

Appendix 3. Table of abridged text from PDAs that include ODX/OTX described as the detection/treatment of a cancer that would not cause death, detection/treatment of a cancer that would not cause symptoms, a potential harm or consequence of screening, and quantitative information.

Title	Cancer Type	ODX/OTX Description	Quantitative Information
Breast Cancer Screening: When Should I Start Having Mammograms? ⁶²	Breast	<p>Each time you have a mammogram, there is a risk that the test:</p> <p>May find cancers that will never cause a problem (called overdiagnosis). Some breast cancers never grow or spread and are harmless. You might have this type of cancer, but a mammogram can't tell whether it's harmless. So you may get cancer treatment—including surgery, radiation, or chemotherapy—that you don't need.</p>	Out of 1,000 women who are diagnosed with breast cancer during screening mammograms, experts estimate that about 190 of them may get treatment they don't need.
Is a mammogram right for me? ³⁴	Breast	<p>Limitations of Regular Mammograms: Some breast cancers detected may not be life threatening, but may still lead to invasive treatment. Mammograms may detect some breast cancers that will never become harmful, such as those that are slow growing and may never progress to produce symptoms or cause harm over a woman's lifetime. It is difficult to determine which cancers will be harmful and which will not, so all are treated as possibly harmful. This may mean that women have surgery or treatment for breast cancer that would never have been life-threatening. For every breast cancer found, approximately 1-10% are non-life threatening. Some breast cancers detected may not be life threatening, but can still lead to invasive treatment. Women are recalled for further testing for many reasons, and this can cause worry and stress.</p>	For every breast cancer found, approximately 1-10% are non-life threatening.

Breast Cancer Screening ³⁰	Breast	<p>Screening Mammography:</p> <p>... What does overdiagnosis mean? This means the diagnosis of breast cancer that, in hindsight, would not have caused harm. Individual patients will never know if they were overdiagnosed. They will really have breast cancer and be treated; however, in some cases the cancer may be very small growing or the patient dies of other reasons before the cancer becomes a problem.</p> <p>... These patients are diagnosed with and treated for breast cancer. In studies, however, some cancers never become clinically meaningful before death before something else. Estimated range from 1 (5%) to 5 (33%). These cases are often called 'over-diagnosis' or 'over-treatment'. It is not possible to know which cases these are after diagnosis.</p>	<p>'overdiagnosed by screening'. These patients are diagnosed with and treated for breast cancer. In studies, however, some cancers never become clinically meaningful before death before something else. Estimated range from 1 (5%) to 5 (33%). These cases are often called 'over-diagnosis' or 'over-treatment'.</p>
Use of a decision aid including information on overdetection to support informed choice about breast cancer screening: a randomized controlled trial ³⁷	Breast	For women in Australia who have breast screening over 20 years: 4 out of 1000 women avoid dying from breast cancer, and 19 out of 1000 women experience over-detection. So that means more women experience over-detection than avoid dying from breast cancer and 19 out of 1000 women are diagnosed and treated for a breast cancer that is not harmful (over-detection).	For women in Australia who have breast screening over 20 years: 4 out of 1000 women avoid dying from breast cancer, and 19 out of 1000 women experience over-detection. So that means more women experience over-detection than avoid dying from breast cancer and 19 out of 1000 women are diagnosed and treated for a breast cancer that is not harmful (over-detection).
Prostate Cancer Screening: Decisions for men with a family history of prostate cancer ⁹⁴	Prostate	Prostate cancers also tend to be slow-growing. Some prostate cancers are harmless, and never cause symptoms so men are unaware they have it. So, only about 10 in 1000 men (about 1%) die from prostate	Prostate cancers also tend to be slow-growing. Some prostate cancers are harmless, and never cause symptoms so men are unaware they have it. So, only about 10 in 1000 men (about 1%) die from prostate

		<p>cancer. Prostate cancer, however, varies across men and can be very serious. Some cancers grow very slowly and don't threaten life. Others grow more quickly and do threaten life. Prostate cancer typically causes no symptoms in its early stages. As it progresses, men may have problems with urination and with sexual function. These symptoms, however, can also indicate the presence of other diseases that are not prostate cancer.</p> <p>Large research studies following men who have, and men who have not, undergone PSA testing showed varying results for the likelihood of dying from prostate cancer over 4 to 10 years. One study showed no difference and another showed that PSA tested men were 20% less likely to die from prostate cancer over the 4 years of following them. The research also suggests that about half of the cases of prostate cancer detected by PSA screening would never cause symptoms. Side effects of treatment can sometimes cause death. If we treat cancers that don't need treating then we inevitably cause harm to people who would otherwise have been well. At present we are not able to identify which prostate cancers will cause harm and should be treated, and which will not.</p>	<p>cancer. Prostate cancer, however, varies across men and can be very serious. Some cancers grow very slowly and don't threaten life. Others grow more quickly and do threaten life. Prostate cancer typically causes no symptoms in its early stages. As it progresses, men may have problems with urination and with sexual function. These symptoms, however, can also indicate the presence of other diseases that are not prostate cancer.</p> <p>Large research studies following men who have, and men who have not, undergone PSA testing showed varying results for the likelihood of dying from prostate cancer over 4 to 10 years. One study showed no difference and another showed that PSA tested men were 20% less likely to die from prostate cancer over the 4 years of following them. The research also suggests that about half of the cases of prostate cancer detected by PSA screening would never cause symptoms. Side effects of treatment can sometimes cause death. If we treat cancers that don't need treating then we inevitably cause harm to people who would otherwise have been well. At present we are not able to identify which prostate cancers will cause harm and should be treated, and which will not.</p>
Prostate cancer screening: It's YOUR decision! ¹⁰¹	Prostate	<p>6 would never have known they had prostate cancer without screening (overdiagnosis)</p> <p>Being worried that you might have cancer when you don't</p>	<p>Being worried that you might have cancer when you don't Being diagnosed with cancer and having unnecessary treatments... So it could be said that the other 17 men were needlessly diagnosed. 6 of these men would</p>

		<p>Being diagnosed with cancer and having unnecessary treatments...</p> <p>So it could be said that the other 17 men were needlessly diagnosed... 6 of these men would never have known that they had prostate cancer in their lifetime if they hadn't had screening. These men are part of what is called overdiagnosis. Overdiagnosis, and the overtreatment it can lead to, are the main disadvantages of prostate cancer screening. Men who are thinking about having screening must understand that when prostate cancer is detected, it's impossible to know if it is a case of overdiagnosis or not.</p> <p>I'm worried my health might get worse if prostate cancer is found without there being any guarantee that I would live longer.</p>	<p>never have known that they had prostate cancer in their lifetime if they hadn't had screening.</p>
PSA Screening Decision-Making Aid ¹⁰⁶	Prostate	<p>A test may detect a slow-growing... This could lead to unnecessary treatment and side effects.</p> <p>If my PSA value is elevated, but further exams do not show prostate cancer, I will have undergone medical testing for nothing, and this will have caused unnecessary anxiety. This point is undeniably correct; the question is how heavy it weighs in the individual's situation. Earlier studies found that 'physical discomfort during digital rectal examination and during transrectal ultrasound was reported by 181 (37%) of 491 men and by 139 (29%) of 487 men, respectively; discomfort during prostate biopsy was</p>	<p>Within the ERSPC study the rate of over diagnosis based on this definition was estimated to amount to about 50%. Overdiagnosis and usually resulting overtreatment is the main reason why screening for prostate cancer is not considered a health care policy at this time.</p> <p>Within the ERSPC study the rate of over diagnosis based on this definition was estimated to amount to about 50%.</p> <p>During the first round of screening in ERSPC Rotterdam, 28.9% of the cancers detected were considered to have indolent features and to be suitable for active surveillance.</p>

		<p>reported by 64 (55%) of 116 men'. At the group level only short-lasting minor effects on health status were described.</p> <p>An elevated PSA test may detect a slow-growing tumor that could possibly never give me any trouble. Over diagnosis strongly depends on age, life expectancy and tumor characteristics. Within the ERSPC study the rate of over diagnosis based on this definition was estimated to amount to about 50%. Overdiagnosis and usually resulting overtreatment is the main reason why screening for prostate cancer is not considered a health care policy at this time. What then to tell the man to whom you are speaking? Knowing that we advance the time of diagnosis through testing by about 5-15 years depending on aggressiveness of cancers, we need to consider a long period of follow-up.</p> <p>Fifteen years seems reasonable if we speak to a man whose life expectancy may be expected to match this period. You should mention that 'over diagnosed cancers' can be identified after biopsy with acceptable certainty and that such a man then becomes eligible for active surveillance which at least initially avoids the side effects of treatment. I may have to deal with the possible complications of diagnostic testing and of prostate cancer treatment without having a life-threatening cancer. The short- and long-term side effects of treatment carry heavy weight in this context, specifically if the</p>	
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		<p>possibility of over diagnosis in a given situation is to be considered. A recent study from one of the recognized US expert centers revealed rates of full continence and erectile function of <75% versus >85% and <20% versus >45% for different surgeons working at the same institution. The recommendation is to take into account the patient's personality as much as possible when making decisions about testing. Men who are at risk should be aware of the risks of anxiety and depression induced by the diagnostic process, and of the possibility of the serious complications of treatment.</p> <p>... downsides of screening, mainly the high level of over diagnosis and the side effects due to treatment in general and in potentially 'over diagnosed' men, are reasons not to recommend the introduction of population-based screening at this time.</p> <p>This will help to avoid unnecessary treatment.</p> <p>If my PSA value is elevated, but further exams do not show prostate cancer, I will have undergone medical testing for nothing, and this will have caused unnecessary anxiety.</p> <p>An elevated PSA test may detect a slow-growing tumor that could possibly never give me any trouble.</p> <p>This statement addresses the important issue of over diagnosis and over treatment. While</p>	
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		<p>decreasing prostate cancer mortality in potentially curable aggressive cancers, the stage reduction seen with screening also leads to the detection of cancers that may be considered 'over diagnosed', meaning that they might never lead to clinical detection or life-threatening disease.</p> <p>Over diagnosis strongly depends on age, life expectancy and tumor characteristics. Within the ERSPC study the rate of over diagnosis based on this definition was estimated to amount to about 50%...</p> <p>During the first round of screening in ERSPC Rotterdam, 28.9% of the cancers detected were considered to have indolent features and to be suitable for active surveillance.</p> <p>Part of the potential of over diagnosis has been addressed when we discussed the downstaging seen with screening...</p> <p>...Over diagnosis and usually resulting over treatment is the main reason why screening for prostate cancer is not considered a health care policy at this time, just as the investigators of the ERSPC study also concluded...</p> <p>I may have to deal with the possible complications of diagnostic testing and of prostate cancer treatment without having a life-threatening cancer. The short- and long-term side effects of treatment carry heavy weight in this context, specifically if the</p>	
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Making the Choice (Prostate Cancer Awareness Month) ³³	Prostate	<p>On the other hand, prostate cancer is a very <i>different</i> kind of cancer. Most prostate cancers grow very slowly and never cause problems. A few grow quickly... If men live long enough, most will have cancer cells in their prostate, but few will die of it. About 60 out of 100 men over the age of 70 have cancer cells whether they know it or not. BUT only 3 out of 100 American men will die from it. Most men die WITH prostate cancer, not FROM prostate cancer. Because it is slow growing men often die from other things first.</p> <p>Decision is Up to You Early stage prostate cancer is different. It may get worse. But it may not. The treatment may save you. Or it may cause problems that you could have avoided.</p> <p>The older you are, the less likely prostate cancer will cause problems in your lifetime. Other health problems may shorten your life enough that prostate cancer may never bother you.</p>	About 60 out of 100 men over the age of 70 have cancer cells whether they know it or not. BUT only 3 out of 100 American men will die from it.
PSA Screening Decision Aid ³⁹	Prostate	It is estimated that half of men treated for PSA detected prostate cancer would not have had clinical symptoms during their lifetime. We call this phenomenon over-diagnosis. What I find interesting here is that all of the 110 men who were diagnosed would likely feel they had been, quote, "saved by the test," when in fact we simply turned many of these men into patients unnecessarily and	It is estimated that half of men treated for PSA detected prostate cancer would not have had clinical symptoms during their lifetime. We call this phenomenon over-diagnosis. What I find interesting here is that all of the 110 men who were diagnosed would likely feel they had been, quote, 'saved by the test,' when in fact we simply turned many of these men into patients unnecessarily and may

		<p>may have led them to treatments that are often unpleasant and perhaps do harm.</p> <p>So for example, you might get that PSA testing could start a chain reaction of biopsies and treatments that in the end could harm you unnecessarily, but you're the type that needs to know and would just want that cancer treated even if it's a turtle cancer, and maybe that's your reason to go ahead. On the other hand, if taking the test for the small chance of saving a life doesn't seem worth the higher chances of unnecessary harm, false reassurance and possibly knowing about a slow growing cancer that you would just watch doesn't seem worth it, you may decide not to have the test.</p> <p>The turtle represents prostate cancer that is never going to harm a patient. You will not have symptoms or die of the turtle cancer as it never leaves the paddock. The screen really doesn't make a difference with the turtle cancer.</p>	<p>have led them to treatments that are often unpleasant and perhaps do harm.</p>
Prostate Cancer Screening Questions to Think about for Men Aged 50-74 ¹¹⁵	Prostate	<p>They recommend NOT to get prostate cancer tests, because men are more likely to get harm than to get benefit.</p> <p>It's not a perfect test, and it can be high and cause worry, even when there is no prostate cancer. That's a real harm. And a high test can lead to other testing, like a prostate biopsy, which is painful and can have complications like infection.</p>	<p>Currently, if you get PSA testing regularly for 10 years, you are at least 50 times more likely to get harm than benefit.</p>

		<p>...and frequently get surgery or radiation treatment that hardly really ever helps them live longer and often leads to serious complications.</p> <p>So, most men with prostate cancer don't die from it? Right. Even if you do have prostate cancer, most of the time it never causes you any harm because it tends to grow slowly and occur in older men.</p> <p>Getting diagnosed with, and treated for, a cancer that never would have affected you, are real harms. So is getting treated earlier than you need it, for a cancer that wouldn't have affected you.</p> <p>Finding and treating a cancer early SEEMS like it should save lives. But in this case, it does more harm than good.</p> <p>Currently, if you get PSA testing regularly for 10 years, you are at least 50 times more likely to get harm than benefit.</p>	
Minneapolis Veterans Affairs Medical Center Early Prostate Cancer: Information you should know about Testing & Treatment ¹¹⁹	Prostate	<p>What is a man's risk of dying from prostate cancer? Most men (70-80 percent) who have prostate cancer do not die from it because most types of prostate cancer grow very slowly. Men have a higher chance of dying from heart disease, stroke or other types of cancer.</p> <p>Does an abnormal PSA or rectal exam mean a man has prostate cancer? No. Most men (70 percent) with abnormal PSA or rectal exam do <u>not</u> have prostate cancer.</p>	<p>What is a man's risk of dying from prostate cancer? Most men (70-80 percent) who have prostate cancer do not die from it because most types of prostate cancer grow very slowly. Men have a higher chance of dying from heart disease, stroke or other types of cancer.</p> <p>Does an abnormal PSA or rectal exam mean a man has prostate cancer? No. Most men (70 percent) with abnormal PSA or rectal exam do <u>not</u> have prostate cancer.</p>

		<p>Do doctors think men should have regular PSA and rectal exams? Some believe testing is helpful because prostate cancer may be found early when a treatment may cure. Other doctors believe testing is harmful because treatment has side effects and has not been shown to save lives.</p> <p>What is the best treatment for early prostate cancer? No one knows. Research is being done to find out which treatment is best and if PSA and rectal exams save lives.</p> <p>Should every man get a PSA & rectal exam? No one knows if a PSA and rectal exam improves life quality or helps men live longer. Many doctors think older men and men with serious medical problems should not have a PSA and rectal exam. Such man usually do not have problems from prostate cancer and are more likely to be harmed by surgery or radiation.</p>	
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