## The Science of Patient Centered Decisions:

#### An ACCORDS Seminar Series





ADULT AND CHILD CONSORTIUM FOR HEALTH OUTCOMES RESEARCH AND DELIVERY SCIENCE

INIVERSITY OF COLORADO | CHILDREN'S HOSPITAL COLORADO

Please sign in and be sure to fill out an evaluation before you leave.

Final talk in this series today:

|                     | Lightening the Load: Personalizing substantive, high- |                     |
|---------------------|---|---------------------|
|                     | volume decisions in                                   |                     |
|                     | primary care with targeted, brief shared decisions    |                     |
| 3/19/2019 Ed2N 1206 | making  | Tanner Caverly, PhD |

Behavioral Science in Health and Health Care: An ACCORDS Seminar Series

|                     | Developing Multi-level Change Capacity: Leveraging       |                         |
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## Lightening the Load

**Personalizing Substantive, Everyday Decisions** 

(like lung cancer screening)

Tanner Caverly, MD, MPH

Data Science to Patient Value Seminar Series

#### Room for one more?



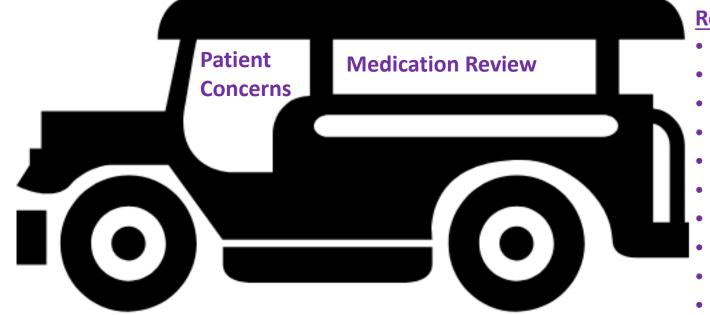
A typical Jeepney ride in the Philippines

Lewis, CL et. al. "PSA Decision Support Interventions in Primary Care." JGIM, 2015.

Tan ASL, Mazor KM, McDonald D, Lee SJ, McNeal D, Matlock DD, Glasgow RE. "Designing SDM Interventions for Dissemination and Sustainment." *MDM P&P*, 2018.

## Substantive everyday decisions

For whom..how frequently? rin? RP meds? Cancer screening? Other preventive services?



#### **Routine Tasks:**

- **ETOH**
- **Tobacco**
- **Diet/Acitivity**
- **Depression**
- Suicide
- **Domestic violence**
- **Risky behaviors**
- **Cognitive decline**
- **Mobility**
- **Immunizations** 
  - **Advanced directives**

## Substantive, everyday decisions (like LCS)

Occur very frequently in primary care (on a daily basis)

Not major, but have important consequences

Personalizing these decisions can add a lot of value

But, they pop up very frequently in primary care and time for personalizing these decisions is scarce

## Time is *very* scarce: Among 1,000 clinicians with typical panels...

None could come close to discussing all highlyrecommended preventive services (like LCS)

Applied even to those working long hours and carrying a smallish patient panel.

Clinicians fall 5.6 hours behind each day completing SDM for all highly-recommended preventive services

Research » Christmas 2018: Time After Time

Much to do with nothing: microsimulation study on time management in primary care



#### **Our VA research initiative:**

Implementing Shared Decision Making (SDM) for Lung Cancer Screening (LCS)







#### **Overview**

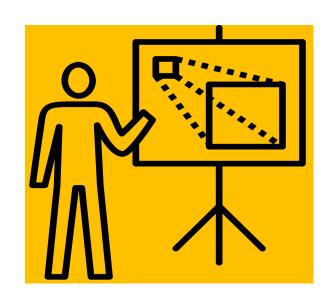
Lung cancer screening: a model to study personalized decision-making

#### 3 things to enhance clinician's capacity to personalize

- 1) Individualized estimates of net benefit
- 2) Bounds on the preference-sensitive zone
- 3) Patient-centered, feasible process that works in routine care: targeted, brief SDM

Caveats

## Lung Cancer Screening: A good model to study personalized decision-making



- 1. Strong evidence that it reduces the risk of total mortality
- 2. Mortality benefit varies dramatically across the population
- 3. False positive results carry major consequences
- 4. It is expensive
- 5. Current guidelines recommend and CMS payment require SDM



# ~2% of eligible screened in 2016

#### Eligible if:

Age 55-80
Smoked  $\geq$  30 pack-years
Current or former smoker quitting < 15 yrs ago
Healthy enough to get curative lung resection

Pham et al. JCO 2016.

# Strong rationale for population screening for lung cancer

Most deadly solid tumor cancer in the US:

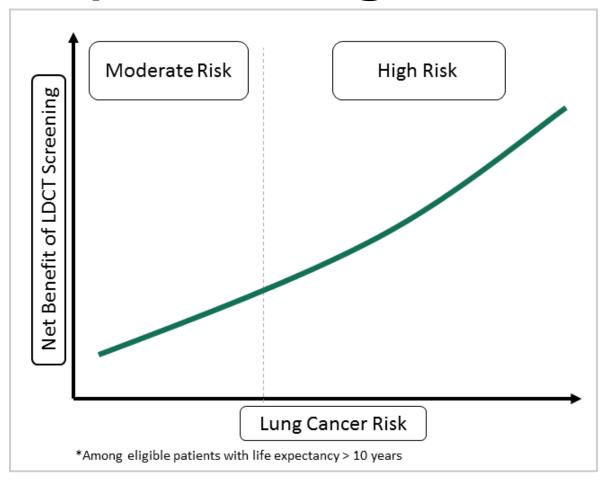
155,870 died from lung cancer in 2017

More than colon, prostate, breast, and melanoma combined

Concentrated on a relatively small, easily identifiable high-risk group: heavy smokers

Lower education, lower income, and higher incidence of mental illness

# Strong evidence that screening helps some patients a great deal



#### For ideal candidates:

LCS >> mammography

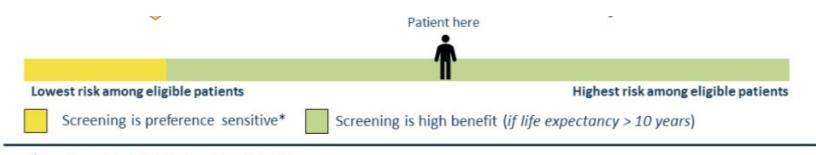
LCS ~ CRC screening

## **Lung Decision Precision**



Web based tool developed as part of our initiative

Studying how to help screening coordinators and primary care teams personalize LCS at 8 VA sites



<sup>\*</sup> Best option depends on patient preferences

# 3 things to enhance our capacity to personalize

- 1) Individualized estimates of net benefit
- 2) Bounds on the preference-sensitive zone
- 3) Patient-centered, feasible process that works in routine care: *targeted, brief SDM*

#### **Overview**

Lung cancer screening as a good model to study personalized decision-making in primary care

#### 3 things to enhance clinician capacity to personalize

- 1) Individualized estimates of net benefit
- 2) Bounds on the preference-sensitive zone
- 3) Patient-centered, feasible process that works in routine care: targeted, brief SDM

Caveats

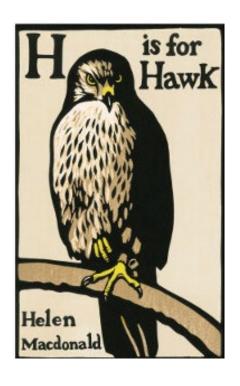
#### Premise for our work:

Clinicians could use a practical approach that enhances their capacity to be skilled health advocates <u>and</u> strong supporters of autonomy

Enhance clinician capacity to be skilled health advocates

But, most patients are also *quite* uninterested in being told what to do

### The goshawk: Accipiter gentilis



A species hawk found in many places including North America.

Accipiter is "hawk", from accipere, "to grasp"

gentilis is "noble"
genteel, refined, worldly-wise, &
sophisticated

# 3 things to enhance our capacity to personalize

To see like a goshawk (skilled health advocate)

- 1) Individualized estimates of net benefit
- 2) Bounds on the preference-sensitive zone
- 3) Patient-centered, feasible process that works in routine care: targeted, brief SDM

Caveats

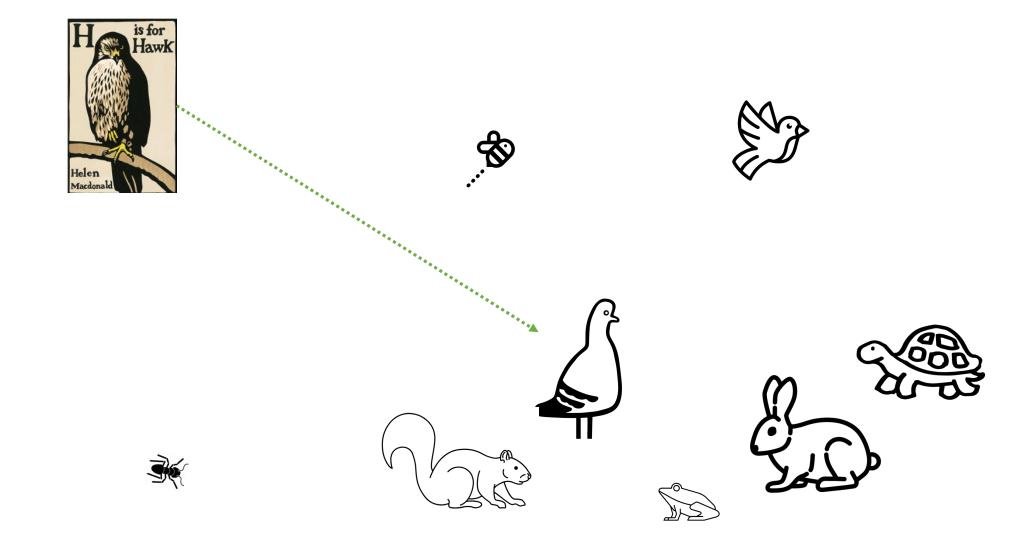
To be elegant and refined like a goshawk (skilled communicator)

# 3 things to enhance our capacity to personalize

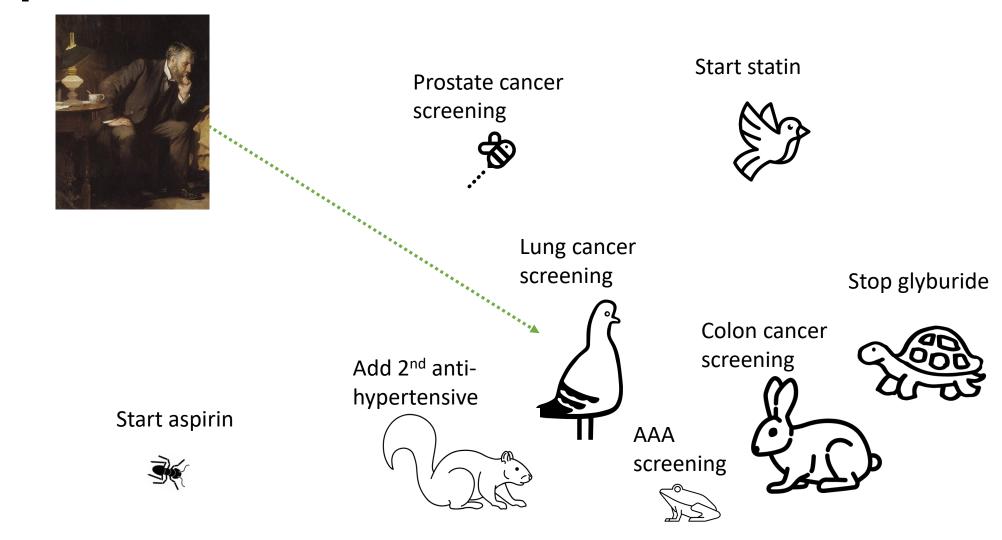
- 1) Individualized estimates of benefit
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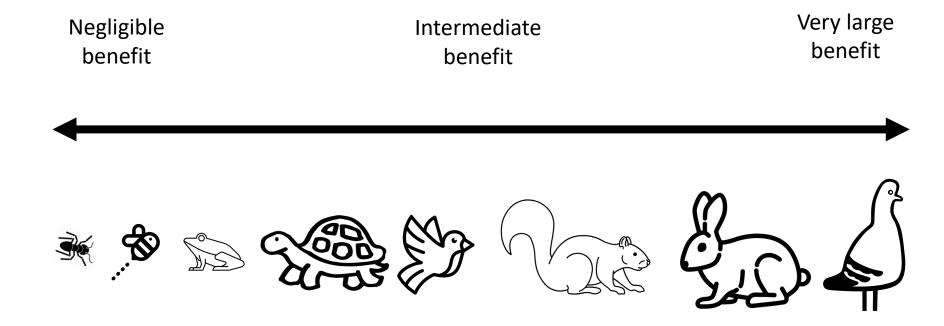
## The visual acuity to find, and the instincts to move directly toward, the most valuable targets



# What's the most valuable thing for this patient?



## Clinicians can use individualized estimates of benefit to see like a goshawk



# $\mathbf{RCT}$ $\mathbf{Benefit (ARR) = risk_{NoRx} * \mathbf{RRR}_{Rx}}$

#### The NEW ENGLAND JOURNAL of MEDICINE

ESTABLISHED IN 181

AUGUST 4, 2011

VOL. 365 NO. 5

#### Reduced Lung-Cancer Mortality with Low-Dose Computed Tomographic Screening

The National Lung Screening Trial Research Team\*

ABSTRACT

"...relative reduction in mortality from lung cancer with low-dose CT screening of 20.0% (95% CI, 6.8 to 26.7; P=0.004)"

There were 247 deaths from lung cancer per 100,000 person-years in the low-dose CT group and 309 deaths per 100,000 person-years in the radiography group, representing a relative reduction in mortality from lung cancer with low-dose CT screening of 20.0% (95% CI, 6.8 to 26.7; P=0.004). The rate of death from any cause was reduced in the low-dose CT group, as compared with the radiography group, by 6.7% (95% CI, 1.2 to 13.6; P=0.02).

#### CONCLUSIONS

Screening with the use of low-dose CT reduces mortality from lung cancer. (Funded by the National Cancer Institute; National Lung Screening Trial ClinicalTrials.gov number, NCT000047385.)

N ENGLJ MED 3655 NEJM.ORG AUGUST 4, 2011

30

## Estimated using validated prediction models from observational studies

Benefit (ARR) =  $risk_{NoRx}$  \*  $RRR_{Rx}$ 

# 4 models most accurately predict lung cancer risk across race/ethnicity groups

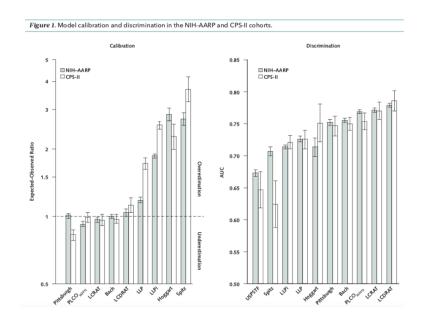
#### **Best Models:**

Bach model

PLCO<sub>M2012</sub>

**LCRAT** 

**LCDRAT** 



Katki et. al. Annals of Internal Medicine 2018.

## Benefit (ARR) = $risk_{NoRx}$ \* $RRR_{Rx}$

# 3 things to enhance our capacity to personalize

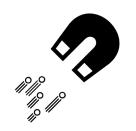
- 1) Individualized estimates of benefit
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Caveats

## The difference between color vision and black & white

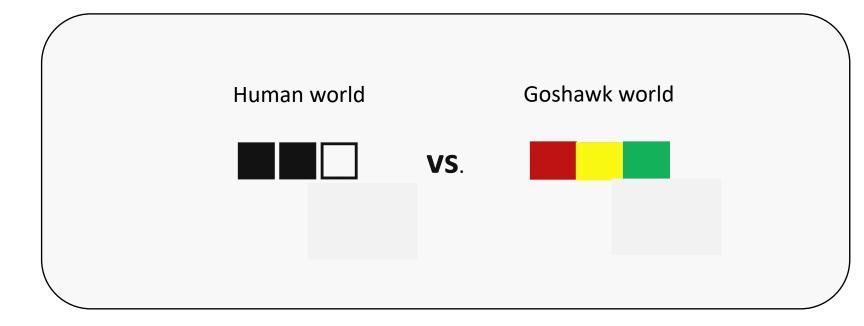












#### Clinicians can use bounds on the preferencesensitive zone to see like a goshawk

Chance of benefit < 0.05% 10% >50%

Current model

Terrible idea!

Recommend against Recommend for

#### A more realistic model





**Uncertainty in benefits & harms Variation in patient preferences** 

**Green zone** (Go, high benefit):

Benefit so large it clearly outweighs downsides



**Red zone** (Stop, net harm):

Benefit so small that treatment harms dominant



Everything else is yellow zone (Caution, uncertain):

Benefit uncertain, depends on context/preferences

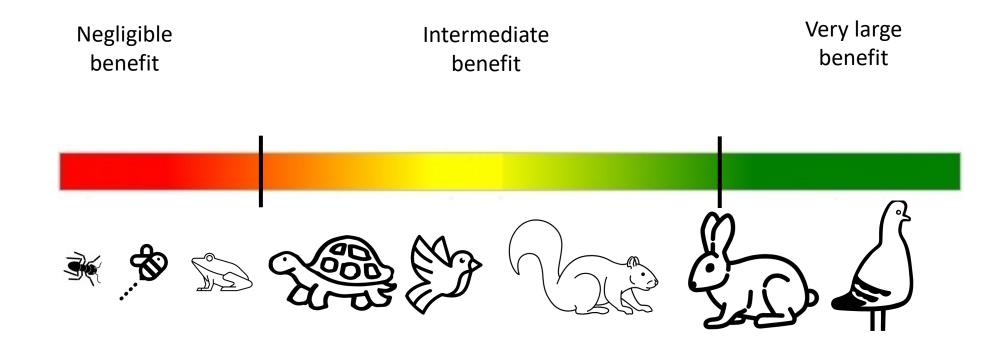






- Individualized estimates of benefit
- Clarity on likely preference-sensitive zone





## 3 things to enhance our capacity to personalize

- 1) Individualized estimates of net benefit
- 2) Bounds on the preference-sensitive zone
- 3) Patient-centered, feasible process that works in routine care: *targeted*, *brief SDM*

Caveats

## Clinicians need an efficient process for everyday decisions like LCS



Caverly TJ, Hayward RA, Burke JF. *BMJ* 2018.

## And a way to make these decisions like LCS more patient-centered





Proposals that promote full SDM are not good fit for substantive, everyday decisions

Progress is unlikely until we have feasible alternatives

## Without a feasible alternative to full SDM, clinicians will usually default to...

#### **Lowest-Scoring Conversations**

Physician: Because of the smoking history, um, I'd like to get a CT scan of the lungs and make sure there's nothing in there. Um, this is a new benefit now. Insurance companies are paying for it.

Patient: Okay

Physician: Okay? Now, I'll just get that set up and we'll move on.

Brenner AT, et. al. Evaluating Shared Decision Making for Lung Cancer Screening. JAMA IM 2018.

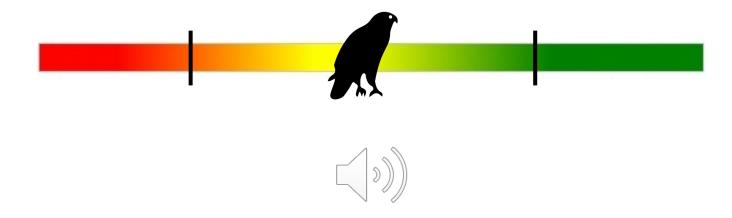
# 3 things to enhance our capacity to personalize

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To be refined, like a goshawk (skilled communicator)



#### Preference-sensitive zone



# Our approach: targeted, brief SDM

#### Make a personalized recommendation

Recommendation strength varies with evidence for and size of net benefit

- Encourage high benefit care
- Discourage risky/trivial care
- Or inform about how the decision is preference-sensitive and how key factors can affect the decision

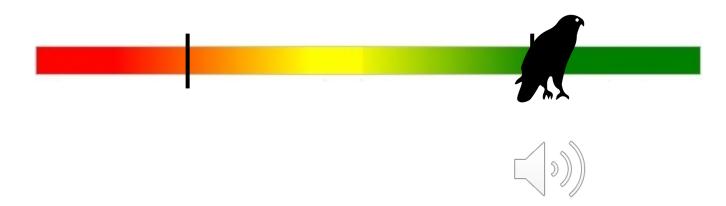
### Fully respect patient requests for more information or disagreement with your initial guidance

On request, ensure access to high-quality quantitative information Fully support patient veto power

### Initial approach in the preference-sensitive zone (1 min 7 seconds)

| 1. | Make a personalized recommendation   | "you are a candidate"   |  |
|----|--|---|--|
|    | Inform the patient the decision is preference-sensitive  | "for you it's a tough decision"  "little bit of benefit with a little bit of downside"  |  |
|    | Briefly present qualitative information about the most important factors affecting the decision                        | "if you're the type of person that would feel"  Recognizes tough decision without being "wishy-washy"   |  |
| 2. | 2. Fully respect patient requests for more information or disagreement   |   |  |
|    | Explicitly state there is a choice, and give patients permission to make the choice based on what matters most to them | "it's really a personal choice between [the small chance of catching a lung cancer early] vs. the risk of false positives and unnecessary biopsies" |  |

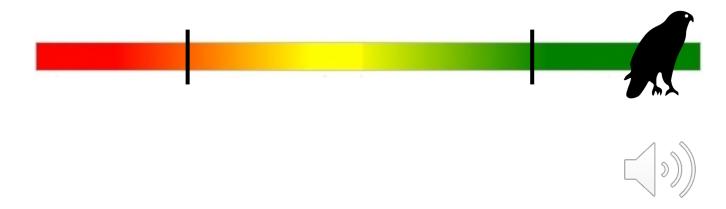
### High-benefit



### High-benefit (40 seconds)

| 1. | Make a personalized recommendation   | "I think it's a good idea for you" "overall I'd recommend"   |  |
|----|--|--|--|
|    | Strength varies with evidence for and magnitude of net benefit                                 | "benefits are fairly high but there are some<br>downsides"<br>"I think this is worth it"<br>"risk of lung cancer is pretty high" |  |
| 2. | Fully respect patient requests for more information or disagreement with your initial guidance | "what are your thoughts about that?"   |  |

### Very high-benefit



## Very high benefit (43 seconds)

| 1  | Make a personalized recommendation   | "I would recommend that you get lung cancer screening"   |  |
|----|--|--|--|
|    | Strength   | "ideal candidate" "greatly improve your life-expectancy" |  |
| 2. | Fully respect patient requests for more information or disagreement with your initial guidance | "unless you have strong objections"                      |  |

#### **Caveats**

- 1) Individualized estimates of net benefit
- 2) Bounds on the preference-sensitive zone
- 3) Patient-centered, feasible process that works in routine care: *targeted, brief SDM*

Caveats

# Substantive everyday decisions are not major decisions

#### For high stakes decisions like major surgery or LVAD:

A neutral (no rec) or "full SDM" approach seems completely justifiable if preference-sensitive

Thompson JS, Matlock DD, Morris MA, McIlvennan, CK, Allen LA. "D&I of Patient Decision Aids for LVADs." *MDM Policy & Practice*, 2018.

#### Neutral approach not suitable for SE decisions like LCS:

- 1. Time, time, time...and volume
- 2. Payors unlikely to pay non-PCPs
- 3. Patient willingness to engage in repeated full SDM

#### Where are the numbers?

#### No numbers initially

Isn't time in the current system

Patients have difficulty processing numbers

Patients should have access to high-quality quantitative information if desired

### Paternalism in disguise?

This approach is NOT about telling patients what to do

Reject unchecked paternalism AND reject the idea clinicians should be passive suppliers of probabilities

Good clinicians make a personalized recommendation and then happily support patients as the final decider

### How to identify preference-sensitive zone?

**Decreases** the stakes of setting thresholds compared to current the screen/don't screen thresholds

Simulation analyses can put clinical outcomes and preferences together to help put bounds on P-S zone

Individual clinicians, expert panels, patients, how to incorporate modeling?

Best process still an open question

#### What's new here?

Moving past providing quantitative information and focusing on improving how recommendations are made

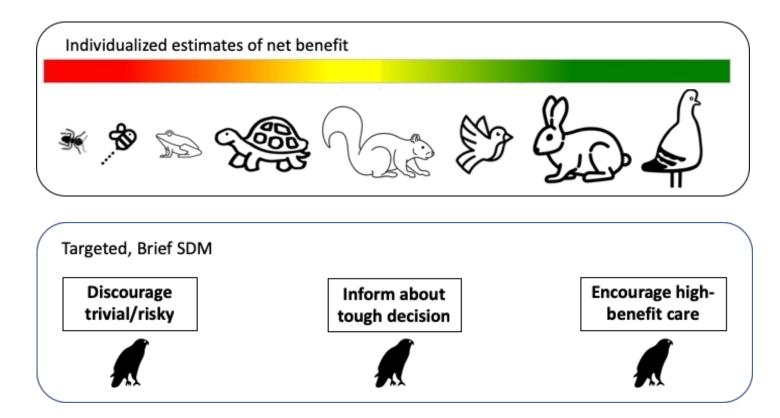
Acknowledge that chance of benefit exists on spectrum and there is a preference-sensitive zone

Focus on feasibility, this is doable!

Systematic approach to support the principles of SDM and meet the transparency standard of informed consent

#### Conclusion

PCPs need a way to make SE decisions more patientcentered than what occurs now:



### "I've thought about the degree of benefit for you specifically"

Strengthen the patient-clinician relationship

#### **Most patients:**

Want their doctor to care for them as individuals

Want information, a recommendation, and no-fault veto power

Fine with us being gentle health advocates as long as we fully respect their autonomy

Schneider, Carl E. *The Practice of Autonomy: Patients, Doctors, and Medical Decisions.* 1998.



# The goshawk: Accipiter gentilis

Accipiter is "hawk", from accipere, "to grasp"

gentilis is "noble"

#### The hawk: fiercely independent

"a creature whose defining trait is the capacity to fly away"





Rod Hayward

Angie Fagerlin, Julie Lowery and the Prove QUERI team including:

Sarah Skurla

Jeff Dewitt

Joe Leishman

**Eve Kerr** 

Brian Zikmund-Fisher

Laura Damschroder

Dan Matlock

Laura Scherer

### The jeepney



### AHRQ checklist for meeting CMS criteria for a LCS counseling and SDM visit

#### During... The Clinical Encounter

Complete all of the following activities.

- Documented all elements in the patient's medical chart.
- Used a decision aid
- Discussed potential benefits of lung cancer screening:
  - » Reduced mortality from lung cancer
- Discussed potential harms of lung cancer screening, including:
  - False-positive results
  - » Followup testing if an abnormality is found (and the possible complications of invasive testing)
  - » Overdiagnosis
  - » Total radiation exposure (screening and diagnostic testing, cumulative)
- Discussed other issues:
- » The impact of comorbidities on screening (the benefit of screening is reduced in patients with poor health)
- » The patient's ability or willingness to undergo invasive diagnostic procedures and treatment
- Counseled about:
  - The importance of adherence to annual lung. cancer screening
  - » The importance of maintaining cigarette smoking abstinence or smoking cessation, as applicable
- » Tobacco cessation interventions (provided information, if appropriate)

## Key feature: The recommendation is not the final decision

Use language and tone to help communicate:

- 1. the strength of the recommendation
- 2. that the patient is makes the final decision and has no-fault veto power

Allows clinicians to continue being health advocates for their patients.

Adds **skilled communication**: clear distinction between the PCP rec and the patients final decision

## Current one-size-fits all discussions (mean time: 59 seconds)

#### **Highest-Scoring Conversations**

Physician: Okay, so, [PATIENT NAME], one of the recommendations, now I just want to discuss this with you. You can decide. Um, one of the recommendations now is that if you have smoked more than 30 pack-years, which you have, and you've quit sometime within the last 15 y, which you have.

Patient: Yeah.

Physician: That you have a yearly chest CT. If you want to do that, I can make it available.

Patient: It's, it's a what?

Physician: A chest CT scan to look for cancer, early cancer. Um, before, we never had anything we could do. If you got lung cancer, bye.

Patient: Yeah.

Physician: Um, now we're finding that if we find these things really early by doing about a yearly CT scan on it, that we can actually intervene and do something about it. Are you interested in getting that done? Patient: Yeah, yeah.

(later)

Physician: (to nurse) I need the code for the, um, smoker CT scan, please.

Brenner AT, et. al. Evaluating Shared Decision Making for Lung Cancer Screening. JAMA IM 2018.

# Persistent wide gap between expectations for full SDM and clinical reality

| Table 2. Presence of Shared Decision Making | Communication Behaviors in Lung | g Cancer Screening Conversation |
|---|---------------------------------|---------------------------------|
|---|---------------------------------|---------------------------------|

| Shared Decision Making Communication Behavior Item by the Clinician (Abbreviated Item Name)   | Mean Item Score<br>(of 0-4) (Range) <sup>b</sup> |
|---|--|
| <ol> <li>Draws attention to an identified problem as one that requires a decision making process<br/>(identifying problem)</li> </ol>   | 0.43 (0-2)                                       |
| 2. States that there is more than one way to deal with the identified problem ("equipoise") (explaining equipoise)  | 0.79 (0-2)                                       |
| 3. Assesses patient's preferred approach to receiving information to assist decision making (eg, discussion in consultations, read printed material, assess graphical data, use videotapes or other media) (assessing preferred approach) | 0  |
| 4. Lists options, which can include the choice of "no action" (listing options)   | 0.50 (0-2)                                       |
| <ol><li>Explains the pros and cons of options to the patient (taking no action is an option)<br/>(explaining pros and cons)</li></ol>   | 0.14 (0-1)                                       |
| <ol><li>Explores the patient's expectations (or ideas) about how the problem(s) are to be<br/>managed (exploring expectations)</li></ol>  | 0  |
| <ol><li>Explores the patient's concerns (fears) about how problem(s) are to be managed<br/>(exploring concerns)</li></ol>   | 0  |
| 8. Checks that the patient has understood the information (checking understanding)  | 0.07 (0-1)                                       |
| <ol><li>Offers the patient explicit opportunities to ask questions during the decision making<br/>process (offers opportunities for questions)</li></ol>  | 0.21 (0-2)                                       |
| 10. Elicits the patient's preferred level of involvement in decision making (eliciting preferred involvement)   | 0.43 (0-1)                                       |
| 11. Indicates the need for a decision making (or deferring) stage (indicating need for decision)  | 0.36 (0-1)                                       |
| 12. Indicates the need to review the decision (or deferment) (indicating need to review or defer)   | 0  |

Simple "rules of thumb" for personalizing LDCT screening discussions based on estimating a person's annual lung cancer risk \*

#### Screening is likely to be high benefit if a person's...

annual lung cancer risk is greater than ~0.3% and less than ~1.3%

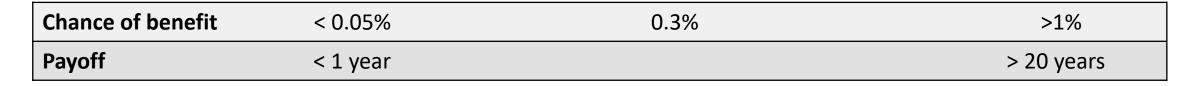
#### Screening is likely to be highly preference-sensitive if a person's...

- annual lung cancer risk is less than ~0.3% OR
- annual lung cancer risk is greater than ~1.3% (due to limited life-expectancy in this group) OR
- life-expectancy is limited (< 10.5 years)</li>

#### Exercise caution if a person's...

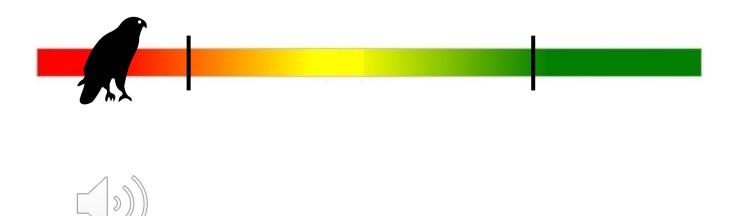
annual lung cancer risk is very low (e.g., less than ~0.3%) <u>AND</u> their life-expectancy is limited (< 10.5 years). Screening may
have negligible benefit or even net harm for these persons.</li>

# Spectrum of benefit for lung cancer screening

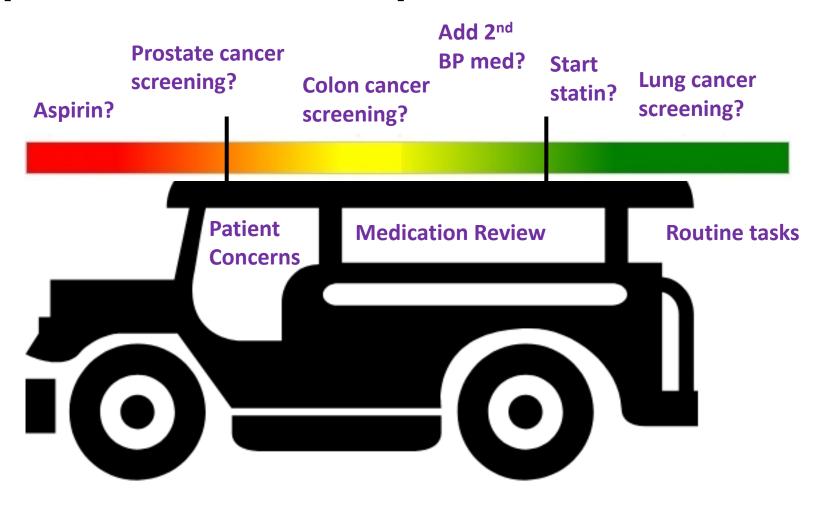




### Red zone (30 seconds)



#### Prevention App: Help PCPs personalize multiple SE decisions



#### ORIGINAL ARTICLE

#### Targeting of Low-Dose CT Screening According to the Risk of Lung-Cancer Death

Stephanie A. Kovalchik, Ph.D., Martin Tammemagi, Ph.D., Christine D. Berg, M.D., Neil E. Caporaso, M.D., Tom L. Riley, B.Sc., Mary Korch, M.Sc., Gerard A. Silvestri, M.D., Anil K. Chaturvedi, Ph.D., and Hormuzd A. Katki, Ph.D.



