Designing Decision Aids:
A Public Deliberation

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This document was prepared for *Designing Decision Aids: A Public Deliberation*, a project funded by the Patient-Centered Outcomes Research Institute.

The **Patient-Centered Outcomes Research Institute (PCORI)** was created by Congress in 2010 as an independent, nonprofit organization with the following goal (as stated on their website http://www.pcori.org/about-us):

"PCORI was established to fund research that can help patients and those who care for them make better-informed decisions about the healthcare choices they face every day, guided by those who will use that information."

The research team leading this project is based at the **Indiana University Center for Bioethics**, at the **Indiana University School of Medicine** in Indianapolis.

What is the purpose of this booklet?

In May, you will be participating in a public deliberation about how to help people make good decisions about their healthcare. This booklet will give you an overview of the topics and discussions that will take place during the public deliberation. You can also use the booklet during or after the event to review the topics.

The booklet gives an overview of:

- how people work with their healthcare providers to make healthcare decisions,
- how decision aids can improve people's decisions, and
- what questions exist about how to design decision aids.

Throughout the booklet, we will explore the example of colon cancer screening tests – tests that are used to check for colon cancer and polyps – and how decision aids may help people choose whether to be screened and which test is best for them.

We ask that you read this booklet to become familiar with the issues. You do not need to be an expert to participate in this public deliberation. None of your fellow participants will be experts. Your perspective and life experiences are what matter.

What is a public deliberation?

A *public deliberation* is a community discussion based on the idea that members of the community should have a voice in decisions that may affect them. Our goal is to involve people from many different backgrounds and with different opinions, needs, and expectations. By using the knowledge, insight, and advice of this group, we can help improve how patients receive information and make choices about their healthcare.

Participants in the public deliberation will:

1. **learn** how people get information and work with their healthcare providers to make decisions about colon cancer screening,
2. **consider** how we know when a patient is making a good decision,
3. **consider** when recommendations and information about the risks and benefits of screening are trustworthy, and
4. **offer advice** about how patients should be supported in making screening decisions that are best for them, especially through the use of decision aids.

During this public deliberation, people from Indianapolis and surrounding counties will meet to discuss their values and opinions. Participants were selected to reflect diverse experiences and perspectives. We believe that the advice of Indiana residents like you will help to design decision aids that can help people and families make health decisions that are best for them.

The group's conclusions will be reported to people and organizations that create decision aids and recommend how decision aids should be made and evaluated.

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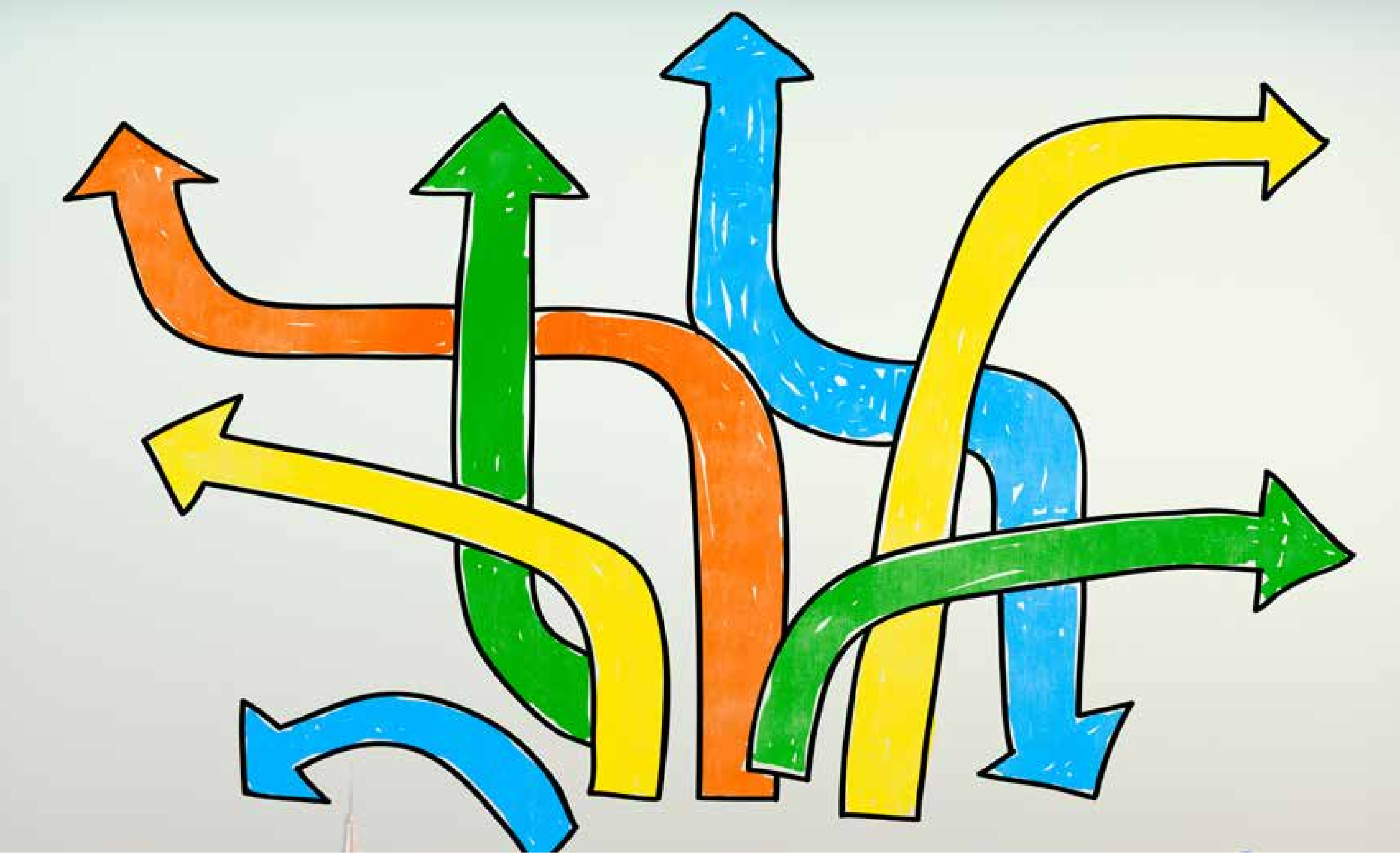

Decision Making And Decision Aids

Supporting informed healthcare decisions

Everyone has to make decisions about healthcare for themselves and their loved ones. These decisions can be relatively simple, such as deciding whether to take a medication for high cholesterol or diabetes. Other decisions can be complex, such as deciding whether to have knee replacement surgery or what chemotherapy to take for cancer.

Sometimes decisions about a patient's healthcare are made by the doctor or healthcare provider: A doctor may say that she recommends taking a certain medication but say little else. Simply telling a patient what to do, however, does not fit with the common view that patients should be equal partners with doctors in making decisions about their healthcare. Providers are supposed to inform patients about the treatment options available and the benefits and downsides of each option. The patient and doctor then should work together to make a decision about what to do. This is called "shared decision-making."

Helping patients participate in making decisions is very important when no single option is clearly best. For instance, some people with severe knee arthritis may want to undergo surgery to have their knee replaced, while others want to try simpler options, such as physical therapy and steroid injections. To make an informed choice, each person needs to know how much benefit they can expect from each of the options and their risks and downsides.

Many people get this information from doctors or other healthcare providers. While some providers do a good job of telling their patients what they need to know, others do not do as well. Some healthcare providers don't provide enough information to allow patients to make fully-informed decisions about their healthcare.

Beyond talking to their doctor and family and friends, many people get information from newspaper articles, television, the internet, and social media. These sources may provide important information, but they are not always reliable. Also, it can be hard to figure out how to find, interpret, and apply the information.

Studies have shown that patients making healthcare decisions often do not know about all the options and are unaware of the pros and cons of each option. One danger of this is that a patient will select an option without fully understanding it. Even worse, a patient may have a complication or suffer harm from a treatment that she would not have chosen if she had known more about it.

Healthcare providers need to provide information and support to help patients make good health decisions.

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Decision aids

Decision aids are booklets, videos, or websites that explain medical decisions and the options available for care. They are designed to help patients make a decision that is best for them.

Many decision aids have been made and tested. There are decision aids about topics such as:

- whether to have knee replacement surgery,
- whether to have a mammogram for breast cancer screening, and
- whether to take medicine to lower cholesterol.

Research studies show that patients who use decision aids know more about the available options and the pros and cons of each option than patients who do not use them. They also report feeling more confident about their ability to have a conversation with their healthcare provider and make a decision about their options for care.

Increasingly, health systems and doctors' offices are offering their patients decision aids. In the near future, health insurance plans may require that patients view a decision aid before making an important decision. For instance, Medicare and Medicaid now will only pay for lung cancer screening for individuals if they have a "shared decision-making" conversation with their healthcare provider, including a decision aid.

Over the course of the public deliberation event in Indianapolis, you will view decision aids about colon cancer screening and consider what you think is useful or not useful about them. If decision aids are going to become part of standard healthcare, they have to be well designed to support patient understanding and decision making.

The following section outlines some of the questions about how decision aids should be designed.

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What information should decision aids include?

Experts do not always agree on how to design a good or useful decision aid. For example, there are differing opinions about how much information should be presented by a decision aid:

- On the one hand, a large amount of information can help patients make more informed decisions.
- On the other hand, too much information can overwhelm or confuse patients.

Experts have different opinions about the right balance.

This is not just a question about whether patients like one type of information or not. For instance, it might be important for patients to hear about the risks or side effects of some treatment, even if they'd rather not think about it. If some information is complex or difficult to understand, it still may be important for a decision aid to present it and explain it as clearly as possible to allow patients to make fully-informed decisions.

Deciding what information to include in decision aids depends on people need to know to make a truly informed choice. And determining what information is important requires the input of a wide range of people, from experts to healthcare consumers such as yourself. These are exactly the sorts of questions we will be discussing during the public deliberation. Your thoughts and opinions will help determine how decision aids are designed and evaluated in the future.

What is a good decision?

People have varying opinions about what makes a decision "good". Some people think that good decisions are ones where the person considered important information and thought about that information carefully before choosing an option with their healthcare provider. Other people prefer to rely on the opinions and recommendations of family or friends and maybe trusted experts, such as their doctor. Others just want to hear about a few things and then make a decision quickly, basically "following their gut."

Different people have different ways of making decisions, and each person approachs decisions in different ways. In any situation, and for any person, a decision is probably not good or high quality if the person was misled about some important fact or if important information was left out. Even people who rely on the opinions of family or trusted experts often say that they want to be informed about key facts.

While reading this booklet and during the public deliberation event, you will consider ways to improve people's healthcare decisions and how to design effective decision aids. You will have opportunities to reflect on your views about what makes a choice a "good decision."

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COLON CANCER SCREENING

Why we are talking about colon cancer screening?

We'll talk about several different medical situations and healthcare decisions as part of this public deliberation. But we'll focus on one area that our Indiana University team studies: decisions that patients have to make about getting tested or "screened" for colon cancer.

Our team studies colon cancer screening, in part because it is a decision that all people over 50 years of age face. In addition, there are several different screening tests for colon cancer, which makes the choice about colon screening more complicated than for other types of screening, where there is only one test. As part of the public deliberation, you will have a chance to look at decision aids that have been created to help people make decisions about colon cancer screeing.

Exploring this area provides an example of the issues involved in medical recommendations and making medical decisions, as well as the sorts of information decision aids may provide to patients.

> **It is up to the individual to decide whether to be screened, and sometimes which test to undergo.**

Cancer screening

Cancer often does not cause symptoms until it is advanced, at which time it is often difficult or impossible to cure. Screening tests find cancer or precancerous growths before they cause symptoms, when they are easier to treat. Some screenings tests you may have heard about are:

- Pap smears to check for cervical cancer, in women from age 21 to 65
- Mammograms to check for breast cancer, for women after age 40 or 50 to 75 (or later)
- Colon cancer screening, for men and women ages 50 to 75

These tests are recommended for almost everybody in these age groups because there is strong evidence that these tests reduce deaths from cancer.

Some tests that can identify cancers or precancerous growths before they cause symptoms are not recommended since these tests do not reduce deaths from the cancer. These tests lead to follow-up testing and treatment that doesn't benefit enough people.

Many people think that having a mammogram to screen for breast cancer, or having a colonosocpy to screen for colon cancer, is simply something the doctor recommends and the patient does, with no real decision needed. But in each of these cases, it is up to the individual to decide whether to be screened, and sometimes which test to undergo. Decision aids can help people make these kinds of decisions.

Introduction to colon cancer screening

Colon cancer is a major public health issue, since it is the second biggest cancer killer in the United States. Every year in America, about 140,000 people are diagnosed with colon cancer, and 50,000 die from it. Colon cancer affects both men and women. Health experts sometimes refer to this cancer as "colorectal cancer," but we will use the simpler "colon cancer" here.

Colon cancer comes from polyps that grow in the colon. These polyps start out harmless, or "benign," and grow slowly. Some may turn into cancer over time. Luckily, there are screening tests that can find and remove polyps, or can find cancers before they start causing symptoms.

Doctors and groups like the American Cancer Society and the United States Preventive Services Task Force recommend that everybody get screened for colon cancer starting at age 50 until age 75 with one of the following tests:

- **Colonoscopy**, performed once every 10 years or more regularly if polyps are found;
- **Stool blood tests**, performed every year;
- **Flexible sigmoidoscopy**, performed every five years;
- **Stool DNA tests**, performed every three years; or
- **CT colonography (Virtual colonoscopy)** every five years.

If the stool blood test, flexible sigmoidoscopy, stool DNA test, or CT colonography has certain results – for example, finding blood or a polyp – then the patient needs to have a follow-up colonoscopy for further testing or treatment.

People over 50 years old need to make two decisions related to colon cancer screening:

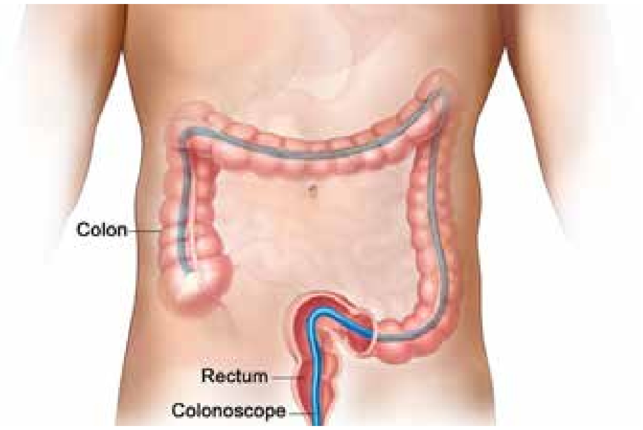
- First, they must decide whether to be screened, and
- Second, if they want to be screened, they must decide which test to have.

Decision aids have been made to present information on colon cancer and all of these tests. For this public deliberation, we'll discuss just colonoscopy and stool blood tests, since these are the most commonly used ones in Indiana and elsewhere in the United States.

> **People over 50 years old need to make two decisions related to colon cancer screening: first, they must decide whether to be screened, and second, if they want to be screened, they must decide which test to have.**

Colonoscopy

In this test, a doctor uses a thin, flexible tube to look at the colon through the rectum. The patient is given medications to help him or her relax. The procedure takes about an hour. If the doctor sees anything unusual, she can take a sample, or biopsy, and examine it for cancer. If the doctor finds a polyp she can remove it. If a colonoscopy doesn't find any polyps, there is no need for the patient to be screened again for 10 years.



There are downsides to colonoscopy, which are:

- Colonoscopy is a medical procedure that has to be carried out in a hospital or similar facility.
- The patient has to "clean out" his or her bowel before the procedure, which involves taking a strong laxative and drinking only clear fluids for a day or two.
- The patient has to take a day off of work to have the test, and needs someone to drive him or her home.
- Colonoscopy has some risks: very rarely, people having a colonoscopy need to be hospitalized because of heavy rectal bleeding or colon tears that need surgery to fix.

Stool Blood Test (FIT)

This test, sometimes called the FIT (for Fecal Immunochemical Test), is based on the fact that polyps and colon cancers often bleed a small amount that isn't visible to the naked eye. The stool blood test detects these small amounts of blood in the stool.

For the stool blood test, an individual collects a small piece of stool (or bowel movement) using a special brush and places the brush into a small tube, which he or she sends back to the lab or the doctor's office. If the test finds no blood in the bowel movement, then nothing else is needed from the patient. The test is repeated annually. If the test does find some blood, then the patient needs a colonoscopy.

The advantage of the stool blood test is that it is easier to do than the colonoscopy and is done at home. The downsides are:

- It has to be done every year.
- Collecting a small sample of stool may be unpleasant for some people.
- If blood is found – that is, if the stool blood test is "positive" – the patient needs to have a colonoscopy.
- The stool blood test does not find polyps and colon cancer as reliably as colonoscopy does. A polyp or cancer that is not bleeding will not be detected by the stool blood test. These may not show up until a later test.

Many patients also wonder: How much will this cost me? Both colonoscopy and the stool blood test are generally covered by health insurance. However, patients are sometimes charged for copays or deductibles, though some efforts are trying to eliminate those. It's important to find out about possible charges when you are thinking about getting screened.

A problem for public health

In the United States, about 66% of people ages 50 to 75 are up to date with a screening test for colon cancer. This is a lower rate than for other cancer screening tests. For example, over 80% of women are up to date on their pap test to check for cervical cancer, and 80% of women ages 40 and older have had a mammogram in the last two years.

In some sense, this low rate of screening is *a public health problem*. When *fewer* people get screened, *more* people get colon cancer and die from it. A number of groups such as the American Cancer Society advocate for more people to be screened, aiming to get the percentage of Americans who are up to date with screening for colon cancer up to 80% by 2018. By one estimate, reaching the goal of 80% would save 30,000 Americans from dying of colon cancer in just 5 years.

This means that public health officials have a reasonable goal of increasing the number of people who get screened. Public service announcements raise people's awareness of colon cancer and the screening tests. Other initiatives focus on eliminating insurance copays or deductible charges that may be a barrier for some people to get screened

A problem with informing patients

Looking at the individual level, there are good reasons to get screened, to reduce the chance of getting colon cancer and dying from it. But each person has to make that decision for himself or herself. A person may make an informed choice not to be screened, as much as they may make a choice to be screened. People are free to choose to be screened or not screened, just as they are free to accept or reject any medical test or treatment.

There is evidence that many people who are eligible for screening do not know enough about colon cancer, their own chances of getting it, or the screening tests to make an informed decision about whether to be screened or which screening test is right for them. Research shows that doctors do not discuss colon cancer screening with patients as much as they do other cancer screening tests, such as mammography or pap smears.

Also, studies show that doctors often recommend only colonoscopy to their patients without describing or offering other approved tests. People who may prefer the stool blood test often do not know that that is an option, and may not get screened because they are unwilling to have a colonoscopy. Research shows that offering patients a stool blood test as well as colonoscopy increased screening rates.

In a recent study of patients who were scheduled to have a screening colonoscopy, over half didn't know that there are other approved tests available. Most patients could not name either of the two major complications of colonoscopy (injury to the colon and bleeding). These patients made poorly-informed choices to get a screening colonoscopy.

Decision aids support the goal of educating patients. Decision aids have been made that present extensive information about colon cancer and the screening tests. Studies have shown that these decision aids improve how much people know about the screening tests and in some cases increase the percentage of people who choose to be screened.

> **People are free to choose to be screened or not screened, just as they are free to accept or reject any mecical test or treatment.**

Considering the benefits and harms of screening

The benefits of colon cancer screening are clear: screening reduces the number of people who will get colon cancer or die from it.

There are also downsides and potential harms to screening, which we've already reviewed for the two most commonly used screening tests, colonoscopy and the stool blood test. But there are also potential downsides that go beyond those, which are drawbacks that colon cancer screening shares with other types of screening. These drawbacks help explain why choosing to be screened or not – based on balancing the potential benefits against the downsides – is a choice that each person should make.

Here are four important downsides or limitations of colon cancer screening:

Most people do not get colon cancer: Even though colon cancer is the second most common cancer killer in the United States, only a small percentage of the population will get it, and a smaller percentage will die from it, even if they never get screened. Out of 1000 people who have an average risk for colon cancer who never get screened, only about 60 in 1000 (6%) people will get colon cancer, and 30 in 1000 (3%) will die from it. That means even if they never get screened, about 940 out of 1000 people (94%) will never get colon cancer. The figure on page 22 shows this.

Screening does not provide 100% protection: Even though screening tests reduce the number of people getting colon cancer or dying from it, they don't reduce the number to 0. Any test can miss a polyp or cancer. While screening reduces the number of people who die of colon cancer from about 30 in 1000 (3%) people to 5 per 1000 people (0.5%), it does not reduce the number to 0. The figures on page 24 shows this.

Screening tests can cause anxiety and worry: If a stool blood test finds blood, it is natural to worry about what the follow-up colonoscopy will find. Similarly, patients who have polyps removed by colonoscopy may worry while waiting for the analysis. In both cases, patients who started out feeling perfectly healthy must deal with temporary uncertainty about whether they have a health problem.

Screening can lead to unnecessary treatment: Many colon polyps that are identified and removed during a colonoscopy would never have developed into cancer. Even some of the cancers that are found during screening would never have caused a problem if they had not been found. This is because either they wouldn't have grown and caused symptoms, or the person would have died from some other cause before that happened. Doctors don't know which polyps or cancers will develop into a problem, so they generally recommend removing or treating all of them. That means some people will benefit from having a polyp removed or their colon cancer treated, but for others this will be unnecessary treatment.

Screening for breast cancer and other screening tests have the same problems. Mammograms, are recommended for all women from age 45 or 50 to age 75. Although this test finds breast cancers and precancerous growths early and saves lives, there are also important drawbacks:

- Even though breast cancer is an important risk for women, it only affects a small percentage. 1 in 8 women will get breast cancer in their lifetime, but that means that 7 in 8 will not.
- Mammograms are not perfect at finding cancer or all pre-cancerous growths. Even after getting mammograms regularly, some women will get breast cancer or die from it.
- Women will have anxiety after a mammogram finds an abnormality, even if it later turns out to be harmless.
- Mammograms will find many cancers and pre-cancerous growths that would never have caused a problem if they had not been found through screening. This leads to unnecessary follow-up tests and treatment.

How do experts decide what screening tests to recommend?

The experts who evaluate screening tests compare:

- the benefits of screening, most importantly how many people the screening tests protect from getting or dying of the cancer, vs.
- the risks and burdens of the tests, including those listed in the previous section.

Experts only recommend screening tests when they think that the benefits outweigh the burdens and risks.

Recommendations, or guidelines, exist for cancer screening. Two of the most influential groups that write guidelines for cancer screening are

- the United States Preventive Services Task Force, and
- the American Cancer Society.

These groups and others like them bring together experts who do not have conflicts of interest to review all the evidence and write unbiased recommendations For instance, it would not be a good idea to have a person who sells colonoscopes – the machine used to perform colonoscopies – to decide whether to recommend this test as superior to the other options for colon cancer screening.

Experts only recommend screening tests when they think that the benefits outweigh the burdens and risks.

The highest quality studies are the ones that measure the long-term health of people who were invited to be screened, compared to the health of people who were not invited to be screened. (This is sometimes called a "randomized, controlled trial.").

Based on the evidence, these expert groups recommend colon cancer screening and breast cancer screening only for people of certain ages: e.g. over 50 years of age for colon cancer screening. The guidelines do **not** recommend screening for people at younger ages. This is because screening tests for people at younger ages find very few cancers and precancerous growths, since very few people at these ages get these cancers. So, the tests don't help many young people.

Once people enter middle age, they are more likely to get cancer or precancerous growths, which is why experts recommend screening for this age group.

For older people, cancers and precancerous growths are relatively common, but screening has less benefit, since other causes of death happen more often. For this reason, most screening tests are not recommended for people above certain ages. Guidelines do not generally recommend colon cancer screening for people over 75 years of age.

Thyroid Cancer Screening: Some screening tests are not recommended for people at any age. For instance, consider thyroid cancer screening. Doctors could do an ultrasound exam of the thyroid gland of healthy people, and would find some early thyroid cancers and precancerous growths (“nodules”) that could be removed. This would protect some people from getting thyroid cancer or dying of it. But there are many reasons why no national groups recommend screening for thyroid cancer in people without any symptoms:

- Thyroid cancer kills very few people, so very few people benefit from getting screened,
- The screening test identifies many thyroid cancers or precancerous growths that would not cause any problems if left alone. This means that screening leads to a lot of tests and treatments that people don’t really need, and
- Surgery to take out thyroid cancers is risky and expensive, meaning that many people will suffer negative side effects.

For all these reasons, groups like the American Cancer Society and the United States Preventive Services Task Force do not recommend thyroid cancer screening.

What is an expert?

Throughout this booklet, there are many references to “experts.” It’s important to realize there are many different sorts of experts who bring many different talents and training to discussions about decision aids and screening tests. Some experts specialize in epidemiology, which is the study of how common diseases are and the impact of testing or treating them. Some are experts in communication or psychology, and some are doctors who specialize in certain areas. In short, there is no single type of expert who knows everything relevant to either cancer screening tests or decision aids. All the recommendations in these areas come from discussions by groups of people with expertise of various sorts, who try to come to agreement about some hard questions.

The experts who evaluate screening tests compare the benefits of screening, most importantly how many people the screening tests protect from getting or dying of the cancer vs. the risks and burdens of the tests.

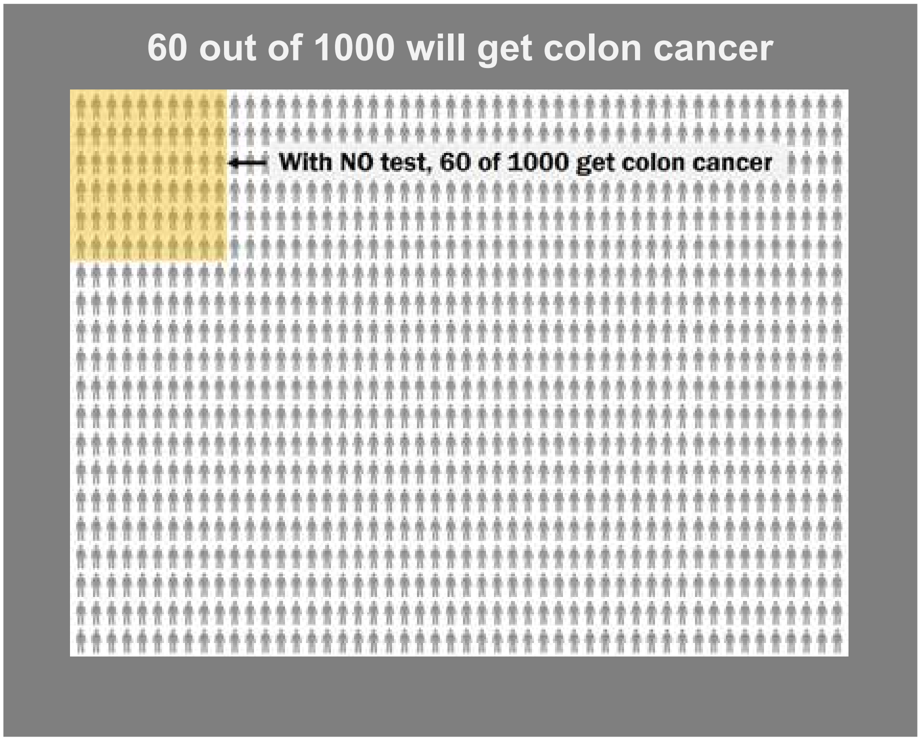
Using numbers to evaluate colon cancer screening tests

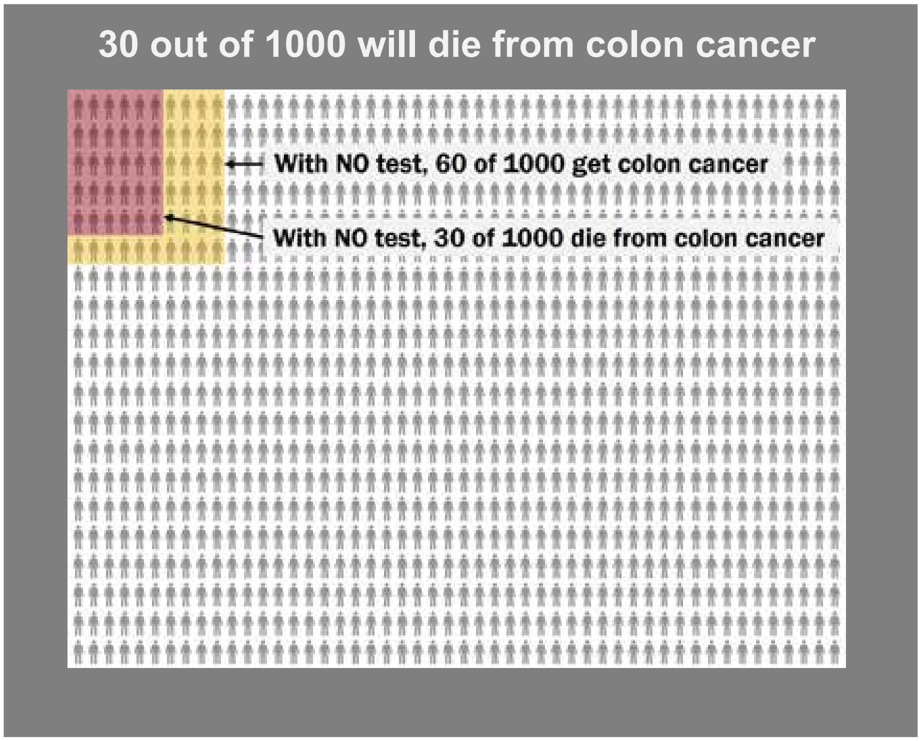
To make recommendations about screening tests, experts collect and evaluate information about many things. These include:

- how often this cancer occurs, when screening is <u>not</u> performed,
- what percent of the precancerous growths (for example, polyps) or early cancers grow and cause problems or death over certain time periods,
- how often the screening tests find cancers or precancerous growths,
- how often the screening tests themselves cause problems or harms,
- what percent of people benefit from finding and removing a precancerous growth or early cancer.

All of this information involves numbers. Here are some of the numbers for colon cancer and colon cancer screening. In each case the numbers are for people 50 years of age with average risk for colon cancer who might or might not be screened with colonoscopy or the stool blood test.

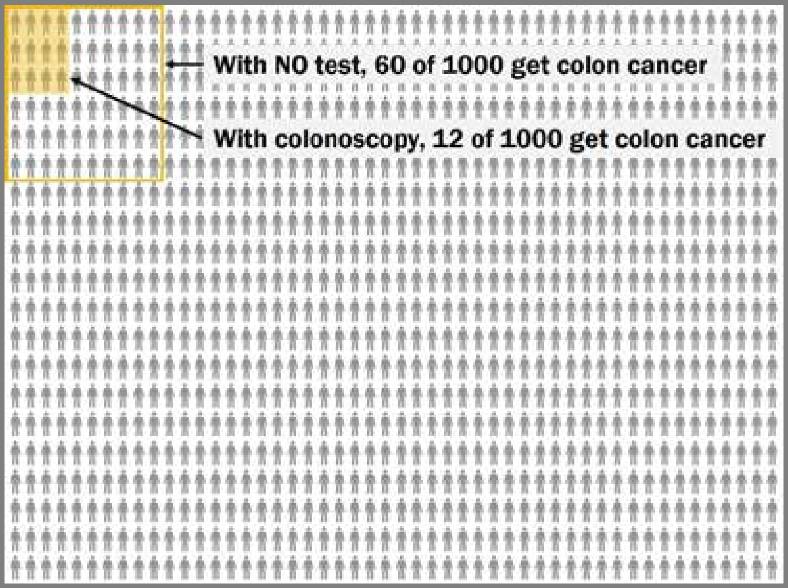
Out of 1000 people who never get screened, 6% (or 60 out of that 1000 people) will get colon cancer in their lifetime, and 3% (or 30 out of that 1000 people) will die from it. These two charts illustrate these numbers. Each chart has 1000 stick figures with each stick figure standing for one person:



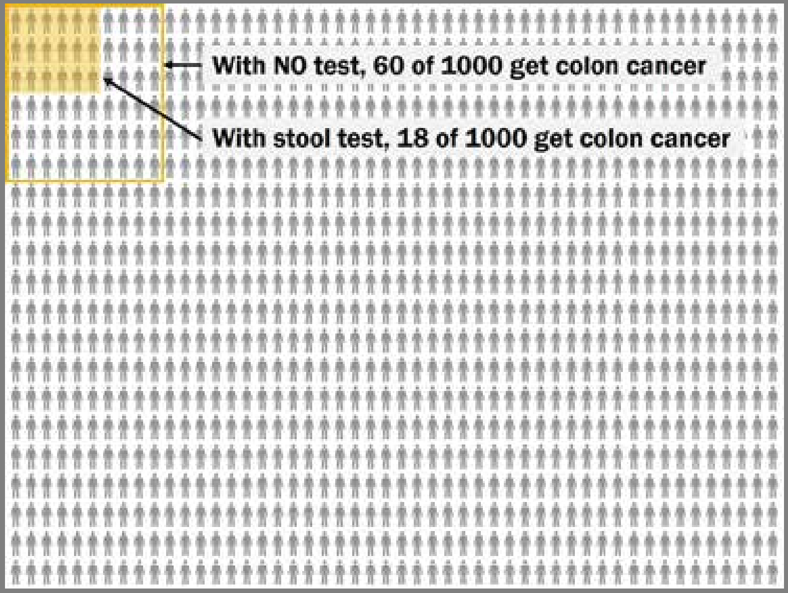


Screening with colonoscopy from ages 50 to 75 reduces the number who **get colon cancer** in their lifetime from 60 per 1000 individuals (6%) to 12 per 1000 individuals (1.2%). Stool blood testing every year, with follow-up colonoscopy when needed, reduces the number of people who get colon cancer to 18 per 1000 individuals (1.8%). Here are two charts that show this:

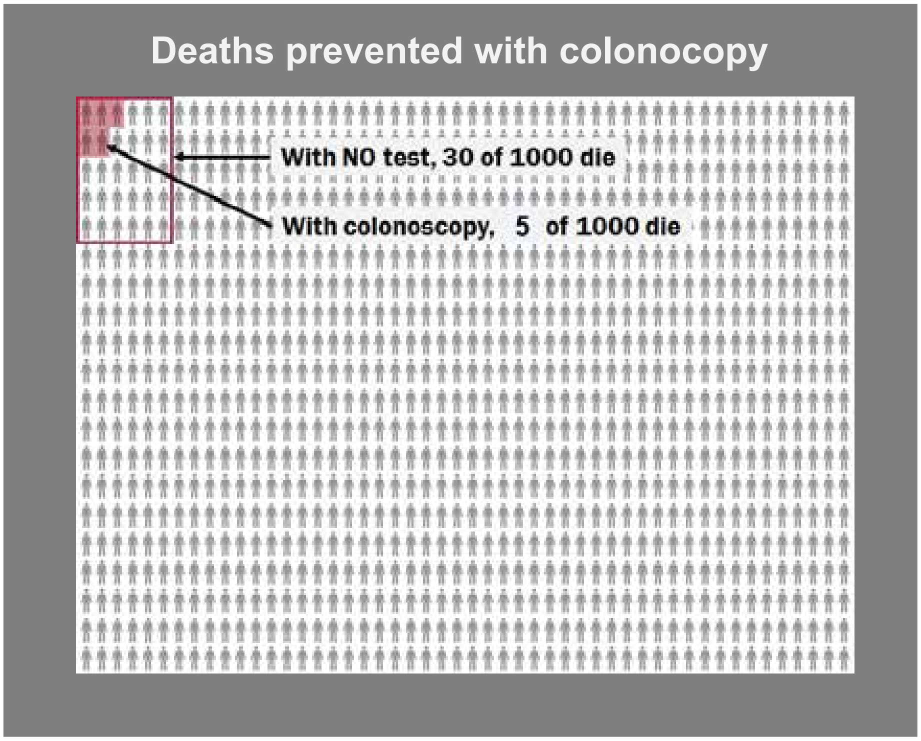
Cancers prevented with colonoscopy

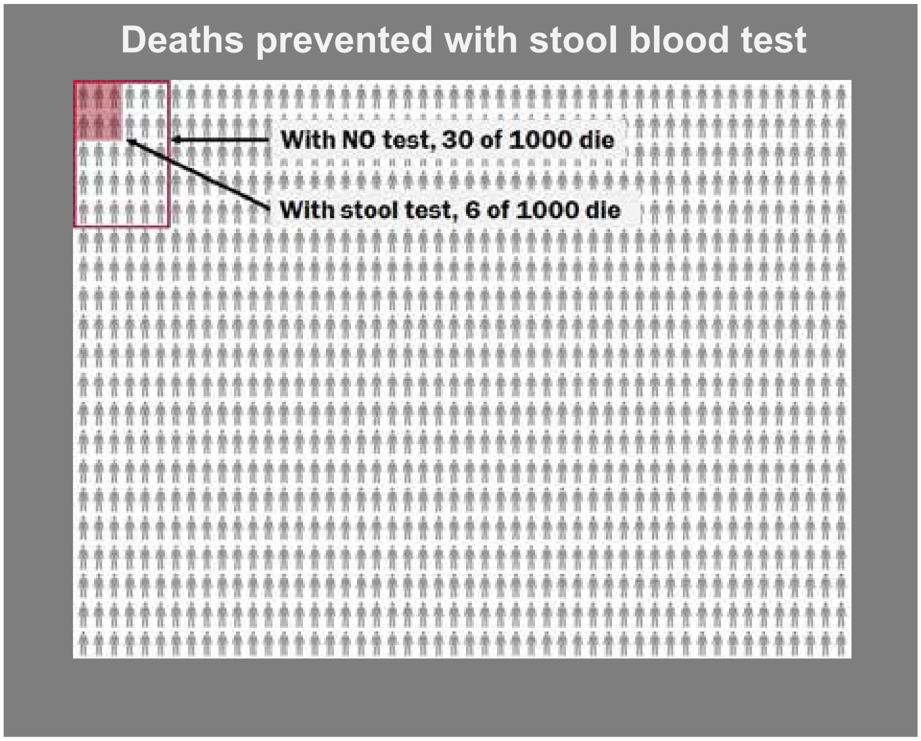


Cancers prevented with stool blood test

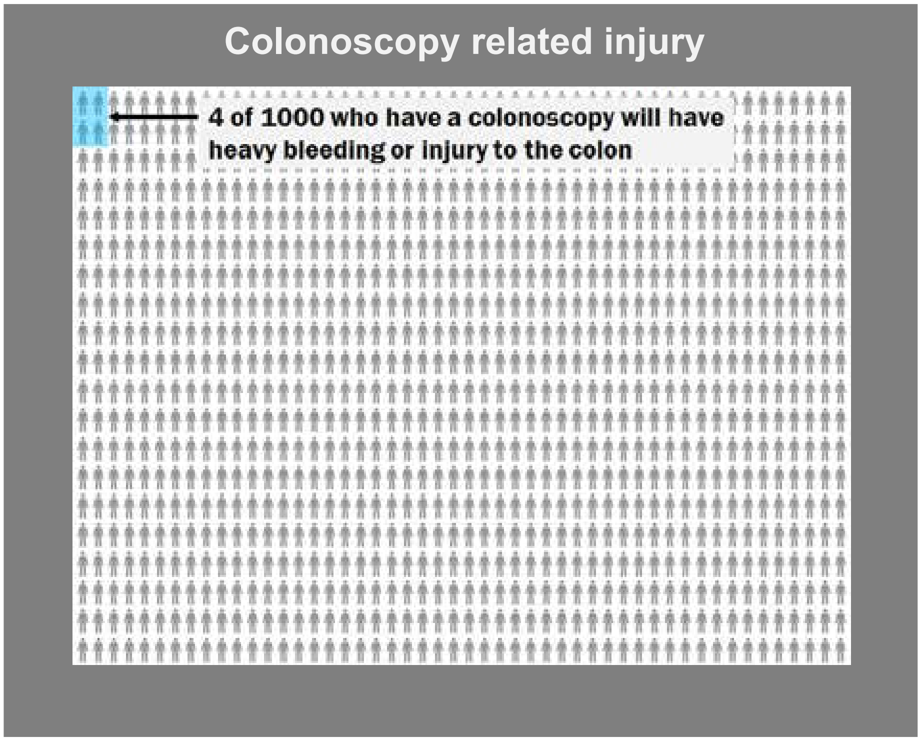


Colonoscopy and stool blood tests also reduce the number of people who **die from colon cancer**. Screening with colonoscopy from ages 50 to 75 reduces the number of people who die of colon cancer in their lifetime from 30 in 1000 individuals (3%) to 5 in 1000 (0.5%). Stool blood testing every year, with follow-up colonoscopy when needed, reduces the number of people who die of colon cancer to 6 per 1000 individuals (0.6%). Here are two charts that show this:



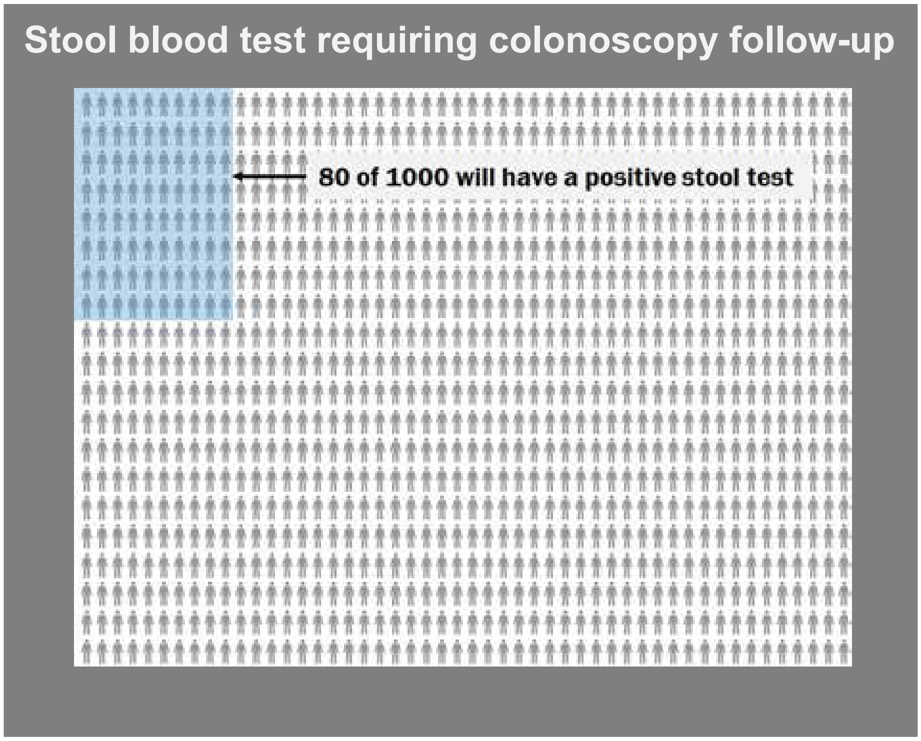


Two key numbers that help explain some of the **downsides or potential harms** of colon cancer screening are the following. Out of 1000 colonoscopies performed, about 4 cause a complication serious enough that the patient is hospitalized. Remember that even though the stool blood test doesn't cause any particular harms, about 8% (or 80 out of 1000 tests performed) will find blood in the stool and thus will be followed by a colonoscopy to see if the blood is caused by cancer.



Colonoscopy related injury

4 of 1000 who have a colonoscopy will have heavy bleeding or injury to the colon



Stool blood test requiring colonoscopy follow-up

80 of 1000 will have a positive stool test

PATIENT DECISIONS AND DECISION AIDS

Two decisions about colon cancer screening

As described above, a person who is eligible for colon cancer screeing really has to make **two** decisions with their healthcare provider. The person has to decide whether to be screened or not. He or she also has to decide which test to have. Each of these decisions can be well informed or poorly informed.

Consider the first question, which is whether to be screened. Each person has to decide if the potential benefits make the burdens and possible harms worthwhile. As described earlier, many people may not get screened simply because they don't know enough about colon cancer or about the screening tests. In this case, these people can be counted as having made a poorly-informed decision. One could say that their choice was not based on reasons, since they did not consider what experts think is relevant information.

Some people who decide **not to be screened** may be making an informed choice, however. They may understand everything they should know about colon cancer, their chances of getting it, and the screening tests but still decide not to be screened. For instance, if a person hates having medical tests and does not like going to the doctor, she might make an informed decision to go without screening. She could choose to live with her chance of getting colon cancer and dying from it, and forego the protection and potential harms that screening would provide.

Similarly, a decision **to be screened** can be informed or uninformed. A person may just agree with his or her doctor and get screened without knowing much at all about colon cancer or the tests, and may not even understand that the tests have risks. Although this person is making a decision that agrees with expert recommendations, it is uninformed. Some people think that this sort of "gut" decision is acceptable, while others are less comfortable with it.

Now consider the second decision that people have to make about colon cancer screening, which is deciding which test to have. Once again, a person may make an informed or uninformed decision. For instance, a person who chooses colonoscopy without knowing that there are alternatives like stool blood testing has made an uninformed choice. Even worse, he may have preferred the stool blood test if he had known about it. The stool blood test is a better screening test for a person who prefers a less invasive test and is willing to be tested every year.

How much information is enough?

Several decision aids – using websites, videos, and brochures – have been created to help people make informed decisions about colon cancer screening. As part of the public deliberation event, you will see some of these decision aids for yourself.

One key question about decision aids is, how much information should they give to patients? There's no question that they need to give basic information about colon cancer and the screening tests. As discussed above, however, there is a lot of additional information that could be provided. Decision aids differ in how much information they provide and the way the information is presented to patients.

Now that you have heard about the various types of information that are available for colon cancer screening, you can review some of the types of information that decision aids about this topic could provide.

Here are some of the types of information that decision aids about colon cancer screening could give, as well as some of the reasons for and against giving that information

Should decision aids tell people that screening is "recommended"?

Some decision aids emphasize that screening is recommended by experts for people with average risk who are 50-75 years old. They want people to know that experts have considered the benefits and harms of colon cancer screening and think that it is worth it. Other decision aids do not stress the recommendations. They want people to choose for themselves, after considering the benefits and harms, without thinking too much about what the experts say.

Should decision aids explicitly point out that many people will not get colon cancer, even if they don't get screened?

As discussed above, even though colon cancer is one of the most important cancers in the United States, and the second largest cancer killer, only a small minority of people will get it during their life or die of it. This means that even though colon cancer screening reduces the chance of getting colon cancer and dying from it, many people who don't get screened will never get colon cancer. Most decision aids mention that colon cancer is a major killer, without also reminding people that the majority of people will not get this cancer.

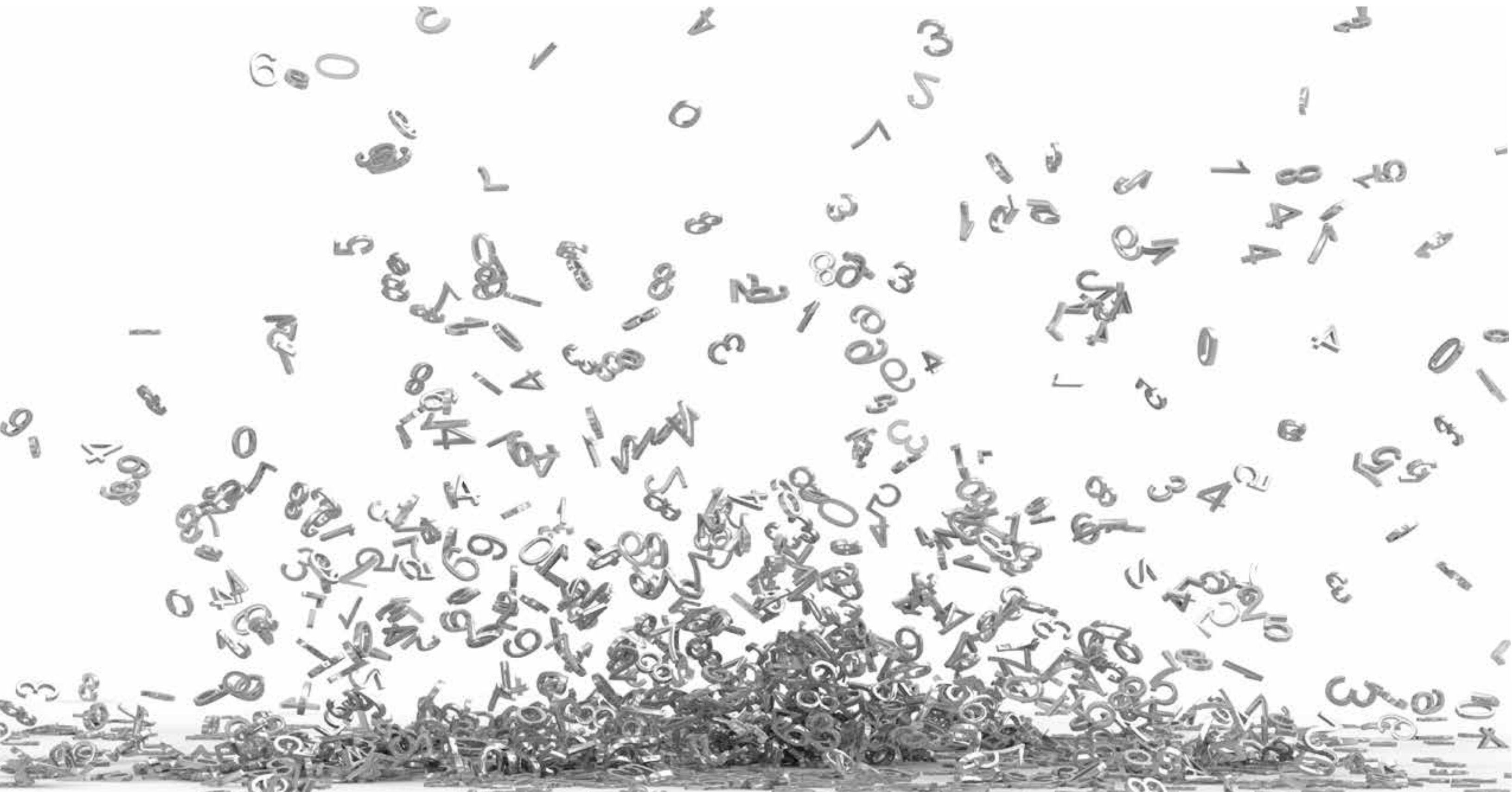
Should decision aids provide numbers and figures?

As discused above, experts deciding whether to recommend a screening test consider lots of numbers about the risk of that cancer and the effect of screening. Some people think that decision aids should present those numbers to patients to allow them to make more informed decisions. Others are concerned that too many numbers will be confusing or overwhelming to many patients. So, how many numbers are enough but not too much?

Should decision aids about colon cancer screening tests explain the likelihood that the test will fail to find a precancerous growth or early cancer?

Should decision aids explain the chance that a screening test will require follow-up tests (colonoscopy) even though it will turn out that there is no cancer or precancerous growth? Some experts support having decision aids present this information, since it explains how accurate the test is. Others think that information about the accuracy of the test might be less important than explaining the bottom line, which is the long-term impact of being screened or not.

In the next two sections, we review some of the leading arguments for giving more or less information of these sorts.



Giving more information

Some of the leading guidelines for the design and evaluation of decision aids favor providing large amounts of information. For example, the International Patient Decision Aids Standards (IPDAS) were put together by over 100 experts, patients, policy makers and health professionals from 14 countries. The IPDAS guidelines state that decision aids should support all the sorts of information listed above. The IPDAS guidelines favor giving detailed numbers of the following sort, using the sort of charts provided earlier in this booklet:

- The probability of getting the cancer or dying from it, with no screening
- How much that probability changes with screening,
- The probability of negative outcomes, including finding something that would not have caused a problem if the person had never been screened.

Another set of recommendations for evaluating decision aids was recently released by the National Quality Forum (NQF). These recommendations recommend giving much of the same data.

These guidelines favor giving large amounts of information to patients, clearly with the goal of helping them make fully-informed decisions. The numerical information, for instance, seems relevant because it is key data that experts themselves review when deciding whether to recommend a screening test. Numbers provide more specific information about screening tests than words do.

Giving less information

Other experts are concerned that giving too much information could overwhelm and confuse patients. For instance, many people have trouble understanding numbers about their "chance" or "risk" of something happening. When many different numbers are presented, they can be hard to keep straight, even if they are presented as clearly as possible, such as using charts like those presented above.

Finally, some people simply do not like numbers or want to think about detailed numbers when making choices. And there's only so much time in the day: Even if a person is perfectly comfortable with numbers, they may simply not want to consider them when deciding about screening. They may have better things to do with their time.

Experts who favor having decision aids give less information are often comfortable with patients making decisions by "following their gut" without considering a lot of information. From their perspective, patients may need to know some basic things, but not necessarily all the complex information that other experts want them to think about.

So, how many numbers are enough but not too much?

Making information optional

One way to compromise between the "more information" and "less information" approach is for decision aids to present some information that everybody should see, while making other information optional, for people to view only if they want. In the decision aids you will review as part of the public deliberation, you will see that some decision aids take this approach.

This approach also raises important questions. For instance, it requires that someone has to decide what information everybody should see, and what information should be optional. Some experts think that everybody should see certain numbers, while others think that people should have that information available if they want to see it, but not be required to view it all.

Your role

During the deliberation you will learn more about decision aides and be asked to discuss with other participants some of these issues related to decision aids for colon cancer screening. You and the other participants will then work together to make recommendations to experts on what information decision aids should present to all patients, what additional information might be optional, or what information should just be left out.

It is important to know that these decision aids are for everyone. The advice that you and your fellow participants provide will be used to develop decision aids offered to all patients to help them make good decisions about their heathcare. That is part of the reason it is important to understand different perspectives when forming the group's recommendations.

Here are the specific questions we will be trying to answer at the public deliberation.

1. What information should be included in all decision aids for colon screening?
2. How should risk information be presented?
3. What makes a screening decision a good one (reasonable or legitimate)?
4. What makes a decision aid and the advice it provides trustworthy?

This booklet and the speakers at the event will provide you with information that is important for your discussion to be informed. Your fellow participants will bring different life experiences and interests that are important for you to understand so that the recommendations you make together are sensitive to different preferences and styles of learning. The recommendations that you make as a group will provide advice to help people who design decision aids and screening policies.

Notes

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