

## **Lung Cancer Stigma in Primary Care**

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### Most importantly...

 Thank you to all the participants who shared their story and provided their thoughts and opinions about this important topic in our research studies.













#### What do both of these patients stories have in common?



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Focus Group Study (2014)

Opt Out Study (2016)

Lung Health Study (2015)

LuCaS Study (2017-2020)



# **Focus Group Study**

- 4 groups (screening-eligible longterm current and former smokers)
  - 2 groups screened
  - 2 groups unscreened
- Explored knowledge and beliefs about lung cancer risk and lung cancer screening



- Major Findings:
  - Confusion about risk factors
  - Unaware lung cancer screening existed or confused about how it is performed
  - Smoking-related <u>stigma</u> as a barrier to screening
  - Distrust of the healthcare system



Focus Group Study (2014)

Opt Out Study (2016)

Lung Health Study (2015)

LuCaS Study (2017-2020)



## **Lung Health Study**

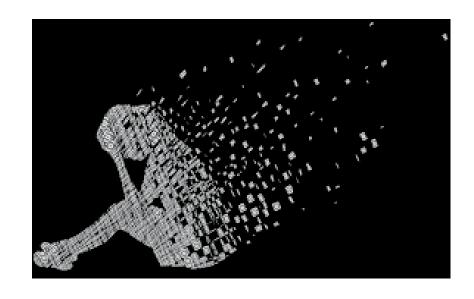
- Survey study with 497 screening-eligible people nationwide
- Examined different variables related to lung cancer screening
  - Health Beliefs (perceived risk, perceived benefits, perceived barriers, self-efficacy)
  - Stigma
  - Healthcare provider recommendation
  - Social influence
  - Knowledge





### **What Seems to Matter**

- Stigma
- Perceived Benefits, Perceived Barriers, & Self-efficacy
- Healthcare provider recommendation
- Knowledge
- Age



Carter-Harris L, Slaven J, Monahan PO, Rawl SM. (2016). Development and psychometric evaluation of the lung cancer screening health belief scales. Cancer Nursing: An International Journal for Cancer Care, 1-8 (ePub ahead of print 05.17.2016). doi:10.1097/NCC.0000000000000386



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## **Opt Out Study**

- Qualitative Study (N=19)
- 1:1 Interviews with screeningeligible patients who received a recommendation from PCP to screen and opted out
- Reasons for opting out:
  - False Positives
  - Stigma / feeling blamed for having a smoking history
  - Perceived Low Value
  - Knowledge Avoidance



Carter-Harris L, Brandzel S, Wernli KJ, Roth JA, Buist DSM. (2017). A qualitative study exploring why individuals opt out of lung cancer screening. Family Practice, 31(2):239-244. PMID: 28122849. doi:10.1093/fampra/cmw146



Focus Group Study (2014)

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# **LuCaS Study**

#### Mixed Methods Study

- Survey (N=551)
  - Multiple variables including perceived stigma
- 1:1 Interview (N=40)
  - Tailored interviews based upon scores on specific variables

#### Preliminary Findings

- Stigma associated with decision not to screen for lung cancer regardless of race, gender, or age
- Participants who scored high on stigma scale described being blamed by their healthcare provider and/or family and friends



Stigma The Common Thread Stigma Stigma Stigma

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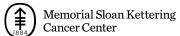
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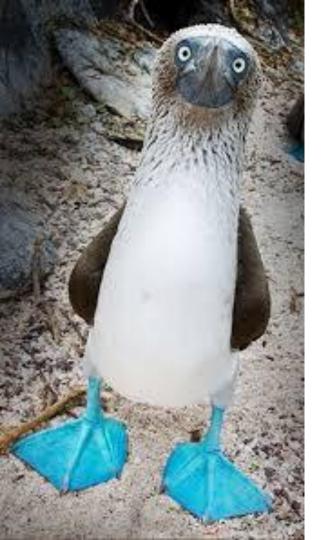
#### What do patients say about lung cancer?

- "My doctor would literally sniff me...I would go in for a sore throat and she'd open the door and say 'still smoking'? Well hello, doctor, good to see you too."
- "My doctor made me feel like a social outcast...like an idiot or stupid or something for smoking. Made me feel like I deserved lung cancer. I don't deserve lung cancer."
- "I went to my primary care doctor shortly after being diagnosed with lung cancer and when she found out she said 'why didn't you tell me you smoked?' I didn't smoke, but the look in her eye...she didn't believe me."

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