A scoping review of screening in Canada

Health Council of Canada
Conseil canadien de la santé
A SCOPING REVIEW OF SCREENING IN CANADA

3 INTRODUCTION AND BACKGROUND

4 KEY FINDINGS
1. HISTORICALLY AND TODAY, SCREENING AS A COMPLEX PROCESS
   1.1 What is screening?
   1.2 How have screening principles evolved?
   1.3 What impedes effective screening policy and practice?

2. THE CASE FOR A NATIONAL APPROACH

3. WHERE TO TURN – BEST PRACTICES, NATIONAL APPROACHES AND INTERNATIONAL MODELS
   3.1 What we need to know about governance models

12 SUMMARY AND SCOPING RECOMMENDATIONS

13 APPENDICES:
   A. LIST OF SUBJECT MATTER EXPERTS
   B. GLOSSARY OF SCREENING TERMINOLOGY
   C. VISUAL REPRESENTATION OF SCREENING CONTEXTS, COMPLEXITIES AND SOURCES OF VARIATION

16 REFERENCES
INTRODUCTION AND BACKGROUND

Canada's Prime Minister and the provincial and territorial premiers established the Health Council of Canada and later enhanced our role through two agreements referred to as "the Accords" - the 2003 First Ministers' Accord on Health Care Renewal, and the 2004 10-Year Plan to Strengthen Health Care. As a leading voice that informs and strengthens Canada's health system, the Health Council’s mission is to report on the renewal of Canada’s health system, focusing on best practices and innovation. Screening straddles a number of themes in the 2003 and 2004 agreements including prevention, health promotion, public health, and primary health care, though the agreements were not specific in identifying targets as a reporting focus for the Health Council.

In 2012, the Health Council undertook a scoping exercise in order to better understand:
- screening, including issues and challenges;
- types of screening activities that are happening at the jurisdictional level (e.g., what diseases are being screened for; where organized programs exist); and
- examples of best practices, nationally and internationally.

Following a review of key articles, books and websites on the topic of screening, the Health Council’s strategy was two-fold:
- interview 17 subject matter experts (SMEs) largely from across Canada, but with additional representation from the United States, the United Kingdom and Australia. The SMEs represented a rich and diverse set of experiences, bringing expertise in policy-making, the management and development of screening programs, and the development of evidence-based guidelines and recommendations. They also had expertise in select areas of screening (e.g., public health, primary health care, cancer, genetics, newborn, and early childhood screening contexts). A list of SMEs is provided in Appendix A.
- briefly survey the provinces and territories about their current programming and interests in screening and the challenges they face.

Below is a summary of findings that are either based on our correspondence with the jurisdictions and SMEs, or drawn from the academic literature. The summary of key findings is organized into three sections:
- a historical perspective on screening, including why it is a complex and controversial process;
- the case for a national approach, including current challenges faced by Canadian jurisdictions; and
- best practices and international models that can provide guidance on the best approach.
KEY FINDINGS

1. HISTORICALLY AND TODAY, SCREENING AS A COMPLEX PROCESS

1.1 What is screening?

Screening involves social, scientific, economic, and political dimensions. This complexity sometimes leads to controversy about: what screening is; whether and how programs should be implemented; benefits versus harms of screening versus not screening for a certain disease or condition; how the trade-offs should be balanced; and, whether resources are better spent on other preventive services that may have a greater impact on population health.

Screening refers to the testing of people without signs or symptoms for a disease or condition, with the aim of reducing their future risk of ill health or of giving them information about their risk (Raffle & Gray, 2007 p34). Formal definitions vary depending on whether screening refers to tests or programs, or individuals or populations (Ibid.p35).

A clear definition of screening reflects what it should be—a complex process, not simply a test (Raffle & Gray 2005). To achieve more benefit than harm, decisions to implement screening programs should be based on established criteria or decision principles and involve an organized series of events, from identifying and informing those to be offered screening, through providing treatment and follow-up for people with abnormalities, and supporting those who develop the disease despite screening (Raffle & Gray, 2007 p37). This differs from opportunistic or “wild” screening, which is provided by a clinician outside of an organized program, or where the screening is not supported by a system of care.

Screening can be made available to whole populations (mass screening) or to high risk groups (selective screening). It can also involve two or more screening tests provided in combination to large groups of people (multiphasic screening). Screening is different from other investigations such as case-finding, surveillance, and early disease detection. Unfortunately, the terminology is often used imprecisely, causing confusion over what is understood to qualify as screening. Appendix B includes a glossary of screening and related terms.

1.2 How have screening principles evolved?

In 1968, the World Health Organization (WHO) commissioned Drs. J.M.G. Wilson and G. Jungner to write a report on screening to provide guidance at a time when technological advances in medicine had made screening an important, and controversial, topic (Andermann et al, 2011; Raffle & Gray, 2007). The result, Principles and Practice of Screening for Disease, is still considered a landmark report. It identified ten lasting principles for evaluating screening programs and provided a foundation to guide population-based screening decisions. The principles specify that:

1. The condition should be an important health problem.
2. There should be an accepted treatment for patients with recognized disease.
3. Facilities for diagnosis and treatment should be available.
4. There should be a recognizable latent or early symptomatic state.
5. There should be a suitable test or examination.
6. The test should be acceptable to the population.
7. The natural history of the condition, including development from latent to declared disease, should be adequately understood.
8. There should be an agreed-upon policy on whom to treat as patients.
9. The cost of case-finding (diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
10. Case-finding should be a continuing process and not a “once and for all” project.

Even during their era, Wilson and Jungner found that while screening appeared deceptively easy, the path to implementation was far from simple (1968, p26). There are multiple and competing influences on policy-making and program development, and the interaction of evidence, resources, values and beliefs plays out in complex ways in different jurisdictions—all of which continues to hinder screening programs today (Raffle & Gray, 2007).

Our interviews with SMEs explored Wilson and Jungner’s principles and provided valuable insights into current screening policy-making and program implementation practices. Often, the principles have been adapted to meet specific program needs, to respond to changing contexts in Western medicine and society, and to reflect a deeper understanding of the complexities and challenges of program implementation. Most notably, these include:

- the evolution of evidence-based medicine;
- the rise of managed care models that focus on cost-effectiveness, quality assurance, and accountability of decision makers;
- increased consumerism; and

In other situations, readers of Wilson and Jungner have misinterpreted the principles to be a simple checklist. Rather than applying an analytical approach to balance the benefits, harms, and costs of screening, individuals have oversimplified or misused the principles to justify a screening program after it has been put into practice (Raffle & Gray p 14; Harris et al, 2011). What does an analytical approach really require? Some key features:

- evaluation of the evidence through systematic reviews, high-quality randomized control trials (RCTs), and long term data collection to determine the balance of benefits and harms of the program relative to the burden of disease;
- a systematic and transparent approach to decision-making that includes a governance framework, a process for stakeholder engagement, and information management systems over the life of a program; and
- consideration of wider collective investments being made in preventive services, including those outside of medicine, such as the social determinants of health (Raffle & Gray, 2007; Andermann, 2010; Harris et al., 2011).

1.3 What impedes effective screening policy and practice?

A host of complicating factors can impact the ability to follow through with an analytical versus checklist approach to screening principles, resulting in barriers to effective decision-making and program implementation. These limiting factors include:
• **Gaps in knowledge** where there is a lack of clear evidence or an evolving understanding of the natural history of disease

• **Competing authoritative voices about the evidence** coupled with emotional, financial, and/or political investment in screening or attachment to a certain screening program. Examples include:
  o lack of adherence to screening guidelines by care providers (e.g., the rejection of the Canadian Task Force on Preventive Health Care updated breast screening guidelines);
  o small ‘p’ politics in which advocacy groups form opinions that differ from what the evidence suggests; and
  o large ‘P’ politics in which political campaigns promise to implement large-scale screening programs that may not be supported by evidence.

• **Competing perspectives on the goals of screening.** Examples include:
  o screening authorities versus disease champions; and
  o individual perspectives (primary care physician) versus population level decision-makers (public health).

• **Lack of clarity on what screening is and is not.** The lines are blurred between clinical management (case-finding) and screening. Opportunistic testing, for example, may appear to be screening, but it does not adhere to the guiding principles. And despite increased interest in developing organized programs, recommendations or guidelines for clinicians focused on best practices may be the limit of an organized intervention. Notably absent is a secondary level of analysis and program development that assesses the health outcomes, costs, benefits and harms of screening, and that prioritizes and coordinates at a higher level than the physician’s office. A number of factors contribute to this situation:
  o screening falls into a gap between medical care and public health policy, and so is not always given the attention and resources of other health care interventions;
  o lack of infrastructure and essential expertise at the jurisdictional level to develop and run programs;
  o lack of infrastructure and capacity to develop high quality evidence;
  o inadequate screening tools (i.e., lacking precision, reliability, and validity); and
  o limitations within primary care settings, including a lack of family doctors, fee-for-service systems, and the paucity of EHRs and EMRs to support monitoring and follow-up.

• **A widening gap between technical and practical feasibility.** This creates pressures to introduce or expand screening programs, often before adequate safeguards and regulatory frameworks have been established (Harris et. al., 2011; Wilson et. al., 2010).
• **Over-enthusiasm for screening and related technologies by both the public and professionals.** When coupled with strong cultural beliefs that early intervention and knowledge is always good, this enthusiasm may cloud the facts—that screening is not always beneficial to one’s health; in fact, it has the potential to cause harm. Despite the evolution of evidence-based medicine, public and professional beliefs, values, and expectations play a large role in decision-making. Furthermore, once a screening mechanism for a disease or condition is “out of the gate,” with or without supporting evidence, it is difficult to reign it in (e.g, PSA testing). (Harris & Woolf, 2012).

• **Limited treatment options.** Screening raises additional issues when treatment options are limited, some examples include:
  - In the case of early childhood screening for social and psychological development, there is strong evidence of the potential to improve outcomes if a condition is identified early. However, trained experts and treatment resources are limited. The result is a moral and ethical dilemma—physicians have a responsibility to treat a problem that is identified.
  - In the case of aggressive cancers that advance too quickly to be treated at an early stage, either treatments must be improved or these cancers must be prevented. To screen in the absence of these other options is, as one subject matter expert suggested, “putting our eggs in the wrong basket.”

• **Disease silos.** Screening must be considered in the context of population health and preventive services that include approaches outside of medicine, for example, addressing the social determinants of health. Screening programs should also not exacerbate inequities—between those that have the ability to access screening and seek treatment and those who do not. Consideration must be given to wider collective investments and getting good value for the choices made.

Taken together, these complexities and challenges point to the value of broadening the dialogue on screening and involving a range of experts and perspectives—scientific, economic, communications, primary care, public health, policy, and program development.

### 2. The Case for a National Approach

Currently, there is great diversity and discordance among screening programs across Canada, with significant variation in screening policies and practices across the jurisdictions. Context (e.g., population needs, service delivery capacity, policy objectives etc.) is a major determinant of whether, where, and how jurisdictions screen. Such diverse approaches contribute to duplication and waste with each jurisdiction conducting its own review of the evidence, development of guidelines, tools and programs; this raises concerns for patient safety, accessibility and equity, program effectiveness, and accountability.

Many jurisdictions offer organized screening programs for breast, colorectal, and cervical cancers, for genetic conditions identified through preconception, antenatal, and neonatal (bloodspot) screening, and for hearing or vision loss associated with newborn or childhood conditions. Despite the general availability of such screening programs, there are important differences between jurisdictions, such as:
• rationale for screening guidelines used;
• decision-making methods;
• governance structures and processes;
• legal structures and patient consent issues;
• service delivery mechanisms (e.g. treatment and follow-up processes, tests used, recommended frequency of screening, variability in target age ranges for screening);
• resources and capacity to develop organized population-based programs; and,
• coverage of disorders identified through screening (CADTH, 2011; Hanley, 2005; Kennedy et al., in Morrison & Dowler, 2011; Mema, McIntire, Musto, 2011; Leddin et al, 2010; Andermann, et al, 2010; Wilson et al., 2010).

Screening is often implemented in an ad hoc or opportunistic way, despite insufficient evidence that the benefits outweigh the harms and that it will improve health outcomes, or despite uncertainty about test reliability or effectiveness of treatment options. Examples in this latter category include Prostate Specific Antigen (PSA) testing and screening for intimate partner violence, diabetes, and HIV/AIDS (MacMillan, et al., 2009; Harris, et al., 2011; Andermann, 2010, p 336). Screening has become a popular and growing prevention strategy, although population health impacts might potentially be greater if resources were shifted elsewhere (MacMillan, et al., 2009; Harris, et al., 2011).

Reflecting on newborn screening, one jurisdiction noted that: “National guidelines would assist jurisdictions with case definitions, defining optimal models for follow-up and monitoring, and facilitating access to resources for affected individuals moving across provincial boundaries. National guidelines would also assist jurisdictions for whom expertise is scarce.” There have also been calls to nationalize the approach to various components of newborn screening (Wilson et al., 2010). Similarly, another jurisdiction indicated that its greatest need is for experts to come together, review national guidelines, ensure they are communicated to providers, and put them into practice.

Even when there is agreement about the efficacy screening (e.g. decreased mortality), other factors present challenges that can block implementation. Key challenges noted by the jurisdictions included:
• lack of consistency within and across the jurisdictions, based on internationally/nationally recognized screening criteria;
• lack of adherence to screening guidelines by care providers;
• screening tools that are unreliable, expensive or unacceptable;
• insufficient capacity and resources to offer organized population-based programs,
• insufficient capacity to support the systematic analyses of evidence for population health impacts and cost effectiveness;
• lack of information and data reporting systems to support timely and accurate collection and monitoring of screening data;
• failure to build coordination across screening initiatives for particular groups (e.g., coordinating newborn metabolic screening with hearing screening);
• over-enthusiasm for screening, over-diagnosis and over-treatment;
• the need to increase participation in under-screened and underserved populations (e.g., Aboriginal peoples and immigrant populations and people in rural, remote, or northern areas); and
• the need to share knowledge and innovative practices.
3. WHERE TO TURN – BEST PRACTICES, NATIONAL APPROACHES AND INTERNATIONAL MODELS

Best practices in screening are based on the highest quality scientific evidence. They include consideration of cost-effectiveness and improvements in quality of life. Best practices are characterized by clear governance frameworks for adjudicating the evidence, transparent screening principles, processes for stakeholder engagement, supportive data systems for monitoring and evaluation, and opportunities for ongoing discussion of challenges with the ability to reflect on whether screening choices are still justified. Organized, population-level screening programs that have these elements show the greatest potential.

The SMEs identified screening programs designed by Cancer Care Ontario, the BC Cancer Agency, and Newborn Screening Ontario as examples of best practices at the provincial level; at a national level, they identified the Canadian Partnership Against Cancer (CPAC) and the Canadian Task Force on Preventive Health Care (CTFPHC). A priority initiative of CPAC in its 2012-2017 strategic plan is to guide organized population-based screening for improved coherence and quality across Canada, and the ‘national conversation’ CPAC has started to facilitate is welcomed by SMEs. According to the SMEs, CPAC’s efforts to improve consistency in the second part of its mandate will contribute positively to cancer screening in Canada.

The Canadian Agency for Drugs and Technologies in Health (CADTH) has a broad mandate, with screening as one area. CADTH provides decision-makers with the evidence, analysis, advice and recommendations required to make informed decisions; it provides an example of a national organization that serves all of the jurisdictions and is funded by Canada’s federal, provincial, and territorial governments. CADTH is an independent, not-for-profit agency with a focus on delivering timely, evidence-based information to health care leaders about the effectiveness and efficiency of drugs and other health technologies. Of particular relevance is the Common Drug Review (CDR) at CADTH, which reduces duplication of reviews by jurisdictions and makes recommendations that may or may not be endorsed by the drug plans within each jurisdiction. The CDR serves as a pan-Canadian process for conducting objective, rigorous reviews of the clinical, cost-effectiveness, and patient evidence for drugs and may provide useful guidance for developing a pan-Canadian approach to screening, particularly in terms of process, structure, and governance.

The Canadian Task Force on Preventive Health Care (CTFPHC), with its revised mandate to develop national clinical practice guidelines (CPGs) for a number of diseases, will support practitioners, policymakers, program developers, and patients/the public, with guidelines for interpreting evidence and making decisions about screening (Birtwhistle, et al, 2012). For example, in 2011, the CTFPHC released an updated guideline for breast cancer screening in average risk women aged 40–74. Screening recommendations for type 2 diabetes, cervical cancer, hypertension, depression, and obesity in adults and children are topics currently under development (Ibid; CTFPHC, 2012). These guidelines should be well received by the jurisdictions, who have expressed interest in these disease areas as well as mental health and substance abuse (particularly Fetal Alcohol Spectrum Disorder), HIV/TB, and newborn/child screening for developmental and environmental risk factors (Health Council Survey, 2012). The CTFPHC has had an international reputation for providing outstanding guidance for practitioners using rigorous, high-quality methods. Its reports have been used around the world, including by the US Preventive

---

1 Although screening is not CADTH’s primary mandate, it has conducted many evidence-based reviews under the themes of mass screening, genetic screening, neonatal screening, vision screening. For more information see http://www.cadth.ca/en/search?q=screening.
Services Task Force (USPSTF), which developed its approach based on CTFPHC methods.” (Birtwhistle, et al, 2012). The USPSTF fulfills a similar mandate to the CTFPHC. These organizations are recognized internationally as groups that produce robust and trustworthy guidelines.

3.1 What we need to know about governance models

While it is difficult to compare international jurisdictions because of their very different contexts, some countries such as the United Kingdom and New Zealand are seeing the benefits of having national standards and leadership in making CPGs available to health care providers (Health Council of Canada 2012). Benefits include, for example, pooling collective knowledge and expertise and avoiding duplications and redundancies (ibid). Current government efforts in Canada, like those of the Council of the Federation, are beginning to focus attention on the need for coordinated efforts on CPGs in Canada (ibid; Council of the Federation, 2012).

Some lessons can be drawn from the United Kingdom’s National Screening Committee (UK NSC) that would benefit Canada in any efforts to establish a national approach to screening. The UK NSC was universally recognized by the SMEs as a model of best practice because it is a national body that guides all aspects of screening policy and practice in a comprehensive manner. Across Europe there is significant variation in screening policy and practice with some countries taking a national approach to some diseases, but the UK NSC is viewed as best practice for organizing screening (Holland et. al., 2006). The UK NSC’s approach enables uniformity of access, broad adherence to screening principles, and transparent decision-making and quality assurance processes, thereby optimizing the opportunity for screening to achieve more benefit than harm given the resources available.

The UK NSC functions as an advisory committee to the Ministers and the National Health System (NHS) in each of the four UK countries (England, Wales, Scotland and Northern Ireland) providing advice about all aspects of screening. It makes policy recommendations based on evidence that are accepted by the Department of Health. For this reason, its knowledge service is highly valued by the jurisdictions. It is viewed positively and not seen as an authoritative, bureaucratic agency that is seeking to control their decisions. Relationships with each jurisdiction, as well as with other national bodies (Departments of Health, the National Cancer Screening Program and the National Institute for Health and Clinical Excellence (NICE)), are collaborative and network-like rather than hierarchical. Additionally, the decision-making processes are established, systematic, and transparent.

The UK NSC’s recommendations are determined by a national group of professionals with a broad range of expertise. While the Committee’s recommendations are mandatory, its effectiveness can also be attributed to the fact that it provides implementation support and follow-up to organizations, ensuring high-quality and safe screening programs. Recommendations are grounded in evidence and based on internationally recognized criteria covering the condition, the test, the treatment options and the effectiveness and acceptability of the screening program. Increasingly, communication with the public and providers is a focus that is yielding improvements in public understanding of screening benefits and harms (UK NSC, 2012).
There are conditions for which early diagnosis can dramatically improve health outcomes and there are conditions for which screening leads to over-diagnosis and harm. As stated by an international screening expert: “Major decisions turn on the question of what is the evidence needed to support screening as a public health service.” Two important cultural shifts are taking place in the UK: a shift from over-enthusiasm to caution, with recognition that screening, or more broadly the misapplication of health care in general, can cause harm; and a shift from silo or sectoral thinking to systems thinking in health care. These important paradigm shifts may be attributed to the success of the UK NSC and are shifts that could benefit Canada as well.

Countries that are also moving towards nationally coordinated approaches to screening are recognizing the many benefits in terms of quality, safety, equity, and effectiveness. For example, in New Zealand there is a National Screening Unit (NSU) that is responsible for the national coordination of five screening programs: breast cancer, cervical cancer, newborn metabolic, antenatal HIV, and universal newborn hearing screening and early intervention. It is also responsible for quality improvement measures for antenatal screening for Down Syndrome (National Screening Unit Strategic Plan 2010-2015). The New Zealand NSU was established in 2001 to deliver safe, effective and equitable screening programs, while ensuring value for money and managing complexity (ibid). It monitors the quality of screening programs and works with expert groups to make sure programs are based on the latest evidence and meet high standards (ibid). The New Zealand NSU identifies a number of benefits that are achieved by running programs on a national basis, such as leadership of sector development, a central pool of expertise to minimize duplication and gaps, consistent quality standards and evidence-based delivery, cross-program learning and development, and effective operationalization of government policy into regional and local service delivery (ibid).

In Australia, the Screening Subcommittee of the Australian Population Health Development Principal Committee (APHDPC) developed a population-based screening framework (2008) based on Wilson and Jungner’s criteria to provide guidance and help inform the judgement of decision makers about whether a new screening program should be introduced. This framework is based on the principles of access and equity, which are deemed to be fundamental elements to all population screening programs. It has proven to be a valuable guiding tool for looking at large scale populations and screening for common diseases. Currently, Australia has nationally coordinated screening programs for breast, cervical and bowel cancer and is in the process of developing a county-wide quality program for prenatal screening tests including Down syndrome, Edwards syndrome and neural tube defects. Experience from the long established breast and cervical screening programs (1991) and the more recently established bowel screening program (5 year pilot) demonstrates the potential of nationally coordinated programs for policy coordination, consistency across jurisdictions and developing a national register.

In the Netherlands, the National Institute for Public health and the Environment (RIVM) is a specialized government agency that coordinates and directs population screening programs on behalf of the Ministry of Health, Welfare and Sport, through the Centre for Population Screening (CvB)(National Institute for Public health and the Environment (RIVM), 2012). “The CvB coordinates the eight national screening programs targeting breast and cervical cancer, influenza, familial hypercholesterolemia, prenatal screening (for infectious diseases, erythrocyte immunization and Down syndrome), neonatal screenings (the ‘heel prick’) and childhood deafness (ibid). The programs are implemented by a chain of executive organizations at a regional and local level (ibid). As overall director of the process, RIVM ensures the best possible coordination between links in that chain (ibid). The CvB tries to maximize (cost) effectiveness, efficacy, reliability, uniformity, and coordination, thus creating a ‘future-proof
system’ (ibid). It has a public (statutory) responsibility and is therefore authorized to impose measures and requirements (ibid).”

**SUMMARY AND SCOPING RECOMMENDATIONS**

There may be justification and valid contextual reasons for some jurisdictional variation in screening policies and practices (e.g., based on burden of disease, health system capacity, local health priorities etc.). However, there is no reason for variation in the basic principles of decision-making, nor is there a reason for redundancies and duplications with respect to the review of evidence and development of guidelines and screening tools.

Recognizing the complexity of screening and the challenges within Canada and abroad, there is an opportunity to take a closer look at innovative practices in other countries, as well as across the jurisdictions and to share successes, challenges, and opportunities. Some countries are moving towards a national approach to screening with the goals of improving equity, quality, and value for money, and to provide leadership and manage complexity.

As a whole, interview respondents saw value in holding a broad discussion about population-level screening writ large; that is, outside of geographical or disease-specific silos, including where it fits as one part of preventive services. They also saw the value that a national approach might have on addressing the discordance among screening programs in Canada. Issues that could be enhanced through a national approach include safety, effectiveness, quality, accessibility, equity, and accountability in screening policy and practice.

Screening is top of mind for Canadians. Not only are screening controversies highlighted in the media on a regular basis, but in May 2012, Bill C-314 was passed by the House of Commons, “an Act respecting the awareness of screening among women with dense breast tissue” (Speaker of the House of Commons, May 9, 2012). The enactment calls on the federal government to encourage the use of existing federal initiatives in order to increase awareness among Canadian women about dense breast tissue and the implications for breast cancer screening. This act highlights the value of national leadership, while recognizing the mandate of the jurisdictions and roles of partner organizations.

The following questions are proposed as the starting point for a deliberative dialogue on screening:

1. What options exist for improving the coordination and organization of Pan-Canadian efforts on screening?
2. What components of screening activity are best suited to increased Pan-Canadian collaboration (e.g., evidence review/synthesis, screening guidance development, quality standards, performance measurement and monitoring, provider engagement, public input, cross-program and cross-jurisdictional learning)?
3. How could coordinated Pan-Canadian screening activities fit/support broader activity and investment in disease prevention, health promotion and public health?
4. What existing Pan-Canadian agencies are in a position to support increased coordination of screening efforts in Canada (e.g., Canadian Agency for Drugs and Technologies in Health, Canadian Task Force on Preventive Health Care, Public Health Agency of Canada, Canadian Partnership Against Cancer)? How would their roles best fit with the roles of the federal, provincial and territorial governments?
## Appendix A – List of Subject Matter Experts

<table>
<thead>
<tr>
<th>International</th>
<th>National</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. David Eddy MD, PhD</td>
<td>Vice-President, Cancer Programs, Clinical and Population Health, Canadian Partnership Against Cancer (CPAC)</td>
</tr>
<tr>
<td>2. Mark Elwood, MBBCh, BAO, MD, DSc Belf, MBA Massey, FRCPCan, FRSS, FFPHM, FAFPHM</td>
<td>Professor of Knowledge Management, Nuffield Department of Surgery, University of Oxford; first program director for the United Kingdom National Screening Committee; pioneered Britain’s breast and cervical cancer screening programs</td>
</tr>
<tr>
<td>3. Muir Gray, Kt, CBE, Dsc, MD, FRCPGlas, FCLIP</td>
<td>Former member of US Preventive Services Task Force (USPSTF) and the National Institute for Health and Clinical Guidance (NICE), UK</td>
</tr>
<tr>
<td>4. Russell Harris, MD, MPH</td>
<td>Director of Programmes for the UK National Screening Committee.</td>
</tr>
<tr>
<td>5. Anne Mackie, MD</td>
<td>Chair of US Preventive Services Task Force (USPSTF) and Agency for Healthcare Research and Quality (AHRQ)</td>
</tr>
<tr>
<td>7. Ann Robertson, FHGSA.</td>
<td>Director, Centre for Community Child Health-The Royal Children’s Hospital Melbourne, University of Melbourne Murdoch Childrens Research Institute</td>
</tr>
<tr>
<td>8. Frank Oberklaid, AOM MD FRACP DCH</td>
<td>Director - Screening Section/Cancer &amp; Palliative Care Branch Population Health Division Australian Government Department of Health and Ageing</td>
</tr>
<tr>
<td>9. Tracey Bessell B Pharm, MPH, PHD</td>
<td>Doctor, Newborn Screening Ontario; Medical Director, BORN Ontario, Chair, Maternal Child Screening Committee; co-author Developing a National Newborn Screening Strategy for Canada</td>
</tr>
<tr>
<td>10. Heather Bryant, MD, PhD, CCFP, FRCP</td>
<td>Child Psychiatrist; Assistant Clinical Professor, Department of Psychiatry and Behavioural Neuroscience, McMaster University</td>
</tr>
<tr>
<td>11. Pranesh Chakraborty, MD, FRCP, FCCMG</td>
<td>Medical Health Officer, Vancouver Island Health Authority</td>
</tr>
<tr>
<td>12. Jean Clinton, MD</td>
<td>Provincial Health Officer, BC</td>
</tr>
<tr>
<td>13. Paul Hasselback, MD, MSc, FRCP</td>
<td>University of Toronto, Dalla Lana School of Public Health; Canadian National Breast Cancer Screening Study</td>
</tr>
<tr>
<td>14. Perry Kendall, MD, MSc</td>
<td>Institute of Health Policy, Management and Evaluation, University of Toronto; Ontario Maternal-Child Steering Committee; Ontario Expert Panel on Phamacogenetics; CIHR Institute of Genetics</td>
</tr>
<tr>
<td>15. Anthony B. Miller, MD, FRCP, FRCP, FFPH, FACE</td>
<td>Vice-President, Science and Public Health, Public Health Ontario (PHO)</td>
</tr>
<tr>
<td>16. Fiona A. Miller, PhD</td>
<td>L’Institut national de santé publique du Québec (INSPQ) Direction du secrétariat général et des communications</td>
</tr>
<tr>
<td>17. George Pasut, MD</td>
<td>Office of Public Health Practice, Public Health Agency of Canada (PHAC)</td>
</tr>
<tr>
<td>18. Jean Rousseau, PhD</td>
<td>Chair, Canadian Task Force on Preventative Health Care (CTFPHC); Associate Professor, Division of Nephrology, University of Alberta</td>
</tr>
</tbody>
</table>
## GLOSSARY OF SCREENING TERMINOLOGY

<table>
<thead>
<tr>
<th>Definition</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Screening:</strong> Screening is a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition.</td>
<td>United Kingdom National Screening Committee (2012).</td>
</tr>
<tr>
<td><strong>Screening</strong> is the systematic, population-based application of a test or inquiry to individuals who do not have symptoms of a specific disease or condition in order to identify those who warrant further investigation and/or intervention to achieve better outcomes.</td>
<td>R. Hayeems &amp; P. Chakraborty, on behalf of the Ontario Maternal Child Screening Committee. (May, 2012)</td>
</tr>
<tr>
<td><strong>Mass screening:</strong> The large-scale screening of whole population groups. <strong>Selective screening:</strong> Screening of selected high-risk groups in the population. It may still be large-scale, and can be considered as one form of population screening. <strong>Multiple or multiphasic screening (also called integrated risk profiling):</strong> The application of two or more screening tests in combination to large groups of people.</td>
<td>Wilson &amp; Jungner, 1968: Principles and Practice of Screening for Disease. <em>Public Health Papers. No.34</em></td>
</tr>
<tr>
<td><strong>Surveillance:</strong> Health surveillance is the systematic ongoing collection, collation, and analysis of data and the timely dissemination of information to those who need to know so that informed action can be taken.</td>
<td>Public Health Ontario</td>
</tr>
<tr>
<td><strong>Case-finding:</strong> Case finding is a strategy for targeting resources at individuals or groups who are suspected to be at risk for a particular disease. It involves actively searching systematically for at risk people, rather than waiting for them to present with symptoms or signs of active disease. Note the similarities to screening - both seek to risk stratify the population for further investigation (e.g., case finding is a key strategy in communicable disease outbreak management. The purpose is to identify at-risk individuals and offer them screening and treatment if necessary).</td>
<td>NHS HealthKnowledge Portal</td>
</tr>
<tr>
<td><strong>Early detection:</strong> A phrase describing prompt identification of incipient or early disease and, by implication, intervention to arrest, treat, and cure it in a timely manner; and the early detection of environmental, social, and behavioral hazards to health. Methods of early detection include questionnaires, interviews, physical examinations, screening tests, procedures and equipment for environmental monitoring, e.g., of drinking water, indoor air quality, ionizing radiation levels. Early detection is an important role of primary care physicians, who can use many opportunities that arise in the course of incidental and continuing care of patients to conduct simple screening tests for early evidence of serious conditions, such as cardiovascular disease, diabetes, and cancer.</td>
<td>Last, J. M. (2006). Dictionary of Public Health.</td>
</tr>
<tr>
<td><strong>Organized vs. opportunistic screening:</strong> Organised screening programmes have to be of a high standard, and the screening services are checked and monitored by people from outside the programme. With organised screening programmes, everyone who takes part is offered the same services, information and support. Often, large numbers of people are invited to take part in organised screening programmes. Opportunistic screening happens when someone asks their doctor or health professional for a check or test, or a check or test is offered by a doctor or health professional. Unlike an organised screening programme, opportunistic screening may not be checked or monitored.</td>
<td>New Zealand’s National Screening Unit.</td>
</tr>
<tr>
<td><strong>Overdiagnosis:</strong> Overdiagnosis occurs when people without symptoms are diagnosed with a disease that ultimately will not cause them to experience symptoms or early death.</td>
<td>Welch G, Schwartz L, Woloshin, S. <em>Overdiagnosed: making people sick in pursuit of health.</em> Beacon Press, 2011,</td>
</tr>
</tbody>
</table>
APPENDIX C: VISUAL REPRESENTATION OF SCREENING CONTEXTS, COMPLEXITIES AND SOURCES OF VARIATION
REFERENCES


7. Canadian Agency for Drugs and Technologies in Health (CADTH) (2012). http://www.cadth.ca/.


