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# Utilizing Patient and Stakeholder Engagement in the Creation of Lung Cancer Decision Support Materials

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# Utilizing Patient and Stakeholder Engagement in the Creation of Lung Cancer Decision Support Materials

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## BACKGROUND/INTRODUCTION

In December 2013, the U.S. Preventive Services Task Force issued a “B” rating for lung cancer screening with low-dose CT scan in adults ages 55 to 80 with a 30 pack-year history and who continue to smoke or quit within the past 15 years.<sup>1</sup> Reimbursement guidelines from Medicare include documentation of shared decision-making (SDM) with patients, though tools to facilitate decision support are limited.<sup>2</sup> Lung cancer screening has limited public awareness due to its relatively recent recommendation.

### OBJECTIVE

To create a lung cancer screening SDM tool and patient educational materials by a Patient and Stakeholder Advisory Committee (PASAC).

## METHODS

### STUDY DESIGN

As part of the Reducing Cancer Disparities by Engaging Stakeholders (RCaDES) Initiative, an iterative process was applied to facilitate the creation of patient materials through regular convening of the PASAC and community testing.

### SETTING

Lehigh Valley Practice and Community- Based Research Network (LV-PBCRN), in collaboration with Thomas Jefferson University, prime contractor.

### PARTICIPANTS

A PASAC comprised of patients, community and health network stakeholders including primary care and specialty clinicians and administrative representatives.

### METHODS

The PASAC reviewed evidence-based literature and screening pathways and developed a tool to facilitate SDM in the clinical encounter, as well as educational material to be distributed to patients who may be eligible for screening. Each committee member was asked to test materials with 10 other community members for readability and feedback.

## PROCESS



- CURRICULUM**
  - Review of terms, pathways, coverage requirements, processes, literature
  - Review of current educational and evidence-based SDM tools
- MATERIAL DEVELOPMENT**
  - Brainstorming – Patient needs
  - Brainstorming – Provider/ Network Needs
  - Iterative mock-up process
  - Draft final products
- CONSENSUS**
  - Community testing and feedback
  - Iterative revision process
  - Consensus of materials
  - Presentation and recommendation to Leadership

## PRODUCT

IS LUNG CANCER SCREENING RIGHT FOR ME?		
Frequently Asked Questions	Screening using low dose CT	No Screening
Who is it offered to?	High-risk smokers or ex-smokers: <ul style="list-style-type: none"> <li>Aged 55 to 80</li> <li>Have smoked at least 1 pack a day for thirty years.</li> <li>No symptoms of lung cancer.</li> </ul> Ex-smokers are offered screening if they have quit in the last 15 years.	People who are not at high risk of lung cancer are not offered screening because there is no proven benefit to them.
How is lung cancer found?	Using low-dose CT: an x-ray offered once a year. This test takes a few minutes and needs no special preparation.	Without screening, lung cancer is usually found after symptoms are present or when other tests are done. In these cases, lung cancer is more likely to be found at a later stage.
What are the benefits of screening?	Low-dose CT finds signs of possible lung cancer in roughly 1 in every 100 screened at a time when treatment has a better chance of success. 65 in every 100 scans will not find any problems.	Does not apply
What are the harms or risks?	<b>False alarms:</b> Roughly 25 in every 100 people have small nodules found in their lungs. To make sure these nodules are not cancer, more tests are done, for up to 2 years. <b>Unnecessary treatment:</b> Some suspicious nodules may be treated even though they may never cause problems. <b>Finding more problems:</b> Low-dose CT sometimes reveals findings in other parts of the body. These may lead to more tests and possible treatment. <b>Radiation:</b> There is a small radiation risk of CT scans, in this case it is similar to a dental x-ray	If are at risk and do not screen, you might worry that you have missed a chance to find the cancer early. If cancer is found because of symptoms (like unexplained weight loss and coughing up blood) then the cancer is probably more advanced, and treatment will be more difficult.
What are the possible results?	25 people in every 100 screened will be told they have nodules, but few of these will be cancer. More tests will probably be done. Roughly 10 in every 100 people screened will be told about other problems, such as infections or lung damage from smoking.	Does not apply



## DISCUSSION

- The PASAC chose the adoption of a standardized SDM tool (Option Grid™) and a de novo patient education tool for incorporation into the developing lung cancer screening program.
- The PASAC led the design, identification of core information, language and testing of the de novo product.
- The PASAC presented final materials to network leadership as part of a lung cancer screening program recommendation.

## CONCLUSION

- Engaging patient and other stakeholders in the design of end-user educational materials is critical in creating culturally appropriate and tailored messaging materials.
- Utilizing a PASAC to create and test materials for patient and clinician end-users provides for low burden and exponential community feedback.

## NEXT STEPS

Materials will be piloted in the clinical setting as part of a comprehensive lung cancer screening and lung health program.

## REFERENCES

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