SHARED DECISION MAKING

COD

Includes a discussion of the **CHOICE** that is to be made, pros and cons of each potential **OPTION** and a joint **DECISION** made by the clinician and the patient

- *It’s your **CHOICE***
- *Here are your **OPTIONS***
- *What will we **DECIDE**?*

**C**: Choice talk: state “you have a choice”

**O**: Options talk: discuss options

**D**: Decision talk: make a decision

What is shared decision making?

Shared decision making (SDM) is a communication technique where the patient and clinician actively participate to make a decision together.

- The clinician provides information about risks and benefits of a test or intervention.
- The patient shares personal values and preferences about the test or intervention.
- SDM applies to situations where there is no single “right” decision because all choices come with pros and cons.

Why would I want to do SDM?

SDM is a key part of true patient-centered care. It improves the clinician-patient relationship, decreases decisional conflict, and increases patient’s knowledge about the clinical situation. Recent national guidelines suggest SDM in deciding about cancer screening tests. In addition, SDM may:

- Improve patient satisfaction
- Decrease the likelihood of being sued.

What should I do if a patient already has an opinion and doesn’t want to participate in SDM?

It is the clinician’s responsibility to make sure that the patient understands the choices and has made a decision in concert with his/her values. Some ways to engage patients include:

- We have good evidence about the benefits and risks of X. Can we take a few minutes to discuss?

- I understand that you have already made up your mind. I want to understand your reasoning. Would you tell me more about how you chose to do X?

- It is your choice. I want to make sure that you have all the information in case you need to make a similar decision in the future. Would it be okay for me to share the information with you?

What should I do if a patient wants me to decide for them?

Some patients may ask the clinician to recommend to them what they should do. It is perfectly fine for the clinician to give their opinion, but engaging in an SDM conversation is also important. Some ways to engage patients include:

- I am happy to give you my recommendation about X, but I’d like to discuss the potential harms and benefits first. Would that be okay?

- I can tell you what I would do, but you are a different person and my choice may not be right for you. How about if we take a few minutes to talk about the potential harms and benefits of X and then we can talk about issues that are important to you. Afterwards, we can make a decision.

- I am happy to share my views and help you get to a good decision. But before I do so, may I explain the options so that you understand what is at stake?
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### SAMPLE PHRASES FOR USE IN SHARED DECISION MAKING CONVERSATIONS

**Talking about choices:**
- “There is good information about the benefits and risks of breast cancer screening. May I show you a tool that uses pictures to show these benefits and risks?”
- “Different things matter to different people when talking about cancer screening.”
- “The choice you make today is whether or not to get screened now. You can make different choices in the future as you think about what matters to you – and those things may change over time.”
- “Not making a decision today is also okay – we can talk about this again next time.”

**Checking for values:**
- “Now that you know about the risks and benefits, what are you thinking most about?”
- “What, from your point of view, matters most to you?”
- “Is there anything that might get in the way of you getting the screening, or any necessary follow-up?”

**Deferring a request to “tell me what to do”:**
- “I’m happy to share my views and help you get to a good decision. Before I do, may I describe the benefits and risks in more detail so you can understand your choices better?”

**Checking for readiness to move on:**
- “Shall we go on?”
- “Shall I tell you about the options?”

**Checking for knowledge/understanding:**
- “What have you heard or read about breast cancer screening?”
- “What questions or comments do you have about the information I have given you?”
- “I know I’ve given you a lot of information. What would you tell your (spouse, child, parent, etc.) about what we’ve discussed?”

**Moving to a decision:**
- “Are you ready to decide?”
- “Do you want more time? Do you have more questions?”
- “Are there more things we should discuss?”

**Reviewing the decision:**
- “Just to be clear, you’re saying that you (do/do not) want to proceed with screening at this time?”
- “Do you want to discuss this issue again in (one/two) years?”
COMMUNICATING RISKS AND BENEFITS SO THAT PATIENTS UNDERSTAND

Why is this important?

- When patients understand possible outcomes they make more informed decisions
- The format in which benefits and risks are presented significantly affects patients’ understanding and perception
- Patients’ understanding is affected by emotion, so the method of communication can affect their decision
- Effective communication is a hallmark of patient-centered care

Specific tips:

- Begin each conversation with the reminder that all options confer some risk
- Share uncertainty if there is no clear “right” course of action
- Avoid using descriptive language; for example, a patient may have a different definition of “low risk” than you
- Use absolute numbers rather than relative risks
- When using fractions, use the same denominator (i.e. comparing 1 in 200 to 1 in 25 is confusing for some patients, so instead say 1 in 200 compared to 8 in 200)
- Some patients understand percentages better than fractions, so explaining both ways may be helpful
- Using visual aids to convey risks can help some people understand; patient decision aids are excellent methods of communicating possible outcomes
- Avoid using technical terms (i.e. say “normal test result” rather than “negative test result”)
- Make sure to include both positive and negative outcomes
- Use neutral and active language (i.e. “if you get this test” rather than “if one would get this test”)

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CLINICIAN BENEFITS OF USING SHARED DECISION MAKING WITH PATIENTS WHEN MAKING HEALTH CARE DECISIONS

Shared Decision Making:

- Provides an opportunity to connect with patients and learn about what is important in their lives
  - Patients know you will listen to and care about their concerns
- Improves patient’s trust in the clinician
  - Patients know that you will tell them all of the possible outcomes
- Improves future care
  - Patients are familiar with the decision making process
  - You can use the knowledge gained about their personal values and preferences for future decisions
- Improves patient satisfaction
  - Shared decision making leads to more engaged and adherent patients, and more engaged patients are more satisfied
- Prepares patients for possible outcomes
  - Patients are less surprised by negative outcomes
  - For example, if you used shared decision making to discuss breast cancer screening, a woman would be less likely to be surprised if she was called back for extra views
- Improves clinician satisfaction
  - More informed patients improve clinician satisfaction with the patient care encounter

Patient Decision Aid:

- Using a patient decision aid provides structure for the visit and for the shared decision making conversation.
  - Clinical time saved (i.e. less time needed to clarify confusion and educate patients)

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MAMMOGRAMS AND OVER-DIAGNOSIS

- Screening mammography has been proven to save lives from breast cancer.

- Over-diagnosis (also called over-detection or over-treatment) is a potential harm of getting a screening mammogram.

- Some estimates suggest that 10-30% of all breast cancers found on mammogram may be over-diagnosed. These estimates are based on mathematical modeling and likely relate to age at diagnosis.

- Over-diagnosis was discovered in large breast cancer screening programs of average risk women and describes finding tumors on screening that would never have developed clinical symptoms.

- In these studies, after a screening program had been instituted, the number of large tumors decreased slightly, but the number of small tumors increased significantly.

- Some breast cancers are aggressive and grow rapidly, but many cancers are slow growing and would not be found if a woman did not have a screening test.

- Some women may be treated for cancers that would never become clinically significant (i.e. they will die from another cause and the cancer will not grow or metastasize).

- We are unable to determine which of the small tumors found on screening mammograms will develop into life-threatening cancer, so all are treated the same. This may lead to unnecessary treatment.
Breast Cancer Screening
Shared Decision Making Toolkit

Increasingly, organizations like the United States Preventive Services Task Force (USPSTF) are recommending shared decision making between patients and their health care providers as the optimal method for determining whether and how often to screen for breast cancer using mammography.

The Breast Cancer Screening Shared Decision Making Toolkit is designed to provide health care providers with information and guidance on how best to approach the shared decision making conversation with average risk patients when considering breast cancer screening.

What does the toolkit contain?

- Breast cancer screening resources for both clinicians and patients
- Materials to support shared decision making
- Information about an interactive breast cancer screening decision aid

How should these tools be used?

- Supplement patient-provider discussions about breast cancer screening
- Print educational materials for average risk women about breast cancer screening
- Guide utilization of a breast cancer screening decision aid in a primary care encounter

Who developed the toolkit?

- Researchers and health care providers at UW SMPH
- Members of a Patient Advisory Committee

Where can I find the toolkit?

- The Breast Cancer Screening Shared Decision Making Toolkit is available free of charge at http://www.hipxchange.org/ScreeningMammo
Lung Cancer Screening SDM Tool Example

With no screening: 5 out of 100 men like you are diagnosed with lung cancer and 4 of them die.

Decision: get yearly CT scans, or not?
For 100 men like you over 6 years without screening:

- 5 are diagnosed with lung cancer.
  - 4 die from lung cancer.
  - 1 survive lung cancer without screening.

- 95 are not diagnosed with lung cancer.
  - 95 do not get lung cancer.

With yearly CT scan: one lung cancer death is saved and one patient is over-treated. 13 patients have at least 1 false alarm and 2 have biopsies that are normal.

Decision: get yearly CT scans, or not?
For 100 men like you over 6 years, with screening:

- 6 are diagnosed with lung cancer:
  - 3 die even with screening.
  - 1 avoid death due to screening.
  - 1 survive even without screening.
  - 1 more cancer diagnosed by screening.

- 94 do not have lung cancer diagnosed.
  - 81 have no false alarms.
  - 13 have at least one false alarm.
  - 2 get invasive procedures like biopsy.
  - <1 have major complications.
Patient FAQs and suggested best responses:

- **What is the benefit of screening?**
  - For those in whom cancer is found, the chance of death from the cancer is lower.
  - For those in whom no cancer is found, the result can be reassuring.

- **What are the harms of screening?**
  - For those who get false alarms, there can be worry and effort for more testing and procedures.
  - For those in whom cancer is found, there is a chance of over-diagnosis causing over-treatment.

- **What is meant by a false alarm?**
  - All screening tests try to find all the cases of real cancer, so they are designed to be “sensitive”.
  - Sensitive tests also pick up other abnormalities that MIGHT be cancer and this can be alarming.
  - When the abnormality turns out not to be cancer the alarm is said to be false.
  - False alarms are always a part of screening tests.

- **What is meant by over-diagnosis?**
  - First, realize that some cancers will never become a problem. They might be very slow growing, or the patient may die of something else before the cancer would have caused problems. But with screening, these cancers are discovered.
  - Because, current science can’t be sure which cancers are safe enough not to be treated, all cancers get treated.
  - In hindsight, we know some patients are over-treated, but we cannot know which patients.

**How to access on the web**

- Go to URL: [www.healthdecision.org/tool](http://www.healthdecision.org/tool)
- Select the “Lung Cancer Screening” tool from the home page

**How to Access HealthDecision tools within Health Link:**

Open a patient chart in a common workspace (office visit, patient, etc.)

1. Click “Customize” in lower left to customize the workspace.
2. Drag the “HealthDecision” activity from ‘occasionally used” to main menu
3. Choose Accept
Breast Cancer Screening SDM Tool Example

With no screening over 10 years, 27 of 1,000 women get breast cancer and 5 of them die.

27 are diagnosed with breast cancer.
> 22 survive breast cancer with or without screening.
> 5 die from breast cancer.

973 are not diagnosed with breast cancer.
> 973 won't have breast cancer.

With 5 mammograms over 10 years: one cancer death is saved and three patients are over-treated.
380 patients have at least 1 false alarm and 63 have biopsies that are normal.

30 are diagnosed with breast cancer.
> 22 survive breast cancer with or without screening.
> 1 saved from a breast cancer death.
> 4 die from breast cancer.
> 3 extra are over-diagnosed by screening.

970 are not diagnosed with breast cancer.
> 590 no breast cancer, recalls or biopsies.
> 380 recalled for one or more false alarms.
> 63 undergo a biopsy that is normal.
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