



# To Screen or Not to Screen, That is the Question:

## A Consumer's Guide to Health Screening

“A good screening test is the one that saves the most lives and harms the fewest healthy people in the process.”

— H. Gilbert Welch, author of *Should I Be Tested for Cancer?* (U of Calif Press, 2006)

Screening in this case refers to looking for signs of disease in an otherwise healthy person, that is, a person without any symptoms. Anyone who has a lump or a bump or anything suspicious related to their health and consults their doctor for further investigation is considered to be undergoing “diagnostic” screening. Here, the physician is looking for the cause or source of a symptom or complaint. The objective of health screening, for the purpose of this guide can be defined as follows: “the early detection of those diseases whose treatment is either easier or more effective when undertaken at an earlier point in time.”<sup>1</sup> Essentially this guide to screening is not directed towards diagnostic investigations, but focuses solely on screening tests: those tests done on healthy people searching for early signs of disease.

An otherwise healthy person has the time to become educated before considering whether they wish to submit themselves to a ‘screen’. A screening test could be as simple as a blood test,

such as a PSA test in men, looking for early signs of prostate cancer; slightly more invasive tests, such as a pap smear for cervical cancer or a mammographic x-ray to search for signs of breast cancer in women, are also common. The screening could involve very sophisticated imaging devices such as CT, PET or MRI scans of internal organs, including hearts or lungs which expose patients to electromagnetic energy or radiation.

The National Cancer Institute of Canada says this about population screening: “because screening involves subjecting apparently healthy individuals to potential risk, population-based screening programs are recommended only when five specific factors are met. We discuss these factors under “Evidence of Benefit.” In constructing this checklist we assume one thing: That any otherwise healthy person presented with a screening test will want to approach the screening decision with as much good information about it as possible. People will want to ask questions and will expect reasonably detailed answers concerning the test’s potential benefits or harms. The decision to get screened is a personal one, and best made with good information and the advice of a trusted health professional. Further quality information can be found in references below.

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This Guide is based on a longer study entitled *What's in a Scan? How well are consumers informed about the benefits and harms related to screening technology (CT and PET scans) in Canada?* by Alan Cassels, Jaclyn van Wiltenburg and Wendy Armstrong, which can be found at [www.policyalternatives.ca](http://www.policyalternatives.ca). The study is published by the Canadian Centre for Policy Alternatives

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Criteria	What should you be asking about?	Notes
Evidence of Benefit <sup>2</sup>	<ul style="list-style-type: none"> <li>• Is there evidence the test can lead to treatment that reduces overall mortality?</li> <li>• Does the test detect the disease in a 'pre-clinical' phase?</li> <li>• Does the test accurately predict when disease does exist (high sensitivity) and it does NOT exist (high specificity)?</li> <li>• Does the test expose the individual to an unacceptable level of risk?</li> <li>• If a cancer is identified through screening, is effective treatment available? (Treatment that reduces morbidity or mortality to a greater extent than no treatment and that does not have unacceptable risks)</li> </ul>	<p>Good evidence should be the bedrock upon which screening recommendations are built. You need to know how strong the foundation is for the recommended screening test.</p> <ul style="list-style-type: none"> <li>• Does the test detect a disease at a point where, once detected, something meaningful can be done about it?</li> <li>• Does the test have a high degree of accuracy?</li> <li>• How often does it find things that turn out to be false alarms?</li> <li>• Is the test safe?</li> </ul>
Quantification of Risk and Benefit	<ul style="list-style-type: none"> <li>• If the screening test is to reduce my risk of becoming sick or dying from a particular disease, what is my risk to start with?</li> <li>• How big is it given my circumstances and age? And how much can a screening test reduce that risk?</li> </ul>	Well-studied, evidence-based screening programs will be able to say how many people may be saved from a harmful outcome if they are screened versus those who are not screened. Not knowing how big your risk is to start with is like seeing a "50% off" sign on a dress but not being told the original price. <sup>29</sup>
Disease Mongering	<ul style="list-style-type: none"> <li>• Is the particular screening test being oversold?</li> <li>• Are the risks of the disease in question made to look as scary as possible?</li> </ul>	Sometimes promoters of screening may exaggerate or over-sell a condition, turn risk factors into diseases or misrepresent the natural history and/or severity of a disease. Look out for spurious statistics, fear mongering, and treating 'signs' of disease as diseases in and of themselves.
Costs of Testing	<ul style="list-style-type: none"> <li>• What does it cost to do the test and is the cost of the test covered by my health plan?</li> </ul>	Screening tests that aren't a publicly-funded benefit in Canada are likely either not strong on the evidence (i.e. PSA testing) or too expensive and difficult to apply to the entire population (i.e. CT screening for colorectal cancer).
What happens next?	<ul style="list-style-type: none"> <li>• If I get a 'positive' test result, what happens next? (see questions below about harms of testing)</li> </ul>	Here's where you need to hear about what the options you'll likely be presented with. You may hear such terms as: biopsy, surgery, further tests, cumulative radiation exposure and "watchful waiting."
Harms of Testing	<ul style="list-style-type: none"> <li>• What are the potential downsides to being tested?</li> <li>• What is the likelihood of finding false positives?</li> <li>• Is there anyway to mitigate the likely anxiety and further stress that an individual may experience?</li> <li>• Should I be concerned about the exposure to radiation or other hazards or more repeated tests?</li> </ul>	These may be among the most important questions you need to ask. If there is a possibility that the test could harm you, you might want to rethink your desire to submit to the test. You should find out as much as you can before you agree to a test.
Sources of Information	<ul style="list-style-type: none"> <li>• Who is promoting a test (is it a for-profit or a non-profit organization)?</li> <li>• Has the test been approved and recommended by a respected national body?</li> </ul>	Sometimes there may be pressure on your doctor to do a test. You should find out if your doctor is under any pressure to recommend screening tests, or is rewarded for recommending them.
Availability of the test	<ul style="list-style-type: none"> <li>• Is the test available where I usually receive health care?</li> <li>• Is the test paid for through a public health plan?</li> </ul>	Non-coverage of tests is a red flag worthy of further investigation. Health systems typically assess screening tests to see if they are justified on the basis of evidence, safety and affordability. If this information isn't available, you should find out why.
Other options	<ul style="list-style-type: none"> <li>• Are there other things you could do to prevent the disease in question?</li> </ul>	There is a range of sensible advice that a physician could give you to help you avoid the disease in question, and advice you need if you think there is something suspicious that may need further investigation.

<sup>1</sup> Sacket, D.L., Holland, W.W. Controversy in the Detection of Disease, the Lancet, August 23, 1975, pp. 357-359

<sup>2</sup> These five criteria are from the National Cancer Institute of Canada report entitled Progress in Cancer Control Screening <http://www.ncic.cancer.ca/> (last modified August 12, 2008)

<sup>3</sup> Steve Woloshin, Lisa Schwartz and H. Gilbert Welch's book Know your chances: Understanding Health Statistics (U of California Press, 2008) is an excellent book to teach you how to read health statistics. They have created very helpful risk charts explaining a person's ten-year risk of dying from various diseases, based on age and smoking status. They also list and explain some very important questions concerning risk: 1. Risk of What. 2. How big is the risk? 3. Does the risk information reasonably apply to me? 4. How does this risk information compare with other risks? If a test or drug can reduce your risk you need to ask further: 5. Reduced risk of what? 6. How big is the risk reduction? 7. Does the risk reduction information reasonably apply to me? 8. What are the downsides that come with the risk reduction? 9. Is the risk reduction—the benefit—worth the downsides. 10. What kind of science is behind the numbers and who is behind the numbers?