behaviour; they explain the effects of paired experience (familiar from classic conditioning) (Bandura, 1977:63-5). Symbolic expectancy learning includes "words that arouse emotion" (Bandura, 1977:64). Vicarious learning involves observing how others deal with situations, and the information gathered includes the emotional displays, vocal, facial and postural cues associated with them (Bandura, 1977:65-6). As reported by many respondents in this study, this is the situation for women who observe others facing cancer or possible diagnoses of it. Thus social learning theory, and especially vicarious emotional learning, explain why Portuguese people's understandings and experiences of health care seem so important to other Portuguese people (Bandura, 1977:66).

Other determinants of behaviour predicted by social learning theory are a woman's expectations about personal efficacy and her judgments about the effect of the activity (also referred to as outcome efficacy). Personal or self-efficacy (an antecedent determinant) involves a woman's own judgments about whether she can perform the behaviour; outcome efficacy (a consequent determinant) describes expectations of the outcome expected from

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1. Social learning theory sits in contrast with other theories that espouse dispositional determinants of behaviour, where "people possess traits or dispositions which lead them to behave consistently under changing circumstances (Bandura, 1977:6). "In the social learning view, contingent experiences create expectations rather than stimulus-response connections." (Bandura, 1977:59)

2. Processes identified as part of the social learning theory include antecedent determinants of behaviour, consequent determinants, cognitive control and reciprocal determinism (Bandura, 1977).
the behaviour (Bandura, 1977:130). The women in the study who reported having had Pap tests emphasized the importance of the Pap test to stay healthy; in behavioural learning theory this is an expectation of outcome efficacy, where the activity has been judged, and rendered a high valuation. In contrast, some women who did not have the Pap test explained the personal limitations that restricted their ability to get to or undergo the test; this can be considered an expectation about self-efficacy, or, more correctly, a lack of it.

Efficacy expectations have four sources: performance accomplishments, vicarious experience, verbal persuasion, and emotional arousal; each of these has several possible modes of induction and may be influenced by situational circumstances (Bandura, 1977:80-3). As important as a woman's own experience of a single interaction is her understanding of the nature of health care services, whether they are oriented to diagnosis and treatment, or to prevention. The objective characteristics of the system, or even the care providers' perspectives, do not necessarily correspond with a woman's perspective. Her expectations may be shaped by other people's stories of diagnostic procedures and poor prognoses. Cognitive functions are important in expectancy learning (Bandura, 1977:67-), because they can mediate effects on emotions; i.e., "Affective reactions can be stimulated cognitively." (Bandura, 1977:68) In addition, the repetition of stories serves to model affect, which can provoke a self-arousal process, i.e., vicarious arousal (Bandura, 1977:66). I think that the cognitive and the emotional are linked in myths, which affirm pessimistic understandings about cancer. Descriptions of the Pap test as intended to detect cancer, along with ideas that cancer is fatal, combine symbolic and vicarious learning in expectations about efficacy. Whether true or not, "we create our own

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1. Antecedent determinants are influences before a behaviour occurs; consequent determinants of behaviour are those which are important after the initial behaviour has taken place. The follow-up interviews (permitting open-ended responses about what had influenced their choices) were only done after the scheduled appointment. And, as described elsewhere, these women's responses did not necessarily discriminate between various actions (i.e., coming to the event, participating in the trial, and choosing to have a Pap test). Thus it was not possible in this study to fully distinguish between antecedent and consequent determinants.

2. Each source of efficacy expectations has various modes of induction. Performance accomplishments induce efficacy expectations through: participant modeling, performance desensitization, performance exposure, self-instructed performance. Vicarious experience involves live and symbolic modeling. Verbal persuasion includes suggestion, exhortation, self-instruction, and interpretive treatments. Emotional arousal involves attribution, relaxation or biofeedback, symbolic desensitization, and symbolic exposure. Success expectations vary depending on the fear of consequences. (Bandura, 1977:83)
information" (Dervin et al., 1977, summarized by Freimuth et al., 1989:13), and the conclusion here is that cervical cancer screening is something to avoid.

11.2.4.1.3 Myths reflect pessimistic and misleading understandings

Myths encapsulate pessimistic and misleading understandings which influence women’s choices about health behaviours either directly, or indirectly, by generating fear or by compromising perceptions of both need and value. Myths had been identified as a barrier to cervical cancer screening by a community respondent, but the precise identity of these myths was not specified. I identified and labelled as myths the understandings suggested or reported by study participants. Myths particularize the incomplete understandings about cancer, cancer screening, and the physician’s role (presented earlier in Table 27, “Myths and their complements”). Kendall’s (1992:6.7) City of Toronto Department of Public Health "Ethnocultural and Health Profile" states "As with many people, the prospect of getting cancer terrifies the Portuguese and they will often avoid treatment or ignore a lump because they are afraid it will be diagnosed as cancer." In myths, diagnostic expectations for Pap tests (and health care in general) overwhelm and obscure its other role, that is, in screening or secondary prevention. Emphasizing current sexual activity as a precondition for the Pap test obscures the issues of history of sexual activity (age at initiation, increasing numbers of partners and partners’ partners) and of increasing age. In these ways, myths may influence invitations for screening and women’s choices about seeking or accepting health care.

The myths identified in this study correspond to misunderstandings, lack of knowledge or attitudes reported by other researchers. Balshem (1993) described her anthropological work in a working class neighbourhood in Philadelphia (European-American), and provides the typical response to a question. "Cancer – what does it make you think of?": "Death. Because most of the time when you have cancer you wind up dead, you know. I know there’s treatment and all but in my opinion I think of death." (Balshem, 1993:73) Mexican women reported in focus groups that cancer was equated with death (Lazcano-Ponce et al., 1998). In Oxford, England, women were reported to have interpreted the Pap test as a means to diagnosing rather than avoiding cancer, and this perception was considered less helpful (Hobbs et al., 1987:256). Medical office reception staff in Wales reported that women did not understand the preventive role of Pap tests (Elwyn & Small, 1998). In the
view of Segnan et al. (1998) absence of symptoms is the most common reason not to have screening. Fear has recently been reported in the context of cervical screening by Mandelblatt et al. (1999). Thus, although labelling these ideas as myths may be novel, the ideas themselves, and their consequent fear, are by no means unique to the Portuguese-speaking immigrant population studied here in Toronto.

Myths are not confined to the community of Portuguese-speaking women – myths are widely circulated. An article describing health technologies states: "Pap smears are performed to detect cervical cancer, which kills over 150 women in the province each year." (Zeidenberg, 1996) Canada's national newspaper, describing Ontario’s database for cervical cytology, repeats: "Pap smears are performed to detect cervical cancer." (The Globe and Mail, 1999 Feb 25). The myth stipulating current sexual activity appeared in two national educational brochures for women. "All women over age 18 who are sexually active should have a Pap test." (Canadian Cancer Society, 1998'). Refugee newcomers to Canada are introduced to the same notion in a health kit folio, which states: "All sexually active women should have regular pap [sic] tests (examination for cancer of the uterus)." (Catholic Immigration Centre, ~1998-9). Such wide currency of myths may help explain underscreening in general, and in particular the relationship between increased age and decreased numbers of Pap tests (e.g., Lerman et al., 1990).

Well-informed readers may discern the fallacies underlying the myths, and dismiss the issues as semantic. On the other hand, busy practitioners or others may unwittingly convey or confirm these ideas. They may emphasize the test's diagnostic role, or even fail to offer Pap tests to older women or those believed to be sexually inactive. If well-informed and well-intentioned practitioners do seek to provide Pap tests as part of preventive care for older women, they must still deal with barriers posed by language, education and illiteracy. How can such barriers be overcome in the limited interactions of health care?

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1. This error was reported to have been corrected in a more recent version of the brochure.

2. This package refers to health care procedures, and handout #6 is called "Keeping Healthy". It includes details regarding exercise and fresh air, nutrition, feeling lonely or sad. Regular health examinations are recommended, for healthy adults every 2-5 years, children yearly, and newborns to age two more often - vaccinations are referred to. "Healthy adults should go for a doctors' examination every two to five years." (Catholic Immigration Centre, ~1998-9)
11.2.4.1.4  Perceived need and value

Adoption of Pap tests, in this model, depends on a woman and her caregiver sharing understandings about the need for preventive care and having compatible perceptions of the value of the Pap test as a means to achieve this. Perceived need echoes ideas from the health administration literature, where it was previously considered meaningful only for conditions with observable symptoms or signs, not for preventive care (Hulka & Wheat, 1985, Andersen & Newman, 1973). Including perceptions for doctors as well as for women echoes early models of health care utilization; in those models, symptoms are either synonymous with, or contribute to perceptions of need, by either the caregiver or the patient (Hulka & Wheat, 1985). Symptoms or their absence define the context and meaning of the test; they shape perceptions of need and value. In acute care, objective physical symptoms prompt use of health care systems; in contrast, for preventive care "felt need is a subjective reality." (Green & Kreuter, 1991:21). Perceived value is similar to "valuation", from Bandura's outcome efficacy in social learning theory (Bandura, 1977:130-3). There, valuation emerged after a behaviour had been tried, as one of the possible outcomes of action. Here, in conjunction with perceived need, it seems to trigger initial action.

Cultivating perceptions of need and value, in this model requires considerable time, contact and communication, to develop a relationship of trust. That trust is essential because the barriers are not just cognitive, they are emotional, and the chief emotion is fear.

11.2.4.1.5  Fear, and theories which explain its origin and consequences

Myths seem to cast a shadow of fear that is not otherwise dispelled by the light of language, literacy or education. The theory of social learning explained how the myths and stories might contribute to the origins of women's fear. Here, social learning theory and the health belief model provide mechanisms for fear's effects on health behaviour.

The report of being too frightened to have Pap tests echoes key elements of both social learning theory and of the Health Belief Model. In social learning theory, "high arousal usually debilitates performance" (Bandura, 1977:82), while in the Health Belief Model fear is postulated to serve as an agent that paralyses people from taking an action (Rosenstock, 1966:101). Using the HBM perspective, fear may have been elicited when phrases such as
"cervical cancer screening" were used. Women understood this test could and would detect cancer (susceptibility), and any such diagnosis might result in their suffering and dying from it (seriousness). Rosenstock (1966:100) warned that where factors contributing to readiness to act are great, and barriers to act are also great, then a person is in conflict, being highly motivated both to act and not to act.1 Rosenstock contended that this conflict could lead to vacillating without decision, or marked increase in fear or anxiety, where an individual was "rendered incapable of thinking objectively and behaving rationally", even if subsequently offered a more effective strategy (Rosenstock, 1966:101). In the situation where high levels of anxiety, associated with high levels of perceived susceptibility, and high barriers to taking action were perceived, the Health Belief Model would fail to predict behaviour (Rosenstock, 1966). If, instead, fear and its paralyzing effect, and the conflicting motivations were acknowledged as originally intended by the model (Rosenstock, 1966:101) then the choice to avoid a Pap test makes sense. Taking fear into account makes sense of the findings in this study. It also helps explain the apparent inconsistency in Lerman et al.'s study (1990), where perceived susceptibility was associated with increased numbers of Pap tests while other measures of susceptibility, including fear of finding cancer, were associated with less recent testing and with fewer total Pap tests.

The phrase "Cancer is Highly Feared" introduces the unique problems of communicating about cancer2 (Freimuth et al., 1989:34). Although fear is well-recognized, and has been the subject of research into perceptions of cancer and how it influences health behaviours, there does not appear to be any consensus on how best to operationalize the concept. To be fair, fear was reported as both a barrier and a facilitator of Pap tests. This study could not differentiate the levels of fear experienced by various women. Fear was operationalized as part of the Health Belief Model's perceived seriousness for adults in Northern Ireland (Murray & McMillan, 1993) and separately from the HBM dimensions for Dutch women (Gutteling et al., 1986). Gutteling et al.'s (1986) exploration of these matters, with Dutch women asked to participate in a cervical screening program, found a correlation between fear of cancer and measures of perceived susceptibility, perceived seriousness, anticipated

1. Rosenstock drew on evidence from a set of laboratory rat studies of conflict behaviour (Miller, 1944), which were, in turn, based on early work in the psychology of behaviour (Smith & Guthrie, 1921, Lewin 1931).

2. The book, subtitled The Cancer Information Service Model, refers especially but not exclusively to comprehensive health communication systems (Freimuth et al., 1989).
preventive behavioural intentions, education and knowledge. Fears were reported to prevent young girls and older women from responding to a letter to have their first Pap test, including fear of finding cancer as well as other unique fears (Fulghum & Klein, 1962:167). At its most benign, fear could be considered a negative attitude towards cancer. Even so, negative cancer attitudes were negative predictors of having had Pap tests (ever and recently) among Spanish- and Haitian-language populations (Mandelblatt et al., 1999, Schottenfeld & Kerner, 1984).

Fear seems a fertile topic for future research, but it poses methodological concerns including definition and measurement. First, anxiety and fear are related concepts which may overlap. Fear could refer to specific phobias, or to diffuse, "free-floating anxiety" (e.g. Barker 1985:191). There does not seem to be a single, standardized way to measure

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1. The fears were identified explicitly as: "the fear of finding cancer, the fear of sterilization, the boy friends' fears that the sex life of their girl friends would be interfered with, the fear of the girls that an examination of this type would reveal their past activities" (Fulghum & Klein, 1962:167)

2. In the Mandelblatt study (1999) negative cancer attitudes were associated with ever having had Pap tests, with an odds ratio of 0.38, with a 95% confidence interval of (0.20-0.72). Negative cancer attitudes were associated with odds ratios of 0.45, with a 95% C.I. of 0.28-0.71 for recently having had Pap tests (i.e., 2 years ago for women aged 40-49 years, & 1 year ago for women 50 years). Model goodness of fit was high (c=0.70 for ever, and c=0.69 for recently) in logistic regression models (adjusted for ethnicity and remaining variables).

3. In regression models adjusted for ethnicity and other variables (including access to care, age, education, health status and acculturation), negative cancer attitudes (i.e., greater anxiety, hopelessness and denial, subscales on the Cancer Attitude scale) (Schottenfeld & Kerner, 1984) were more common among Hispanic than among other women; among black women they were statistically significant predictors of Pap tests.

4. Anxiety is a short hand term "for a very complex pattern of behaviour ... [which] 'is characterised by subjective feeling of apprehension and tension accompanied by, or associated with, physiological activity'" (Paul, 1969:64). Anxiety may manifest itself affectively (e.g., apprehension, fear, dread, helplessness) and somatically (including disturbances in the musculo-skeletal, cardiovascular, respiratory, gastro-intestinal, genito-urinary, and / or central nervous systems (Barker, 1987:179, describing Zung's work). Zung's 1971 review was summarized as "Anxiety may be an affect, a symptom or a disorder" (Barker, 1985:179).

5. Although beyond the scope of this study, general anxiety may also be a problem for some Portuguese women. One expression heard regularly is that of having "too much nerves", or "too much nervous". This may mean high levels of anxiety, somatic manifestations of it, or something else entirely.
anxiety or fear: there are physiologic\(^1\) and questionnaire or interview measures.\(^2\) The measurement tools themselves might pose ethical problems for research with the Portuguese-speaking community. Options are explored more fully in the later section on recommendations for research.

11.2.4.1.6 Time, contact & communication to develop trust

Time, contact and communication help to establish a trusting relationship with a woman who needs it. These permit an underscreened woman to come to understand what is necessary, to help her recognize the need and value for preventive care.

Doctors indicated explicitly that trust was essential if women were to undergo Pap tests in the absence of symptoms. Portuguese-speaking women and community respondents agreed that doctors were considered ideal sources of recommending Pap tests because they were respected. Trust may not characterize all women-doctor relationships; community respondents cited problems in communication, including lack of time and lack of respect. Women indicated that they were not always sure if their doctor was telling them everything; the women thought that incomplete communications implied that a condition might be serious or lethal. Indeed, in the initial planning group, women cautioned that, in the absence of symptoms, it might seem suspicious for a doctor to suggest a test.

Trust may not be easy to measure, but one proxy might be the tenure of the relationship between doctor and patient. Certainly, care providers in our study noted the unique opportunities and challenges provided by the "new patient". They also posited that if women (patients) are not comfortable with the advice received, they may choose not to return. We did not investigate tenure per se in our investigations, but two U.S analyses

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1. Physiologic assessments, which might be considered gold standards, can include changes in blood pressure, heart rate, skin galvanic responses. Even there, measurement of the response to particular stimulus statements might be complicated by high (and possibly relevant) baseline measures.

2. Surveys where fear is explicitly addressed include: the 'Fear Survey Schedule' (50 items) (Akutagawa, 1956); the 'Self-rating Anxiety Scale' (a patient administered version) and the related 'Anxiety Status Inventory' (a medical staff-administered version, with 5 affective and 15 somatic symptoms) (Zung, 1971); the 'Fear Questionnaire' (23 items) (Marks & Mathews, 1979); and the Cancer Attitude scale (Schottenfeld & Kerner, 1984). This last scale, developed under the auspices of the National Institutes of Health, includes subscales to measure anxiety (six items), hopelessness (eight items) and denial (two items) (Schottenfeld & Kerner, 1984).
have investigated this and preventive care behaviours (Ettner, 1996, Weiss & Blustein, 1996). Women in the U.S. National Health Interview Surveys of 1988 and 1990, who reported having a usual source of medical care had Pap smears done more recently than those who did not' (Ettner, 1996:1749). An Australian questionnaire on a consecutive sample of general practitioners' patients found that continuity of attendance (i.e., length of time attending that practice) was associated with the reporting certain preventive care procedures (i.e., blood pressure check, cholesterol measurement, discussion of diet and exercise, and instruction in breast self-examination) (Steven et al., 1998). In contrast, the relationships between continuity of care and both tetanus immunization and a cervical smear in the past 2 years were not as clear; those who had attended the practice for 2-5 years were more likely to report having had the Pap smear (70-71%) than were those who had attended the practice for 1 year or less (67%) or for 6 or more years (61%). (Steven et al., 1998) Among enrollees aged 65 or more in the US Medicare program surveyed in 1991, longer duration of tie to a usual source of health care was associated with a greater likelihood of having had an influenza vaccine in the previous visit, decreased likelihood of hospital admissions, lower reimbursements for medical costs, and fewer office visits (Weiss & Blustein, 1996).² This kind of research seems promising, and might best be explored using existing administrative databases.

Trust may also be important when a test involves an intimate procedure. As reported of the Portuguese community, "Any infection or illness that is sexually related or is located in the genital area is considered embarrassing." (Kendall, 1992:6) It is notable that in this study women rarely referred to embarrassment directly; its importance was indicated obliquely by their citing shyness, or reluctance to have the examination, or appreciation of or preference for a "lady doctor", i.e., a female provider. Indeed, physical aspects of the examination, including physical or emotional discomfort, were not explicitly described by the women.³ Respondent-researcher differences in age or language may have contributed to this, but it

1. The econometric technique called instrumental variables, with length of residence as the "instrument", was used to investigate whether having "a particular clinic, health center, doctor's office or other place" was associated with various health behaviours (Ettner, 1996:1749).

2. Statistical tests (chi-square and ANOVA) examined only overall associations between duration of tie and the health behaviours. Mammograms did not show any association; Pap tests were not included in this study. (Weiss & Bluestein, 1996)

3. The absence of such comments is in marked contrast to their prominence when English-speaking Canadian women have talked with me about Pap tests.
may also be a cultural matter: "The whole area of illness is considered a personal matter and something preferably kept quiet; cancer in particular is a taboo subject." (Kendall, 1992:6). The Portuguese-speaking community is not the only one which features fear and/or shame (e.g., Lazcano-Ponce et al., 1998). Certainly, for many women at the health events, the notions of open communication about body parts with sexual connotations and reproductive or sexual language were new. Notwithstanding the unfamiliarity of the topic, the combined openness and levity of the discussion was received with appreciation and delight. A receptionist emphasized that instructions about gynecologic concerns had to be explicit and delivered with humour, otherwise they would be useless or offensive.

Trust could also be important in women's relationships with their partners. In this study, reports of partners who were emotionally communicative or supportive were rare, and for women experiencing stress and problems, spouses might even be contributing to distress. Rarely, husbands were reported to drive their wives to medical appointments. Although having a partner encourage or even accompany a woman to screening seems sensible (e.g., Lazcano-Ponce et al., 1998. Miller, 1992:25), this approach was not identified by respondents in this study as feasible.

Trust did seem relevant in other relationships, with receptionists, social service agency providers, family members, friends, and even the university researcher and her assistants. Receptionists pointed out the importance of establishing relationships, including by persistently following-up women for their appointments for preventive care, and calling them with their test results. Portuguese women's group leaders acknowledged that it took considerable time of attending before women might choose to make changes in their lives, e.g., taking English classes. Contact in these groups seemed to involve both social interaction, being in the same place, in a group, and also being in fairly close physical proximity. Various community respondents identified women who were isolated as being likely to have family problems and unlikely to undergo cervical cancer screening.

Communication was a recurring theme, meaning more than simply "the act of imparting"; it seemed to include the notions of sharing a feeling or understanding, or relating socially (Fowler & Fowler, 1995:268). Women were reported (and observed) to enjoy interaction, whether with displays or the presenter, or simply being in company with each other. The underscreened women participating in the trial conveyed their pleasure that a university
researcher was "within arm's reach". Given that one objective of this study was to identify and reach underscreened women, this emphasis on physical proximity is noteworthy.

The women in the initial planning group had distinct ideas about conveying certain information. They said it was not good to put "cancer prevention" on the flyers because it would be too frightening. They also said it was fine to talk about such things at the health events or in my home, because "that's different". What was different was the context: they were comfortable because they had come, with their friends, ready to listen, learn and ask questions. While this study could not fully explore mechanisms of communication, the emphasis overall was clearly on how relationships and context made it possible to share otherwise difficult information and ideas.

In this model, a trusting relationship helps an otherwise difficult and perhaps frightening behaviour to occur. Adoption of a new behaviour means relinquishing an old one; achieving the necessary trust may be particularly difficult in a situation of immigration and resettlement, where language and culture differ.

11.2.4.1.7 Stress and problems, immigration and class

"Stress e problemas" (stress and problems) is an evocative phrase used by Portuguese women and contacts to describe the burdens associated with chronic family and health and perhaps other, unstated problems. It is not known whether chronic health conditions reported in the Portuguese community are any higher than in the population as a whole, because provincial studies do not differentiate them as a group. Nevertheless, it is recognized that "[t]he Portuguese family experiences stress from different sources immigration, social adaptation, familial/marital stress, work pressures, etc. However, there are limited health and social service resources that are culturally and linguistically accessible." (Kendall, 1992:10) One area where this is believed to be a problem is
domestic violence, for which women feel responsible: "Many Portuguese women will not seek outside help until their situation becomes very serious." (Kendall, 1992:10).\(^1\)

Migration and resettlement involves, by definition, an uprooting or displacement from one’s origins, and may include an introduction to a new social system, including a different health care system (Remennick, 1997). Baker (1993:265-8) describes physical, social and cultural changes inherent in resettlement. Physical disruption for Portuguese women included the climate, which the women involved in the initial study considered a barrier to their participation in the project. Social disruption, or changes in the social networks and status from those enjoyed in the originating country, could be negative.\(^2\) Finally, cultural disruption involves values, beliefs and social expectations, as well as language, a stressor in itself (Aroian, 1990). Masi et al. (1993c) affirm how migration may contribute to stress:

"Migration for any reason and within any context is a source of major stress for anyone. The potential loss of friends, familiar surroundings, and the changes of employment are always significant stresses for any individual or family who must undergo relocation. These stresses are magnified considerably if the linguistic or cultural milieu [in] the new environment is also unfamiliar." (Masi et al., 1993c:251)

In the Portuguese community limited education and lack of English language fluency impose serious and well-recognized restrictions on social and economic opportunities (Kendall, 1992:2-3).\(^3\) Most Portuguese-speaking residents in Toronto from Portugal and the Azores have low education: the 1986 Census reported that 72% of them had a Grade 10 education or less.\(^4\) And "47% of the Portuguese living in Metropolitan Toronto spoke no English or had only a "poor" command of the language (Access Alliance, 1989, cited by Kendall, 1992:2).

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1. As awareness about spousal and elder abuse within the Portuguese (and other minority) communities increases, social service agencies are seeking to establish services that are accessible and culturally appropriate. For the Portuguese community, Abrigo provides services for perpetrators of domestic violence (Community Partnerships Group, 1998:8-12) and staff of St. Christopher House contribute to efforts to "develop an elder abuse intervention and action plan" and to increase awareness and education, including developing guidelines of best practices for social work professionals (Kharas-Daver & Koster, ~1998:2).

2. According to Aroian (1990) these social disruptions could lead to unemployment and subordination.

3. Household income as an indicator of socioeconomic status may be relatively high for Portuguese families; this is postulated to be due to their working long hours, or moonlighting (Pepeler & Lessa, 1988). Another explanation is that a single household may include many income earners.

4. With recent immigration of better-educated immigrants from Brazil and other Portuguese-speaking countries, the percent is expected to decrease, but individuals here in 1986 are not expected to have increased their education in the interim.
Some immigrant communities maintain or develop ethnic group cohesions, and these have both positive and negative aspects. Baker (1993:269) describes Herberg's (1989) work this way:

"the forces of ethnic group cohesions that maintain an ethnocultural community ... are: language retention, residential proximity, maintenance of ethnic religious institutions, marriage within the ethnocultural community, creation of an ethnic media and organizational elaboration" (Baker, 1993:269)

These ethnic group cohesions may also serve to isolate individuals from the mainstream community, if there are marked differences between the originating and the host countries (e.g., Herberg, 1989). Portuguese women (not just the ones in this study) report that maintaining Portuguese traditions remains a priority in Canada. Using Baker's (1993, cited above) description of the forces that maintain an ethnocultural community: the underscreened women in this study spoke Portuguese at home; the community resides in a geographically defined, central location; churches, newspaper, television and social agencies provide Portuguese language services and information. As reported by the Portuguese women in this study, Pap tests and other preventive care services were not routinely provided in their originating countries. Immigrant women who maintain their social ties with other Portuguese women, and do not learn English, may also maintain understandings and expectations about health care services that they learned where they were born and grew up. Disman's (1997) compelling image of this shows immigrants maintaining two “homes”, i.e., their country of origin and their adopted country.

Riessman (1994) contrasts two views about how social class is related to the use of health care services: the "culture of poverty" and the "structural" view. Reissman (1994) reviews literature with a culture of poverty perspective (e.g., Lewis, 1965, Rosenblatt & Suchman, 1964, Rosenstock, 1975, Kegeles et al., 1965), that includes notions of: predisposition of crisis-orientation, lack of future orientation, negative attitudes toward medical care (e.g., efficacy) helplessness, and resignation in coping. In contrast, the structural view (e.g., Duff & Hollingshead, 1968, Strauss, undated) cites material and organizational constraints (including transportation) that prevent low income patients from accessing services. This perspective considers the "culture of medicine" (Levine et al., 1969) responsible for the pattern of health care utilization which emphasizes emergency and chronic care, and may involve somatization and prescriptions for it (Kendall, 1992). This view contends that "the poor have had multiple negative experiences with organizational systems, leading to
avoidance behavior, lack of trust, and hence a disinclination to seek care and follow medical regimens except in dire need." (Riessman, 1994:426) The Two Streams Model developed in this study does not fit neatly into either perspective. Instead, it considers how both of these perspectives might individually and in combination limit the use of preventive care services.¹

The relationship between social class and health care services is controversial. Riessman (1994) contrasts two important findings about social class and the use of health care services: people of lower social class have higher rates of use of health care services (National Center for Health Statistics, 1982), but when analysis takes into consideration level of illness, low income groups have the lowest rates of use of health care services (Kleinman et al., 1982, LaPlante, 1982). Certainly, underutilization of (the U.S.) Cancer Information Service by the less educated, and by ethnic groups other than Asians and whites is well-recognized (Freimuth et al., 1989:200). Within Ontario, less education, speaking a language other than English or French, and having recently immigrated were associated with not having a recent Pap test (Goel, 1994). In the Two Streams model, these factors and others serve to reinforce the isolation of women and make it difficult for them to learn about the need and value of Pap tests. As reviewed in the literature: "Individuals characterized by lower income, lower educational levels, and less exposure to information in general - this corresponds to the profile of women who are inadequately screened for cervical cancer" (Freimuth, -1997b). Scott's provocative label for this is "foot dragging" and "false compliance", two of "the ordinary weapons of relatively powerless groups" (Scott, 1985:29). Freeman (1989) provides a less inflammatory but nonetheless disturbing summary of the situation and its consequences:

"'poverty acts through the prism of race (culture) to decrease survival,' citing inadequate physical and social environment; inadequate information and knowledge; risk-promoting lifestyle, attitude and behaviour; and diminished access to health as factors working against early diagnosis, the single most important factor in cancer cure." (Markland & Turnbull, 1993, citing Freeman, 1989)

In slightly less provocative terms, the diffusion of innovation classifies these women as the "late majority" or "laggards" (Rogers, 1983).

¹. This model avoids invoking blame, sometimes inferred by the use of the terms culture of poverty or the culture of medicine. Instead, misunderstandings in this model may be shared.
11.2.4.1.8 Diffusion of innovation

Aspects of this study can be related to work on the diffusion of innovation. From what the trial participants and other Portuguese-speaking women told us, they are interested and open to learning about ideas from the media and from people they know; however, not a single trial participant described having decided to come because of the posters describing the event. In terms of the diffusion of innovation, this suggests the mixed influence diffusion model is functioning (Valente et al., 1994, Valente, 1995). Both external influences (e.g., media) and internal forces (e.g., interpersonal communication) would influence women's choices. Even if they were aware of the event from the posters, it was being invited by a relative or someone they knew from a women's group that made them decide to come.

As a group, the underscreened women and most of the women attending the health events were readily described by those who knew them in terms that correspond to the "late adopters" identified in the diffusion of innovation. Thompson (1993:213) refers to Green and McAlister (1984) who define "late adopters" as those who are usually socioeconomically disadvantaged; "they are socially more isolated or alienated, and tend to be suspicious of organizations, including government agencies..... Reaching these people and organizations requires... more labour-intensive forms of community organization, communication and outreach." Mamon et al. (1991) describe those who are late in adopting innovation: "Typically, they are resistant to change and, as such, tend to require more intensive, direct and individualized educational strategies. Furthermore, they tend to place greatest credibility in the subjective experiences of their peers in their decision to adopt a new practice or behavior." (Mamon et al., 1991:30)

Underscreened women who came to the health events provided evidence of the changeability of the screening behaviour. In the diffusion of innovation model, having underscreened women in the same room with a majority of women who routinely have Pap testing, as we did at the health events (Valente, 1995, Valente & Saba, 1997) was a potential influence because screening adequacy was used to divide the women into two groups. The underscreened women could have recognized that they were in the minority, that they were missing out on something that other Portuguese-speaking women had
adopted. If so, Green & Kreuter's quip about diffusion theory applies, i.e., "observability influences changeability" (Green & Kreuter, 1991:172-3).¹

Theories about behaviour change that stipulate stage by stage progression received both supporting and contradictory findings in this study. Within the trial, distinct temporal stages defining the transition from underscreened to screened might be surmised. That is, some women came to a health event but chose not to learn about or participate in the trial or to have Pap tests. In contrast, some women reported having gone from not knowing about the Pap test to adopting it, simply when their doctor told them it was time to do it. To be fair, this model would suggest the pre-existence of trust in the relationship between the woman and her doctor. Nevertheless, the transition was reported more as a sudden "leap" than a set of temporally distinct stages in the adoption of Pap testing. This does not seem to correspond with either the diffusion of innovation model, in which the stages are awareness, interest, trial, decision and adoption (Rogers, 1983) nor to the stages of change model (Prochaska & DiClemente, 1986). The other contradiction was with respect to social learning theory, which includes both acquisition and adoption of innovative behaviours. "With regard to acquisition, modeling serves as the major vehicle for transmitting new styles of behavior." (Bandura, 1977:50) Although screened women may well have served to establish certain norms before and during the health event, modelling does not seem to be the only key. Indeed, although multiple sources of information about health were acknowledged, most informants in the study recognized doctors as primary or certainly very credible sources of health information. There was some debate about how certain women might respond to invitations from their doctors, and indications that a supportive and consistent receptionist could enhance that role; however, there was no disagreement about the importance or the appropriateness of the physician as the source of recommendations about how a woman should stay healthy at a particular time of her life.

Decline is an important feature of this model, because our contacts insisted that no matter how good an invitation is, or how professional the care provider is, some women will say no. Deliberate refusers present an alternate perspective on adoption than that suggested by the diffusion of innovation. As the Health Event Representatives told us, with the same

¹ This recognition of screening status differences could be a part of the interpersonal contact and communication important in the mixed influence diffusion model. Here there is overlap with the modelling concepts from the social learning theory.
exasperation that health scientists, educators or promoters must share: "The ones who need it most don't want to come". The expression frequently used to convey the notion that people make their own choices about behaviour was: "Everybody's different."

11.2.4.2 Outstanding issues

This model does not include the full set of feedback loops and patterns of repeated behaviour, including some predicted by social learning theory. If Pap testing is undertaken, this will involve additional time, contact and communication, and lead to increased self-efficacy and perceived value for the Pap test. The model does not emphasize the situation of discordant perceptions of Pap tests, or how they might be particularly problematic to resolve. This scenario, though troublesome, nonetheless raises possibilities for intervention research (next section). Social learning theory elaborates a set of factors (as discussed earlier, called consequent determinants) that influence behaviour after it is initially tried. (Bandura. 1977:96) "Adoptive behavior is highly susceptible to reinforcement influences." (Bandura, 1977:51) This corresponds to the emphasis that practitioners placed on persistence in recommending women have the Pap test, making appointments for them, and following up on them.

Although this model indicates that myths and stress and problems contribute to fear, some ambiguity remains about the existence, prevalence, characteristics, identity, correlates or function of each of these, and how they might best be counteracted. Ambiguity about the myths, whether among community respondents or among researchers, could reflect any of three things: myths are not consciously recognized as discrete pieces of knowledge or understanding; they are not assessed as incorrect or incomplete; or they are not recognized to function as barriers to Pap testing. The model does not discriminate the relative contribution of the sources of the fear, whether it is due to the myths, or to stress and problems, or even whether it is a characteristic associated with other demographic factors such as education and isolation. This model does not stipulate the identity, origin, or nature of the interaction, or the time necessary to establish contact and communication necessary to establish a trusting relationship. Yet, even with all these outstanding issues, certain recommendations for research or action can be made.

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1. For example, the social learning theory steps from initial acquisition to permanent adoption are not explicitly addressed in this model.
11.3 Recommendations for research and practice

Recommendations for major policy or program changes on the basis of this study are not warranted, but certain strategies for research, policies, programs and practices are recommended. The term recommendation is chosen because these are suggestions for a particular course of action, fit for a particular purpose or use (Thompson, 1995:1148). Recommendations were devised on the basis of this entire work, not just the quantitative analyses. The context intended is the real world, here and now, where resources and time are limited. In my opinion, these recommendations, though limited in number and conservative, are relevant and suitable, whether viewed from scientific, pragmatic, or ethical perspectives.

The constraints of this feasibility study are serious: results are theoretical or based on such small numbers that statistical analysis is precluded. Conventional approaches to further investigate the phenomena are critically considered and found wanting. They are presented first, and largely constitute what is “not recommended”. Then, three recommendations for research in public health are made: assessing educational materials regarding their content: evaluating traditional didactic approaches to health education using cytology lab data; and developing narrative health promotion approaches for professionals and the Portuguese-speaking community, beginning with interactive theatre. Any of these research endeavours would best be coordinated by an academic researcher, in a collaborative way with public health practitioners, health care and community agency providers.

This section begins by critically considering research options that might be expected following a feasibility study. Each objective is considered briefly, then the conceptual model is considered at length. Problems apparent in these approaches are identified; these provide a basis for contrast with practical opportunities for improving screening and its evaluation.
11.3.1 Research expected following feasibility study

11.3.1.1 Attempt collaborative research with another immigrant population

Having completed the feasibility study and found that community partners involved in the development of a research project provided valuable guidance, one might suggest this same approach be used with another (perhaps immigrant) population anticipated to have high rates of cervical cancer and low rates of screening to prevent it. There are compelling scientific reasons to do this, first and foremost being that additional or different factors may be important in influencing other underscreened populations’ choices about health behaviours. Valuable though it may be in advancing research, it takes a lot of time and effort to implement and engage a particular community in this kind of research. It is probably more realistic to view community collaboration as a strategy to raise awareness about health promotion and disease prevention.

11.3.1.2 Continue health events to identify and reach underscreened women

Since some underscreened women attended health events and were willing to complete health event questionnaires, is this strategy recommended on its own to identify and reach underscreened Portuguese-speaking women? No. Low attendance overall meant that few eligible women attended the health events, and underscreened women “in black” did not attend the events at all. Screening initiatives should not rely on this approach to identify and reach large numbers of Portuguese-speaking women.

The sensible alternate to health events alone would be physicians’ offices. Underscreened women attended doctors’ offices, and were identifiable, to a certain extent, by their physicians. Some physicians and receptionists indicated an interest in further research. The key would be to ensure a comparable context to that provided by the interactive women’s health events. The model suggests that the forum necessary would provide adequate time for contact and communication about preventive care.
Fortunately, current billing structures for physicians provide an option that may be suitable, that is, a counselling session about preventive care (Ontario Schedule of Benefits code K013, K033¹). At the end of the counseling session, a physician's enquiries might well have elicited a number of specific barriers and facilitators to preventive care in general, and/or cervical cancer screening in particular, and a woman could then be invited to have Pap tests. This strategy may be relatively easy to implement, but formal testing might require randomizing by office, rather than by individual women. Randomizing also raises the question of what control, other than current practice, would be appropriate.

Even so, health events, offered as a complement to physicians’ office efforts, may promote community awareness of women’s health issues, strengthen relations among medical and social service providers, and enhance project credibility.

11.3.1.3 Continue the randomized trial until adequate sample size is achieved

Having piloted the randomized trial and attained a high response rate among eligible women, should the same approach be continued? No. The high response rate may have been due to the co-intervention of setting the trial in a health event. The challenge would be duplicating the comfort of the group setting afforded by the women’s health event.

11.3.1.3.1 Immediate versus later appointments

A larger trial comparing immediate versus later appointments no longer seems necessary, because both options seemed acceptable. Based on this study, I recommend that women due for a Pap test be offered an immediate appointment, especially if the woman already has a good relationship with staff. If that is unsuitable, or if the woman is a new patient, an appointment may be booked for a later date, and followed up to be sure the woman attends.

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¹ It is not clear whether the billing code would accommodate a woman bringing a friend or relative along to the session (as a substitute for the group experience).
11.3.1.3.2 Portuguese versus Portuguese and English invitation brochures

A trial comparing a Portuguese brochure to Portuguese and English ones simply does not seem important enough to pursue in this setting. Women used written materials to navigate on public transit, and to broach the topic of Pap tests with their health care providers. My recommendation is that bilingual brochures should be provided as a matter of course: the risks and costs are low and the potential benefits are high. Testing unilingual versus bilingual brochures is a simple, straightforward design that could be used in other settings or populations. It would lend itself to a combined quantitative and qualitative investigations, e.g., written materials might prompt various types of interactions, so mechanisms of communication following health education or health promotion efforts could be examined.

11.3.1.4 Build on findings that isolated women did not regularly attend health events or women's groups

If a randomized trial is to be done, a useful design would investigate the utility of a support person to help ensure that underscreened women receive and attend appointments for preventive care. We know that "knowledge alone is generally insufficient to change health behaviours." (Thompson, 1993:212) "Treatments combining modeling with guided participation have proved most effective in eliminating dysfunctional fears and inhibitions" (Bandura, 1977b). A support person could help mediate and foster relationships with care providers. The appropriate methods and design, including sample selection, follow-up strategies, choice of control intervention, and selection of relevant outcomes, would need to be developed. This design could be based in an existing women's group, with referrals of isolated and underscreened women from physicians.

11.3.1.5 Test the conceptual model

Having produced a set of proposed relationships in the theoretical model, the expected next steps would be to test the model. This involves taking the abstract or theoretical ideas, and operationalizing them to determine whether the concepts are valid and the postulated relationships exist. This could be done initially with Portuguese and then with other populations. The first task would be to develop standardized tools with which to validly and reliably measure the concepts of interest. Standardized tools for non-English-speaking
communities require not simply linguistic but cultural equivalence. Other challenging issues include determining the prevalence and roles of myths and fear, and what is meant by the establishment and function of a trusting relationship. Scientifically and practically speaking, how does one measure the prevalence of a partial versus a complete truth? Ethically speaking, should one attempt to measure the prevalence of a myth or fear, particularly within a population with limited education? Let us deal with each of these matters in turn.

The technical aspects of validly and reliably estimating the prevalence and role of particular myths are perverse. Providing a set of statements (i.e., the myths identified in this study), and asking whether each is true or false would provide a convenient quantitative measure.\(^1\) The problem is that partial truths are not completely false; even well-informed respondents could label myths as true as far as they go. The confusion might be particularly troublesome for a non-literate population.\(^2\) One might anticipate a high prevalence of myths, but the next and more important question would be whether “belief” in any of the myths predicts Pap test screening behaviour.

Besides these technical issues, there are ethical implications of trying to determine whether myths influence women’s choices directly, or indirectly, through fear. As presented earlier in the discussion of barriers and facilitators, there are many ways to measure fear, or anxiety. Notwithstanding the measurement challenge, if fear is important, and the model is correct, underscreened women are likely to be at the extreme end of the clustered spectra of isolation, lack of knowledge and fear. Therefore, identifying a myth or fear in a direct research encounter may not be appropriate, because it could exacerbate anxieties; in an uneducated or illiterate woman’s mind it may affirm, incorrectly, that her understandings and fears are valid. In our study, we were able to raise questions about Pap tests in group

---

1. The most straightforward approach would weight each of the myths equally and standardize the result: Myth recognition index = number\(_{\text{true}}\) / (number\(_{\text{true}}\) + number\(_{\text{false}}\)) \(\times 100\%\). Depending on the intentions, this could yield a generic “cancer myth index”, a myth-specific measure, or a disease-specific index, e.g., “cervical cancer myth recognition index”.

2. To determine the extent of misunderstanding, it would be necessary to distinguish, among all those who acknowledge each myth to be true, who considers it a full truth, and who recognizes it as incomplete or misleading. So, for each topic, one might provide a set of statements and ask: “Which of the following is most true?” This approach may have face validity, but is far from ideal. Experienced questionnaire respondents would probably anticipate more complex statements as correct. At the same time, longer and more complex statements might prove troublesome for those with literacy limitations.
sessions with women they knew. Any opportunity to counter women's concerns should take place in a context that is comfortable and reassuring.

The impetus to seek formal proof may also be low where program ideas are consistent with the sensibilities of researchers and care providers, where the interventions appear to pose little risk, and where they are compatible with existing agency and practitioner services or policies. Certainly, the notion of fear is acknowledged in cancer education, where messages are "designed to alleviate this fear" (Murray & McMillan, 1993:1). "Whatever form the message takes, it should be carefully worded to enable the recipient to understand the importance and benefit of being screened..." (Miller 1992:32-3) "Motivation is required for perception and action" is considered a truism (Mettlin & Cumming 1982:144, Rosenstock, 1966:98), and this study suggests that education efforts in the Portuguese-speaking efforts should not try to motivate by heightening perceptions of susceptibility (recall the Health Belief Model), because they are high enough already to yield paralysing fear. Two quotes summarize the issues clearly: "Threat is the key. The greater the threat perceived or actual the greater the anxiety." (Barker, 1985:164) And "Fear reactions generate further fear." (Bandura, 1977:82) This study proposes that it is reasonable to assume that underscreened women may be frightened, to some extent, by the notion of cervical cancer screening. The recommendation here is that the Pap test be intentionally, widely and persistently recommended as part of a comprehensive program of preventive care, and ideally within the context of an established, trusting relationship. Health education should seek to convey messages to reduce fear, and that increase women's sense of self-efficacy, ideally providing them in settings and social situations they find comfortable. Mettlin & Cummings (1982:140) point out: "People continue to note that they would be more likely to try to change their behaviors if their physicians strongly recommended such changes." It is unlikely that every woman will agree to undergo or adopt Pap testing, but this should not exempt providers from recommending them.
11.3.2 Some suggestions for research and development

The previous sections grappled with the sorts of research that would generally be expected to emerge from a study like this, and recognized that for various reasons they are largely inappropriate. This section shifts to consider other suggestions for research and practice that emerge from this work. The first set of approaches would provide findings from this thesis as didactic health education materials to health care providers. The second approach shifts to using narrative and dramatic materials. These would complement the didactic materials to develop appropriate and detailed content for a comprehensive social marketing campaign. Without formally presenting specific rationales for each, these recommendations implicitly recognize the limitations and inclinations of the relevant populations and communities. The ideas are innovative, and optimistic but realistic in terms of what was reported by study participants.

11.3.2.1 Didactic health education materials for physicians' offices

Selected results could be provided as health education materials to physicians' offices, including receptionists. Three options for didactic health education materials are: pragmatic recommendations, the Two Streams Model, and the set of myths and their fuller complements. Any of these could help a physician and/or receptionist identify and address the factors that influence an underscreened woman's choice about Pap tests. It might be possible to investigate whether providers' interactions with their patients were affected; ideally this could be examined with quantitative data from cytology laboratories. These initiatives would be useful research in themselves, and could serve as valuable prefaces to ensure a social marketing campaign was sound in its development.

Cytology laboratory data might permit a longitudinal study to investigate the effect of educating providers using didactic materials. An effective educational intervention directed to health care providers could prompt any of the following: an increase in Pap tests; an increase in Pap tests among women who have not previously or recently received them; a

1. Participating community agencies and physicians' offices could receive an abstract or executive summary in both English and Portuguese, with contact information to get more details about the study. The Portuguese Interagency Network could receive an extract with key tables, figures, and text. Options could be reviewed with community partners, bearing in mind that certain concepts (e.g., relative risk) are difficult to convey (Freimuth et al., 1989:36-7).
shift upwards in the age distribution of women undergoing Pap tests; or even an increase in the prevalence of cytologic abnormalities (suggesting a greater proportion of unscreened women).

In this case, a factorial design could investigate the relative value of emphasizing: a) the practical findings; b) myths and their counterparts; or c) the theoretical ones (i.e., using the Two Streams Model). Sample size for the eight cells of providers in this two-by-two-by-two factorial design poses a problem. Other variations might be appropriate, and should best be devised in collaboration with health care providers and their receptionists. To simplify the study design and reduce the number of cells, one might choose to combine two of the approaches and use a two by two factorial design. Even so, to ensure adequate sample size, the study could be extended beyond providers known to care for Portuguese-speaking women; this would test whether the findings were generalizable.

11.3.2.1.1 Pragmatic hints for doctors and their receptionists, and for social service and public health practitioners

Pragmatic ideas about encouraging preventive care for underscreened women may be useful for health care providers and their receptionists, and for public health and social service agencies that work with them. Hints for practice are straightforward and require little additional materials or training. Some of the most obvious from this study are:

a) scheduled appointments for preventive counseling are covered by Ontario's Schedule of Benefits (Ministry of Health SOB Preamble, 1998:5);
b) Portuguese-speaking women expect their doctors to make recommendations about preventive care;
c) some Portuguese-speaking women understand English if it is spoken slowly;
d) receptionists who speak Portuguese and understand a practice's orientation to preventive care can play practical roles in overcoming barriers to screening;
e) timing recommendations for women to have Pap tests could focus on new patients (whether new immigrants or transfers from other doctors, who may be disposed to consider

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1. It might make sense to provide everyone a set of the most traditional educational material, perhaps the practical hints. This could serve as the placebo control; study participants could be randomized to receive the myths and/or the conceptual model using the two-by-two factorial design.
preventive care options), and on peri-menopausal women (who may believe that their symptoms indicate serious underlying health problems, see also myths);

f) offering to refer a woman to a female doctor or obstetrician/gynecologist may address some women's concerns;

g) recommending or even prescribing attendance at a woman's group may emphasize social support as a contributor to health.

11.3.2.1.2 Myths and their complements

Myths and their complements (Table 27) could be used to inform health care providers about particular notions presumed to prevent Pap tests: screening detects cancer; cervical cancer screening is for young, sexually active women; and (cervical) cancer detection is equated with death. The parallel set of fuller truths would address and correct the misunderstandings within the myths.

11.3.2.1.3 The Two Streams Model

The Two Streams Model option is the most abstract of the three didactic approaches to health education. Although it might be feasible to send out a brochure to health care practices with Figure 5 (page 245), it is not yet clear what supporting text would be most useful. Because it is conceptual, the Two Streams model may better suit narrative and dramatic interactions, presented later in more detail. Alternately, it could accompany the other material described above.

11.3.2.2 Narrative and dramatic approaches to health promotion: a preface to social marketing

The most complex, and the most compelling, research would involve developing and testing standardized narrative material based on this study's findings and model; interactive theatre represents a first step in this process. Forum theatre (Boal, 1992), an interactive theatre technique, is commended because it is likely to be appealing and accessible to these women. It could also provide an interesting contribution to physician training and education. Forum theatre begins with a trained facilitator helping community members develop and present "scenes" to demonstrate selected, predefined conflict. These would
be based on the set of myths, or incomplete truths, which are expected to serve as barriers to Pap tests, and their complements, the fuller truths which may represent facilitators of Pap tests. The first presentation by community members is followed by an opportunity for the "audience" to replace any of the "actors", attempting to bring the scene to a different and more acceptable resolution. At every stage, the facilitator challenges the audience to indicate whether the actions portrayed are "true" or not. As theatre, it may be acceptable to underscreened women, e.g., those who declined to attend the health event. Using drama in this way to explore and elaborate aspects of the model and the myths identified in this study provides a non-threatening introduction to ideas that could otherwise be unwelcome.

Forum theatre could be developed and implemented with existing Portuguese-speaking community groups. Forum theatre might be delivered in settings that had resisted overtures (e.g., churches), or in settings less suited to a traditional didactic presentation (e.g., malls, festivals), among others (e.g., language classes, private homes, schools). Participation does not require literacy or English language skills, as long as facilitators and staff are available and adequately trained to translate into whatever language a particular population speaks. Ultimately, with skilled assistance, it may be possible to devise scenes for forum theatre that are mimed, making this research / intervention even more transportable across populations who speak different languages.

Forum theatre may be useful to return research findings, to assess whether they seem valid to a particular audience, or as an intervention for underscreened women and their care providers. It could enhance women's and health care providers' understandings of the health care interactions. Having health care providers and audience members "act" out solutions and consider which ones seem reasonable and which they might attempt evokes recollection of other relevant theories.

Forum theatre techniques resonate with ideas from social learning theory, particularly notions of modelling as a means to develop skills necessary for self-efficacy (Bandura, 1977:81-2). On a practical note, forum theatre could prompt awareness and consideration

1. St. Christopher House staff and Portuguese seniors have used forum theatre to address Elder Abuse and Senior-Youth conflict.

2. I recognized that this kind of initiative is unusual and would not necessarily be easy to carry out, due to the logistics and to the sensitivities of women and their health care providers.
of women's groups among those who have never attended them. Forum theatre could also provide an intermediate step to developing the characters, scenes, and dramatic conflicts necessary for any long-term plans for a more formal narrative intervention (e.g., soap opera) about Pap tests. In the medium term, however, it could serve as another approach to physician education, e.g., in educational workshops, seminars or conference settings. Strategies to document and evaluate forum theatre need to be developed; these would investigate whether the model is generalizable, and whether various groups report comparable or different barriers and facilitators to Pap tests.

Once the material was refined and found to be meaningful in the small group sessions, it could contribute to the development of a mass media or social marketing campaign. My sense is that a mass media campaign, styled like a soap opera, and aired during or after the popular South American soap operas, warrants investigation to reach illiterate, non-English speaking women who are underscreened. Such a campaign would require an ancillary or prefacing campaign with health care and social service providers, possibly using CDs with the planned promotional materials. The CDs could include the planned "soap opera commercials" and accompanying didactic educational material.

11.3.2.3 Options for public health

11.3.2.3.1 Survey about Cervical Screening

A survey of public health units, done on behalf of the Recruitment and Recall Group of the Ontario Cervical Screening Collaborative Group (OCSCG, Jun 1999) was done to identify gaps and barriers to recruitment and recall. The recommendations are compatible with this dissertation. The recommendations from the survey (including responses from 35 of 37 health units) were:

1. Develop a clearinghouse for cervical screening educational and promotional materials.
2. Develop pamphlets, videos and a standard presentation on cervical screening for specific target populations. [To produce culturally sensitive, resources written in plain, non-threatening language for hard-to-reach populations.]
3. Develop and implement a province-wide, multi-media social marketing campaign. [This would involve partnering with the College of Family Physicians, the Society of
Obstetricians and Gynaecologists and the Association of Local Public Health Agencies.

4. Develop and implement a province-wide cervical screening registry.
5. Increase accessibility to cervical screening services. (OCSP, Jun 1999:iv,v)

These recommendations are laudable and all logical; they are likely to be most valuable if they are undertaken within the context of a comprehensive and systematic effort to develop materials that are truly useful for underscreened women and their health and social service providers. The most useful approach will bring to bear the perspectives of those who know the situation of underscreened women. My research work affords three complementary distillations of these perspectives: the practical hints, the Two Streams Model and the myths and their complements.

Thus, the clearinghouse of resources recommended by the survey (carried out by the Ontario Cervical Screening Collaborative Group, 1999) could serve as the basis for research to investigate content of existing material. Standard content development could be based on the conceptual model as well as the didactic and narrative approaches investigated. The materials could promote women's health directly, or could contribute to it through education of health care providers and their receptionists.

One approach would consider whether the theoretical notions are acknowledged or reflected in material developed for other populations and settings. This would involve collecting health education materials developed throughout the world, and assessing which of the model's concepts and ideas are apparent in them. This would include describing the characteristics of health education materials in terms of their origins, form and content, and identifying to what extent they address issues or myths identified in this study. This would complement traditional literature reviews, as well as Cochrane Collaboration reviews on influencing people's experience of screening (Bastian et al., 1998) and on the impact of mass media on health services utilization (Grilli et al., 1997). This approach is recommended because it would make good use of available resources, and could in turn serve as a resource for service providers (as recommended by the Ontario Cervical Screening Collaborative Group, 1999, described later).
A complementary study would investigate how selected materials (i.e., the ones that seem the best) are understood by underscreened populations. Given the likely difficulties in identifying or reaching them, it would probably be sensible to approach social service or health care providers (including receptionists) or other women in the communities of interest. The greatest merit for such an initiative would be if it yielded identification of a set of materials for a “best practices” resource library, and to the development of a set of core and optional “modules” of information for women who are difficult to reach.

**11.3.2.3.2 Challenges for public health in Ontario**

This study and the recommendations challenge public health units to improve their collaborations and education strategies, and they challenge the Ontario Ministry of Health and Long-Term Care’s Public Health Branch to provide leadership. No major policy or program changes are warranted, because the findings are largely consistent with the requirements and standards articulated for Public health units and an existing billing code might help physicians to identify and overcome barriers to preventive care. Indeed, any provincial strategy would need formal review, probably by several branches of the Ministry of Health and Long-Term Care. For example, if any new or modified requirements for boards of health were to be devised, a process led by the Public Health Branch, with a Technical Review Committee, would be necessary. A valuable and needed role for the Public Health Branch would be to develop internal Ministry linkages and strengthen partnerships with relevant external agencies for the types of research described earlier, necessary to create a social marketing campaign. The recommendation to work with the College of Physicians and Surgeons of Ontario, and the Society of Obstetricians and Gynaecologists (OCSP, 1999) makes sense in terms of the results of this study, because health care providers (and their receptionists) are understood to play such an important role in identifying and reaching underscreened women. These partnerships could also contribute to the development and provision of meaningful educational interventions for providers and their staff.

If nothing else, the findings in this research consistently indicate that Portuguese-speaking women in Toronto remain unscreened or underscreened with respect to cervical cancer. Public health practitioners may be in a unique position to help overcome the barriers to Pap testing, and so the recommendation of the survey to solicit the collaboration of the
Association of Local Public Health Agencies (OCSCG, 1999) makes sense. Staff in public health units might encourage relationships that will support screening, for example, by recommending women seek out physicians oriented to preventive care, and by encouraging physicians to so orient their practices. They might guide women to Portuguese women's groups, widely acknowledged as important sources of social support. Together, health care and social service providers committed to preventive care have the capacity to play complementary roles in enhancing women's understandings and behaviour.
11.4 Conclusion

In studying various approaches to identify and reach underscreened women, an important lesson was that the key issues relevant to promoting adoption of Pap testing are also likely to constrain the feasibility of research. If our experience can be generalized, these women may not speak English, read written material provided to them, or respond openly with people whom they do not know and trust. In this study, age, lack of English language and literacy skills were considered barriers to screening, as were “myths”, or incomplete understandings about cancer and cancer screening. Care providers who do not routinely recommend screening Pap tests are, by definition, barriers. Those who emphasize the role of the Pap test as a diagnostic tool, or only for sexually active women may unwittingly affirm women's misperceptions and fears. The women who are most difficult to identify and reach are most in need of Pap tests to prevent invasive cervical cancer.

Research is a "systematic investigation" or an "organized quest for new knowledge" (Thompson, 1995:1169), seeking to discover and disclose patterns of phenomena and explanations for them. Summarizing the complexities of any subject, including human behaviour, invariably simplifies reality. Systematisation or abstraction "always accompanies our investigation of particular situations and ... always reduces their rich abundance". (Nola, 1997, citing Feyerabend's autobiography, Killing Time). The conceptual model, though difficult and complex to produce, conveys a message that may be too simple. Yet its simplicity may mean that it can be easily grasped and used. In essence, the models holds that health care providers, and women themselves, have powerful but perhaps unspoken perceptions about health care, and whether interactions are for diagnostic or preventive purposes. This work was not intended to lay blame on any individuals or groups of individuals. The work was intended to express moral aims consistent with social science's mindset: "aims of widening peoples' perceptions of their situations and of enlarging their perceptions of social arrangements [...] [to] open the way to humane social change" (Lofland & Lofland, 1995:171-2). Recognizing this need, public health staff may be in an ideal position to help both health care providers and women identify opportunities to develop trust, to acknowledge and overcome barriers posed by misunderstandings. The prospect is enticing.
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Appendices
1996 POPULATION
HOME LANGUAGE - PORTUGUESE
CITY OF TORONTO

MAP 4

Source: Statistics Canada 1996 Census of Population
Toronto Community & Neighbourhood Services Dept., Social Development & Management Services Inc., February 1998

1 DOT = 20 PERSONS
DOTS ARE RANDOMLY DISTRIBUTED
WITHIN CENSUS TRACTS AND DO NOT
REPRESENT ACTUAL POINTS OF POPULATION
Appendix 2. Priority population estimates

Table 1. Calculations for top priority population: Portuguese-speaking women, aged 40 or more years, underscreened for cervical cancer in Toronto

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percent</th>
<th>Priority group size</th>
<th>Minimum¹</th>
<th>Maximum²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Portuguese women in Toronto</td>
<td>100</td>
<td>57500</td>
<td>75000</td>
<td></td>
</tr>
<tr>
<td>2. Age 40 years or more³</td>
<td>28</td>
<td>16100</td>
<td>21000</td>
<td></td>
</tr>
<tr>
<td>3. Speak little or poor English (Access Alliance, 1989)</td>
<td>47</td>
<td>7567</td>
<td>9870</td>
<td></td>
</tr>
<tr>
<td>4. Never-screened (Ferreira, 1990)</td>
<td>31</td>
<td>2346</td>
<td>3060</td>
<td></td>
</tr>
<tr>
<td>5. Ineligible (i.e. women with complete hysterectomies or previous cancer)</td>
<td>-5</td>
<td>-117</td>
<td>-153</td>
<td></td>
</tr>
<tr>
<td>6. Total priority population</td>
<td></td>
<td>2228</td>
<td>2907</td>
<td></td>
</tr>
</tbody>
</table>

Note:
1. 1986 Census, reported Portuguese ethnic origin (Ferreira, 1990)
2. Portuguese Consulate General, immigration figures (Consulado-Geral de Portugal, -1994)
3. Based on age distribution of Canadian female population

Clustering of any of characteristics 2-4 would mean that the size of the priority group is larger than the total estimated here.
We're glad you've come to this Women's Health Event. We hope that you enjoy talking with other women, and learning about preventive health care opportunities. We hope you will fill out this anonymous quiz, to help us to learn about the women who came to this Health Event today.

If you have any questions right now, ask one of our Health Event Representatives to help you. If you prefer not to answer this quiz, feel free to leave any or all questions blank.

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<th>Q.</th>
<th>Answer Options</th>
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</thead>
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<tr>
<td>Q01</td>
<td>In general, would you say your health is:</td>
</tr>
<tr>
<td></td>
<td>- Excellent?</td>
</tr>
<tr>
<td></td>
<td>- Very good?</td>
</tr>
<tr>
<td></td>
<td>- Fair?</td>
</tr>
<tr>
<td></td>
<td>- Poor?</td>
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<tr>
<th>Q06</th>
<th>Have you ever had your blood pressure taken?</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>- Yes</td>
</tr>
<tr>
<td></td>
<td>- No</td>
</tr>
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<td></td>
<td>- Don't know</td>
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<th>Q08</th>
<th>At the present time do you smoke cigarettes?</th>
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<tr>
<td></td>
<td>- Daily?</td>
</tr>
<tr>
<td></td>
<td>- Occasionally?</td>
</tr>
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<td></td>
<td>- Not at all?</td>
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<table>
<thead>
<tr>
<th>Q10</th>
<th>Other than a mammogram, have you</th>
</tr>
</thead>
</table>

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For office use only

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<th>Date:</th>
<th>(MM/DD/YY)<strong><strong>/</strong></strong>/____</th>
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</thead>
<tbody>
<tr>
<td>ERP-1</td>
<td>Eligible for research project?</td>
</tr>
<tr>
<td></td>
<td>- Yes ➞ Go to ROR-1</td>
</tr>
<tr>
<td></td>
<td>- No ➞ End of quiz, thank woman for attending</td>
</tr>
<tr>
<td></td>
<td>- Unsure ➞ Refer to researcher</td>
</tr>
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<table>
<thead>
<tr>
<th>ROR-1</th>
<th>Response to offer to learn about research</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- Chooses to hear about it</td>
</tr>
<tr>
<td></td>
<td>- Declines to learn about it at this time</td>
</tr>
</tbody>
</table>
Appendix 4. Form FQ: Follow-up Questionnaire

Women's Health Event  FQ3-IDCode: __________
Follow-up Questionnaire, 3 months after (telephone)

INTRO Hello, my name is _______________. How are you? I'm helping Elizabeth Rael in her important study about the Pap test. We are in the phase of making the last phone calls to the women. Therefore, I would like to ask a few final questions. Many of the questions are repeated but that's part of the study.

FQ3-Per May I ask you those questions now?
1 ☐ Yes.
2 ☐ No, or hesitation. [Prompt: “Would there be a better time for me to call you back?”
Prompt: You know that this research is confidential and will be used to help make recommendations on how to help other Portuguese-speaking women choose preventive care. May I continue? You can choose not to answer any questions that you want.]

FQ3-Eve What made you decide to come to the Health Event?
[Prompts (as necessary): Where did you hear about the Health Event? With whom did you come?]

FQ3-Res What made you decide to participate in the research on Pap tests?

FQ3-1a Did you keep the invitation brochure after that day?
1 ☐ Yes
2 ☐ No
3 ☐ Don't know

FQ3-1b Did you make use of the invitation brochure after that day?
[Prompts: i.e., look at, show to anyone, refer to it]
1 ☐ Yes
2 ☐ No  => Interviewer: Write in '0' or 'zero' for FQ3-1c
3 ☐ Don't know

FQ3-1c How many times? __________
FQ3-IDCode: __________

**FQ3-2**  After that day, did you talk to anyone about the Pap test?

1. Yes
2. No
3. Not sure / don't remember

Probes: Was that person a friend, relative, or health care provider?
Was that person male or female?
In what language did you speak?

<table>
<thead>
<tr>
<th>List the people</th>
<th>Role or relationship</th>
<th>Gender</th>
<th>Language(s) spoken</th>
</tr>
</thead>
<tbody>
<tr>
<td>(if necessary)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**FQ3-3a**  Did you decide to have a Pap test?

1. Yes  => FQ3-3b
2. No  => FQ3-3d
3. Undecided  => FQ3-3d

**FQ3-3b**  Have you

1. already had the Pap test?  Date (MM/DD/YY) weekday/month/year

OR

Where?  ____________________________

2. got an appointment for a Pap test?  Date (MM/DD/YY)

Where?  ____________________________

**FQ3-3c**  What made you decide to have the Pap test?

[Prompt: We know why you participated in the health event, why you participated in the study, but now why did you decide to do the Pap test?]
FQ3-IDCode: __________

FQ3-3d What would help you decide to have a Pap test in the future?

________________________________________________________________________
________________________________________________________________________

FQ3-5a Do you expect to have Pap testing in the future?
1 Yes
2 No
3 Uncertain / not sure
4 Prefers not to answer

FQ3-Con We're finished with the series of questions. I would like to thank you for your participation. Your involvement in this research will greatly help us make recommendations concerning how to get other women to do this test.

FQ3-4x Are there any other things that you would like the researcher to know about your reaction to the invitation, to the Pap test, to the research project, or to the health event?

________________________________________________________________________
________________________________________________________________________

Additional comments

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

FQ3-Val This research project is interested in comparing women's reports of about when they had their Pap test with the medical records. We need your written permission to contact the office where your Pap test was done. [Note medical office name and address and confirm woman's name and address to mail out form permitting doctors to release this information to us.]

Doctor's Name: ___________________________________________
Address: ________________________________________________
Woman's Ont Health Care Card Number: ______________________
Woman's Name: __________________________________________
Address: ________________________________________________

FQ3-INT Interviewer's name: __________________________________

FQ3-DAT Date: ____________________________________________

Form FQ3_E.981026
Appendix 5. Form DO: Doctors' Office Survey

DOCTOR'S OFFICE SURVEY FORM:
Portuguese preventive health care services in the College corridor
Researcher: Elizabeth Rael (416) 535-7290
University of Toronto, Graduate Department of Community Health, McMurrich Building
Thesis supervisor: AB Miller; Co-supervisor: EH Hodnett

<table>
<thead>
<tr>
<th>Item</th>
<th>Comments</th>
<th>I.D.__________</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.a) Date</td>
<td>1.b) Time</td>
<td>(YY/MM/DD) <strong>/</strong>/_____</td>
</tr>
<tr>
<td>2.</td>
<td>Name</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Address</td>
<td></td>
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<tr>
<td>4.</td>
<td>Telephone number</td>
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</tr>
<tr>
<td>5. Number of doctors</td>
<td>&amp; gender</td>
<td>5.a) Male</td>
</tr>
<tr>
<td>5.b) Female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.a) Number of people in waiting room</td>
<td>7.a)</td>
<td></td>
</tr>
<tr>
<td>7.b) Number of adult</td>
<td>7.b)</td>
<td></td>
</tr>
<tr>
<td>8.a) Portuguese language spoken</td>
<td>8a) Yes</td>
<td>8b) By whom? ____________</td>
</tr>
<tr>
<td>10. Office hours</td>
<td>10.a) Days</td>
<td>10.b) Evenings</td>
</tr>
<tr>
<td>a) Monday</td>
<td>☐</td>
<td></td>
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<tr>
<td>b) Tuesday</td>
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<tr>
<td>c) Wednesday</td>
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<td>f) Saturday</td>
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<td></td>
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<tr>
<td>g) Sunday</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>11.a) Number of Portuguese-speaking women served here?</td>
<td>11.a) _________</td>
<td></td>
</tr>
<tr>
<td>11.b) Proportion of total female clientele?</td>
<td>11.b) _________</td>
<td></td>
</tr>
<tr>
<td>12.c) Does Dr. prefer to refer women for Pap tests or to do them him/herself?</td>
<td>12.c) ☐ Refers women</td>
<td></td>
</tr>
<tr>
<td>12.d) What proportion of women patients here get regular Pap testing, to prevent cervical cancer?</td>
<td>12.d) _________</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Would the doctor be interested in our research, about healthy Portuguese-speaking women having Pap testing</td>
<td>13. ☐ Yes</td>
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<td></td>
<td></td>
<td>☐ No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☐ Maybe / not sure</td>
</tr>
<tr>
<td></td>
<td></td>
<td>☐ Not asked</td>
</tr>
<tr>
<td>14.</td>
<td>Respondent</td>
<td></td>
</tr>
</tbody>
</table>
Dear Dr. FIELD(LAST_NAME),

This letter is being sent to you because you belong to the Department of Family and Community Medicine at The Toronto Hospital and your practice is geographically situated in an area where Portuguese-speaking women may live. The following letter invites you to participate in a feasibility study which seeks baseline descriptive information about how many Portuguese-speaking women might be underscreened for cervical cancer, as well as information about factors that may serve as barriers or facilitators of Pap testing for these women.

This research work is being carried out as part of Elizabeth Rael's doctoral thesis work in the Department of Public Health Sciences at the University of Toronto. It has received the approvals of the University's Human Subjects Review Committee and the Hospital's Committee for Research on Human Subjects. Any information you provide will be treated carefully; your name or other identifying information will not be used in any publication. Elizabeth Rael approached Dr. Ellison because she wanted to be sure to include information from physicians who provide care for Portuguese-speaking women, and Elizabeth and Dr. Ellison have met to ensure that the questions are appropriate.

Dr. Ellison and Elizabeth want the research to be as convenient for you as possible, and are, therefore, offering you the choice of responding by fax, mail, or telephone. If you have no Portuguese-speaking patients, do not wish to participate, or if you require further information, please call (416) 535 7290. If you decide to participate, the telephone interview will only take 2-5 minutes. Elizabeth looks forward to hearing from you shortly.

Sincerely,

P Ellison
Physician-in-Chief
Department of Family and Community Medicine
The Toronto Hospital

Dr.'s fax number: FIELD(FAX)
Re: Pap Test Invitations for Portuguese-speaking Women

Doctors' Questionnaire

Dear Dr. FIELD(LAST_NAME),

We are undertaking a study to understand how different invitations and appointment scheduling affect Portuguese-speaking women's decisions about having Pap testing, and I am writing to invite you to participate in the study. Our research project has been developed with input from community partners, including Portuguese-speaking women. One of our objectives is to identify factors that serve as barriers or facilitators of Pap testing in women who are underscreened with respect to cervical cancer. The results of this project will be used to make recommendations about how to invite other women in need of screening to prevent cervical cancer.

I should like to book a convenient time with you, when I could undertake a short (5-minute) telephone survey. The survey is about factors that serve as barriers or facilitators of Pap testing. To facilitate arranging this, could you please fill out the form below and return it to me.

Thank you for your help in our study.

Yours sincerely

Elizabeth Rael, MSc
Department of Public Health Sciences

P.S. If you need more information, telephone (416) 535-7290 and I will get back to you.

I am willing to participate in the survey. ☐Yes ☐No

Signed ☐ Date

Name

for Dr.

Address

Postal code Phone number ☐

Best time and day to reach me

Please FAX back to (416) 351-3771.

Form DP.990202
Appendix 7. Forms WCL & PL

Appendix 7a. Form WCL: Walk-around Covering Letter

Appendix 7b. Form PL: Physician’s Log

Re: Pap Test Invitations for Portuguese-speaking Women

ID code: IDCODE

Dear Dr. LAST_NAME

We are carrying out a research project about Portuguese-speaking women who may not have Pap tests. We are studying approaches to identify and reach underscreened women, and how best to invite these women for Pap tests. Can you help us by completing a brief survey in the form of a log of the next ten Portuguese-speaking women who visit your office?

Logs completed by you or your receptionist will provide important information for our study. Any comments you care to make about factors that serve as barriers or facilitators of Pap testing for these women will help us to understand this problem more fully. The results of this project will be used to make recommendations about how to invite other women in need of screening.

This research work is being carried out as part of Elizabeth Rael’s doctoral thesis work in the Department of Public Health Sciences at the University of Toronto. We are not collecting any information which could identify individual clients; any information about your practice will be grouped or obscured in any publication. If you would like to speak with me at greater depth about any of these matters, please do not hesitate to call and suggest a time that we could meet, either in person or over the telephone. Thank you for your help in our study; your participation will help contribute to efforts to prevent cervical cancer incidence and mortality.

Yours sincerely

Elizabeth Rael, MSc
416 535 7290
(If my Call Answer is on, please leave a message & I will get back to you.)

Ellen Hodnett, RN, PhD
Department of Public Health Sciences
Professor and Heather M. Reisman Chair
Perinatal Nursing Research
Faculty of Nursing

Dr.’s fax number: FAX

Form WCL:981210
# Physician's Log of Portuguese-speaking Women and Pap Tests

Thank you for participating in this survey.

<table>
<thead>
<tr>
<th>#</th>
<th>Date (YY/MM/DD)</th>
<th>Woman's birthplace</th>
<th>Woman's year of birth or age</th>
<th>Woman's postal code (First 3 characters only if you prefer)</th>
<th>Is this woman eligible* to have Pap tests? (If not, use next page to explain)</th>
<th>When was her last Pap test? (Best guess if records are not available)</th>
<th>Is this woman due** for a Pap test? (Go to next page, please)</th>
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<tbody>
<tr>
<td>1.</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<td>Yes</td>
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<td>No</td>
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</table>

* Eligible: I.e. Has she ever had sexual relations and does she have an intact cervix?
  e.g. If she had two baseline Pap tests one year apart that were both normal, was her last Pap test ≥3 years ago?

** Due:
Physician's Log of Portuguese-speaking Women and Pap Tests

Thank you for participating in this survey.

| #  | Date (YY/MM/DD) | Woman's birthplace | Woman's year of birth or age | Woman's postal code (First 3 characters only if you prefer) | Is this woman eligible* to have Pap tests?  
(If not, use next page to explain) | When was her last Pap test?  
(Best guess if records are not available) | Is this woman due** for a Pap test?  
(Go to next page, please) |
<table>
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</tbody>
</table>

* Eligible:  
I.e. Has she ever had sexual relations and does she have an intact cervix?
** Due:  
E.g. If she had two baseline Pap tests one year apart that were both normal, was her last Pap test >3 years ago?Form PL.981021
Appendix 8. Form RAF: Research Agreement Form

Pap Test Invitation Study
Research Agreement Form

This research study is interested in how different invitations and appointment schedules affect Portuguese-speaking women's decisions about Pap testing. The results of this project will be used to make recommendations about how to invite other women in need of screening to prevent cervical cancer.

Participant’s agreement
I understand that this research project involves these things:
• Today I will be asked to provide some background information about myself.
• Today I will be given information about Pap testing and offered an appointment for a Pap test.
  I can choose whether to have a Pap test or not, and if I choose to have one, I can book it wherever and whenever it suits me.
• A Portuguese-speaking woman will call me one month from now and three months from now to find out my reactions to the invitation.

If I wish, I can choose not to answer particular questions. I can withdraw from this study at any time, and for any reason. I can discuss this Pap test invitation project with anyone I wish. I understand what the research study involves, and want to participate in it.

Signed ≠ ___________________________ Date ___________________________
Name
Address ≠ ___________________________
Postal code ___________________________ Phone number ≠ ___________________________
Best time for Portuguese-speaking woman to call me ≠ ___________________________

When this study is complete, in about one year from now, I would like to receive a summary of what the researchers learned. ☐ Yes ☐ No

Researcher’s agreement
I, Elizabeth G.S. Rael, the project researcher, promise to be careful in my research.
• I will ensure that all the information forms are stored safely in a private place.
• I will check that data is entered properly into the computer.
• I will analyse the data carefully.
• I will present what we learn with respect for women's privacy and dignity. Responses will be grouped, wherever possible, into summary categories. Where details are presented, no identifying information such as names will be used.

Signed ≠ ___________________________ Date ___________________________
≠ c/o Department of Preventive Medicine and Biostatistics
University of Toronto
4th floor, McMurrich Building
12 Queen’s Park Crescent West.
Toronto, Ontario M5S 1A8.

Form RAF.961026b

For office use only
HED-1 Date ___________________________ IDC Identity code: ___________________________
CAP-1 Choice about whether to participate or not
☐ 1 Chooses to participate (fill in the form above)
☐ 2 Prefers not to participate at this time

ALL-1 Allocation:
☐ IP-1 Invitation provided by (i.e., your name): ___________________________
☐ BL-1 Brochure ___________________________
☐ APO-1 Appointment date offered: / /
☐ APR-1 Appointment response ___________________________

Form RAF.961026b
to any unusual symptoms such as spotting after intercourse, or bleeding after the menopause. You should see your doctor at the first sign of anything abnormal. Keep in mind that though the Pap test is very successful in detecting cervical cancer, which is found in the neck of the womb, it isn't as effective in detecting the other major form of uterine cancer, endometrial cancer. This is a type of cancer found in the lining of the uterus which is called the endometrium. Here, the reporting of any abnormality and regular gynecological exams will help in the early detection and treatment.

Has the Pap test helped?

Cancer of the cervix was formerly a major cause of death from cancer among Canadian women. However, there has been a significant decline in the death rate from this disease. One of the most important reasons is early diagnosis and treatment as a result of the Pap test.

The Seven Steps to Health

Protect yourself and your family. By knowing and acting on these Seven Steps to Health, you can help prevent cancer.

1. Choose to be a non-smoker and avoid second-hand smoke.
2. Choose a variety of lower fat, high fibre foods.
   Maintain a healthy body weight and limit your alcohol intake.
3. Protect yourself and your family from the sun. Practise regular skin examinations and report any changes immediately.
4. Regularly scheduled Pap tests and mammograms, according to age, are vital.
   Practise monthly breast self examination.
5. See your doctor and dentist regularly for checkups.
6. Be aware of changes in your normal state of health. If you discover a lump or a mole that has changed, or a sore that won’t heal, check with your doctor immediately.
7. At home and at work, follow health and safety instructions when using hazardous materials.

Consult your local Unit of the Canadian Cancer Society for more information.

We hope you will keep this brochure. Feel free to discuss it with your family, friends and health care providers.
The uterus, or womb, is a small, pear-shaped organ located in a woman's pelvis. It has two parts; the uterus itself, and the neck of the uterus, or the cervix.

How is it done?

An instrument is inserted into the vagina and cells are gently taken from the surface of the cervix and placed on a glass slide which is sent to a laboratory. The cells are then examined under a microscope. In most women, these cells are absolutely normal. In a very few, the cells do not look normal. When this occurs the test is repeated and, if necessary, further examinations made.

Then what?

Even if further investigation or treatment is required, the Pap test enables doctors to discover cancer, or precancerous changes, early so that the chances for a complete cure are greatly increased. If any abnormality is found, some additional procedures may be done by your doctor.

A very common diagnostic procedure is a biopsy, where a small piece of tissue is removed and examined under a microscope. In a "cone-biopsy," the doctor removes a cone-shaped piece of the cervix which may not only be helpful in diagnosis, but also as treatment. Another simple diagnostic procedure is a "colposcopy," which is done in much the same way as a Pap test. The doctor uses a special microscope to examine the tissues of the cervix and vagina.

If abnormal cells are found, one simple treatment is "cryotherapy," a procedure which 'freeze-burns' away the abnormal cells and is often done in a special clinic. It is unlikely to have any effect on a woman's fertility or future child bearing. Another simple treatment is "laser cautery," where a very fine, precise beam of focused light vaporizes pre-cancerous cells on the cervix or vagina.

Good advice

If you are told that your test is normal, you will naturally feel very happy. Remember though that the preservation of good health requires that the test should be repeated regularly. You should also remain alert...
BONS CONSELHOS

Um exame normal dá razão para estar feliz, mas lembre-se: para manter boa saúde o exame deve ser repetido com regularidade.

Desde que o exame PAP foi introduzido no Canadá, o número de mortes causadas pelo câncer do colo do útero tem diminuído muito. Uma das razões mais importantes é que as mulheres podem receber tratamento mais cedo quando o câncer está ainda na fase inicial.

O exame PAP é muito efectivo em detectar câncer no colo do útero, mas não detecta câncer em outras partes do sistema reprodutivo.

Deve consultar o seu médico assim que notar qualquer sintoma estranho, como hemorragias depois de relações sexuais ou depois da menopausa. Faça um exame pélvico todos os anos para detectar câncer nos ovários ou no interior do útero.

Esta informação é fornecida por Canadian Cancer Society
Tradução por M. Menestro Bsc.N Rev. 1996:
Parkdale Community Health Centre

SETE PASSOS PARA UMA BOA SAÚDE

Escolha não fumar

Coma uma alimentação equilibrada, com pouca gordura e rica em fibra. Isto também ajudará a manter um peso ideal.

Consulte o seu médico e dentista com regularidade.

Investigue qualquer caroço ou ferida que não cure, ou qualquer mudança no seu estado normal de saúde.

Proteja-se do sol.

Aprenda a evitar substâncias no seu ambiente que provoquem o câncer: no trabalho, em casa, ou na sua comunidade.

Faça o exame PAP com regularidade e examine os seios todos os meses.

PREVENÇÃO DO CANCRO
QUEM ESTÁ EM RISCO?

As mulheres estão em risco de desenvolver câncer no colo do útero assim que começarem a ter relações sexuais.

O risco aumenta, se:
- Começarem a ter relações sexuais antes dos 20 anos de idade.
- Tiveram mais do que dois parceiros sexuais.
- Fumam.

O EXAME PAPANICOLAU (PAP)

O exame PAP é feito para ver se há mudanças no colo do útero que podem ser pre-cancerosas ou cancerosas. O exame é simples, demora só uns minutos e não provoca dores.

Células na superfície do colo do útero são cuidadosamente tiradas e postas numa peça de vidro. No laboratório, as células são examinadas ao microscópio. Na maioria dos casos, as células são normais, mas aproximadamente 6 casos em cada 1000, têm células que não aparentam normais. Quando isto acontece, o exame é repetido, e se for necessário, outros exames são feitos.

Se uma anormalidade for encontrada, os seguintes exames ou tratamentos podem ser utilizados:

- **Biopsia**: uma porção pequena dos tecidos do colo do útero são tirados e examinados.
- **Biopsia “Cone”**: Uma porção dos tecidos na abertura do colo do útero são tirados. Isto pode servir não só para análise mas também como tratamento.
- **Colposcopy**: É feito duma forma parecida com o exame PAP, mas o médico usa um microscópio especial para ver os tecidos da vagina e do colo do útero.
- **Cryotherapy**: Este tratamento simples, desfaz as células por um processo de congelação. Normalmente é feito numa clínica especial e não afecta a capacidade de ter filhos no futuro.
- **Laser Cautery**: Este tratamento aponta um raio de luz muito fina ao colo do útero ou a vagina e faz evaporar as células defeituosas.
Appendix 10. Draft of letter to trial participants

Dear

Thank you for coming to our women’s health event and participating in our study of invitations for Pap tests to prevent invasive cervical cancer.

Perhaps you remember Helena Monteiro, Oligia Resendes, Margareth Toste or myself, Elizabeth Rael? This letter describes some of the things that I learned with Portuguese-speaking women.

I learned that Portuguese-speaking women enjoy being with each other, talking together and helping each other with their problems and stresses. At our health events, and at women’s groups, I met women who rarely had a Pap test; some never.

Many underscreened women agreed to participate in our trial of invitations and to be interviewed by the research assistant Margareth. Most women had learned that the Pap test is important, in order to stay healthy. Many trial participants told us that they had a Pap test either on the day of the event or afterwards, to detect unusual cells that can be treated in order to prevent health problems. Some women told us they will have Pap tests in the future, in order to prevent invasive cervical cancer.

Some women told us that their doctor had never before suggested or asked them to have a Pap test; others said that going for a Pap test was not easy. Some women told us that they were frightened; some told us they were embarrassed in front of their doctors, especially if the doctor was a man. Others told us how hard it was to get to the appointment, because they were busy or got lost. Some women were not able to take their Pap tests because of infections; we hope these women will keep going to their doctor until the infections are resolved.

Obrigado

prevenir cancro ...
Esta carta dizes algumas coisas que aprendi com mulheres qui falam português.

Aprendi que mulheres qui falam português degostam estar com outras, falar juntas, e ajudar outras com problemas e stresses. ...saúde, aos grupos mulheres, conheci mulheres que não tinham ... Pap teste muito tempo; algumas nunca.

Multas mulheres ... concordar com participar em ... e ?esse entrevistar para assistente pesquisadora?, Margareth. Maiora de mulheres tinham aprendo que eu Pap test esse importante? para ficar saudável. Multas participantes do estudo? falaram tenho? Pap teste qualquer ....
As researcher for the project, I appreciate your involvement. Your ideas help explain a serious problem to the researcher. Enclosed you will find a set of "myths" which, though not completely true, may help explain why some women do not get Pap tests to prevent invasive cervical cancer. As I finalize my doctoral thesis for the university, I am making some recommendations.

1. Portuguese-speaking women expect and want their doctors to recommend how to stay healthy. Doctors should invite all underscreened women to have a Pap test, and make an appointment for a convenient time.

2. Researchers should investigate, with community workers, whether health companions could help frightened or embarrassed women to talk with their doctors about their health and how to take care of it.

Please accept my appreciation and thanks for your contribution to the work. Please feel free to share this letter with your friends, relatives or doctor.

God bless you,

Elizabeth G.S. Rael

Enclosure: 3 top myths about cervical cancer and the fuller truths

General Standards

Equal Access

Goal
To ensure that all Ontarians have access to public health programs.

Objective
To reduce educational, social and environmental barriers to accessing mandatory public health programs.

Requirements and Standards

1. The board of health shall provide mandatory public health programs and services, whenever practical and appropriate, which are accessible to people in special groups for whom barriers* exist. Broadening access may require adjusting existing programs, promoting accessibility and developing special programs including special educational materials, tailored service delivery and active outreach.

2. When planning to use facilities and sites for mandatory public health programs, the board of health shall select those which are barrier-free and have suitable access for special groups.

3. The board of health shall establish ongoing community processes to identify needs, recommend approaches and monitor progress toward achieving access to the mandatory public health programs and services.

* Barriers can include, but are not limited to: literacy level, language, culture, geography, social factors, education, economic circumstance, and mental and physical ability.

Program Planning and Evaluation

Goal
To ensure that local programs address the health needs of the community, with cost-effective, efficient, evidence-based approaches.

Objectives

1. To ensure that programs and services are based on community health status information.

2. To ensure program development and design is based on evidence of effectiveness and efficiency.

Requirements and Standards

1. The board of health shall liaise with district health councils, social service and municipal organizations, educational institutions, law enforcement agencies, social planning bodies and other health professions, in order to access all data relevant for local health planning.
2. The board of health shall assess annually the community health status in the health unit using as a minimum, data on:

- demographics;
- mortality rate;
- morbidity rates;
- reproductive outcomes;
- risk factor prevalence;
- health conditions that are known or suspected to be associated with exposure to health hazards; and
- dental health indices.

3. The board of health shall produce an annual report covering current key public health issue(s) that is communicated to the community.

4. The board of health shall ensure the use of community health status information in assessing local health needs and in the planning and evaluating of programs.

5. The board of health shall, in collaboration with researchers and practitioners:

- ensure the development of innovative, cost-effective, evidence-based programs and services that are consistent with mandatory health programs and services;
- ensure evaluation is undertaken in areas directly related to mandatory health programs and services; and
- ensure the dissemination of the knowledge gained from program development and evaluation.

6. The board of health shall encourage continuing education for public health practitioners in order that they develop and maintain the knowledge and skills for the most effective delivery of mandatory health programs and services.
Program Standards

Early Detection of Cancer

Goal
To reduce mortality from breast cancer and cervical cancer by increasing early detection.

Objectives
1. To reduce female breast cancer mortality by 10 per cent by the year 2010.
2. To increase to 70 per cent the proportion of women ages 50-69 who receive screening mammography through the Ontario Breast Screening Program (OBSP) by the year 2010.
3. To reduce the mortality from cervical cancer by 50 per cent by the year 2005.
4. To increase the proportion of women screened according to the guidelines of the Ontario Cervical Screening Collaborative Group to 85 per cent and to increase the proportion of ever-screened to 95 per cent by the year 2010.

Requirements and Standards:
1. The board of health shall work with and assist regional OBSP centres to increase recruitment to the OBSP. This shall include as a minimum:
   - work with community groups, women and health professionals to coordinate services, identify gaps and barriers to screening, and develop and implement strategies to reduce barriers and increase the level of use of OBSP;
   - ensure that a community-wide education campaign using a variety of strategies such as television, radio, newspapers, posters/pamphlets occurs not less than once a year aimed at increasing awareness and knowledge of effectiveness and availability of screening through OBSP;
   - provision of group education sessions for women and their family members at a frequency of one per 100,000 population or two group sessions per year, whichever is greater; and
   - provision of continuing education and resource materials to health professionals to promote awareness of OBSP.

2. The board of health shall work with community groups, women and health professionals to coordinate services, identify gaps and barriers to screening, and develop and implement strategies to increase recruitment for cervical cancer screening, particularly those in hard-to-reach groups.
Sexual Health

Goal

To promote healthy sexuality.

Objectives

1. To decrease the rate of pregnancy in women 15-19 years of age to 40 per 1,000 population by the year 2005.

2. To increase access to contraception for individuals in need to decrease unplanned pregnancy.

3. To increase the awareness and knowledge about personal responsibility and life skills required to deal with sexual relationships and behaviours including the impact of alcohol and other drugs.

Requirements and Standards

1. The board of health shall work with community partners to ensure the provision of programs to the public that promote appropriate individual reproductive and sexual health choices. Content of programs shall include: knowledge, attitudes and the development of behaviours appropriate to the individual’s reproductive age and maturity.

Programs shall include, as a minimum, the following topics:

- sexual behaviour, personal responsibility and decision-making;
- relationships and assertiveness, including techniques for negotiating safer sex;
- methods of contraception, including abstinence;
- prevention of sexually transmitted diseases;
- sexual orientation;
- sexuality and aging; and
- sexual assault and abuse.

These programs shall include as a minimum:

- three hours of sexual health education annually to all students in grades 7-9 by the person or organization that operates the school. The board of health shall assist in school curriculum development and implementation. In schools where this education is not provided, the board of health will report this to the Ministry of Health and Long-Term Care, and a program of equivalent activities targeted to school-aged children shall be delivered through other community settings;

- provision of information for parents on an ongoing basis that will assist them in their role as the primary sexuality educators of their children;
• health promotion strategies, including an annual workshop for individuals such as educators, health professionals and community workers involved in education and counselling; and

• activities that promote awareness about sexuality to the targeted population, including those with special needs.

2. The board of health shall provide clinical services, at a minimum of four hours per week per 150,000 or less population, and such additional services as are required to meet local needs.

Activities associated with these clinical services shall include as a minimum:

• client's health assessment:

• contraception counselling, provision of prescription and other contraceptives at cost and or free for clients in financial need:

• preventive counselling and screening for cancers of the cervix and additional physical and laboratory examinations as appropriate:

• pregnancy tests and comprehensive pregnancy counselling:

• post-abortion counselling:

• education and counselling on reproductive and sexual health choices, with appropriate client referral to: smoking cessation programs, nutrition counselling, assertiveness training groups, alcohol and drug abuse programs and other health and social service agencies and groups:

• provision of hepatitis B vaccine at no cost, according to Ministry of Health and Long-Term Care eligibility criteria; and

• development of a management plan appropriate to client needs, including discharge planning and referral where necessary to health care and/or social agencies.

3. The board of health shall work with coalitions/networks of community groups and health and social services partners to coordinate and address gaps in sexual health programs in the community.
Participe na sessão informativa sobre A MULHER E A SUA SAÚDE

TÓPICOS:

• alimentação saudável

• cuidados com sua saúde

• projecto de pesquisa

Traga suas amigas e passe uma tarde agradável conosco!!!

Escolha um dos seguintes domingos:

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<td>West End YMCA 931 College Street (College e Dovercourt)</td>
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<td>27 de outubro e 10 de Novembro</td>
<td>das 2:00 as 5:00 da tarde</td>
<td>Davenport-Perth Community Health Centre 1900 Davenport Road (Davenport e Symington)</td>
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e participe!!!

Para mais informações, telefone para Fatima ou Ana no PIN: 5306808

Este acontecimento é patrocinado por:
- Centre for Research in Women's Health
- Davenport-Perth Community Health Centre
- Doctor's Hospital
- Immigrant Women's Health Centre
- Portuguese Women's Network
- HealthWest, Women's College Hospital
- University of Toronto, Department of Preventive Medicine & Biostatistics
- YMCA
Come to our Women's Health Event for Portuguese-speaking Women

The Women's Health Event is planned for busy Portuguese-speaking women who may be unfamiliar with preventive care opportunities available through the health care system.

During the Women's Health Event, we will provide basic information about these topics:
- nutrition
- managing your health
- a research project for women who have not had a recent Pap test.

Choose one of the following Sundays to participate:

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