



Making a Decision about Colon Cancer Screening

A Guide for Older Adults



PROM-IS
PROMOTING INDIVIDUALIZED SCREENING





Who is this booklet for?

Older adults who are considering colon cancer screening.

This booklet will help you decide whether getting screened for colon cancer is the right choice for you.

You will be presented with information about the possible benefits and the harms of screening. This will help you to make your own choice about whether or not to be screened.

Some of the information in the booklet may be surprising to you. In fact, it may surprise you that you have a choice about screening or that there are reasons why some people might not want to be screened. *The purpose of this booklet is not to tell you what to do but to help you understand your options.*





What is colon cancer screening?

Colon Cancer

Colon cancer is a medical condition where a tumor or growth forms in the lining of the colon, part of the digestive system where stool or poop is made.

Screening

Screening is when we look for colon cancer or colon polyps in someone who doesn't have any symptoms.

Colon cancer screening tests look for colon cancer or polyps before you have problems.

If we find colon cancer at an early stage before symptoms start, it's usually curable. If we detect it at a later stage, after symptoms have already started (like blood in the stool or belly pain), it's a lot harder to treat.



How do you **screen** for colon cancer?

There are two main ways to screen for colon cancer: colonoscopy and stool tests.

1. Colonoscopy

A colonoscopy is a type of screening test where doctors insert a flexible tube into the colon to look for cancer or polyps. To get a colonoscopy, you first need to drink a “prep” solution to clean out your colon the day before the procedure. This prep works by causing severe diarrhea, which is what cleans you out.

2. Stool Test

A stool test (also known as a stool card or vial, or “FOBT”) requires you to put a small sample of stool or poop on a paper card or into a vial. This card or vial is sent back to the hospital, where it is tested in the laboratory for small amounts of blood.

If you decide to get screened, your doctor can help you decide which test is right for you.



What are the **benefits** and **harms** of screening?

Screening has the potential to benefit you, but it can also cause harm.

Screening can benefit you by...

- Preventing you from developing colon cancer.
- Preventing you from dying from colon cancer.
- Giving you a sense of well being from having done something to protect your health.

Screening can harm you by...

- Leading to complications from a colonoscopy.
- Leading to treatments that can cause side effects and complications.
- Causing unnecessary worry due to positive test results that turn out not to be cancer.

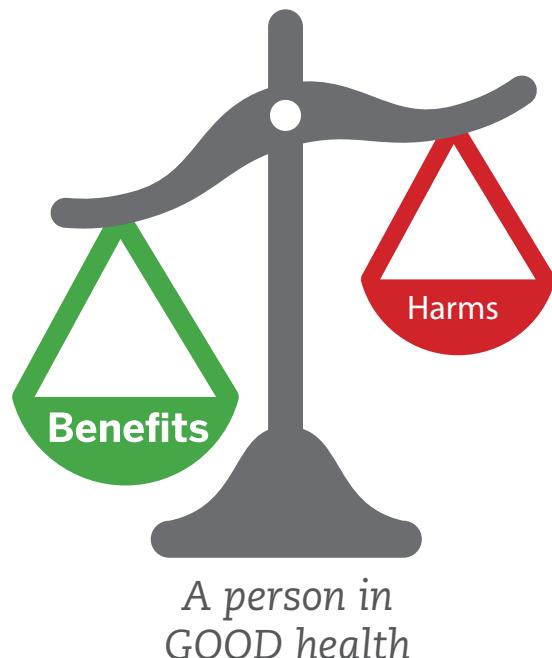
In the pages ahead, you'll learn more about these benefits and harms from stories about patients who got screened.



Why do experts recommend starting screening **at age 50?**

Experts recommend that everyone should get their first colon cancer screening test at around age 50. Getting a screening test around age 50 has proven benefits. At this age:

- Screening decreases the chances that people will die from colon cancer.
- The chances of being harmed by screening are small.
- *This means that the benefits of screening clearly outweigh the harms.*





What happens if they **find** cancer?

- Some people with colon cancer will need *surgery* to remove the cancer.
- Some people will need *radiation therapy* or *chemotherapy*.
- Treatment can last for several months, and most patients will need monitoring for years after the treatment is finished.
- In some patients, this treatment will cure the cancer for good.



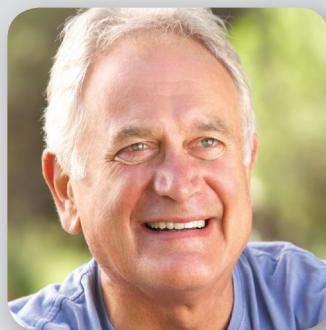


Here are two stories about people who **benefited** from colon cancer screening.

Joe

Joe is a 58-year-old mechanic who is a colon cancer survivor.

When Joe was 53, his doctor suggested stool cards for colon cancer screening. At first, he didn't want to get screened, but his wife talked him into it. His stool cards showed traces of blood in the stool, so he got a colonoscopy. He was shocked when he found out that he had colon cancer.



Fortunately, the cancer had not spread, and he ended up having surgery to remove the cancer. Because the cancer was only in the colon, he didn't need any chemotherapy or other treatments. The doctors say that he's cured.

Joe knows that things might have been different if he had waited to get screened.



Sam

Sam is a 64-year-old firefighter with diabetes and high blood pressure. He started seeing a VA doctor just a couple of years ago.



When Sam was 60, his doctor suggested that he get a colonoscopy for colon cancer screening. The colonoscopy showed that he had several large colon polyps, the kind of polyps which often turn into cancer if not removed. However, Sam's doctor removed these polyps.

Sam knows that if these polyps had not been removed, he might have eventually gotten cancer.

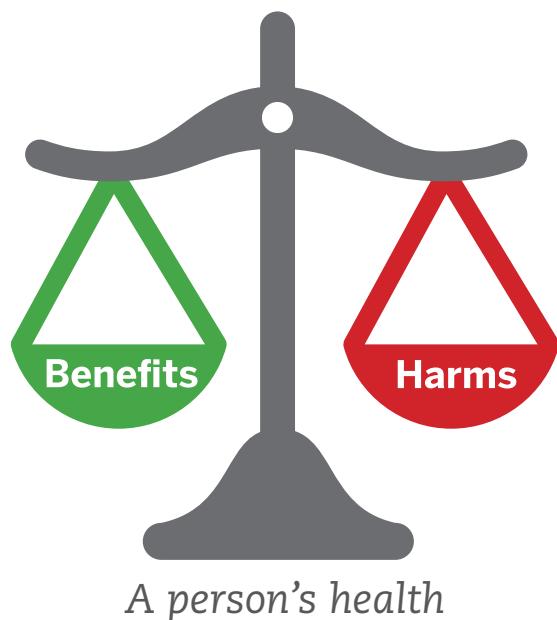


Why is colon cancer screening **different** as I get older?

The balance of screening benefits and harms changes as people get older.

Experts therefore recommend that *older people should decide for themselves*, with the help of their doctors, whether they want to have colon cancer screening.

In the next few pages, we will explain in more detail how the balance between benefits and harms changes as you get older.







What is **different** now that I'm older?

1. The chances of getting colon cancer go up as people get older.

- The older people get, the more likely they are to develop colon cancer.
- But it can take a long time for cancer to grow big enough to cause symptoms or problems.
- In most cases, colon cancer is the kind of cancer that grows very slowly.
- If a person develops colon cancer today, they might not even know about it for at least 5 years, and maybe as long as 10 years.





2. The risk of getting serious health problems goes up as people get older.

- Older people start to have other serious health problems like heart disease, stroke, diabetes, and other types of cancer.





What is **different** now that I'm older? continued

3. Serious health problems can change how long people might live.

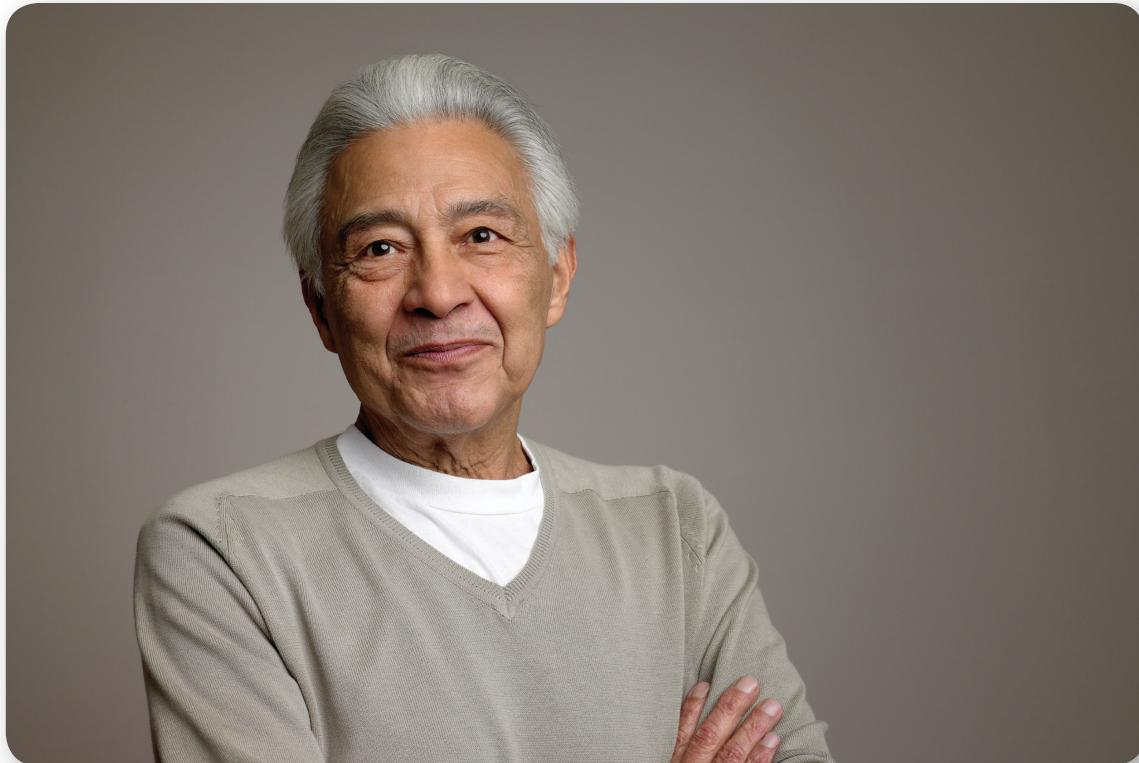
- On average, older people with serious health problems die sooner than people with fewer or less serious health problems.
- On average, older people without serious health problems have a better chance of living longer.





4. Other serious health problems can lead to death before colon cancer causes any problems.

- People might die from colon cancer, or they might die from another health problem.
- Colon cancer is just one of many serious diseases that can affect older people.





What is **different** now that I'm older? continued

5. Colon cancer screening will not help all older people.

- People probably need to live about 10 years for colon cancer screening to help them.
- Depending on older adults' current health problems, they might not be expected to live 10 years.





6. There is uncertainty about who will benefit from colon cancer screening.

- The problem is that no one can know exactly how long any person will live.







*It's all about the **balance**
between benefits and harms.*

Your age and how healthy you are can change the balance.





*It's all about the **balance** between benefits and harms.* continued

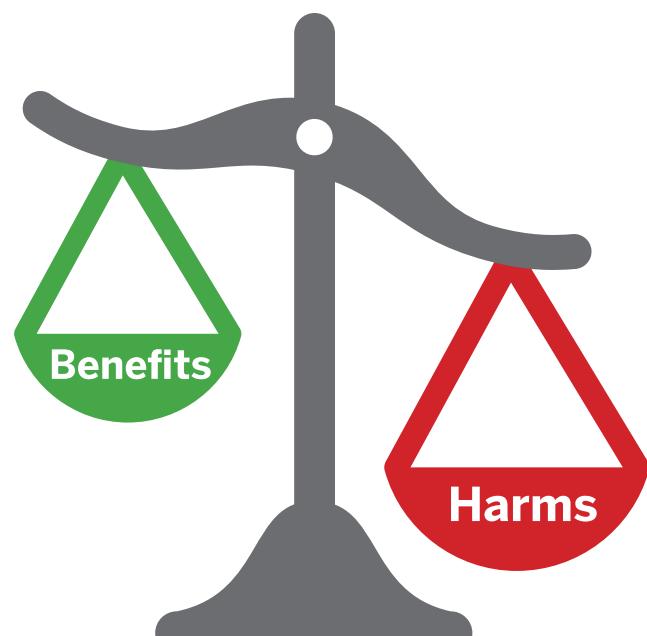
An older person *in good health* is likely to have more benefit than harm from colon cancer screening. This is because they are more likely to live at least 10 years, during which time colon cancer might cause them problems.



*A person in
GOOD health*



An older person *in poor health* is likely to have more harm than benefit from colon cancer screening. This is because they are unlikely to live at least 10 years, which means they won't benefit from screening.



*A person in
POOR health*

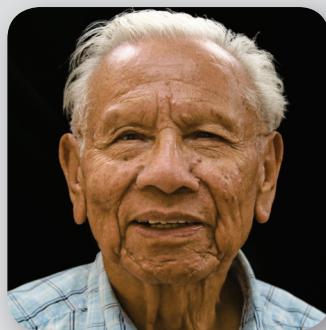


Here are two stories about older people in poor health who **were harmed** from screening.

Robert

Robert is a 79-year-old man with diabetes, heart disease, and rheumatoid arthritis.

Robert's doctor suggested that he get a colonoscopy for screening, and he agreed. His colonoscopy found a large cancer in the colon.



Initially, the doctor recommended surgery and chemotherapy. But the surgeon did not think Robert would do well with a surgery because of his health problems. The doctors also told him that the cancer would probably grow very slowly. As a result, he probably wouldn't live long enough for it to matter.

After talking with the doctors, Robert decided that he didn't want any treatment for the cancer. In fact, he wished he had never gotten the colonoscopy, because knowing he had cancer weighed heavily on his mind.



Fred

Fred is a retired 78-year-old man with heart disease and emphysema.

Fred decided to do stool cards for screening after one of his close friends passed away from colon cancer. His stool cards showed traces of blood in the stool, so he got a colonoscopy. His colonoscopy discovered a cancer in the colon. He was having no symptoms.



After speaking with his doctors, Fred decided to get treatment for the cancer with surgery. After recovering from the surgery, he got chemotherapy to get rid of any leftover cancer in the lymph nodes and other parts of the body. The treatment was long, and it wasn't easy, but Fred got through it.

About 3 weeks after finishing chemotherapy, Fred had a stroke while watching television at his home. He died on the way to the hospital. The doctors said that the stroke was not related to his cancer. His family wondered if getting screened for colon cancer had been worth it.



A person in **fair health**

For a person in *fair health*, it is hard to know whether they will live 10 years. For this person, the benefits and harms of colon cancer screening are pretty much equal.



*A person in
FAIR health*



How do I decide if the balance of benefits and harms has changed for me?

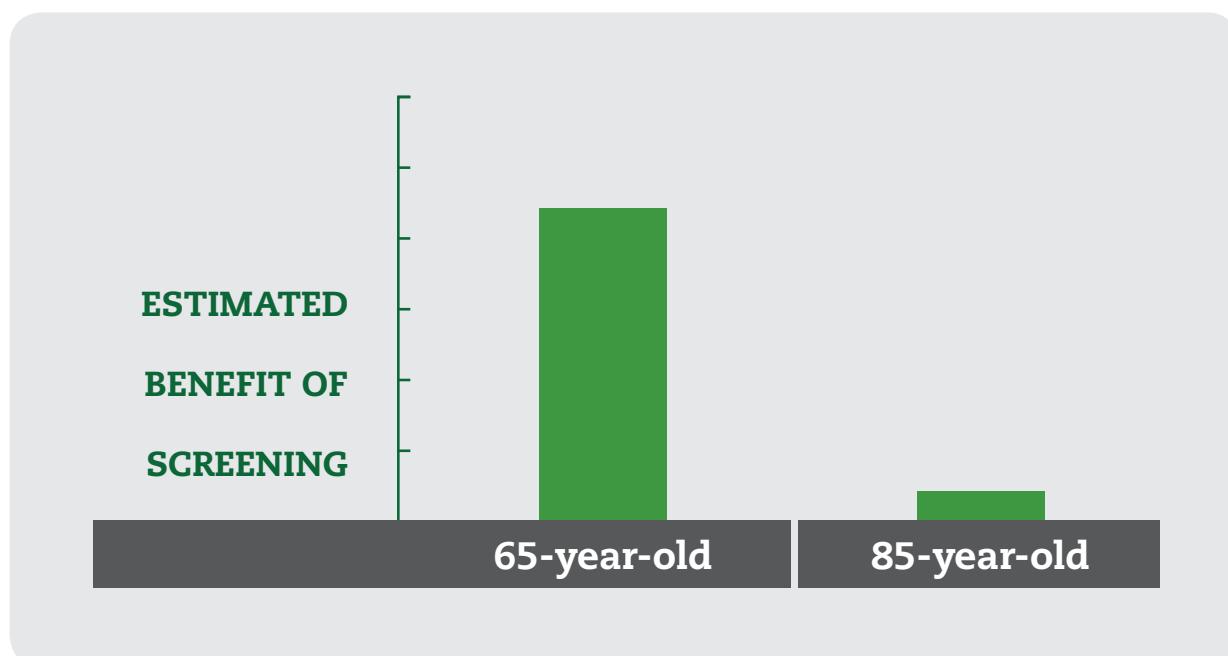
To figure this out, you need to think about which way your age and how healthy you are might have tipped the balance.





Let's go over what you need to **think about**.

1. In general, screening is more likely to help younger people than older people.



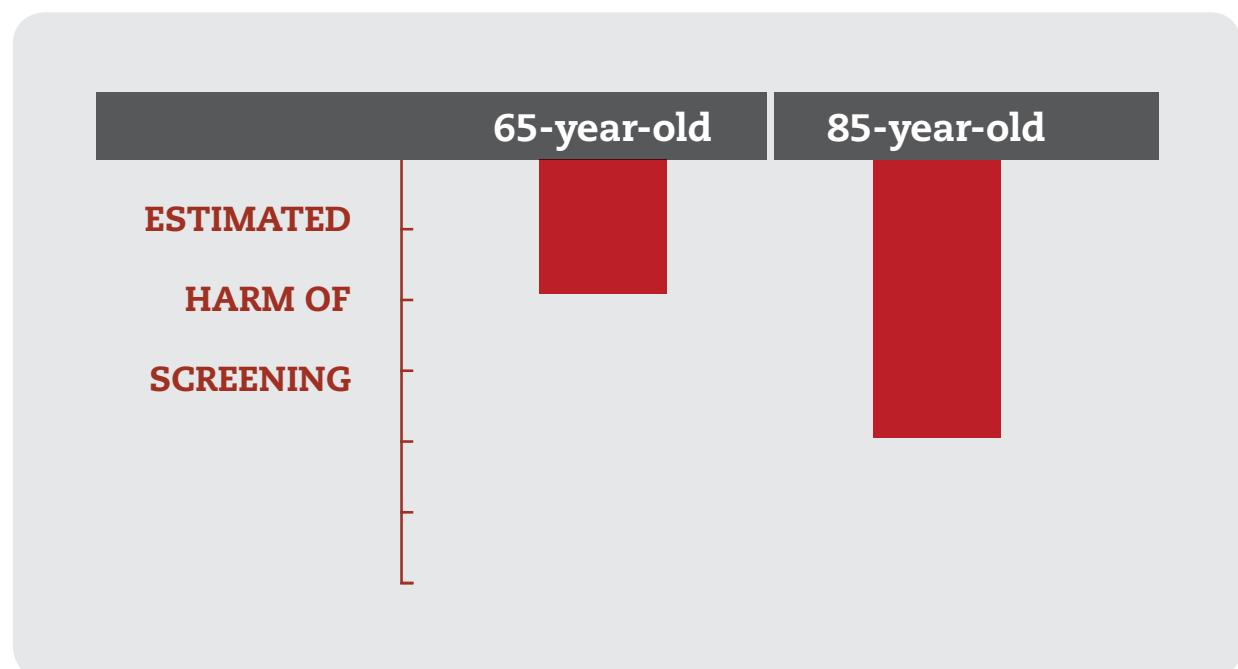
- On average, screening is about 10 times more likely to help a 65-year-old than an 85-year-old.

Note:

- “Benefit” means colon cancers prevented by screening.



2. In general, screening is more likely to harm older people than younger people.



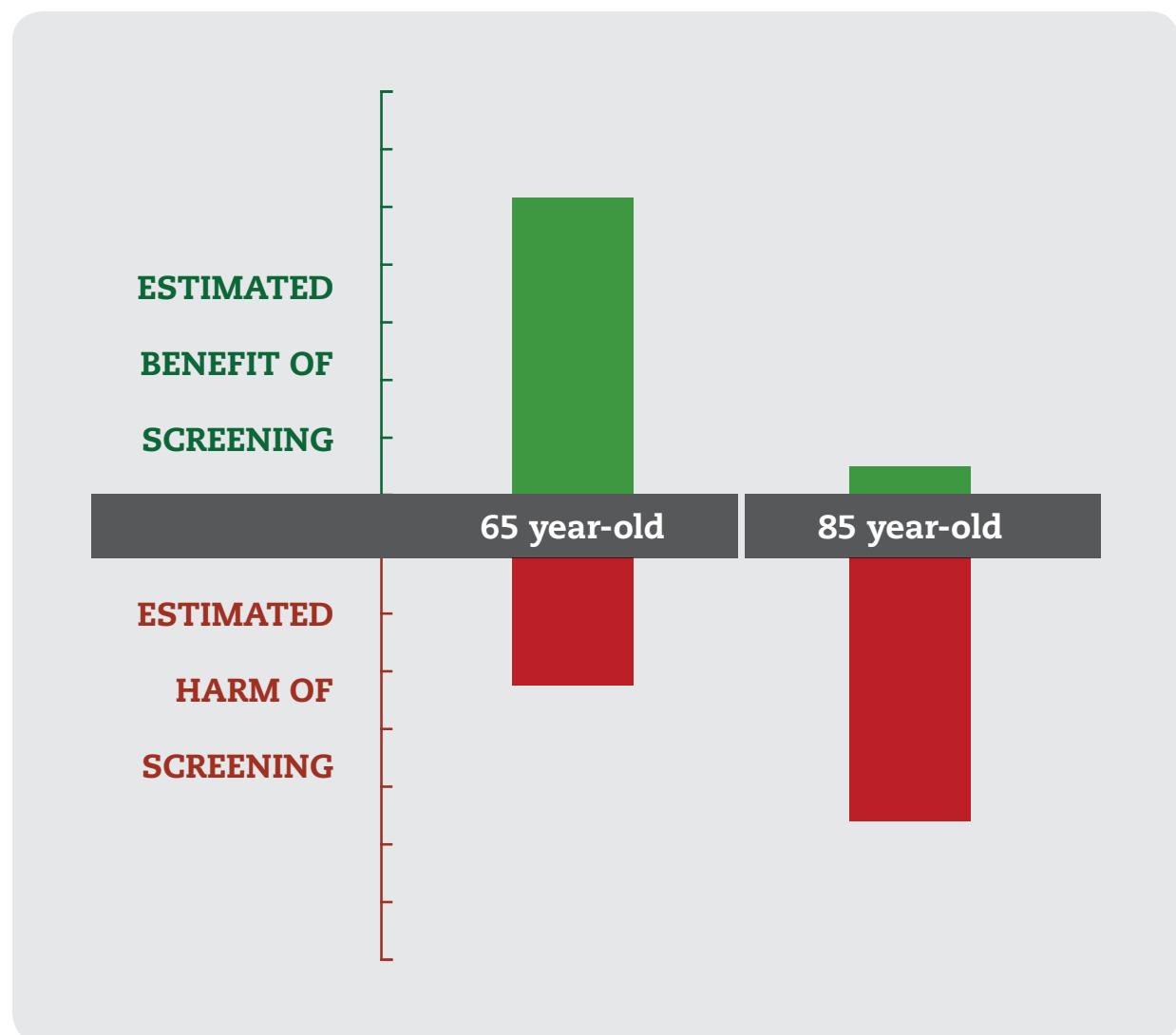
- On average, screening is about 2 times *more likely* to harm an 85-year-old than a 65-year-old.
- Harms of screening include bowel perforation or bleeding and heart complications, such as heart attacks.

Note:

- “Harm” means bowel or heart complications caused by screening that were serious enough to require an emergency room or hospital visit.



3. So, as people get older, they are less likely to benefit from screening and more likely to be harmed by it.



Note:

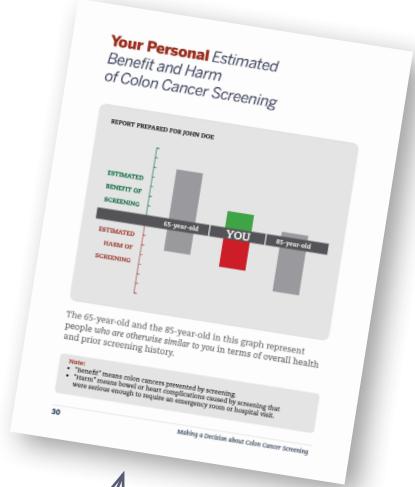
- “Benefit” means colon cancers prevented by screening.
- “Harm” means bowel or heart complications caused by screening that were serious enough to require an emergency room or hospital visit.



Where Do I Fit In?

Your Personal Estimate (page 30)

- To help you figure out where you fit in between the two extremes described above, we estimated **your personal benefit and harm** of screening.
- To do this, we used your health history, your screening history, your family history, and your other personal characteristics (like your age and whether you're a man or a woman).
- On the last 2 pages of this booklet, you will see:
 1. **Your Personal** Estimated Benefit and Harm of Colon Cancer Screening.
 2. **Your Personal** Colon Cancer Screening Decision Worksheet.
- After you review your estimate, we would like you to fill out **Your Personal Colon Cancer Screening Decision Worksheet** on page 31.
- You should take your answers into your doctor's visit today. It will help you and your doctor think about what screening choice is right for you.



Your Personal Colon Cancer Screening Decision Worksheet

For each row, please choose one answer, either A or B, that best describes you and your wishes.

<input type="checkbox"/> 1A. Based on my present condition, colon cancer screening is important compared with other health concerns.	<input type="checkbox"/> 1B. Based on my present condition, colon cancer screening is not important compared with other health concerns.
<input type="checkbox"/> 2A. I would want surgery if colon cancer was found, even though it might not extend my life.	<input type="checkbox"/> 2B. I would not want surgery if colon cancer was found, even if it could extend my life.
<input type="checkbox"/> 3A. I am willing to take the risk of having a complete colonoscopy in order to have a chance to benefit from colon cancer screening.	<input type="checkbox"/> 3B. I am not willing to take the risk of having a colonoscopy in order to have a chance to benefit from colon cancer screening.
<input type="checkbox"/> 4A. It is important for me to be screened for colon cancer even though it is uncertain whether or not it will prolong my life.	<input type="checkbox"/> 4B. It is not worth it to me to be screened for colon cancer because it is uncertain whether or not it will prolong my life.

Please share this page with your doctor at today's visit.

31

Your Personal Decision Worksheet (page 31)



Your Personal Estimated Benefit and Harm of Colon Cancer Screening

The 65-year-old and the 85-year-old in this graph represent people who are otherwise similar to you in terms of overall health and prior screening history.

Note:

- “Benefit” means colon cancers prevented by screening.
- “Harm” means bowel or heart complications caused by screening that were serious enough to require an emergency room or hospital visit.



Your Personal Colon Cancer Screening **Decision Worksheet**

For each row, please choose **one answer**, either A or B, that best describes you and your wishes.

1A. Based on my present condition, colon cancer screening is **important** compared with other health concerns.

1B. Based on my present condition, colon cancer screening is **not important** compared with other health concerns.

2A. I would **want surgery** if colon cancer was found, even though it might **not** extend my life.

2B. I would **not want surgery** if colon cancer was found, even if it could extend my life.

3A. I am **willing** to take the risk of having a complication in order to have a chance to benefit from colon cancer screening.

3B. I am **not willing** to take the risk of having a complication in order to have a chance to benefit from colon cancer screening.

4A. It is **important** for me to be screened for colon cancer even though it is uncertain whether or not it will prolong my life.

4B. It is **not worth it** to me to be screened for colon cancer because it is uncertain whether or not it will prolong my life.

Please share this page with your doctor at today's visit.



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Lewis CL, et al. A targeted decision aid for the elderly to decide whether to undergo colorectal cancer screening: development and results of an uncontrolled trial. BMC Med Inform Decis Mak. 2010 Sep 17;10:54.