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PCCSI National Guidance Document on Correspondence for Cervical Cancer Screening Programs

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Executive Summary

Cervical cancer screening in Canada and elsewhere has resulted in dramatic declines in cervical cancer rates since its introduction over the last five decades. In recent years those declines have stabilized. To achieve further reductions in cervical cancer rates, effort is needed to ensure participation in screening and the appropriate follow-up on abnormal results. The European Guidelines for Quality Assurance in Cervical Cancer Screening stressed that screening should be based on guidelines, have a quality assurance program, have regular monitoring and evaluation of the screening program, and have a robust correspondence initiative.[1] Correspondence, or direct contact, between a cervical cancer screening program and a woman and/or her health-care provider has been identified as a key component of an organized cervical cancer screening program. Directly informing and involving a woman in her cervical cancer screening choices has been shown to be an effective means of improving adherence to recommended screening guidelines.

Currently in Canada the degree of correspondence activity and the manner in which it is carried out varies widely among jurisdictions. This national guidance document aims to describe the elements and characteristics of a robust correspondence initiative within cervical cancer screening programs and to promote best correspondence practices leading up to optimal screening participation and follow-up. This includes a(n):[1]

- Invitation to participate in cervical cancer screening
- Notification of screening results
- Recall notice to return for next screening
- Follow-up on abnormal test results

The recent development of human papillomavirus (HPV) vaccines and the association between HPV infection and the onset of cervical neoplasms have underlined the importance of organized cervical screening programs. This era of primary prevention has highlighted the need for extra efforts in organizing, rationalizing and streamlining screening practices where necessary.

Under the auspices of the Canadian Partnership Against Cancer, the Pan-Canadian Cervical Screening Initiative (PCCSI) network focuses on the continued implementation and enhancement of organized cervical cancer screening programs (including their integration with HPV vaccination programs), optimal screening technologies and surveillance initiatives.

This PCCSI document includes information about the types of correspondence and addresses inputs to the planning and prioritization of a correspondence initiative. Among the inputs are enablers, key attributes, factors for prioritization, privacy and information technology.

> The Network recommends the implementation of all correspondence elements across all Canadian cervical cancer screening programs. Each province or territory should conduct their own prioritization exercise to determine the approach and correspondence elements appropriate for them, reflecting on capacity, resources and overall program goals.

Given the current economic climate in Canada, it may not be possible for a program to initially implement all elements of a correspondence initiative. However, programs should work toward having a full complement of correspondence with implementation informed by local factors, including prioritization and other considerations identified in this document.

PCCSI supports jurisdictional cancer agencies and health ministries in their efforts to build capacity in correspondence initiatives, a key component of a high-quality cancer screening program. That support includes information on the different types of correspondence, key attributes and considerations for prioritization when implementing correspondence in their jurisdiction, and linkages between screening programs and sample resources on the PCCSI collaborative space.

A note about PCCSI:

The PCSSI network includes representatives from Canadian provinces and territories, health-care professional groups, the Public Health Agency of Canada, the Canadian Cancer Action Network and the Canadian Cancer Society. Through its collaborative work, PCCSI is helping to optimize the contribution of screening programs to overall incidence and mortality reduction for cervical cancer.

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Introduction

Cervical cancer screening in Canada and elsewhere has resulted in dramatic declines in cervical cancer rates since its introduction over the last five decades. In recent years those declines have stabilized. The recent development of human papillomavirus (HPV) vaccines and the association between HPV infection and the onset of cervical neoplasms have underlined the importance of organized cervical screening programs. This era of primary prevention has highlighted the need for extra efforts in organizing, rationalizing and streamlining screening practices where necessary. This document addresses a key component of programs, the correspondence initiative, and includes information about the types of correspondence and inputs to the planning and prioritization of a correspondence initiative. Correspondence, or direct contact, between a cervical cancer screening program and a woman and/or her health-care provider has been identified as a key component of an organized cervical cancer screening program. Directly informing and involving a woman in her cervical cancer screening choices has been shown to be an effective means of improving adherence to recommended screening guidelines.

A correspondence initiative[1]

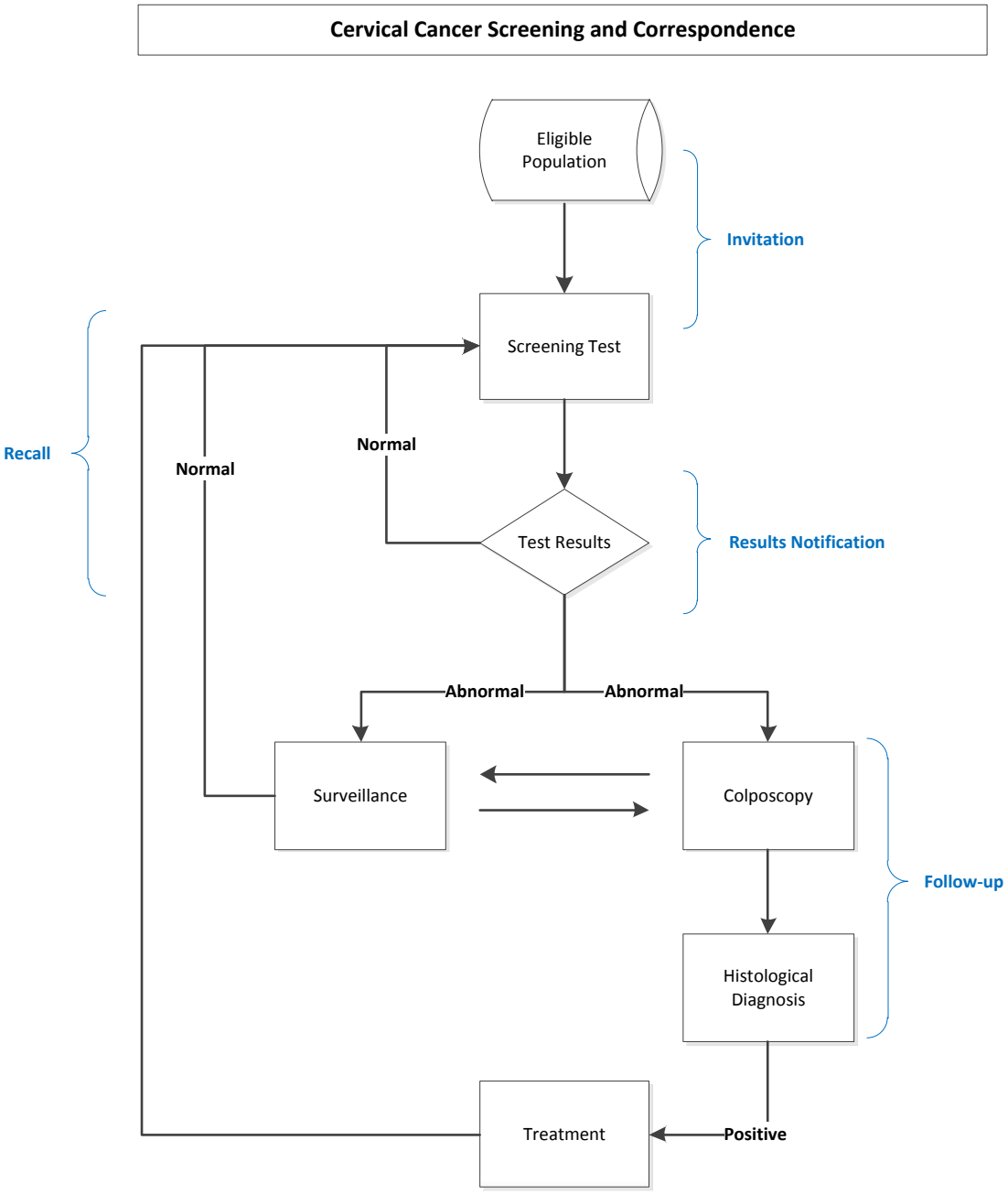
- *Invites* a woman to participate in cervical cancer screening
- *Notifies* a woman of the screening results
- Sends a *recall* notice to return for next screening
- *Follows up* on abnormal test results

Acknowledging the key role played by a correspondence initiative, the PCCSI Network sponsored a workshop on April 13th, 2011, in Montreal, to share strategies for the development, dissemination and uptake of key correspondence elements for cervical cancer screening programs in Canada. This national guidance document is an outcome of that workshop and the work done by the National Correspondence Guidance Document Working Group (see Appendix B for the Working Group membership).

The goal of the working group was to develop and disseminate a national guidance document that promotes the best correspondence practices for optimal screening participation and follow-up.

The workshop clearly illustrated that despite variances in jurisdictional organization and practice in correspondence activity, all screening programs share common elements. Figure 1 shows how the various elements of correspondence fit within the cervical cancer screening pathway. Generally, screening begins with the identification of eligible population. A primary screening test, typically the Papanicolaou (Pap) test in Canada, follows. Depending on the results, the woman may be sent to triage testing (e.g., HPV reflex testing), repeat screening or colposcopy for further follow-up and treatment if needed. In the future, the use of primary HPV testing may become the norm.

Figure 1: Cervical cancer screening pathway and correspondence



Some terminology relating to the cervical cancer screening pathway and correspondence initiative is noted below. Terms have been adapted where appropriate.

Screen-eligible

- Any woman eligible to participate in a screening program as defined by jurisdictional guidelines.

Correspondence

- Any information directly transferred between a screening program and a woman and/or her health-care provider(s).
- Communication methods include letters, emails, phone calls.
- Goal: Engaging women in screening and associated follow-up requirements. Includes initial screening invitation, recall for next screening, notification of test results or follow-up on abnormal test results.

Invitation

- Correspondence from a cervical screening program to a *never screened* woman, providing information on screening and her eligiblity.
- Goal: Allow the woman to make an informed decision about screening.

Recall

- Correspondence from a cervical screening program to a *previously screened* woman, informing her that she is due for repeat routine screening.
- Goal: Allow the woman to make an informed decision about rescreening.

Result Notification

- Correspondence from a cervical screening program to a woman providing a summary of the outcome of a screening test.
- Goal: Informing the woman of her test results and any required follow-up action.

Follow-up

- Correspondence from a cervical screening program to a woman and/or her health-care provider(s).
- Goal: Ensure appropriate investigation of abnormal screening results; usually occurs when action is overdue.

Reminder

- Any correspondence to a woman subsequent to previously sent communication.
- Reminder can follow an invitation, recall or follow-up notification.
- Goal: Reinforce message(s) of the original correspondence.

Registry

- Collection of organized data from one or more parties. May be population-based, may include information on all screen-eligible women or be a subset of a population (e.g., previously screened women).
- Goal: Support program operations, including sending correspondence.

Opt Out of Program

- A woman's choice to not participate in a screening program, have her data collected and/or be contacted by a screening program.
- Available in most jursidictions.
- Provisions to opt out may be specified in privacy legistlation and regulations.
- May or may not involve de-identification or deletion of results within a registry.

Environmental Scan of Current Practices

One key resource that PCCSI maintains is a summary of current correspondence practices in Canada. The table below summarizes these practices according to four key elements: invitations, recall, result notification and abnormal follow-up.

Table 1: Current correspondence practices in Canadian provinces and territories as of May 31, 2012

Province/Territory	Population-based registry	Elements of a robust correspondence initiative			
		Invitations	Recall	Result notification	Follow-up (abnormal)
Yukon	N/A	N/A	N/A	N/A	N/A
British Columbia	No	No	TP	TP	TP
Northwest Territories	No	No	No	No	No
Alberta	Yes	Yes	TW	TW	TPW
Saskatchewan	Yes	Yes	TW	TW	TP
Nunavut	N/A	N/A	N/A	N/A	N/A
Manitoba	Yes	Yes	No	No	TPW
Ontario	Yes	No	No	No	No
Quebec	No	No	No	No	No
New Brunswick	Yes	No	No	No	No
Prince Edward Island	Yes	Yes	Yes	No	TPW
Nova Scotia	Yes	No	No	No	TP
Newfoundland	No	No	TP	No	TP

TP: To a provider
TW: To a woman
TPW: To a provider and woman

National Overview

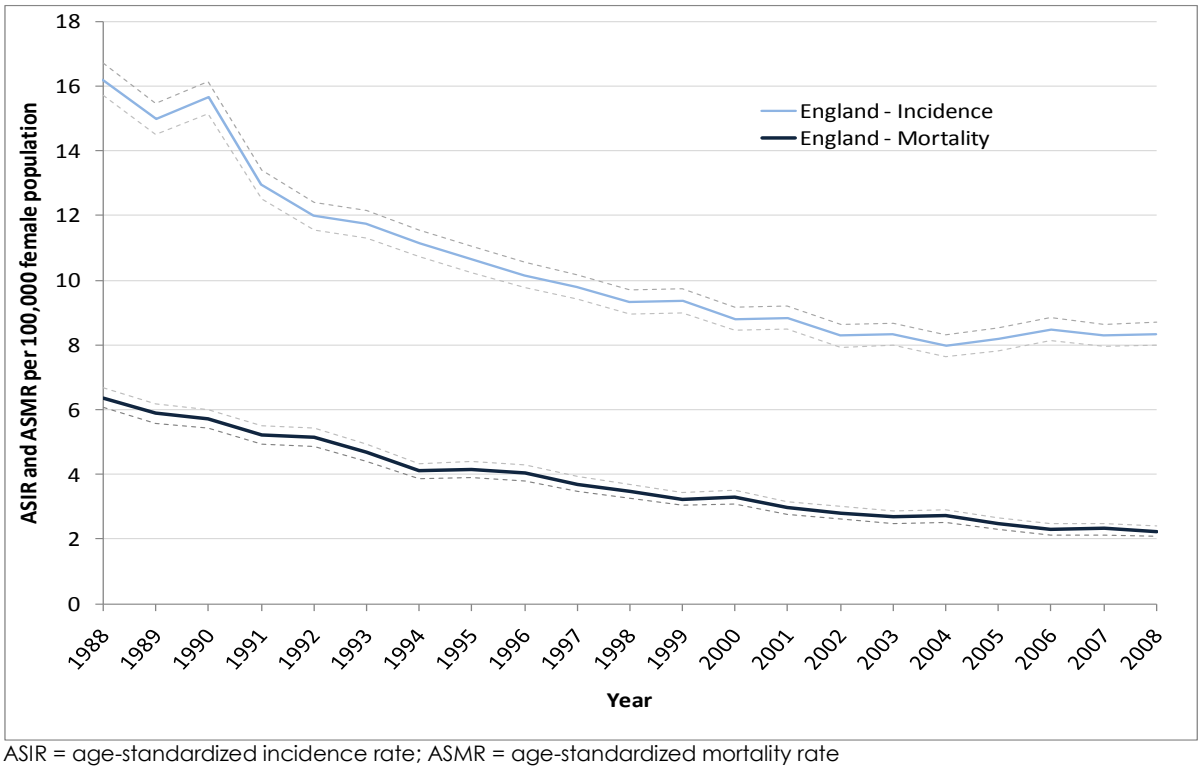
Cervical cancer screening programs in Canada incorporate some elements of a correspondence initiative and are in the process of planning and implementing additional components. Highlights of current program activities include the following:

- Seven of 13 jurisdictions identify eligible women through population-based registries.
- Five jurisdictions send invitations for screening.
- Five jurisdictions send recall letters.
- Two jurisdictions send result notifications to women.[i]
- Seven of 13 jurisdictions send letters to follow up on abnormal test results.

International Overview

The European Guidelines for Quality Assurance in Cervical Screening note that the key characteristics of a cervical cancer screening program include a robust correspondence initiative with invitations, recalls, result notification and follow-up of abnormal results.[1] Generally, programs that have invested in more correspondence elements have seen improvements in their cancer rates, such as Finland and Britain. Figure 2 shows how England decreased the incidence of cervical cancer by 50 per cent and reduced mortality rates by two-thirds just by incorporating correspondence within its organized screening program.[2]

Figure 2: Trends in incidence and mortality, England 1988–2008



ASIR = age-standardized incidence rate; ASMR = age-standardized mortality rate

i. This does not include the normal medical practice of the health-care provider receiving the test results, typically from the testing laboratory.

Countries vary in their correspondence methods. Some European countries and Australia use mail to connect with women for invitations, recalls and reminders. Also, the recipient and type of correspondence for result notifications can vary, with about half of European programs sending normal results to both the woman and her health-care provider (e.g., physician, midwife, nurse) and half to only the health-care provider. For abnormal result notification, a few countries send results to the woman while most send them only to the health-care provider(s), retaining the providers' responsibility for notifying the woman. Many countries have a step-wise approach to improving patient adherence with follow-up, targeting women and their primary health-care provider (e.g., reminders are sent to the woman and/or her health-care provider). In some countries women receive a pre-arranged appointment for colposcopy or reminders if the woman misses a colposcopy appointment. Appendix C provides a summary of correspondence practices in 15 countries.

National Health Service

At the national correspondence workshop in Montreal, T.J. Day, Access Manager for National Health Service (NHS) Cancer Screening Programs in England, delivered an informative presentation on the NHS's experience in developing and delivering a cervical cancer screening program. The presentation highlighted the NHS's history and current practices.

- National screening program has been in place since 1994.
- "Informed Choice" was launched in 2001. This was a major initiative to ensure women were told what screening can and cannot achieve, supporting ownership of their decision regarding participation.
- Invitations are sent to women from age 25.
- The call and recall system invites and reminds women of appointments to ensure follow-up of screening results.
- Invitation system (including recall) operates as follows:
    1. A prior notification list is sent to general practitioners (GPs).
    2. GPs are asked to identify women who were due for screening and who no longer require screening (a type of correction).
    3. Invitations are sent directly to a woman just prior to the end of an interval (e.g., a three-year interval means an invitation is sent every 35 months). Currently 4.1 million invitations are sent annually. This includes initial invitations and recalls.
- Reminders are sent three to six months after a missed screening date.
- Women receive a notification of their test results. A failsafe system ensures tests are appropriately followed up and that required colposcopy referrals take place.
- The program provides extensive supporting materials for all correspondence components.

Challenges that the NHS cervical screening program faces include the following:

- A decline in screening participation in younger women
- Inappropriate screening by practitioners (e.g., ceasing)
- Changes to screening protocols to include HPV testing

(The conference proceedings in Appendix A contain a more detailed summary.)

Summary of Evidence on Correspondence Effectiveness

There is a substantial body of literature, including trials, case studies and systematic reviews, that looks at correspondence with screen-eligible individuals in cancer screening programs. Some literature is specific to cervical screening while some is for other programs (e.g., breast and colorectal cancer screening). Most of the literature has focused on traditional mail correspondence.

The literature notes the difficulty in evaluating evidence from diverse populations, particularly when linking correspondence activities to outcomes, despite evidence that invitation letters are useful. Often there are multiple activities that occur in overlapping timeframes acting as confounders of any evaluation of the specific impact of program correspondence. An evidence review and annotated bibliography can be found on PCCSI's collaborative space.

Invitations and Recalls

The literature notes some key findings on engaging women in screening through invitations and recalls:

- Screening attendance increases when invitations are mailed, particularly from a woman's physician.[3,4]
- Patient recalls or reminders increase screening attendance and are cost-effective.[5,6]
- Correspondence is more effective among women in higher socio-economic groups than in lower socio-economic groups.[7]
- Customized messages increase a woman's participation in screening. These messages are specific to a target group or are tailored to an individual and likely use technology to include specific information (e.g., previous screening activity such as the date of her last test).[8]
- Screening attendance increases when a reminder letter follows an invitation.[9-11]
- Women who are overdue for screening are more likely to participate in a subsequent screen than those who have not previously been screened.[3,10,12]
- Sending a reminder to physicians is an effective way to increase screening participation, particularly when combined with reminders sent to a woman.[13,14]
- One study found recalls or reminders effective in increasing uptake for both a mammogram and Pap screening.[13]

Result Notification

Regarding result notification in a correspondence initiative, the literature has noted the following:

- Failures by providers to inform patients of clinically significant abnormal test results or to document that they have been informed appeared to be relatively common, occurring in one of every 14 tests (more than 7 per cent).[15]
- Correspondences on abnormal test results may increase a patient's follow-up adherence.[16]
- Women prefer to receive prompt notification of all lab test results, including normal results, from their physician via phone. Their second choice is to receive normal results in the form of a report or letter.[17,18]
- Women prefer to have their physician directly and promptly communicate to them about abnormal results (telephone call or in person).[19]
- Women prefer to receive detailed information about their test results and what the results mean.

Follow-up Adherence

Follow-up adherence for an abnormal test has also been referenced in the literature. The following are some of the key findings:

- There is an increase in initial follow-up rates with personalized patient reminders (mail or phone).[20]
- Patient appointment reminders (phone or mail) prior to a follow-up procedure reduce missed appointments, thereby increasing follow-up adherence (e.g., repeat Pap test or colposcopy).[21,22]
- There is an increase in follow-up adherence, in comparison to a reminder letter, when the correspondences include details about the abnormal result and recommended procedure.[23,24]
- Mail is a less effective correspondence reminder tool for women of lower socio-economic status and/or lower educational status.[7]

A chart summarizing the above and additional literature can be found in Appendix D.

Approaches to Correspondence

Several overarching principles apply to all types of correspondence: appropriateness, accuracy and timeliness.

Appropriateness – Making sure the right information is available so the message is appropriate such that the woman has the right information to make an informed choice. The information would be consistent with guidelines.

Accuracy – Ensuring that the correspondence reaches the right woman or provider.

Timeliness – Ensuring that the correspondence reaches the woman or provider at the right time.

It is important to consider and clearly define the following factors when preparing and before sending correspondence. These considerations apply to all types of correspondence (invitations, recalls, results notification and follow-up of abnormal results).

- Goal(s) of the communication
- Target audience
- Key messages
- Most effective tool(s) for the type and goals of the communication
- Evaluation or outcome indicator that indicates the impact of the communication and tools used

The content of any communication message must be balanced, providing information about both the benefits and risks of screening. It is recommended that the content focus on cervical cancer screening instead of just Pap tests. The broader reference facilitates the transition to new screening tests (e.g., primary HPV testing) and supports the integration of generic messages with other screening programs (e.g., breast and colorectal cancer).

For the purpose of this document, correspondence focuses primarily on traditional letters. Correspondence can also include other media, such as emails, tweets and phone calls. Typical correspondence includes a letter to a woman and/or her health-care provider, along with supporting material such as a brochure or fact sheet. The letter should be short, clear and concise. It must have a clear "call to action" specifying next steps and requirements. The supporting material should contain information the woman needs to make an informed choice about screening or follow-up. Research indicates that customized letters signed by a champion, medical director and/or a woman's physician are more effective than generic letters. Customization entails tailoring the message to the individual. A customized letter would be specific to a particular woman. For example, it would include information about previous screening activity, with the date(s) of previous test(s).

It is important to remember that the target audience for most correspondence is *screen-eligible* women as defined by jurisdictional guidelines. Attention should be given to women who should not receive letters. Typical exclusion criteria include clinical ineligibility for screening (e.g., women who have had a hysterectomy), a prior diagnosis of cancer, having opted out of the program, being deceased or residing outside the province or territory.

In addition, consideration needs to be given to ensuring that the content is appropriate and culturally aligned to the target audience. Use plain language and an appropriate literacy level. (Additional information is found in the Factors for Consideration section and in Appendix E.) Be sure to meet provincial or territorial requirements (e.g., bilingualism). As well, programs may wish to offer letters and supporting materials in multiple languages, available either by request or on public websites.

While research has demonstrated the effectiveness of correspondence, a screening program's engagement strategies should not rely solely on letters. Letters should be supplemented by other strategies, including phone calls, electronic communication, targeted activities for those who are more difficult to reach, health promotion activities, mass-media campaigns and strategies directed to health-care providers.

As a general principle, a limited number of invitations should be sent to a woman. If an unscreened woman is invited regularly (e.g., every two or three years) for routine screening three times with no action, continuing to deliver the same message using the same medium will likely be ineffective. Alternative strategies should be considered to reach these women who remain unscreened.

Invitations

An invitation is correspondence from a cervical screening program to a *never screened woman* informing her about screening and her eligibility to participate in screening. The following table highlights key components of a typical invitation. Each province and territory should consider this as a guide and should determine its specific goals, audience, message and tools.

Communication goals	▪ Provide women with appropriate information about their screening options, including information about cervical cancer risk reduction or prevention opportunities, to support an informed screening decision. ▪ Optimize screening participation.
Target audience	Women of screen-eligible age as defined in provincial or territorial guidelines (e.g., women 21–69 years of age in many provinces and territories) that have not opted out of the program and have not been determined to be clinically ineligible to participate by a health-care provider.
Key messages	Consider the following when creating the messaging content: ▪ Include the four Ws and H: what, where, when, why and how. ▪ Indicate why screening is important and what will be gained from it. ▪ Explain screening and its risks and benefits. Include a description of the test and the screening pathway. ▪ Explain how and where to get screening. ▪ Offer information and reassurance regarding privacy. ▪ Ensure the message is balanced and supports a woman in making an informed choice, including opting out with no impact on other clinical services. ▪ Include a positive tagline that prompts action and that can be used across varied communication mediums (e.g., letters, brochures, advertising).
Appropriate time to communicate	Invitations should be sent at intervals throughout the year. This spreads out the demands on operational (creation and distribution of invitations), screening and colposcopy services. Intervals can be set according to a region or a woman's birth date or age, or they can be randomly organized.
Effective communication tools	The most effective tool is a short letter with a strong call to action with supporting materials (e.g., fact sheets, brochures) that support a woman in making an informed screening choice.
Evaluation or outcome indicator	▪ Proportion of women successfully reached (invited), enabling them to make an informed screening decision.

	▪ Proportion of invited women screened. ▪ Proportion of invited women who actively opt out of the program.

All messages should be informed by evidence and refer to guidelines, as appropriate. They can focus on a sub-population (e.g., never screened, seldom screened or newly eligible for screening). Resources to help create invitation correspondence are available:

- **National Health Services** has published information about improving the quality of written information sent to women about cervical cancer screening through invitations, recalls and results notifications. It also addresses the content of letters and leaflets.[25]
- **Pan-European Group of Professionals and Programs** has provided recommendations for improving the quality of communication in organized cervical screening programs, including message content.[26]

Alberta's cervical screening program has tested a number of different correspondence approaches and evaluated their impact. For the population of women who were not screened during the program's first five years, an absolute increase in screening uptake was achieved with invitations compared with a control group that was not invited.

In the literature, message framing has consistently been shown to have a measurable and significant effect on behavioural decision-making. However, the literature is conflicting as to whether messages that emphasize the potential gain of regular screening (gain framed) are more effective at increasing screening uptake compared with those that emphasize the potential loss of not being screening (loss-framed). In Alberta the finding is that the tone of the message—positive, negative or neutral—has little difference on the outcome (response rate).

An analysis of cost suggested that the average correspondence cost per additional woman screened was $65 for all ages combined.

Alberta also compared the impact of standard letters with enhanced letters that included an offer of special female provider run clinics for screening to address perceived access issues. There was no difference (neither substantive nor significant) in the response rate for the two types of letters.

The Alberta program is continuing to monitor and evaluate its ongoing real world experience of sending correspondence to women.

Recalls

A recall is correspondence from a cervical screening program to a *previously screened woman* informing her that she is due for repeat routine screening. The following table highlights key components of a typical recall. Each province or territory should consider this as a guide and should determine its specific goals, audience, message and tools.

Communication goals	Similar to invitations in terms of optimizing rates and supporting informed choice, plus the following additions: ▪ Achieve regular screening and retain participants. ▪ Enable guideline adherence and optimal screening utilization by supporting participants and providers to minimize under- and over-screening.
Target audience	Screen-eligible women, as defined by provincial or territorial guidelines, who are due for repeat routine screening.
Key messages	Messaging is similar to an invitation except this correspondence is for recalling a previously screened woman. Consider the following when creating the messaging content: ▪ Include the four Ws and H: what, where, when, why and how. ▪ Indicate why screening is important and what will be gained from it. ▪ Explain screening and its risks and benefits. Include a description of the test and the screening pathway. ▪ Explain how and where to get screening. ▪ Offer information and reassurance regarding privacy. ▪ Ensure the message supports a woman in making an informed choice, including opting out with no impact on other clinical services. ▪ Include a positive tagline that prompts action and that can be used across varied communication mediums (e.g., letters, brochures, advertising).
Appropriate time to communicate	Be sure to keep local factors, including prioritization, in mind when timing the sending of recall correspondence. For example, some jurisdictions elect to send recalls to all women before they are due for rescreening. Others choose to send the recall a short time (e.g., a couple of months) after the recommended screening interval to those who have not yet been rescreened.
Effective communication tools	The most effective tool is a short letter with a strong call to action with supporting materials (e.g., fact sheets, brochures) that support a woman in making an informed screening choice.
Evaluation or outcome indicator	▪ Proportion of women successfully recalled, enabling them to make an informed screening decision. ▪ Program retention rate. ▪ Proportion of recalled women who are screened at the recommended intervals.

Recall letters can support health-care providers to extend the screening interval from annual to guideline-recommended intervals, particularly if providers do not have an electronic medical record (EMR) system. Some providers without EMRs default to annual screening and over-screening rather than risking under-screening.

Over time the content of the recall message may evolve as the program, the correspondence initiative and the audience mature. Women who are regularly screened and who have received repeated recall letters and result notifications will not need as much information as a woman being invited to screening who has never been screened.

Result Notification

Result notification is correspondence from a cervical screening program to a woman providing a summary of the outcome of a screening test, apprising a woman of her test results and any required follow-up action. Result notification is intended to support or complement the care provider–patient relationship. The health-care provider retains responsibility for notifying the woman of her test result and ensuring that she receives appropriate follow-up care. Result notification should act as a backup or failsafe to ensure each woman is informed of the results of her screening test.

Communication goals	▪ Ensure women receive appropriate and timely notification of their test results. ▪ If the results are normal, to ensure women return for screening at the recommended interval per guidelines. ▪ If the results are abnormal, to ensure women are given information about the importance of following up on abnormal test results to support women to receive timely follow-up.
Target audience	All women who have had a screening test.
Key messages	Consider the following when creating the messaging content: ▪ Clearly describe the test result, what it means and any appropriate next steps. ▪ Provide balanced information to ensure the recipient does not have a false sense of security. ▪ Include information on symptoms that would warrant an earlier return to their health-care provider (e.g., abnormal bleeding). ▪ Provide information about when the woman should be screened again (if test results are normal). ▪ Clearly identify the appropriate next steps, which include talking to their health-care provider (if results are abnormal). It is critical that an abnormal result notification message balance reassurance with a call to action. Use plain language and use terms such as “normal” and “abnormal” rather than technical terms. Avoid terms such as ASCUS (Atypical Squamous Cells of Undetermined Significance) or HSIL (High Grade Squamous Intraepithelial Lesion).
Appropriate time to communicate	A woman should receive a result notification in a timely manner after her provider receives the test results so that the provider has an opportunity to inform the woman, particularly if the results are abnormal. Timing depends on when a screening program receives all necessary data. In jurisdictions where screening consists of a primary test followed by a triage test (e.g., primary cytology with HPV triage), the correspondence should be a single letter and sent when results from both tests are in. The program letter should reinforce the provider’s discussion with the woman and act as a failsafe for women with an abnormal result.
Effective communication tools	The most effective tool is a short letter with a clear message and strong call to action with supporting materials (e.g., fact sheets, brochures) that support a woman in making an informed screening choice.

Evaluation or outcome indicator	▪ Proportion of women successfully mailed their test results. ▪ Program retention rate. ▪ Proportion of women with an abnormal test result who receive appropriate follow-up care.

Follow-up (Abnormal)

Follow-up is correspondence by the screening program to health-care providers, women or both to ensure appropriate investigation of abnormal screening results, usually when this action is overdue. Depending on resources, provinces and territories may elect to focus on significant abnormalities.

Communication goals	Ensure women receive appropriate and timely follow-up of abnormal test results.
Target audience	Women who need follow-up after an abnormal screening test; letters can be sent to either women or their providers.
Key messages	Consider the following when creating the messaging content for letters to women: ▪ Indicate the need to follow up with their provider about the (abnormal) test results. ▪ Give specifics of the test in plain language, possible next steps and a recommendation to complete follow-up activities (e.g., repeat Pap test or colposcopy). ▪ Explain that an abnormal test result does not mean the woman has cancer and that abnormal cells can usually be monitored and treated, if necessary, so that cancer does not develop. ▪ Indicate if the woman is overdue for follow-up. Messaging content for letters to the health-care provider would focus on the result, the recommended follow-up and whether the woman is overdue for follow-up.
Appropriate time to communicate	Follow-up correspondence should be sent when a woman is overdue for assessment and treatment. Factors such as local wait times for colposcopy and the severity of the test result will also inform when a follow-up message is sent.
Effective communication tools	The most effective tool is a short letter with a clear message and strong call to action with supporting materials (e.g., fact sheets, brochures). The message in this follow-up correspondence should be stronger than the result notification.
Evaluation or outcome indicator	Proportion of women with an abnormal test result who receive timely, appropriate follow-up care.

There are two approaches to follow-up: 1) corresponding with a woman directly and 2) corresponding with a woman's health-care provider, who in turn communicates with the woman. Messages to a provider are more specific and detailed with regard to the result and more clinically focused in terms of recommendations for follow-up. For example, a letter to a woman may say that the screening test found abnormal cells, while the physician letter would cite the actual cytological finding (e.g., ASCUS, HSIL).

Follow-up letters are part of a broader organized screening program approach to follow-up of abnormal results and should be integrated with other strategies that may be undertaken. For example, in some provinces laboratories may follow up with physicians regarding women with abnormal screening test results who have not had diagnostic assessment and/or treatment.

> In Newfoundland and Labrador the abnormal follow-up protocol is a three-step process. The first notification with information on the individual woman's test result, test date and personal identifiers is sent to the attending health-care provider. If there is no response a second reminder is sent to the same health-care provider. The next step is to send correspondence directly to the woman to encourage follow-up attendance.

Because the data sources used to generate follow-up letters may be less that 100 per cent complete, the message content will need to include acknowledgement that some women receiving the letters may have actually had follow-up procedures and are not, in fact, overdue. These women should continue to follow the next steps recommended by their health-care provider.

Reminders

Reminders are any correspondence sent to a woman subsequent to previous correspondence to the same woman to reinforce the message of the initial correspondence. A reminder can follow an invitation, recall or follow-up notification.

The timing of reminders will be influenced by financial considerations and the potential response rate. Correspondence sent a few weeks after an invitation or recall will increase the overall response rate. However, it will be more costly than waiting until some set interval (e.g., three months) after the initial letter before sending the reminder to all non-responders. As with other aspects of correspondence, a program may want to conduct evaluation research to determine the best interval for reminders.

The key messages and outcome indicators would be similar to the initial correspondence. The target audience would be non-responders to the initial correspondence.

> As more and more cancer agencies are moving to integrated cancer screening programs, consideration should be given to including integrated messaging in letters to women. For example, a cervical cancer screening invitation to a woman in her 50s could also include a message related to breast and colorectal cancer screening. The messaging could be a generic statement that is inserted in similar types of letters. As a program's information technology improves the message can be customized for individuals based on their screening history.

Planning Considerations and Enablers

Implementing a correspondence initiative is complex. The initiative needs to be part of the broader design of an organized screening program.

A number of planning considerations and enablers for a correspondence initiative have been identified. The following is a list of significant factors for consideration. The list is not exhaustive and the importance of these factors will vary across jurisdictions as the approach is informed by local factors (e.g., culture, politics and legislation).

1) Screening guidelines
2) Population-based data registry
3) Data completeness and accuracy
4) Privacy and opting out
5) Information technology
6) Clinical engagement
7) Plain language
8) Fulfillment house or in-house mailing
9) Other media
10) Evaluation
11) Staged implementation
12) Risk assessment
13) Funding

Screening Guidelines

To the extent possible, decisions regarding correspondence should be informed by screening guidelines and evidence. Screening guidelines in many Canadian provinces and territories are converging (e.g., age of screening initiation moving to 21 years). However, differences remain between jurisdictions and need to be kept in mind. For example, the degree of adherence to guidelines by clinicians varies. In many parts of Canada, family physicians perform screening tests annually, regardless of guidelines.

Program correspondence can be used to inform participants, and thereby care providers, of the recommended guidelines, promoting better adherence. For example, a result notification letter, in addition to providing information on a test result, can also provide information on guideline recommendations (e.g., screening intervals). Recall letters are a key enabler for providers because these letters support the move from default annual screening to more appropriate screening intervals and assure providers that women will be notified to return for screening.

> In 1996, British Columbia changed screening mammography policy for women 50–79 years of age from annual to biennial screening. With a recall letter system already in place, B.C.'s Screening Mammography Program sent out information about the policy change to women at the time of their annual recall, and then supported their behaviour change by sending recall letters when they were due at the two-year mark.
>
> Program data showed that within two years the retention rate at 18 months changed from 70 to 20 per cent, with women returning later at the recommended two-year interval.

Population-based Data Registry

Implementing any element of program correspondence requires a population-based database or registry. Without information on all women in the target population it is not possible to invite or recall all eligible women. Cervical screening databases have historically contained laboratory test information that often does not include contact information for all women in the target population. Data completeness, privacy and funding are among other factors that need to be considered.

Data Completeness and Accuracy

Complete and accurate data are a prerequisite for many elements of an organized screening program, particularly correspondence. Incomplete or inaccurate information can result in a woman not being invited or recalled for screening. If the data on screening tests and the results cannot be matched to the correct contact information, the wrong woman could be incorrectly informed of the results. If there is no access to follow-up investigation data (e.g., colposcopy), then follow-up correspondence for abnormal results cannot be implemented.

Timely access to data is as important as data accuracy and completeness. The frequency (e.g., daily, weekly or monthly) and method of data access (e.g., direct linkage, data feed) need to be considered in the context of correspondence requirements.

Ensuring the accuracy and completeness of data is an ongoing endeavour for the screening program and all who collect and enter data. There must be confidence that correct correspondence will be provided to the correct person (woman or provider) at the right time.

Privacy and Opting Out

The privacy environments in provinces and territories differ, not only in the legislation but also in the rulings and orders from the local privacy commissioner. In addition to the federal privacy act, *Personal Information Protection and Electronic Documents Act* (PIPEDA), most jurisdictions have their own legislation regarding the collection, use and disclosure of personal health information. It is critical that a privacy impact assessment be conducted before embarking on any new participant correspondence initiative.

Privacy considerations can influence how correspondence is implemented. In several provinces (Alberta, Saskatchewan and Ontario), based on privacy advice or rulings, a privacy notice must be sent out before program correspondence containing personal health information is launched. For example, in 2011, prior to Alberta's province-wide expansion of its cervical screening correspondence function, introductory letters explaining the program were mailed to all eligible women in advance of the launch of result notification. The letters described the program—how it works, how to participate and how to withdraw.

An important aspect of privacy is the ability for women to opt out of the program. As with many other elements, provinces vary in the meaning and implementation of an opting out option. A 2005 report by the Saskatchewan Information and Privacy Commissioner states that for opting out to be meaningful the woman's identifiable information must be purged from the program database.[27] In Ontario, "opt out" means that a woman no longer receives correspondence (e.g., invitations, recalls, results) from the program but her identifiable information remain in the database. The opt-out process should address the numerous reasons for opting out, including privacy concerns and personal choice. It is important to consult the office of the information and privacy commissioner in your jurisdiction before embarking on correspondence or making significant changes.

Another important element of privacy to consider is consent. Most provincial and territorial privacy legislation includes provisions for program designs that do not require explicit consent. For a population-based screening program to maximize its effectiveness the program must be able to issue invitations to members of the screen-eligible population who have not been screened. This can be done only if the

privacy legislation allows for opting out rather than insisting that eligible women opt in. An understanding of the local privacy context, including legislation and regulations, is important.

An element related to privacy that is often overlooked is the envelope in which correspondence is sent. In several provinces, logos and program names have been removed from the envelopes because of privacy concerns. The general thinking seems to be that if the outer mailing envelop indicates that it is from the cervical screening program the woman's privacy may be infringed, as the sender will be revealed to anyone who sees the envelope.

As correspondence media channels evolve to include email, among others, additional privacy factors will need to be considered. For example, emails that contain test results and other personal health information must be encrypted in many jurisdictions.

Information Technology

Information technology (IT) and its associated systems are key enablers of program correspondence. IT systems allow a large amount of data from a number of disparate sources to be integrated to support correspondence processes and algorithms. Sources include government health databases of insured women, government claims databases and laboratory information on test processing and results. Technology can enable an invitation or recall letter to be customized based on the characteristics of a woman and her screening history. Technology can provide consistent, high-quality privacy and data security safeguards and auditing tools to monitor adherence to privacy and security policies. As well, technology can enable correspondence evaluation.

When designing a program it is important to invest time and resources to develop evidence-based algorithms and processes and to consider the data sources that are available and the accuracy of the data. These processes and algorithms will be foundational for the development of IT systems focused to support program correspondence. The number of interfaces required will influence the complexity of the IT system.

> An organized cervical cancer screening program for eligible women in New Brunswick (NB), inclusive of an automated invitation and recall system, is currently in development. To date, the focus has been to develop a population-based repository of women screened for cervical cancer in order to identify and invite those who are un-screened. With this complete, the next phase will be to interface the cervical screening repository with existing provincial data client registries and information systems to facilitate correspondence.
>
> NB is presently defining the requirements and planning for the development of one centralized IT solution that will be used to monitor, invite and recall New Brunswickers who are eligible for both cervical and colorectal cancer screening.

Clinical Engagement

Clinical engagement is a critical factor in the success of a correspondence initiative. Health-care providers should be involved at all stages. During program design, clinicians can provide key input regarding algorithms and processes, including who should get what type of letter. For example, in Ontario clinicians were critical to defining and refining the approach to result notification. Initially, based on clinical practice guidelines, a large number of templates were contemplated. An expert clinical panel was able to streamline the approach to six templates. Clinical input is also important to ensure the accuracy of the letters and supporting materials.

Correspondence initiatives should be designed to strengthen the patient-provider relationship. A component of this is to inform health-care providers about the launch of new correspondence elements. Providers need to be aware of and support any letters being sent. This communication should also be linked to broader knowledge transfer and exchange activities related to clinical practice guidelines. Letters to women need to be supported and reinforced by clinical tools that address such topics as screening intervals and the appropriate follow-up of women with an abnormal screening test.

Plain Language

It is important when writing for the general public to assume that the audience does not have a high-school education or a science or health background and will not understand technical terms. Plain language should be used and jargon avoided. Letters about screening can adopt a straightforward factual tone. However, the tone of brochures, websites and in particular correspondence communicating abnormal results should be reassuring, empathetic and warm. Appendix E has more information on plain language writing.

Fulfillment House or In-house Mailing

When beginning correspondence, consideration should be given to who mails the letters. While the screening program must generate the list of who receives which letters and when, the mailing can be contracted out. A fulfilment house is a business that specializes in providing services related to mailing, including printing and storing materials, preparing mailings and doing the actual mailing. If a fulfillment house is used, the details of these processes must be addressed in the program's privacy impact assessment.

For any correspondence mailing, the following functions need to be carried out:

- Verifying addresses
- Checking for address changes
- Printing letters and brochures
- Stuffing envelopes
- Managing returned or undeliverable mail

Using a fulfilment house obtained through competitive procurement processes can be more efficient, effective and cost-effective than in-house mailing. For example, most fulfilment houses will verify addresses against address accuracy software approved by Canada Post, reducing the amount of mail undeliverable owing to incomplete or inaccurate addresses. Fulfilment houses also use Canada Post's National Change of Address (NCOA) database. Each year, approximately 1.2 million households file a change of address notification with Canada Post. The NCOA database contains over 10 million movers—a six-year history of permanent address changes. Use of the NCOA database facilitates more accurate mailings, including minimizing undelivered or returned mail.

Other Media

Correspondence is any information directly transferred between a screening program and a woman, either directly or indirectly via health-care provider(s) responsible for engaging them in screening and associated follow-up requirements. This type of direct communication could include letters, emails or phone calls. The primary focus for this document is letters.

Participant correspondence is an important element of an organized, population-based screening program and allows the program to directly reach individuals. Participant correspondence is different from

mass media campaigns that target groups and may not reach some individuals. However, participant correspondence should not be the only mechanism used to engage and retain women in screening programs. Letters should be reinforced and supported by other strategies, including the following:

- Phone calls
- Electronic communication
- Targeted activities for those who are more difficult to reach
- Health promotion activities
- Mass media campaigns
- Clinician-directed strategies

The combined effect of letters and mass media campaigns can be greater than employing either as a standalone initiative. For example, a woman who sees a television ad and then receives an invitation is more likely to participate in screening than a woman who only views an ad or only receives a letter. Similarly, a woman who receives a recall letter may forget to schedule a screening test appointment but a radio ad may remind her to call her physician's office.

Evaluation

Research has demonstrated the effectiveness of various correspondence strategies. However, it is important that organized cervical screening programs include evaluation as a component of any correspondence strategy. This evaluation will help determine the impact of a correspondence initiative in that particular jurisdiction. It can also identify sub-populations for which a particular strategy is not effective or identify areas for improvement (e.g., timing or content of letters).

Dr. M. Bretthauer and Dr. G. Hoff of the Norwegian screening program recently highlighted the importance of evaluation in a discussion on comparative effectiveness research in cancer screening programs.[28] They state that while screening during clinical trials is often innovative, cancer screening programs are largely static and not designed to generate new, evidence-based knowledge. They recommend using the principles of comparative effectiveness research to overcome the obstacles associated with making changes to screening programs.

Evaluation is usually done after implementation and is often overlooked during the design and launch phase of a correspondence initiative. There are advantages to considering evaluation early in program design, such as ensuring the availability of data and access to resources (e.g., analytical tools and funding) that support evaluation. Moreover, addressing evaluation from the beginning will expose evaluation opportunities, highlight elements that may affect implementation plans and support decision-making about what to evaluate. This is important when managing the challenges and confounding variables that can occur, such as media campaigns and other intervention strategies.

In the section discussing approaches to correspondence and invitations, a box described the evaluation of various aspects of Alberta's correspondence program (page 16). It illustrates how local, real-world experience is not always the same as research. Specifically, Alberta found that the tone of the message—positive, negative or neutral—makes little difference to the outcome (response rate).

Staged Implementation

Consideration should be given to implementing correspondence incrementally (e.g., pilots, phased implementation). Doing so allows for experimentation and testing of such things as information systems, correspondence algorithms and messaging content before full implementation and expansion throughout the jurisdiction. In addition, a phased implementation approach minimizes the impact of any challenges

that come up in the initial stages and provides an opportunity to make changes or corrections before expansion.

Even when planning to implement correspondence in phases it is important to first consider the overall plan or end-state you are building toward. The overall plan for different correspondence elements should result in all women receiving some type of letter every couple of years, but not too often. The initiative needs to determine how often women will be invited (e.g., once every two years if no recent screening activity) and how often they will be recalled (e.g., once every three years).

Risk Assessment

An important exercise during the planning stages of a correspondence initiative is to identify risks and develop mitigation strategies. Risks can be large or small and could include the following:

- Sending the wrong letter to a woman (e.g., result notification)
- Sending a letter to the wrong address
- A letter not being delivered
- A letter not being read or being read by someone other than the addressee
- Information system failure
- Postal strikes
- Major power disruption

Risks should be assessed for both likelihood and impact. For example, while a postal strike may not be likely it would have a significant negative impact, particularly in sending results in a timely manner. It is important to ensure executive sponsors are aware of and sensitized to the risks. While it is ideal to have no privacy breaches associated with sending correspondence to the wrong person, it is likely that a small proportion of letters will be sent to the wrong address. Sponsors should be aware of and accept the expected level of risk. Processes for managing these eventualities should be in place before any correspondence is sent.

Funding

An overarching consideration that runs through all the above considerations is funding. Funding influences how much can be done and how it is done. If funding is not available to support the development of an information system and the integration of data from different sources, a program's options for sending correspondence are constrained.

In today's economic climate resources available to programs are limited. The next section of this document, Factors for Prioritization, outlines some considerations for assessing and prioritizing correspondence options. Ongoing funding for correspondence needs to cover a wide range of areas, including the following:

- Maintaining and enhancing the information system and infrastructure
- Managing the cost of letters and collateral material
- Tracking and managing returned or undelivered mail
- Addressing corrections and making updates
- Updating letters and collateral materials regularly
- Having the capacity to respond to calls from the public, including women wanting to opt out of a screening program

- Reporting regularly on operations
- Evaluating the correspondence initiative

Implementing correspondence in a phased approach or through pilots gives an opportunity to realistically assess costs and to spread up-front costs over a longer period. Factors for prioritization can influence what correspondence elements are implemented and when, and are based on needs and anticipated return on investment.

Factors for Prioritization

When prioritizing correspondence implementation, data is needed to inform decisions, such as what age group should be targeted first for invitations. The best source of data is a jurisdiction's own program performance data. A good source of comparison information is the national report on cervical cancer screening in Canada, *Cervical Cancer Screening in Canada—Monitoring Program Performance 2006–2008*.[29] The assessment and prioritization of correspondence elements should consider data from the relevant province or territory.

- The median age at diagnosis of cervical cancer is much younger than for many other cancers, such as breast and colorectal.[30]
- Mortality rates are low among younger women but increase steeply after age 40.[30]
- Screening participation is higher in younger women than in older women, particularly those aged 60–69.[29]
- Program retention rates in Canada range from 75 to 87 per cent.[29]
- A research study in Ontario found that more than 26 per cent of women with high-grade dysplasia did not receive follow-up (e.g., colposcopy).[31]

The vast majority of invasive cervical cancers are related to the following factors:

- Poor Pap screening history – Inadequate screening or having never been screened is a primary factor contributing to the development of invasive cervical cancer.[32,33] A systematic review, including studies from the United States, Canada, Australia and many European countries, estimated that 54 per cent of women diagnosed with invasive cervical cancer had inadequate screening histories and 42 per cent were never screened.[32]
- Failure to complete follow-up after an abnormal Pap – Failure to follow up on abnormal screens can result in increased morbidity, mortality and health-care costs.[34] Several studies have found that approximately 11–13 per cent of invasive cervical cancer cases had poor follow-up of abnormal results. [23,32,35]
- False-negative Pap test – A systematic review, including studies from the United States, Canada, Australia and many European countries, estimated that 29 per cent of failures to prevent invasive cervical cancer could be attributed to false-negative Pap tests.[32]

Since most women who develop cervical cancer were either never screened or under-screened, interventions to increase cervical cancer screening participation and adherence to follow-up are needed to reduce cervical cancer incidence and mortality. Priority setting for correspondence implementation will be informed by whether the program is more concerned about screening rates, loss to follow-up or the goals for each type of correspondence as outlined in the Approaches to Correspondence section. For example, for a screening program to contribute to a reduction in incidence and mortality, it would need to focus on hard-to-reach populations, particularly those who are most at risk of being lost to follow-up. To enable result notification and follow-up of women with abnormal results, data linkages, particularly with cytology and histology (colposcopy), are needed.

Another factor to be considered when phasing invitation messages is system capacity. This is important when there are long turnaround times in cytology. Similar concerns with colposcopy access and wait times may need to be dealt with while addressing loss to follow-up with correspondence about follow-up of abnormal results.

Recommendations

Much has been written about the principles of organized population-based screening and the policies necessary to ensure high-quality screening that minimizes adverse effects and maximizes benefits. The European Guidelines for Quality Assurance in Cervical Cancer Screening[1] stress that screening programs should be based on guidelines, have a quality assurance program, perform regular monitoring and evaluation and, of significance for this document, include a robust correspondence initiative.

Corresponding with program participants can have a number of positive outcomes on a screening program, including the following:

- Supporting informed decision-making by women
- Optimizing screening rates
- Improving adherence to guidelines (e.g., reducing over- and under-screening)
- Improving program retention rates
- Ensuring women are informed and knowledgeable about the outcome of their screening test
- Increasing the proportion of women who receive timely follow-up after an abnormal screening test

The first national report on cervical cancer screening in Canada, *Cervical Cancer Screening in Canada—Monitoring Program Performance 2006–2008*, includes data that confirm performance gaps that could be addressed through program correspondence initiatives.

- The proportion of women who have not been screened within the past three years ranges from 20 to 36 per cent.[29]
- The proportion of women who do not return for rescreening ranges from 13 to 25 per cent.[29]
- The proportion of women with high-grade dysplasia who did not get follow-up within six months ranged from 14 to 44 per cent.[29]

A key characteristic of cervical cancer screening programs is a robust correspondence initiative that ensures women are *invited* to participate in cervical cancer screening, *notified* of their screening results, *recalled* when it is time for them to return for screening and reminded of any appropriate *follow-up* action.

The Network recommends the implementation of all correspondence elements across all Canadian cervical cancer screening programs. Each province or territory should conduct their own prioritization exercise to determine the approach and correspondence elements appropriate for them, reflecting on capacity, resources and overall program goals.

Given the current economic climate in Canada, it may not be possible for a program to implement all the elements initially. However, programs should work toward having a full complement of correspondence, with implementation informed by local factors for prioritization, including those identified in this document.

While correspondence is important, it should not be a standalone element. Other complementary or supplementary approaches are needed to increase screening rates (e.g., mass media) or improve follow-up of abnormal results (e.g., reports to health-care providers).

A fundamental principle is that correspondence should not replace the woman's relationship with her care provider; it is an adjunct or complement that supports the relationship. As well, correspondence should not supersede existing medical practice and standards of care. Laboratories remain responsible for sending test results to the health-care provider who ordered the test and providers remain responsible for notifying women of their test results. Another key principle is that correspondence and supporting materials must provide balanced messaging on the benefits and harms of cervical cancer screening, thereby supporting a woman's ability to make an informed choice about being screened.

As part of implementation and ongoing operations, it is important to continue to assess value for money, impact and outcomes.

A note about PCCSI:

The PCSSI network includes representatives from Canadian provinces and territories, health-care professional groups, the Public Health Agency of Canada, the Canadian Cancer Action Network and the Canadian Cancer Society. Through its collaborative work, PCCSI is helping to optimize the contribution of screening programs to overall incidence and mortality reduction for cervical cancer.

Appendix A: PCCSI Workshop Summary

Pan Canadian Cervical Screening Initiative Correspondence Meeting

April 13, 2011

Summary of Proceedings

Prepared by:
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Introduction

On April 13th, 2011, representatives from cancer control programs across Canada participated in a meeting to *share strategies to develop, disseminate and encourage uptake of key cervical screening program correspondence elements*. Dr. Meg McLachlin welcomed the group to the session and provided an overview of the Pan-Canadian Cervical Screening Initiative (PCCSI), with the mandate of serving as a national forum to discuss and take action on matters related to cervical cancer screening programs and its integration with HPV testing and vaccination initiatives. With an emerging priority to focus on correspondence with screening participants and the goal of bringing and keeping women in cervical screening programs, a decision was made in January to host a correspondence meeting. Jenny Colin, Chair of the session's planning team, extended her thanks to all involved and invited participants to review the poster boards that showcased the correspondence activities of seven jurisdictions.

The session was structured such that information to inform correspondence strategies was presented to the group during the morning, with opportunities for discussion. Participants were then divided into three breakout sessions in the afternoon to develop correspondence strategies.

Proceedings from the retreat are presented as follows:

1. *A Review of Evidence of Effective Correspondence to Improve Cervical Cancer Screening Compliance* – Highlights of evidence gathered from an extensive review of literature and guidelines that supports the need for effective correspondence to improve screening compliance.
2. *The National Health Service Experience: Cervical Screening in England* – A summary of the correspondence approaches tried, tested and implemented in England by the National Health Service (NHS).
3. *Current Practice in Correspondence in Canada* – A summary of an environmental scan of the cervical correspondence practices and concerns across Canadian jurisdictions.
4. *Summary of Breakout Discussions of Correspondence Elements* – A summary of outputs from three discussion groups focused on i) inviting patients to participate in screening, ii) recalling and reminding patients, and iii) providing results and follow-up for patients.
5. *Correspondence Priorities and Next Steps* – Discussion of the priorities arising from the breakout group discussions, and the identification of next steps for the PCCSI and provincial programs.

Note that the presentation materials delivered during the planning day provide additional content and are intended as a companion document to these proceedings.

1. A Review of Evidence of Effective Correspondence to Improve Cervical Cancer Screening Compliance

Dr. Verna Mai presented a summary of a literature review to identify evidence supporting existing best practices and guidelines in correspondence, used in major industrialized countries, for increasing compliance for cervical cancer screening. This review was conducted by Dr. Clarence Clottey, a medical resident under Dr. Mai's supervision. Given the gap in current knowledge about existing evidence, an extensive review of literature and guidelines was undertaken. This was then filtered to produce a

summary of nine articles from studies undertaken in developed countries was prepared to inform discussions during the meeting.

Two meta-analyses, five primary publications and two sets of guidelines were reviewed. Highlights of the findings include the following:

- Most studies noted how difficult it is to evaluate the evidence given diverse populations and challenges in linking correspondence activities to outcomes. However, there is consistent evidence that invitational letters are useful.
- Letters under the signature of a physician have been shown to increase participation.
- Appointments and scheduling offered in the letters increases the effectiveness.
- Follow up from findings for abnormal tests from a second search of the literature indicated that there are many psychological factors that must be addressed, and can be supported by things like interactive phone counselling, helping women understand issues for concern (rather than just straight reminder letters), the use of thorough yet simple terms, and the need to address fears and anxiety.
- The need for informed decisions – brought up by Cochrane review and others – was stressed. Women must understand aims and limitations of screening, framing potential harm and benefits.
- Clear information must be given in the invitation materials about HPV testing.
- The accuracy of population registers is very important, there is a high need for correct contact details above all else.

Following her presentation, Dr. Mai responded to questions. Discussion focused on the need for direct and personal communications (with increasing opportunities to use social media), the need to use the evidence carefully when applying it to unique jurisdictional contexts, and the role of the physician in signing letters to increase participation.

An annotated bibliography of "A Review of Evidence of Effective Correspondence to Improve Cervical Cancer Screening Compliance" was distributed to all session participants and contains more detailed information.

2. The National Health Service Experience: Cervical Screening in England

TJ Day, Access Manager for NHS Cancer Screening Programs in England, delivered an informative presentation about the NHS' experience in developing and delivering a cervical screening program. TJ provided highlights of the program and its history which include:

- an overview of the publicly funded NHS,
- annual statistics with over twenty years of cervical screening with average coverage of 80%,
- key moments in the program's history including a national screening office set up in 1994 based in the north of England and run by Primary Care Trusts,
- launch of informed choice in 2001,
- increase in age to 25 from 20,
- implemented two week turnaround for results in 2007, and
- have HPV triage into the program.

Since 1988, the NHS has halved the incidence of cervical cancer. There is significant primary care involvement, with most screening taking place in General Practitioners' (GP) offices. GPs are incented with payment if a woman is successfully put through the whole framework. A Quality Assurance structure has been put in place with regional QA reference centres.

A challenge for the NHS remains the screening age range, and cross-border movement (e.g., between England and Wales). A high profile death due to cervical cancer at the age of 27 caused a push to lower the screening age to 20. The evidence was re-reviewed by the Advisory Committee on Cervical Screening who unanimously supported 25 as the most appropriate age to start cervical screening. However the NHS has had to spend considerable time and resources to explain why screening women under 25 is not optimal.

The NHS has implemented a call and recall system which includes accessing a list of all patients, sending Prior Notification List (PNL) to GPs to identify women who are due for screening, and developing a process flow for routine call and recall. PNLs are generated electronically 3 months prior to test due date and sent to GPs with options.

Failsafe actions were identified to ensure women are invited and re-invited, test results are followed up. These include:

- For call and recall – sends reminders, routine and early recalls
- For those referred for colposcopy – automated system
- Ceasing – be sure that ceasing audits are completed to ensure no inappropriate causes for ceasing of screening

For written information, a simple pathway regarding program letters has been developed. There are sixteen standard letters based on the Pap test results and previous history, however TJ noted that these require updating. Guidelines were developed for the various letters in 1997 with very specific criteria and information regarding content and presentation of materials. All invitations must be accompanied by Cervical Screening – The Facts leaflet. The NHS is being asked to produce better, more attractive information based on behavioural research, but there is also concern regarding the cost of leaflets. In general, the NHS suggests trying to make information (letters, posters, website) as simple as possible, with the use of the words normal and abnormal rather than positive or negative.

In the future, the NHS must respond to the following challenges:

- Fall in screening rates: high profile death of celebrity Jade Goody produced a massive peak in screening rates, but it quickly went back down and there doesn't seem to be a lasting effect
- 2 week TAT for results
- Revision of letters for invitation and results
- HPV triaging to be implemented in 2011/12
- HPV test of cure to be implemented in 2012/13
- Possibility of HPV primary screening

Session participants engaged in a Q&A session with TJ. Discussion topics included:

- Electronic reporting of physician PNL list
- The need for accurate information that links screening and treatment
- The positive influence of the registration of patients to individual physicians, with letters going out under GP's signature
- The importance of explaining two week turnaround times for results so that women can be mentally prepared to receive results, particularly for abnormal results which are shared in person
- The positive role of quality assurance practices that are built into the program
- The role of strong electronic communication between the NHS program and GPs in delivering results, ensuring follow up, etc.
- The role of informed consent in a multicultural society

3. Current Practice in Correspondence in Canada

Jenny Colin presented a summary of an environmental scan conducted among participating jurisdictions. Highlights from program activities include:

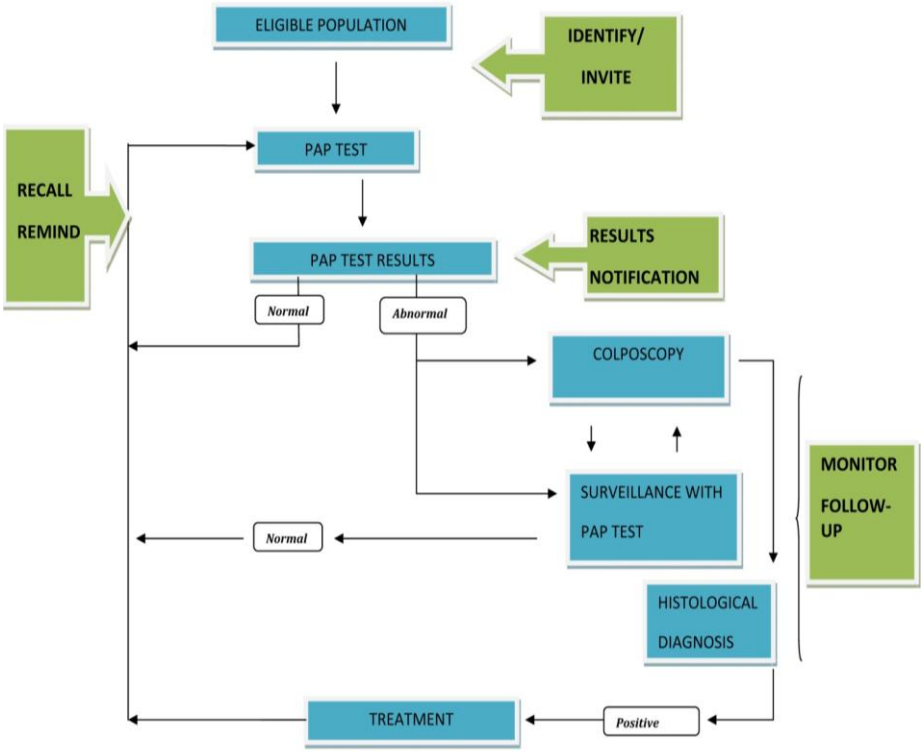
- Identification of eligible women by population-based registries or opportunistically currently occurs in five jurisdictions
- Five jurisdictions currently send invitations for screening
- Recall/reminder and result letters are currently sent by only two programs, others are nearing implementation
- Six jurisdictions send follow up for abnormal screens to care providers and sometimes to women themselves

Issues and concerns expressed by programs include:

- Lack of standardization regarding IT mechanisms such as algorithms, timing for letter generation
- Distribution of correspondence such that all women receive the same
- Data registries are not necessarily population based
- Screening guideline recommendations and actual clinical practices often differ
- Sometimes programs don't get timely notice when a women is referred for colposcopy, impacting follow-up and resulting in redundant activities

4. Summary of Breakout Discussions of Correspondence Elements

Catherine Hunter introduced the group to the structure of the breakout discussions. Discussions will focus on each of three elements of correspondence as per the following pathway:



Correspondence: Any information directly transferred between a screening program and a woman and/or her care providers, for the purpose of engaging them in screening and associated follow up requirements. This type of direct communication could include letters, emails, phone calls that:

The three groups (1 – Inviting Participants; 2 – Recall and Remind; and 3 – Results and Follow-up) were asked to address the following questions and present their recommendations to the larger group upon completion:

1. What is the communications objective(s) for this step?
2. Who, specifically, is the target audience for this correspondence? Consider primary and/or secondary audiences and define.
3. What are the preferred messages to be delivered via this correspondence?
4. What could be the most effective tools for delivering this kind of correspondence?
5. What are the main priorities and next steps for implementing this kind of correspondence on a pan-Canadian basis and that can be supported by the PCCSI?
6. Are there any other considerations or issues that should be noted?

Each group's findings are briefly discussed below.

GROUP 1 – INVITING PARTICIPANTS

- Communications objectives:
  - Increase participation rate in screening
  - Deliver the right message to the right woman at the right time
  - Educate and empower women

- Target audiences:
  - Primary: women in target age group (per jurisdictions) who are unscreened (e.g., either never or not in past 5 years)
  - Secondary: all women in target age group
  - A limited number of invitations and reminders to be sent, with some alternative strategies to avoid delivering same message repetitively
  - Providers need to be part of the communication strategy but not necessarily receiving copies of all letters
- Preferred messaging for invitation:
  - Focusing on what, when, why, how, where
  - Need a tagline: will be jurisdiction-dependent, such as "you should get screened" or something more passive such as "come and get screened" but overall it needs to prompt action
  - Must indicate why screening is important, and what will be gained from being screened
  - Explains screening and the risks and benefits
  - Explains how and where to get screening
  - Offers reassurance of privacy
- Most effective tools for inviting participants:
  - Must have a letter of invitation together with accompanying collateral/supporting material such as a brochure or fact sheet; letter would be customized and signed by a champion/medical director and/or woman's physician and screening program representative
  - Should be augmented with e-communication, face-to-face or 1:1 for those who are more difficult to reach
  - Invitations must be accompanied by awareness and/or health promotion strategies
- Priorities for implementation include:
  - Funding to build and sustain the invitation process
  - Build or access a population-based registry which is a single source of credible information, including contact information, screening history, and medical history
- Should have an evaluation strategy from the outset
- Other considerations include the ability to access pap tests, strengthen the patient/physician relationship, and integration with other screening initiatives

GROUP 2 – RECALL AND REMIND

- Communications objectives:
  - Maintain regularity of screening, keep patients in the program
  - Enforce guideline compliance for optimum screening; support physicians to prevent under or over screening
  - Provide education
- Target audience:
  - Routine recall
  - Non-responder to invitation/recall letter, need to be reminded
  - Under-screened, infrequently or sporadically screened
- Preferred messages on a letter template include:
  - Have a tag line with a positive tone
  - Make a clear statement that this is a recall/reminder
  - Include guideline reference regarding what is required
  - Emphasize the importance of regular testing

  - Be able to answer "Do I need a pap test, am I overdue?" and "Where do I get a pap test done?"
  - Suggested tag lines – "we care about your health" or "we look forward to supporting you"
- Letter is most effective tool, other considerations include phone cards, reminders, physician lists and/or prompts, making the envelope look official by adding "confidential", websites providing additional support by creating option to register for a reminder. This would be separate from correspondence, more likely via social marketing.
- Other considerations include recall and reminder letters to be sent following Pap test due date.

GROUP 3 – RESULTS AND FOLLOW-UP

- Communications objective:
  - To ensure that women receive appropriate and timely results & follow up (Notification and Quality Control)
  - Two considerations: notification to health care provider of result should be accompanied by standardized recommendation (responsibility for duty of care) and notification to women (provider and/or program)
- Four principles for correspondence
  - Accuracy – right patient/right provider
  - Efficiency – best value for money
  - Expedience – timelines
  - Appropriateness – privacy, release of information, data completeness and data validity
- Target audience:
  - For follow up and failsafe, correspondence should be with health care provider (and secondarily to women) and improve the quality of care
  - Notification of all results to women
- Preferred messages:
  - Getting women who have been screened with abnormal cytology into an appropriate follow up management protocol
  - Ensuring that women are informed of their results and have opportunities
- Most effective tools:
  - Clinical management guidelines
  - Standardized follow up algorithms
  - Standardization of key messages and standard letters per diagnosis with special attention to strengthening the patient/provider relationship
  - Create the appropriate tools and mechanisms tailored to the audience, e.g., allow women opportunities to access their information through a secure website, electronic health record etc.
- Priorities include:
  - Focus on reaching the hard to reach and reducing the risk of loss to follow up if there is going to be a significant reduction in incidence and mortality
  - Linkages for cytology and histology/colposcopy for quality control of clinical management for individual women
  - Notification of all results
- Possibilities for implementation in the Canadian context were identified and include:
  - Vision of having pan Canadian guidelines for cervical screening with the opportunity for women to assist the development of content for correspondence
  - Let us explore the possibility of reviewing the European guidelines for the Canadian context.

  - Focus on reaching the hard to reach and reducing the risk of loss to follow up if there is going to be a significant reduction in incidence
- Other considerations include:
  - Programs need to have the information to ensure that women are individually managed so they are not lost for follow-up
  - Reduce over-screening by educating women about guidelines
  - With future applications and the electronic health record the patient records should be accessible by the patient

5. Correspondence Priorities and Next Steps

Dr. Meg McLachlin led the group in a discussion of Pan Canadian and jurisdictional priorities for correspondence. Firstly, the role of PCCSI in advancing correspondence strategies was discussed, and it was agreed that PCCSI would lead the following initiatives:

- Advancement of the environmental scan, and facilitating sharing of correspondence materials among all jurisdictions
- Development of national best practice guidelines for correspondence that are formalized and identify required and optional components
- Definition of the role of correspondence in supporting change in cervical screening programs, e.g., informing both patients and providers

Following the discussion of PCCSI's commitments, representatives from each jurisdiction were asked to indicate their own priorities:

- British Columbia:
  - Send abnormal results to women
- Saskatchewan:
  - Develop a roll out strategy for new age range
  - Refresh existing letters
  - Revise website messaging
- Manitoba:
  - Develop a dissemination plan for education, health promotion and awareness
  - Develop a communications strategy
- Ontario:
  - Develop new guidelines for screening
  - Develop an educational campaign for guidelines
  - Develop a population-based registry
  - Develop correspondence
- Quebec:
  - Develop a new cancer registry
  - Implement screening guidelines
  - Revise invitation strategy
- New Brunswick:
  - Implement IT and data to support program planning

- Nova Scotia:
  - Review correspondence elements and establish priorities
- Newfoundland and Labrador
  - Provide functional follow-up for abnormal results
  - Confirm results of research protocol and effectiveness
  - Establish population based registry to support change

While all of the priorities identified were important to each of the jurisdictional programs, it was noted that they are not all focused on correspondence elements. Dr. McLachlin asked that *each jurisdiction define their top three priorities specifically related to correspondence* and be prepared to share with PCCSI.

In her closing remarks, Dr. McLachlin expressed her thanks to all involved. She identified several highlights from the day to inform the future initiatives of PCCSI and jurisdictional programs, including:

- Educating and empowering women
- Need for messaging to be clear, simple and positive
- Importance of having multiple communication pathways which must all fit together and have a common message
- Ability to engage health care providers
- Need for failsafe mechanisms to be in place to ensure follow-up for women with abnormal results
- Ensure privacy and confidentiality of information
- Supportive health promotion strategies
- Access and interface with population-based registries
- Guidelines and algorithms for correspondence to be aligned across provinces and territories
- Strengthen ability of programs to support the relationship between patient and primary health care provider

Appendix B: Working Group Membership

Chair:

Karen Atkin (Cancer Care Ontario)

Members:

Melissa Stark (New Brunswick Department of Health)

Shirley Koch (New Brunswick Department of Health)

Joanne Rose (Cervical Screening Initiatives Program, Newfoundland and Labrador)

Joan Murphy (Society of Obstetricians and Gynecologists)

Lisa Kan (British Columbia Cancer Agency)

Ruth Sellers (Health Prince Edward Island)

Laura MacDougall (Alberta Health Services)

Meg McLachlin (Pan-Canadian Cervical Screening Initiative)

Verna Mai (Canadian Partnership Against Cancer)

Susan Fekete (Canadian Partnership Against Cancer)

Appendix C: Correspondence International Comparison (including incidence and mortality rates)

Country	Invitation	Normal result	Abnormal result	Recall	Reminder	Follow-up	Incidence (per 100,000) ASR[36]	Mortality (per 100,000)[36]
Australia	Yes	To MD	To MD	27-30 months since previous Pap	To MD and/or woman depending on Pap result, follow-up, etc.	***Step 1:*** Mail questionnaire to MD. If no response & high-grade lesion, phone MD ***Step 2:*** If no MD response, mail letter to woman ***Step 3:*** If no response, mail reminder	4.9	1.4
Austria	Yes	Mail or phone smear taker (gynecologist)	Mail or phone smear taker				7.8	2.3
Belgium	Yes	Report to smear taker (gyne/MD)	Report to MD				9.4	2.7
Denmark	Yes (Registry mails to women not screened within last 3 years)	Directly to woman to contact MD	Report to MD		▪ Registry mails to women who do not respond to invitation (6–18 weeks after invite, depending on county) ▪ Some counties may remind a 2nd time	▪ MD performs initial follow-up or refers woman to gynecologist for colposcopy ▪ In some counties, lab sends reminder to MD in cases of missing follow-up ▪ Lab sends to MD list of patients with incomplete follow-up	11.0	2.5
England	Yes (By Primary Care Trusts or PCTs) Letter sent 6 months before age 25	Report to MD; letter to woman	Report to MD; letter to woman No letter sent to women requiring urgent referral for colposcopy (moderate dyskaryosis or worse)	PCT sends letter to woman 5-6 weeks before test due date	▪ PCT mails letter to woman 20 weeks after test due date ▪ If no Pap test, then mail letter to MD ▪ If still no test, then 2nd letter to MD (optional)	For follow-up Pap: ▪ PCT mails letter to woman ▪ If no test, then PCT mails reminder to woman ▪ If no test, then PCT mails letter to MD ▪ If still no test, then PCT mails MD (optional) ▪ If still no test, then PCT mails letter 12 months after repeat Pap was due For colposcopy: ▪ Colposcopy clinic mails letter to woman who missed appointment ▪ If no response, clinic mails	7.2	2.0

Country	Invitation	Normal result	Abnormal result	Recall	Reminder	Follow-up	Incidence (per 100,000) ASR[36]	Mortality (per 100,000)[36]
						letter to MD and lab ▪ If no response, clinic mails 2nd letter to MD and lab ▪ Labs notify MDs of results requiring urgent colposcopy referral ▪ Phone or fax MD ▪ Follow-up letter to MD confirming details ▪ 4 weeks after Pap test result date, confirm with MD referral was made ▪ 6 weeks after test date, confirm with clinic woman was seen and record diagnosis OR contact MD if woman has not attended ▪ Failsafe enquiries kept open for 6 mos. ▪ PCT recalls woman 24 mos. from date test result recorded		
Finland	Yes	Letter to woman	Phone and always by letter with fixed appt.				3.7	0.9
Germany		Smear taker notifies woman	Smear taker mails or phones woman				6.9	2.3
Greece	Yes	Letter to woman	Phone or personal meeting with MD or house call				3.8	1.5
Ireland	Yes	Letter to woman	Advised to contact MD				10.9	3.1
Italy	Yes	Letter to woman	Letter or phone call to woman with pre-arranged appt. for colposcopy		If no-show for colposcopy		6.7	1.5
Netherlands	Yes	Via the MD	Via the MD. Pre-arranged colposcopy appt.		If no-show for colposcopy	Lab sends MD list of patients with incomplete follow-up	5.4	1.5

Country	Invitation	Normal result	Abnormal result	Recall	Reminder	Follow-up	Incidence (per 100,000) ASR[36]	Mortality (per 100,000)[36]
Norway	Yes (to women who have not been screened)						9.3	2.3
Portugal	Via MD	Letter via MD	Letter via MD				12.2	3.6
Spain	Yes	Letter via MD	By MD				6.3	1.9
Sweden	Yes (Invite women with appt. who have not had Pap during previous 3 years when turn 25 years)	Letter to woman (in most counties); some counties do not inform women of negative results	Reported to gyne clinic Refer woman to gyne out-patient clinic for test result	▪ Recall women with no Pap test during previous 3 years until age 59 ▪ Women who do not attend within a year after invitation are invited every year	To women within 14 days of non-attended appointment; some counties will re-invite woman following year		7.4	1.8

ASR = age standardized rate

Appendix D: Evidence of Effective Interventions to Increase Uptake and Follow-up

Study	Invitation	Results	Recalls/reminders	Improve adherence to follow-up
PEBC Guidelines				
Brouwers (2009)[5]			▪ Patient reminders increase uptake of cancer screening	
Randomized Controlled Trials				
Jensen (2009)[3]	▪ Specific targeted invitation from MD plus a facilitating visit to MD increase screening ▪ Non-attenders with previous Pap test more likely to attend than those without previous Pap			
Morrell (2005)[9]			▪ Pap test rates significantly higher among under-screened women (no test in 48 months) who received reminder letter vs. those who had not received a letter	
Stein (2005)[6]			▪ Letter from local cervical screening program commissioner resulted in small, non-significant increase in Pap test uptake in women not screened for >15 years (age 39-64) ▪ Above intervention more effective than either a phone call from a nurse, a letter from a celebrity, or taking no action ▪ Intervention more cost-effective than phone call from nurse or letter from celebrity	
Eaker (2004)[10]	▪ Modified invitation did not increase attendance vs. standard invitation ▪ Reminder letter (to women unresponsive to invitation after 5 months) increased attendance by 9.2% vs. women not receiving reminder letter ▪ Phone reminder to women unresponsive to reminder letter (after 2 months) plus offer to schedule appointment increased attendance by 31.4% ▪ Modified invitation plus written reminder gave 44% cumulative attendance (11% higher than standard invitation alone) within 12 months ▪ Modified invitation plus written reminder plus phone reminder gave 64% cumulative attendance (almost double vs. standard invitation letter only) and number of women diagnosed with CIN1+ more than tripled (vs. standard		▪ Reminders by letter and by phone both strongly increased attendance ▪ Reminder letter increased attendance substantially, most strongly in women who had had a prior Pap test and among women who had not received social welfare ▪ Overall, the effect seemed to be stronger among women from higher socio-economic groups	

Study	Invitation	Results	Recalls/reminders	Improve adherence to follow-up
	invitation letter only)			
Lynch (2004)[37] [cost-effective analysis of Valanis, below)			▪ Cost-effective outreach intervention increases screening uptake ▪ Outreach cost $168 for each woman randomized to outreach; incremental cost-effectiveness of outreach over usual care was $818 per additional woman screened ▪ Sensitivity analyses estimated incremental cost-effectiveness between $19 and $90 per additional woman screened	
Burack (2003)[13]			▪ Reminder systems targeting both patients and MDs increased screening rates (patient reminder prompts MD visit and medical record reminder prompts MD to promote screening) ▪ 30% of women receiving combined reminder had Pap test vs. 23% in mammogram-only reminder group). Odds of having Pap test 39% higher for women in combined vs. mammogram-only reminder groups ▪ Women with previous Pap tests more likely to complete study-year Pap tests	
Valanis (2002)[38]			▪ Overdue women aged 52-69, unresponsive to regular reminders, motivated to get screened with outreach intervention (tailored letter plus, if not screened, phone counselling 7-9 mos. later ▪ Women without a Pap >5 years were significantly less likely to obtain a Pap test	
Hogg (1998)[8]			▪ Provider customized letters to patients increase MD visits seeking preventive care services	
Marcus (1998)[39]	▪ Letters mailed to patient populations effective, especially in promoting interval screening when personalized letters are used. Letters to non-patient populations not generally successful		▪ Letters mailed to patient populations effective, especially in promoting interval screening when personalized letters are used ▪ Letters to non-patient populations not generally successful	
Miller (1997)[40]				▪ Phone counselling improves initial and long-term adherence to follow-up in underserved women vs. either the phone reminder or letter with result and follow-up recommendation
Byle (1995)[41]	▪ Direct mail strategies effective for prompting overdue women to attend for cervical		▪ Direct mail strategies prompt overdue women to attend for cervical screening	

Study	Invitation	Results	Recalls/reminders	Improve adherence to follow-up
	screening			
Paskett (1990)[42]				▪ Letter plus pamphlet designed to motivate adherence with repeat Pap recommendation for abnormal results increased adherence by 13% vs. letter alone (64% compliant versus 51%)
Systematic reviews/meta-analyses				
Anhang Price (2010)[43]	▪ Stepped approaches to recruitment, beginning with inexpensive, standardized reminder letters for patients highly motivated to screen and advancing, as needed, to tailored mailings or phone counselling to predispose and reinforce patient screening, are effective ▪ For patients attending MD visits, MD reminders improved screening recommendation/ referral		▪ Stepped approaches to recruitment, beginning with inexpensive, standardized reminder letters for patients highly motivated to screen and advancing, as needed, to tailored mailings or phone counselling to predispose and reinforce patient screening, are effective ▪ For patients attending MD visits, MD reminders improved screening recommendation/ referral	
Task Force on Community Preventive Services (2010)[44-47]			To increase Pap uptake ▪ Provider reminder and recall systems ▪ Client reminders	
Zapka (2010)[48]			▪ Reminder systems for providers and for patients (mail & phone) significantly beneficial	
Weller (2009)[49]	▪ Direct invitations and scheduled appointments increase uptake ▪ Direct invitations produce higher rates of uptake than strategies relying on patients responding to awareness-raising efforts ▪ Messages customized to target group effective		▪ Targeting office systems and automated prompts and reminders increase uptake (MDs offer screening to patients) ▪ Messages customized to target group effective	
Eggleston (2007)[21]			▪ Appt. reminders (letter/call) reduce missed follow-up appt.	▪ Appt. reminders (letter/phone call to woman 1 week before appt.) reduce missed appointments ▪ Phone counselling ▪ Instructive and culturally relevant pamphlets
Bastini (2004)[50]			▪ Mail and phone reminders improve follow-up rates	▪ Mail and phone reminders ▪ Phone counselling ▪ Print educational interventions ▪ Insufficient evidence regarding effectiveness of provider-focused interventions
Zapka (2004)[7]			▪ MD reminder systems (computerized and manual) prompt MDs to promote screening ▪ Patient reminders, when due for next screening, increase	▪ Patient phone reminders and confirmation improve follow-up

Study	Invitation	Results	Recalls/reminders	Improve adherence to follow-up
			screening–personalized letters especially effective for interval Pap tests ▪ Patient reminders less effective in lower socio-economic groups	
Yabroff (2003)[20]				▪ Patient reminders (mailed or phone) increase rates of initial follow-up ▪ Patient appt. reminders (phone) confirming follow-up appointment effective
Cochrane review (2011)[4]	▪ Invitation letters increase Pap uptake			
Abercrombie (2001)[51]				▪ Phone counselling ▪ Educational interventions (e.g., brochures) among more advantaged women
Khanna (2001)[24]				▪ Personalized patient reminders improve follow-up (ensure clear communication of Pap result, its importance, and appropriate follow-up care)
Kupets (2001)[11]			▪ Patient reminder letters increase Pap screening ▪ Physician reminder systems (computerized or manual) increase Pap screening	
Tseng (2001)[52]			▪ Patient reminder letters increase cervical cancer screening; less efficacy in lower socio-economic groups	
Jepson (2000)[14]	▪ Invitation letters increase screening; fixed appointment time more effective than open appointment ▪ Phone invitations increase uptake, but not routinely used in U.K. screening programs		▪ Physician reminders effective ▪ Combination of physician reminders and patient invitations effective ▪ Patient reminder following initial invitation may increase uptake	
Yabroff (2000)[23]				▪ Patient appointment reminders increase patient adherence by up to 18% ▪ Mailed and phone reminders increase patient adherence to follow-up
Shea (1996)[53]			▪ Manual reminder systems improve Pap screening ▪ Computerized reminder systems not effective	
Observational studies				
Grimes (2009)[18]		▪ Patients prefer to be notified of all lab test results (normal & abnormal)		

Study	Invitation	Results	Recalls/reminders	Improve adherence to follow-up
		▪ Patients & MDs prefer mail notification of normal lab test results and direct phone call for abnormal results		
Mullins (2009)[54]			▪ Reminder letters for overdue women aged 65-69 increase screening ▪ Targeted reminders do not further improve screening attendance over general reminders (4.3% of women screened who received targeted reminders vs. 4.7% of women who received general reminder) ▪ Effectiveness limited to women ≥10 years over-due; particularly effective for 3-5 years overdue	
Balasubramani (2008)[22]			▪ Appt. reminders decrease missed colposcopy appointments	▪ Significant decrease in missed colposcopy appointments when women sent (1) comprehensive leaflet explaining colposcopy and need for follow-up and (2) reminder letter 7-10 days prior to appt.
De Jonge (2008)[55]			▪ Mailed invitation to non-attenders (no Pap in past 30 mos.) aged 25-64 increased screening (6.4% of women invited were screened) ▪ Larger effect in older women (age ≥46 years)	
Karwalajtys (2007)[56]			▪ MD reminder letters to women (due and over-due for Pap) seen as useful and influenced women's decisions to undergo screening	
Richardson (2007)[57] (NHSCSP)	▪ Should send letters 5-6 weeks before test due		▪ Should send letters 5-6 weeks before test due	
Baldwin (2005)[17]		▪ Patients want to be notified of all lab test results (normal & abnormal), in a timely way and with detailed information		
Zapka (2004)[58]				▪ Women with abnormal Pap result of LSIL reported confusing/ conflicting information vs. women with other Pap result categories ▪ Fewer women with abnormal Pap (vs. abnormal mammogram) completed follow-up because of confusing/ conflicting information: clinician changed recommendation (e.g., colposcopy replaced repeat Pap) and

Study	Invitation	Results	Recalls/reminders	Improve adherence to follow-up
				different providers gave different messages ▪ Patients need clear messages about recommendations, especially with equivocal findings and where multiple providers are involved in process of making clinical decisions
Johnston (2003)[12]			▪ One-time letters to unscreened (no Pap in >10 years) and under-screened (no Pap in 3 years and only 1 Pap in 3-10 years) women improved Pap uptake ▪ Non-attenders with previous Pap test more likely to attend than non-attenders without previous test	
Quinn (1999)[59]	▪ Greater incidence and mortality reduction after introducing call/recall system		▪ Greater incidence and mortality reduction after introducing call/recall system	
Reeves (1999)[60]			▪ Patient reminders associated with increased uptake	
Palm (1997)[61]				▪ Family practices with fail-safe system had better follow-up adherence vs. those without ▪ Highest follow-up adherence occurred in practices also involved in call system (invitations/ recalls)
Del Mar (1995)[16]		▪ Mailing results to women may reduce loss to follow-up of those with CIN findings		▪ Mailing results to women may reduce loss to follow-up of those with CIN findings
Schofield (1994)[19]		▪ Women prefer prompt written notification of normal Pap test results ▪ Women prefer phone call from MD of abnormal results		
Marcus (1992)[34]				▪ Transportation incentive (abnormal result letter with bus ticket) significantly improved follow-up of more socio-economically disadvantaged women with more severe Pap result* ▪ Combined intervention of (1) personalized follow-up (letter with detailed information about results and required action, in English & Spanish) and (2) 12-minute slide-tape program (viewed in waiting rooms prior to

Study	Invitation	Results	Recalls/reminders	Improve adherence to follow-up
				initial Pap test-English & Spanish) improved follow-up among relatively more advantaged women with less severe Pap result

*Although only 27% of the women who were assigned transportation incentives reported using the bus passes, they returned nonetheless because receiving this incentive conveyed that the health care system "really cared" about their well-being and underscored in a unique way the seriousness and need to return for follow-up care.

Appendix E: Plain Language Writing

It is important when writing for the general public to assume that the audience does not have a high school education or a science or health background and will not understand technical terms. Plain language should be used and jargon should be avoided. Correspondence letters about screening, such as invitations or test results, can adopt a more straightforward, factual tone, but the tone of brochures and website content, particularly for people with abnormal screening results and their loved ones, should be more reassuring, empathetic and warm.

Good sources of information about plain language writing abound on the web; for example, the U.S. government's plain language website, http://www.plainlanguage.gov.

Here are some basic tips to help you use plain language in your writing:

- Pretend you are speaking to the reader.
- If your audience is the general public, write to a grade eight education level.
- Use personal pronouns: you, I, we.
- Organize your information into a logical sequence.
- Put the most important information first.
- Group related information together.
- Use informative titles and subtitles.
- Use examples, charts, tables or graphics to explain your text.
- Keep paragraphs short.
- Keep your sentences short and concrete. Limit sentences to an average of about 25 words.
- Include only one idea in each sentence.
- Use the active voice.
- Be direct. Avoid ambiguity.
- Be consistent.
- Use the same word to mean the same thing throughout your document.
- Use parallel grammatical structure.
- Choose simple, familiar, specific words (e.g., "get" not "obtain" / "call me" not "contact the undersigned").
- Avoid jargon and acronyms.
- Define technical and unfamiliar words, jargon and acronyms if you must use them.
- Omit unnecessary details.
- Omit all unnecessary words.
- Avoid negatives.

Terms that are overly scientific should also be avoided and replaced with plain language equivalents:

- incidence = number of new cancer cases diagnosed
- indicated for cancer treatment = used to treat cancer
- median = half of all people who get cancer are over (or under) 45, not median age of onset is 45
- morbidity = amount or degree of illness the cancer causes
- mortality = death rate or number of people who die from cancer
- negative result = normal result
- positive result = abnormal result or a result this is not normal
- pre-cancerous/pre-cancer = early cell changes
- prevalence = number of people with a disease
- prognosis = likelihood or chance of surviving the cancer

If it is determined that a more technical term is needed, it must always be defined first.

The *European Guidelines for Quality Assurance in Cervical Cancer Screening, Second Edition* (2008) suggest that:

- Material follow the ethical principles of autonomy (respecting a person's right to make his or her own decisions), non-maleficence (obligation to avoid causing harm), beneficence (obligation to provide both benefits and risks) and justice (obligation of fairness in the distribution of benefits and risks).
- The tone be honest, respectful, informal, impartial, non-prescriptive and polite.
- The language should be personal, simple and written in the active voice (e.g., "You should get screened," not "Screening should occur").
- The information be comprehensive, tailored to the specific needs of different groups in different situations and at different stages of screening, available in a wide variety of detail, and positively framed (e.g., nine out of 10 women get normal results).
- The content include the name of the patient's own health-care provider.

More information on writing about cancer and cancer screening for the public, including tips on specific content, is available in Appendix 1 of the *European Guidelines for Quality Assurance in Cervical Cancer Screening, Second Edition*, as well as in the NHS Cancer Screening Programme's *Improving the Quality of the Written Information Sent to Women about Cervical Cancer* and in chapter 10 of the *European Guidelines for Quality Assurance in Colorectal Cancer Screening and Diagnosis, First Edition*.

When writing for people who have abnormal test results, aside from following the general principles outlined above, it is important to be truthful, yet sympathetic, reassuring and encouraging when talking to people who have or may have a negative change in their health status. For example, instead of saying "If you want to discuss any of these topics with a specialist, call us" try saying "If you have abnormal test results, it is normal to have questions about your health and well-being, so feel free to call us to discuss your concerns."

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