

Shared Decision Making for Lung Cancer Screening

Jamie L. Studts, PhD



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Centers for Medicare and Medicaid Services



*"The Centers for Medicare & Medicaid Services (CMS) has determined that the **evidence is sufficient** to add a lung cancer **screening counseling and shared decision making visit**, and for appropriate beneficiaries, **annual screening for lung cancer with low dose computed tomography (LDCT)**, as an additional preventive service benefit under the Medicare program **only if the following conditions are met...**"* (February 5, 2015)

<http://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx?NCAId=274>

History and Stages of Coping with Lung Cancer Screening Policy

- Protracted frustration and near exhaustion (early trial data)
- Optimism and hope (NLST Data)
- Exuberance for implementation (USPSTF Policy Statement)
- Relief for coverage (CMS National Coverage Determination)
- But then we read the details.... (Apologies to Dr. Kubler-Ross)
 - 1) Shock... what is this shared decision making business?
 - 2) Denial... surely they don't really mean that, do they?
 - 3) Anger... they are just trying to reduce uptake?
 - 4) Depression... we can't possibly do this.
 - 5) Bargaining... hmmm, maybe we can do this a little bit
 - 6) Acceptance... well, maybe this is the right thing to do.

Overview

- What is Shared Decision Making?
- Why Shared Decision Making?
- Why Now, Shared Decision Making?
- How can Decision Aids help?

What is Shared Decision Making?



image: <http://shareddecisions.mayoclinic.org/>

(Courtesy Dr. Mary Politi)

Definition of Shared Decision Making

- **Shared decision making (SDM)** is a collaborative process that allows patients and their providers to make health care **decisions** together.
- It takes into account the best clinical evidence available, as well as the patient's values and preferences.

Shared Decision Making: A Meeting of Experts

<p>PRACTITIONER</p> <ul style="list-style-type: none"> • Invite patient to participate • Present options • Discuss risks, benefits, alternatives, uncertainties (using best available evidence) • Elicit values and preferences • Check understanding • Discuss next steps 		<p>PATIENT</p> <ul style="list-style-type: none"> • Describes health, symptoms, and history • Discusses values, preferences, implementation challenges, and preferred style of decision making
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Patient is *invited* to and *engages* in decision making at the desired level.

Slide c/o Dr. Dominick Frosch, Adapted from Charles, Soc Sci Med 1999; 49: 651-61.

Shared Decision Making (SDM)

Informed decision making occurs when an individual...

- **understands** what the clinical service involves, including...
 - **potential benefits, harms, limitations, alternatives, & uncertainties**
- has **considered personal preferences**, as appropriate;
- has **participated in decision making** at the desired level
- makes a decision **consistent with those preferences**...

Shared decision making connotes a process in which **providers and patients collaborate as partners** in the decision-making process.

(Rimer B, Briss P, et al, 2004)

The SHARE Approach to SDM

SHARE is a five step process that explores and compares benefits, risks, unknowns and harms with patients based on their individual wants.

- S:** Seek the patient's participation
- H:** Help the patient explore and compare options
- A:** Assess the patient's values and preferences
- R:** Reach a decision with the patient
- E:** Evaluate the patient's decision

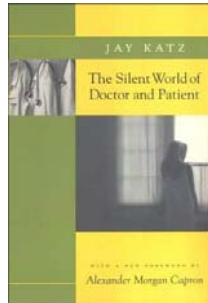
<http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/>

Why Shared Decision Making? How Did We Get Here?

- 1970s: medical ethicists began to focus on patient autonomy.

- 1984: Jay Katz: "The Silent World of Doctor and Patient."

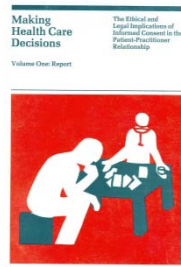
- Critique of paternalism/ "just trust the doctor."



Presidential Commission Report: 1982

- "Shared decision making is the appropriate ideal for patient-professional relationships..."

- "Shared decision making requires that a practitioner seek...to understand each patient's needs...develop reasonable alternatives to meet those needs...present the alternatives in a way that enables patients to choose one they prefer."



Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship. Washington, DC, USA: US Government Printing Office; 1982.

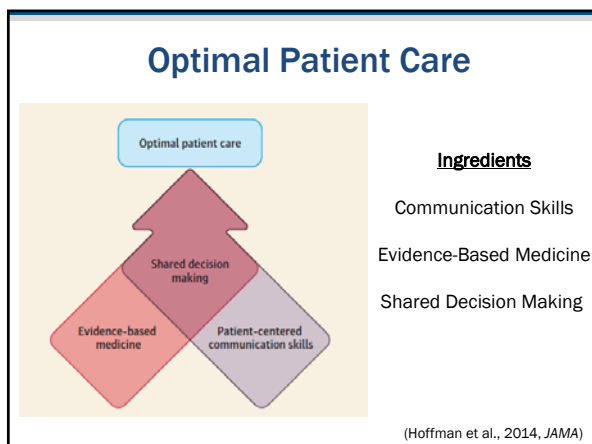
USPSTF Definition of Shared Decision Making



....a particular process of decision making by the patient and clinician in which the patient:

- 1) understands the risk or seriousness of the disease or condition to be prevented;
- 2) understands the preventive service, including the risks, benefits, alternatives, and uncertainties;
- 3) has weighed his or her values regarding the potential benefits and harms associated with the service; and
- 4) has engaged in decision making at a level at which he or she desires and feels comfortable.

(Sheridan et al., 2004, *AJPM*)



- ## Shared Decision Making: Benefits for Patients
- Improves knowledge
 - Clarifies values for risks/benefits of options
 - Reduces decisional conflict
 - Reduces decision regret
 - Improves realistic expectations about options
- O'Connor AM, Bennett CL, Stacey D, et al. Decision aids for people facing health treatment or screening decisions (Cochrane Review). *Cochrane Database of Systematic Reviews*. 2009(2):Art. No.: CD001431.

- ## Shared Decision Making: Benefits for Clinicians
- Improves informed consent procedures
 - Might save time...
 - Expand counseling beyond constraints of busy office visits
 - Improve baseline knowledge prior to consultation
 - Might reduce malpractice claims or the success of malpractice lawsuits
 - May decrease practice variation and reduce cost
- Brooks & Cochran (2007) OCER, http://dms.dartmouth.edu/ocer/pdf/shared_decision_making.pdf;
King & Moulton (2006); Barry, Wescott, Reifer, Chang & Moulton (2008)

Why Now, Shared Decision Making (for lung cancer screening)?

- 1) Lung cancer screening is novel and awareness is low (virtually non-existent).
- 2) Lung cancer screening is complicated and has numerous concomitant potential benefits, harms, and unknowns.
- 3) There is a greater need for patient engagement because individuals eligible for lung cancer screening commonly experience stigma and bias and are less likely to be actively involved in their own healthcare.
- 4) It is suggested/recommended by every authoritative organization that has weighed in on lung cancer screening implementation.
- 5) We have to do it in order to be compensated for services.
- 6) *It can facilitate optimal outcomes from lung cancer screening.*

LDCT Participants Pilot Project Mixed Methods Approach

- Conducted interviews and surveys with 27 individuals who had participated in LDCT for lung cancer screening within the last year at private practice radiology clinics in Kentucky or South Florida.
- Results showed that screening participants:
 - 1) were **very** satisfied with their experience
 - 2) almost completely unaware of any of the potential harms associated with LDCT for lung cancer screening
 - 3) were motivated to participate to reduce lung cancer mortality and the simplicity of the screening (painless, quick)
 - 4) reported that they did **not** talk with health care providers (or family members) about their decision to have LDCT.

(Lillie, Studts, & Byrne, *Under Review*).

Perceived Barriers to Lung Cancer Screening Focus Groups with Screened & Unscreened

Stigma

- Feeling stigmatized from younger healthcare providers, describing them as *"people that don't know the culture we grew up in"*
- Worried about being blamed or made to feel like a social outcast, *"making me feel like an idiot or stupid for smoking"*

Distrust

- Uncertainty about the value of screening, comparing *"new machines to screen"* to a *"scam...a money-making scam...like a bait and switch"*

(Carter-Harris, et al. (2015), *Health Expectations*)

USPSTF Final Guideline for Lung Cancer Screening



Shared Decision Making

- “The decision to begin screening should be the result of a thorough discussion of the possible benefits, limitations, and known and uncertain harms.”

(Humphrey et al., 2013, Annals of Internal Medicine, Online)
(Moyer et al., 2013, Annals of Internal Medicine, Online)
<http://www.uspreventiveservicestaskforce.org/uspstf13/lungcan/lungcanfact.pdf>

Centers for Medicare and Medicaid Services

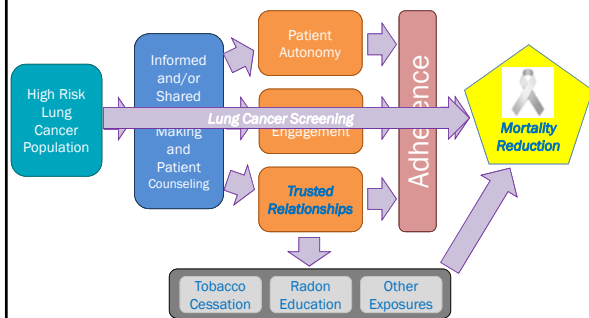


For the initial LDCT lung cancer screening service: a beneficiary must receive a written order for LDCT during a **lung cancer screening counseling and shared decision making visit**:

- ① Determination of beneficiary eligibility
- ② **Shared decision making**, including the use of **one or more decision aids**, to include benefits *and* harms of screening, follow-up diagnostic testing, over-diagnosis, false positive rate, and total radiation exposure;
- ③ Counseling on the importance of adherence to annual lung cancer LDCT screening
- ④ Counseling on the importance of maintaining cigarette smoking abstinence or **tobacco treatment**

<http://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx?NCAId=274>

LCS targets a unique population that likely requires substantial engagement efforts to achieve optimal outcomes.



How can Patient Decision Aids (PtDA) or Decision Support Tools (DST) help?

■ Evidence-based tools to prepare people to participate in their health decisions in ways they prefer (decision role)

■ Patient DAs aim to accomplish three things to prepare a person for decision making...

- 1) Provide facts about condition, options, and features
- 2) Clarify values (about features) that matter to patient
- 3) Help people share their values with health care providers and others

Patient Decision Aids for LCS

- Patient Decision aids (PtDA) must be used in SDM process
- PtDAs vary greatly in content but mostly include:
 - > Clear statement of the decision being considered
 - > Information about health condition, treatment options, benefits, harms, probabilities, appropriate statistical values, and scientific data
 - > Description of the options that allows patients to imagine how their personal preferences, beliefs, and values would be impacted by making a decision to have screening.
- CMS acknowledges that many decision aids exist and does not require the use on any single one of them; they only require that a decision aid is used.

<http://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx?NCAId=274>



Outcomes of Patient Decision Aids (PtDAs)

• Patients and practitioners who use DAs make better decisions.

- 1) Patients participate more
- 2) Patients know more
- 3) Patients have more realistic expectations
- 4) Patients are more likely to receive an option with features they most value

International Patient Decision Aid Standards Collaboration (IPDAS) Quality Criteria



I. Content

- Facts, values, guidance in decision making

II. Development Process

- Attention to a systematic development approach

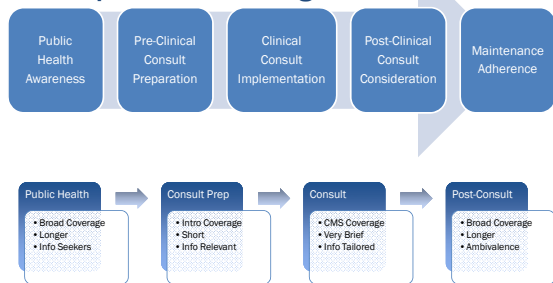
III. Effectiveness

- Designed with attention to key outcomes

<http://ipdas.ohri.ca/>

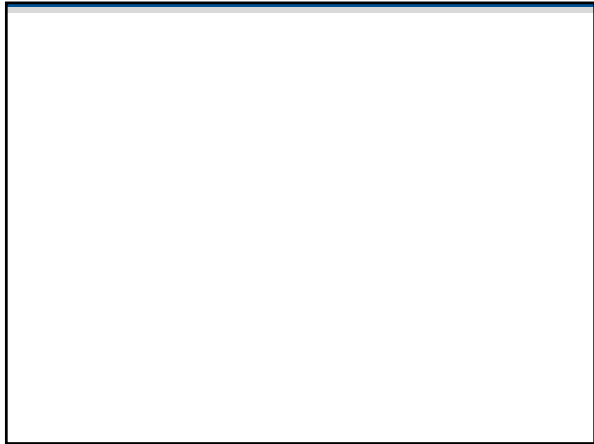
To promote informed decisions, many LCS Decision Aids are needed.

Implementation Algorithm



Takeaway

- While implementing SDM may not be the norm within cancer screening programs, SDM can be reasonably justified as a viable platform to facilitate implementation of high quality lung cancer screening.
- There are numerous resources available with an emerging database to support the utility of decision support tools for lung cancer screening.
 - AHRQ Suite of Lung Cancer Screening Tools
 - <http://effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/patient-decision-aids/lung-cancer-screening/>
 - Lung Cancer Alliance Resources
 - <http://www.lungcanceralliance.org/am-i-at-risk/screening-center-resources/>
 - The Ottawa Hospital Research Institute Decision Aid Inventory
 - <https://decisionaid.ohri.ca/AZinvent.php>



Overview

- Shared Decision Making is a collaborative approach to facilitating complex healthcare choices.
- There are numerous patient, clinician, and system benefits to implementing SDM.
- SDM has become a supported (and in some cases mandatory) component of the lung cancer screening process.
- Decision aids can provide structure and support SDM and several tools are available specifically for lung cancer screening.

Primary Challenges

- Identifying and selecting from the available patient decision aids to support the various decision support needs for your program.



- Monitoring accuracy and updating of these tools as new data is available and shifts occur in lung cancer implementation and policy.

Steps/Structure of a SDM Consultation

1. Invite the patient to participate
2. Present the decision/option(s)
3. Provide information
 - potential benefits, harms, uncertainties
 - check for understanding
4. Assist patient in evaluating decision based on goals and concerns
5. Facilitate deliberation/decision making
6. Assist with behavioral implementation



(Adapted from Informed Medical Decisions Foundation, 2012)
