Supporting Informed Decision Making about Lung Cancer Screening

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Conducted a mixed methods study to explore decision making among LCS participants.

- Free-standing radiology clinics were offering lung cancer screening outside of a clinical trial protocol.
- Demand was light, but consistent.
- Increased demand when coupons were offered in the local newspaper around Valentine’s Day.
- Opportunity to describe...
  1) LCS seekers/early adopters,
  2) decision making influences,
  3) knowledge of LCS, and
  4) LCS implementation procedures.
Studts-Byrne LDCT 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).
Byrne/Studts
LCS Program of Research

Patient Decision Making

Patient Informed Decision Making

Provider Informed Decision Making

Shared Decision Making

LDCT Implementation, Policy & Community Initiatives
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…

Conjoint Study of LCS Decision Making

Overall Goal

Develop and test a conjoint valuation tool for integration into a LCS decision aid as a preference elicitation strategy
Identify salient variables regarding lung cancer screening decisions

Methodology: Sequential Mixed Methods

1. Semi-structured interviews to develop instrument (identifying attributes and levels for conjoint survey)
2. Cognitive interviewing to refine instrument
3. Administer survey to a nationally-representative sample of individuals at high-risk for LuCa+

[The project was supported by the National Cancer Institute (R21CA139371).]
Procedure & Design

- Participants were drawn from the Knowledge Panel (N=223)

- Eligibility Criteria
  - 45 years of age and older
  - ≥ 20 pack years of smoking

- Sawtooth Software
  - used to generate 20 scenarios
  - used to conduct preliminary analyses using OLS regression
Participants

- 223 respondents met eligibility criteria
- 210 (94%) individuals consented

Sample Demographic Characteristics:
- Pack-years smoking: 40 (±20)
- Years of age: 61 (±8)
- Females: 109 (52%)
- Race/Ethnicity:
  - 51 African American (24%)
  - 59 Hispanic American (28%)
Conjoint Attributes (5) & Levels (17)

- Out of Pocket Costs (3)
  - $50, $275, $500

- Mortality Reduction (3)
  - 1%, 10%, 20%

- HCP Recommendation (4)
  - Against, For, “Personal decision,” No discussion

- False Positive Rate (3)
  - 10%, 25%, 40%

- Access to Screening (4)
  - Convenience of Location & Hours of Operation
Conjoint Analysis Results

- Mean rating across scenarios: 3.63 (±1.6)
- Lowest mean scenario rating: 2.60 (±2.0)
- Highest mean scenario rating: 5.57 (±2.1)
Conjoint Analysis of Lung Cancer Screening Decisions

Overall Goal: Develop and test a conjoint valuation tool for integration into a LCS decision aid

* Higher importance scores indicate greater influence on the screening decision.
The study also evaluated the impact of the conjoint survey on decisional conflict.

- **Decisional conflict** is defined as personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values.

- What is the immediate impact of receiving brief education and completing a values clarification exercise on decisional conflict regarding participation in lung cancer screening?
Receiving a brief educational intervention and completing the conjoint survey dramatically reduced decisional conflict regarding LCS choice.

![Bar chart showing changes in uncertainty, informed, values clarity, and support before and after the intervention.](chart.png)

- Uncertainty: $t(192)=10.06, p<.001$
- Informed: $t(192)=15.99, p<.001$
- Values Clarity: $t(192)=11.78, p<.001$
- Support: $t(192)=9.26, p<.001$
Conclusions

■ Overall Interest in LCS
  Participants were less favorably disposed to LCS uptake than expected

■ Screening Influences
  most influenced by the HCP recommendation & cost
  less influenced by benefits (mortality reduction) & risks (false positives)

■ Characteristics of Screening Attributes
  Overall, results were consistent with hypotheses
  Participants dramatically favored lower cost and favorable HCP opinions

■ Preparation to Make a LCS Decision
  ▪ Individuals at elevated risk for lung cancer were initially unprepared to make informed decisions about lung cancer screening.

■ Potential Impact of a Decision Aid
  ▪ Decisional conflict decreased dramatically after brief introduction to LCS combined with completing a values clarification exercise.
LuCaS Choices:
A Web-based Decision Aid to Support Informed Decision-Making About Lung Cancer Screening

Jamie L. Studts, PhD
Margaret M. Byrne, PhD

[This project is funded by the National Cancer Institute (R21CA173880).]
Development & Feasibility of LuCaS Choices: A Web-based Lung Cancer Screening DA

■ Aim 1:
   Develop a DA to help individuals make informed decisions about LCS that are consistent with their values and preferences.

■ Aim 2:
   Conduct a feasibility trial of the DA among individuals at high risk of lung cancer due to heavy cigarette smoking.

[This project is funded by the National Cancer Institute (R21CA173880).]
LuCaS Choices Decision Aid
Applying the KEV Model (Knowledge, Empowerment, Values)

Figure 1.
What is cancer screening (General)?

- Some types of cancer can be found before they cause symptoms. Checking for cancer (or for changes that may lead to cancer) in people who have no symptoms is called **screening**.

- Screening can help doctors find and treat some types of cancer early.

- Generally, cancer treatment works better when cancer is found early.

- Screening works best when there is a treatment that can help.

- Sometimes the initial screening test will lead to more tests to diagnose cancer.
Risk Assessment and Guideline Eligibility

To help you make the choice about whether or not to be screened for lung cancer, it is often helpful to know two things:

- What is your risk of lung cancer?
- Whether you are eligible for lung cancer screening

In the following pages, we will discuss these two topics and then have you answer some questions, so that we can estimate your risk and see whether or not you are eligible for screening based on the US Preventive Services Task Force and the National Comprehensive Cancer Network.
What is empowerment and how can we improve it?

This section of the lung cancer screening decision aid addresses empowerment. By empowerment we mean helping you take an active role in choosing whether lung cancer screening is right for you.

The section is designed to help you make a decision about whether or not to start lung cancer screening. Some people find it helpful to talk with their health care provider about this choice.

The empowerment section includes two parts to help you in the decision making process: (1) a description of a process you can use to make a choice, and (2) a Question List to help get answers to your questions about lung cancer screening.
Values Clarification

As mentioned in other sections of this website, knowing what is important to you is a very important part of deciding whether or not you should be screened for lung cancer, and an important part of informed decision making.

This is because there are both good and bad aspects to being screened, and there are uncertainties as to the outcomes of screening. Therefore, it is important for you to think about and consider what is important to you — your own preferences and values — before deciding about screening.

To help you do this, we have developed a values exercise that will help you explore your opinions about lung cancer screening.
Feasibility of the interventions, methodology and instruments for a future two arm RCT comparing LuCaS Choices DA against an enhanced usual care condition (NCI LCS website)

50 participants from Kentucky and South Florida

Figure 2. LCS-DA Feasibility Study Design

- PRE Assessment
- Intervention Group (LCS-DA)
- Enhanced Usual Care (Online NCI LCS Pamphlet)
- POST1 Assessment
- POST2 Assessment

Week 0: N=50
Week 2: N=41
4 Months: N=0
## LuCaS Choices
### Phase II – Feasibility Study

<table>
<thead>
<tr>
<th>Study Variables</th>
<th>PRE-Survey (Baseline)</th>
<th>POST$_1$-Survey (2 weeks)</th>
<th>POST$_2$-Survey (4 mos.)</th>
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<tbody>
<tr>
<td>Demographics/smoking history</td>
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<tr>
<td>Effects of LCS-DA (knowledge, empowerment, values clarification)</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Beliefs and attitudes about LCS; lung cancer worry</td>
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<td>X</td>
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<tr>
<td>Reactions to the LCS-DA; usability and satisfaction with website and methods</td>
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<td>X</td>
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<tr>
<td>Willingness and intention to undergo LCS; uptake of LCS; discussions of LCS</td>
<td>X</td>
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<td>X</td>
</tr>
<tr>
<td>LCS Uptake</td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
To promote informed decisions, many LCS Decision Aids are needed.

Implementation Algorithm

Public Health Awareness
Pre-Clinical Consult Preparation
Clinical Consult Implementation
Post-Clinical Consult Consideration
Maintenance Adherence

LuCaS Choices DA

Public Health
- Broad Coverage
- Longer
- Info Seekers

Consult Prep
- Intro Coverage
- Short
- Info Relevant

Consult
- CMS Coverage
- Very Brief
- Info Tailored

Post-Consult
- Broad Coverage
- Longer
- Ambivalence
Informed Decision Making Principles

All efforts to communicate about LCS should seek to achieve IDM.

Marketing and Awareness → Patient Education → Clinical Consultation → Follow-Up and Retention

Informed Decision Making Principles
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)*
Developing Socially Responsible Marketing Efforts Regarding Lung Cancer Screening

1) Convey accurate information about lung cancer screening

2) Encourage engagement with a healthcare clinician

3) Seek a balanced presentation of benefits and harms

4) Avoid fear-based appeals that may stigmatize and engender distrust

[Funded by a grant from the Bristol-Myers Squibb Foundation (501c3).]
LCS targets a unique population that likely requires substantial engagement efforts to achieve optimal outcomes.
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The scenario given below describes what lung cancer screening might be like. Please select the button that best describes how likely it is that you would be screened in this situation.

- $500 out of pocket cost
- Screening leads to a 1% reduction in lung cancer deaths
- Your doctor recommends that you do not get screened
- A 40% false positive rate
- Imaging center is in an inconvenient location, but is open evenings and weekends

Choose one of the following:

- 0
- 1 Definitely Would Not Get Screened
- 2 Probably Would Not Get Screened
- 3 Might or Might Not Get Screened
- 4 Probably Would Get Screened
- 5 Definitely Would Get Screened

Please select the button that best describes how likely you would be screened in this situation.
Future Directions – Research

- **Development and Feasibility Testing of a Lung Cancer Screening Decision Aid** (R21CA173880)

- **Investigators**
  - Jamie L. Studts (UK)
  - Margaret M. Byrne (UM)
  - Richard Thurer (UM)
  - Christina R. Studts (UK)

- **Consultants**
  - Mary Politi (Wash U.)
  - Mark Roberts (Pitt)
  - Sarah Hawley (Michigan)
  - Saul Dobney (Dobney Assoc.)
  - Phil Haubert (Wintermute)

- **External Advisory Board**
  - Graham Colditz (Wash U.)
  - Jamie Ostroff (MSKCC)
  - Amy Copeland (LCA)
  - Angela Webb (UK)
Ongoing Research

Development and Feasibility Testing of a Lung Cancer Screening Decision Aid (R21CA173880)

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Welcome to LuCaS!

Welcome to LuCaS, a Lung Cancer Screening Decision Aid. This webpage will tell you about lung cancer screening options and help you make a decision about whether or not to get screened for lung cancer.

Lung cancer screening is a test to see if you have lung cancer in an attempt to find it early.

We will be sharing information with you that can be important when making a decision about whether or not to get screened for lung cancer.

Before we start, we want to share some information about how and why we made this decision aid to help with your lung cancer screening choice.
Here you will see your 6 year probability of developing lung cancer based on the Brock University model.

\[ P = 0.012 \]

Equivalently, there is a 12 out of 1000 chance that you will get lung cancer within the next six years.

To understand this probability, consider that if your probability is 0.001, this means that there is a 0.1% chance that you will develop lung cancer over the next 6 years. This is the same as saying that you have a 1 in 1,000 chance of developing lung cancer in the next 6 years.

How you fit within the guidelines from the two expert groups is shown below. If you do not fit within the criteria, the reason is also listed. It is important to remember that you should talk to your health care provider about the pros, cons, and unknowns.

For a 60 year old, who has smoked 30 pack-years, and quit 12 years ago:

- **USPSTF** 
  - Eligible

- **NCCN** 
  - Not Eligible  
    - no additional risk factor
Question List for Lung Cancer Screening using LDCT

This section includes a list of questions about lung cancer screening that people might want to ask when they think about lung cancer screening.

You can place a mark in the box next to the question if you would like to add it to your personal list. You can also add your own questions to the list if you have other questions. The questions are divided into 6 areas: (1) general questions about LDCT, (2) LDCT pros, cons, and unknowns, (3) lung cancer screening program questions, (4) LDCT-specific questions, (5) lung cancer screening results, and (6) other/new questions.

When you have finalized your list, you can print it by clicking on the button on the bottom. There is also a "Select All" button if you want to print all of the questions.
1. General Questions

☐ What is my risk of developing lung cancer?

☐ What are the pros of low dose computed tomography (LDCT)?

☐ What are the possible harms of low dose computed tomography?

☐ Are there options for screening other than low dose computed tomography?

☐ Which lung cancer screening programs include a team of dedicated lung cancer care experts?

☐ Will lung cancer screening prevent me from developing lung cancer?

☐ How often will I need to be screened?

2. Lung Cancer Screening — Pros, Cons, and Unknowns

☐ How beneficial is lung cancer screening?

☐ How likely am I to benefit from lung cancer screening?

☐ How will screening impact my quality of life?

☐ Other than reducing my chances of dying from lung cancer, are there other potential benefits to lung cancer screening?

☐ Will the radiation dose during screening hurt me?
Lung Cancer Screening Study

LCS_9:: The scenario given below describes what lung cancer screening might be like. Please select the button that best describes how likely it is that you would be screened in this situation.

Remember that a "false positive" screening result is one where some abnormality of the lung is discovered, but the abnormality is not cancer. However, further testing, for example a biopsy, might be needed to determine if it is or is not cancer.

How likely are you to get screening in this scenario?

- Your doctor recommends that you do get screened
- A 1% reduction in lung cancer deaths
- 40% false positive rate
- $300 out of pocket cost
- Imaging center is in a convenient location and is open evenings and weekends as well as 9-5 on week days

Definitely Would Not Get Screened

Probably Would Not Get Screened

Might Or Might Not Get Screened

Probably Would Get Screened

Definitely Would Get Screened

7%
Definitions

Below are some words in used in this decision aid that may be less familiar to you. We provide a simple definition of each.
LuCaS Choices
Phase I – Usability Study

- We will evaluate the 5 E’s
  - Effectiveness, efficiency, engagement, error tolerance, ease of learning

- Recruit approximately 20 people in Kentucky and South Florida
  - Ages: 45-60/60 and older
  - Sex: Male/female
  - Education: Less than high school/high school or greater
  - 20 pack years or more of smoking

- Pre-survey on demographics

- Qualitative data:
  - Talk-aloud approach; usability scenarios/tasks; semi-structured debriefing interview

- Quantitative data: Post-survey
  - System Usability Scale; Computer System Usability Questionnaire; ODSF Acceptability Survey
Assessment of Feasibility

- Criteria for success/feasibility/acceptability

- Access of intervention: 65%

- Acceptability: Recommendation rate of 80%

- Methodological feasibility
  - Contact rate: 5 individuals per week
  - Eligibility rate: 60% of contact rate
  - Retention rate: 90% Post$^1$-survey; 80% Post$^2$-survey
Next Steps

- Randomized controlled trial of LCS-DA versus enhanced usual care (pamphlet with LCS information)

- Dissemination
  - Lung Cancer Alliance
  - American Cancer Society
  - NCI Cancer Information Service

- Development of the instruments/educational tools to be used in the pre-clinical and post-clinical settings
If you build it, they will come...

Baseball in cornfields... yes;
Lung cancer screening... not so much.
Lung cancer screening needs to be implemented differently than other cancer screenings.

Screening as Guideline Compliance vs. a Personal Choice

Screening as an Event vs. an Algorithm
Infusing Informed Decision Making Principles Across the Screening Process

- Consumer-focused
- Unique population