

Stigma in Cancer Survivors with a Smoking History: What Cancer Coalitions Need to Know

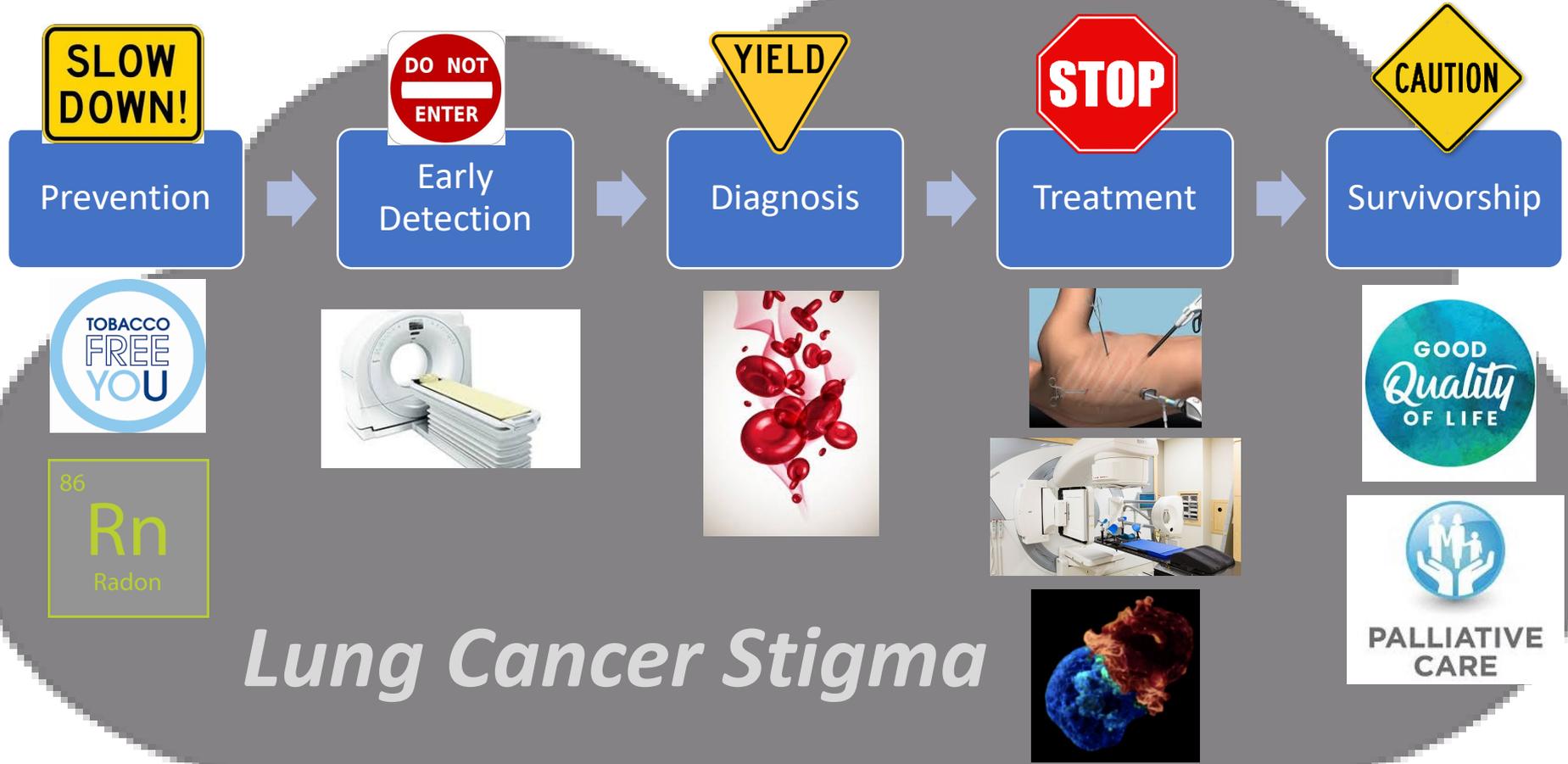


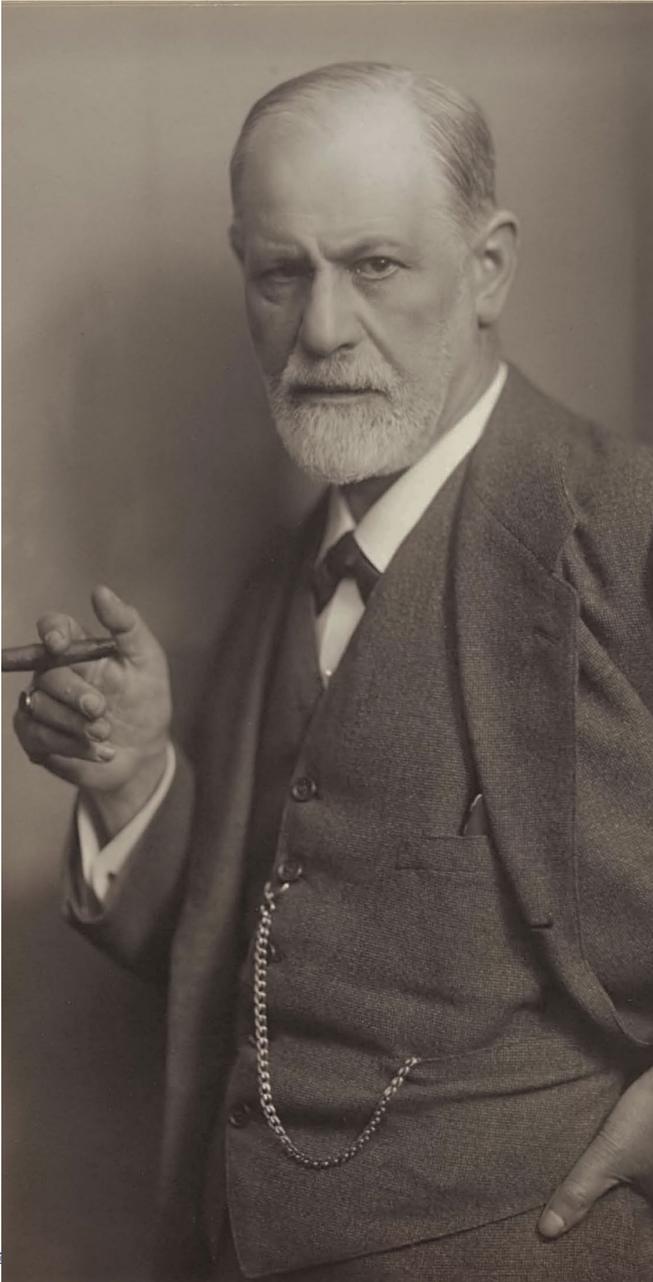
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Professor of Behavioral Science

Faculty Disclosure

- I have no conflicts of interest to report.
- My presentation addresses lung cancer stigma, but I do not claim to be immune to its insidious and malicious weaving into my own thoughts and actions.

Lung Cancer Control Continuum





What are your thoughts or feelings about this photograph?



***Which lung cancer survivor deserves
more empathy and support?***

My Lung Cancer Stigma Story...



Mildred Coughlin Blink
1915-2011



Grandma's Concealed
Weapon

What is Stigma?

... a mark of shame or discredit

...a mark of disgrace associated with a particular circumstance, quality, or person.

...an attribute that is deeply discrediting that turns an individual from a whole and usual person to a tainted, discounted one. (Goffman, 1963)

“othering”

What about Lung Cancer Stigma?



Three Types of Health Stigma (Plus One)

- *Perceived Stigma*

- Recognition of negative appraisal and devaluation from others

- *Enacted Stigma (Bias)*

- Overt acts of discrimination from others

- *Internalized Stigma (Self-Blame)*

- Belief that negative attributions are true and deserved

- *Constrained Disclosure*

- Reduced willingness to discuss diagnosis, restricted support options



What evidence do you have?

How about some examples of lung cancer stigma?





Did

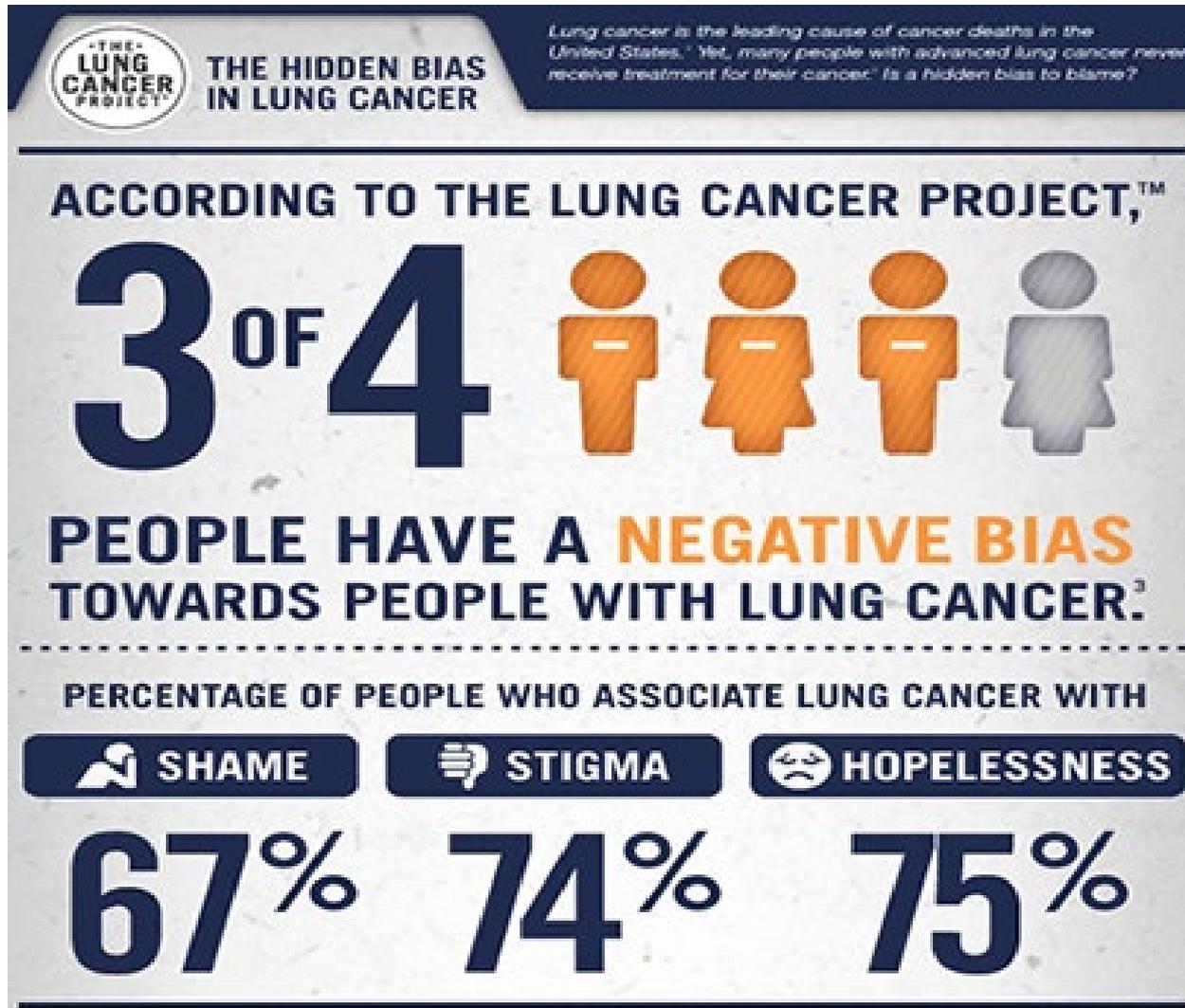


you

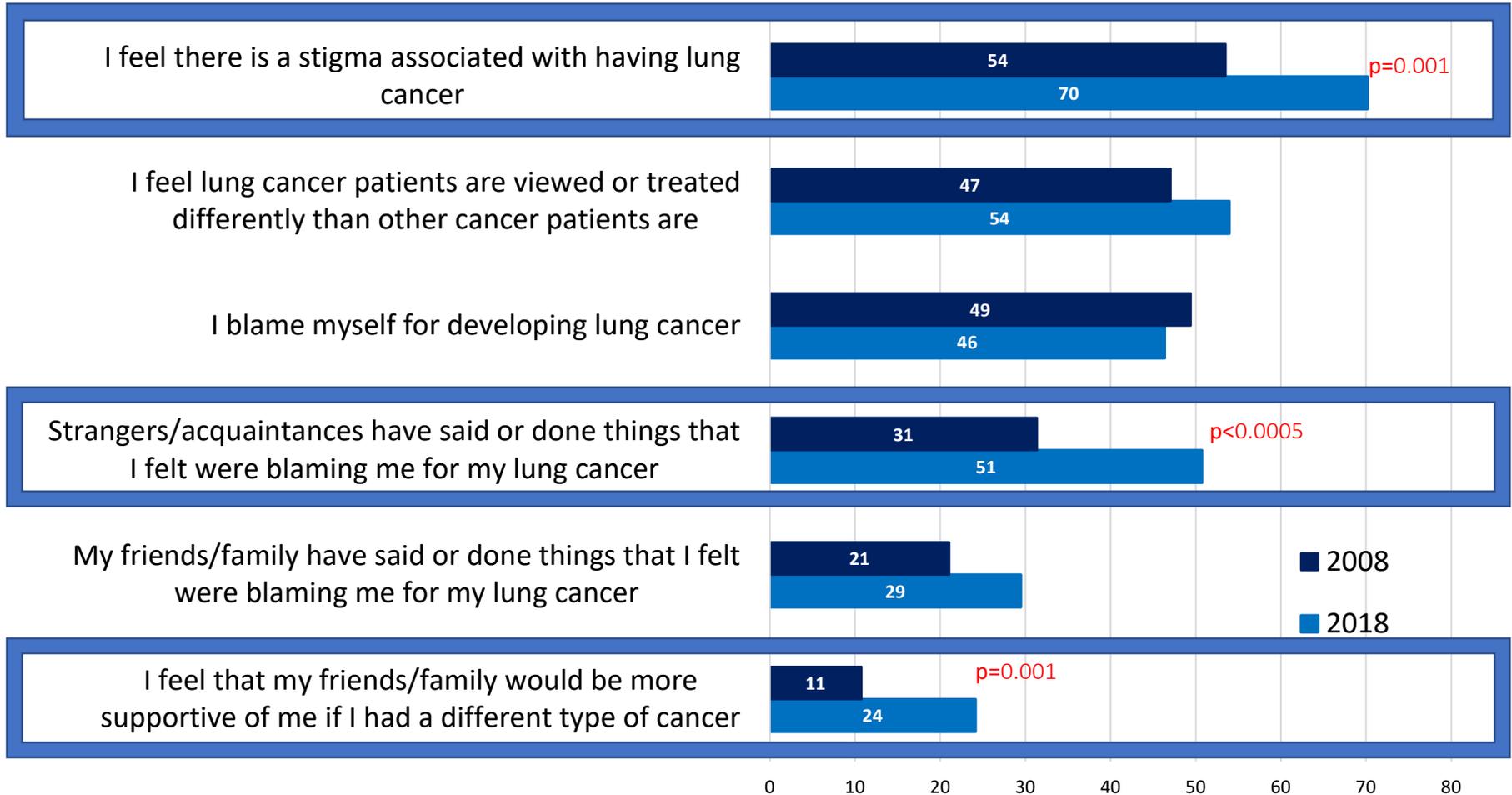
smoke.?



Perceived Lung Cancer Stigma



Patients are Experiencing More Stigma



Enacted Lung Cancer Stigma

US Cancer Deaths vs. Federal Research Funding per Death ^{1, 8-9}

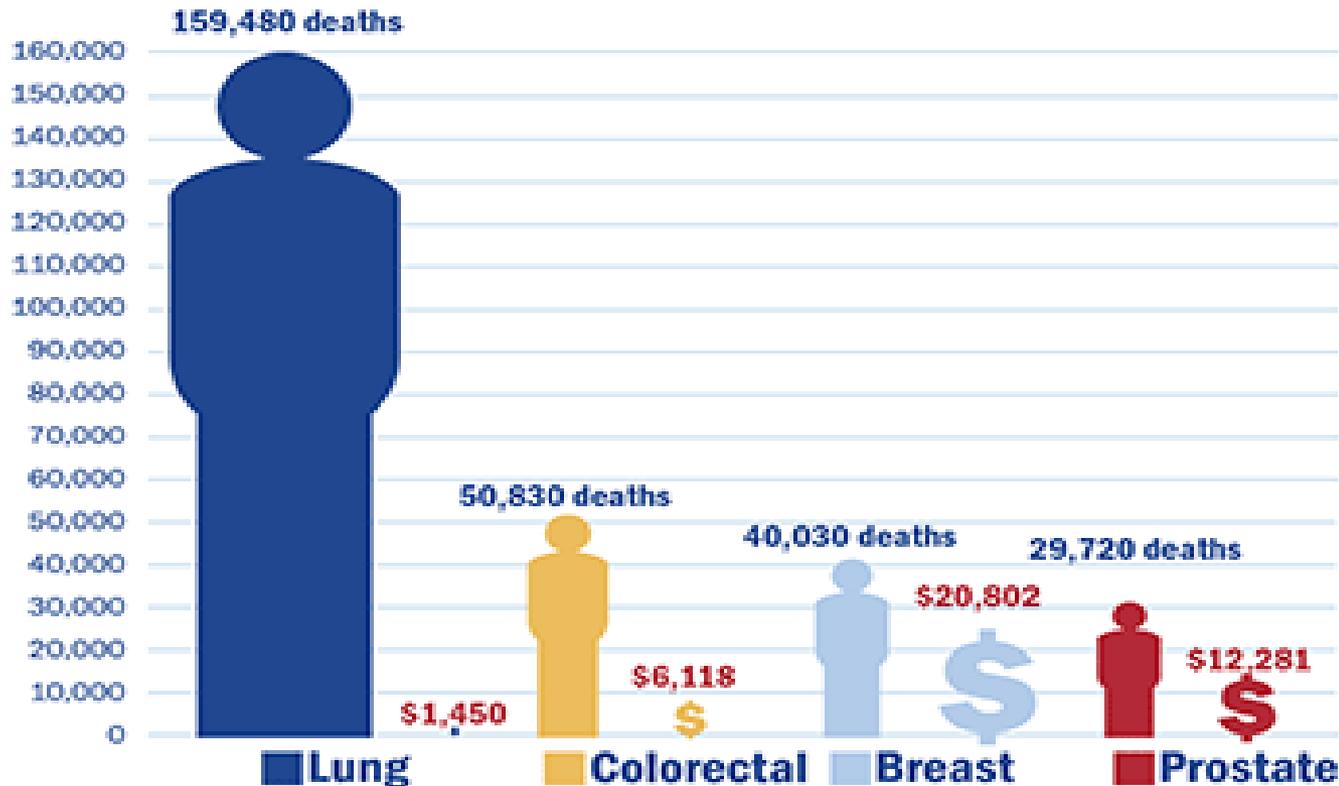


Figure ©2013 National Lung Cancer Partnership. All rights reserved.

Enacted Lung Cancer Stigma – II

CDMRP/DOD 2019 Proposed Funding

<i>TYPE of CANCER</i>		Projected Deaths	Projected Incidence	Research \$\$ by Death	Research \$\$ by Incidence
Breast Cancer + Semipostal	\$130,600,000	42,260	268,600	\$3,090.39	\$486.22
Melanoma	\$10,000,000	7,230	96,480	\$1,383.13	\$103.65
Ovarian Cancer	\$20,000,000	13,980	22,530	\$1,430.62	\$887.71
Prostate Cancer	\$100,000,000	31,620	174,650	\$3,162.56	\$572.57
Kidney Cancer	\$20,000,000	14,770	73,820	\$1,354.10	\$270.93
Lung Cancer	\$14,000,000	142,670	228,150	\$98.13	\$61.36

Sometimes well-meaning people get it wrong too...

WHY NOT KIDS?

- We believe children deserve equal access to life saving research and treatment as adults, **WHY NOT KIDS?**
- \$9.8 million was appropriated in the last biennium for lung cancer research, a disease usually diagnosed after decades of smoking, **WHY NOT KIDS?**



Slide presentation delivered to a budget subcommittee on Health and Family Services in the Kentucky legislature (2018).

What about lung cancer stigma in clinicians or clinical settings?

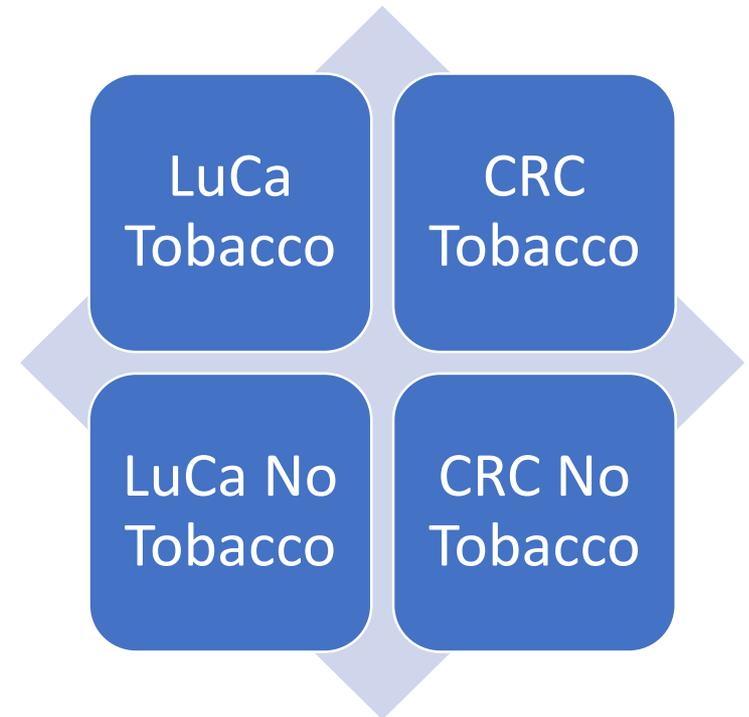
- Research has shown that approximately 50% of individuals diagnosed with lung cancer reported feeling stigmatized by their oncologist.

Research Design

Sample Brief Vignette

Alex is a married 70-year-old with 2 adult children. Last month Alex was feeling fatigued and experiencing persistent headaches, and therefore went to an Urgent Treatment Center. A primary care provider discovered a tumor after ordering an imaging study, and the following biopsy led to diagnosis of a localized *lung cancer*. *Alex has smoked a pack of cigarettes per day for the past 50 years*, and reports eating a well-balanced diet. Alex has been scheduled for surgery and adjuvant chemotherapy. Alex seems to be doing well, but is concerned about the impact of cancer treatment on the rest of the family.

2 X 2
Design

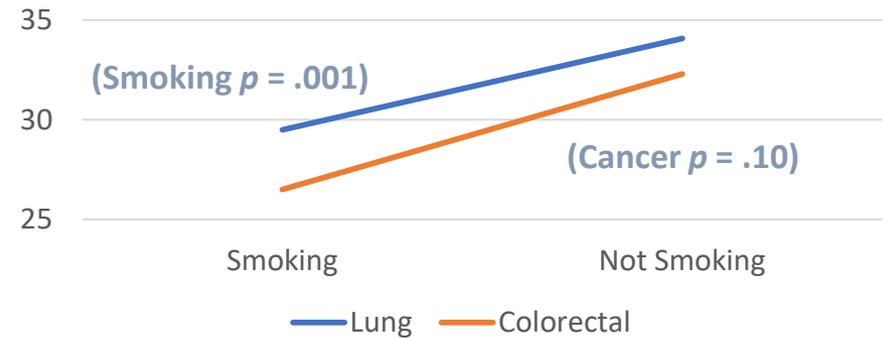


Study 1: LC Stigma Ratings (N = 94)

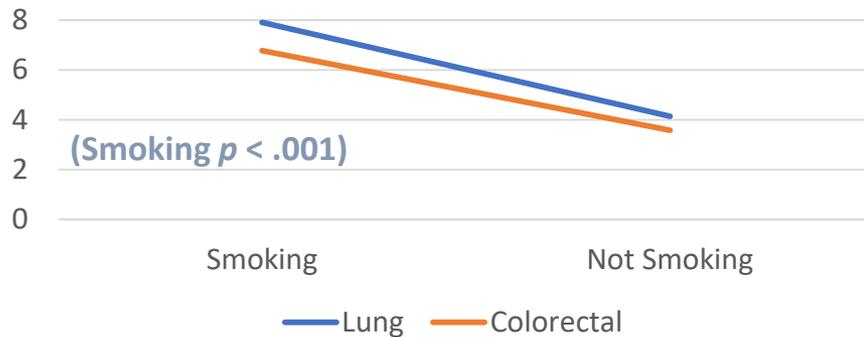
Pity



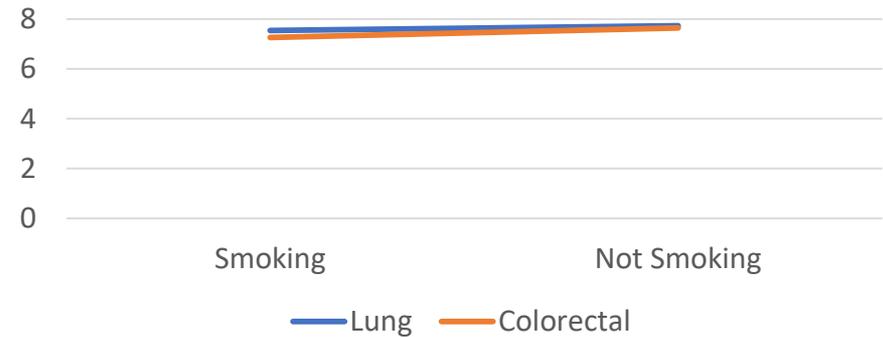
Helping



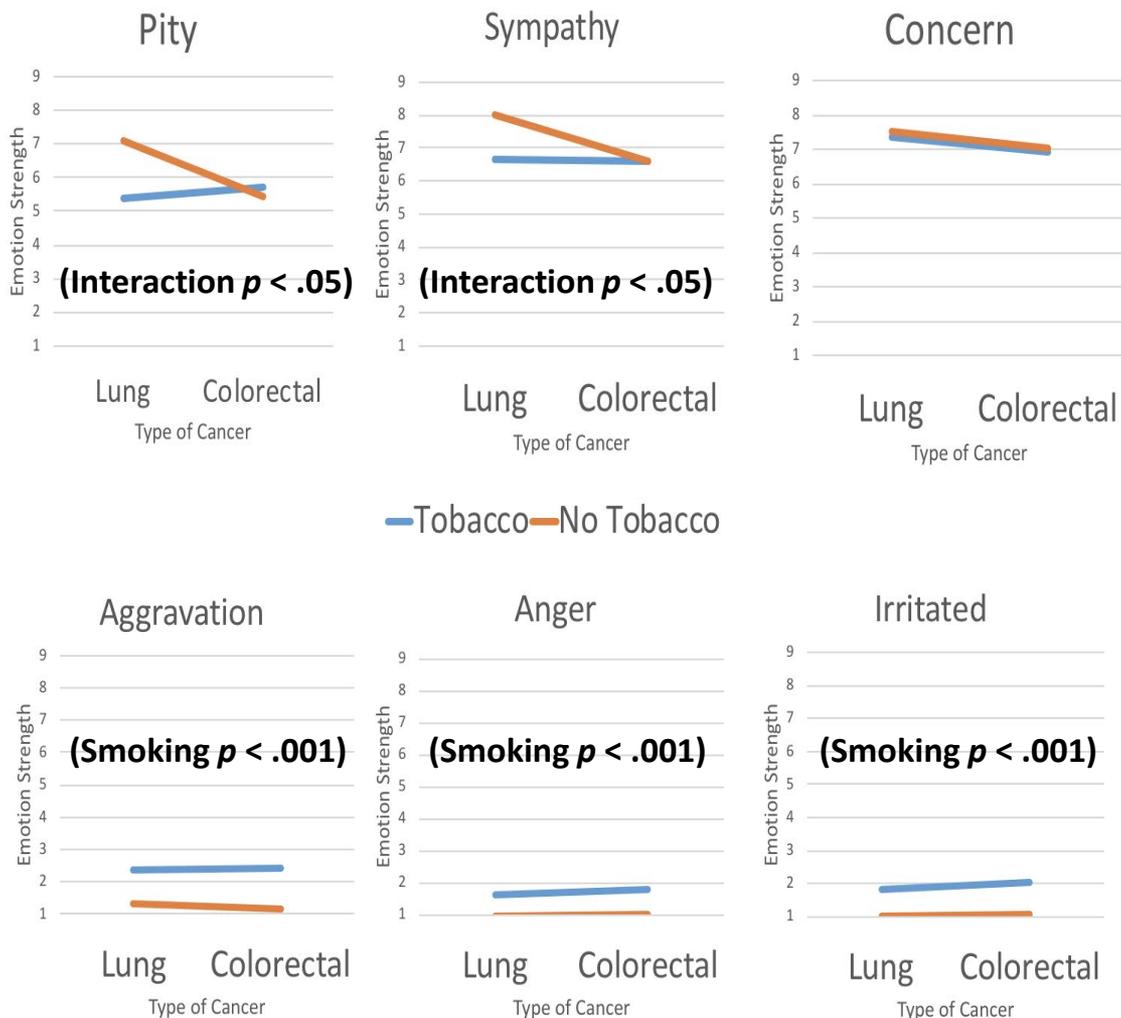
Anger



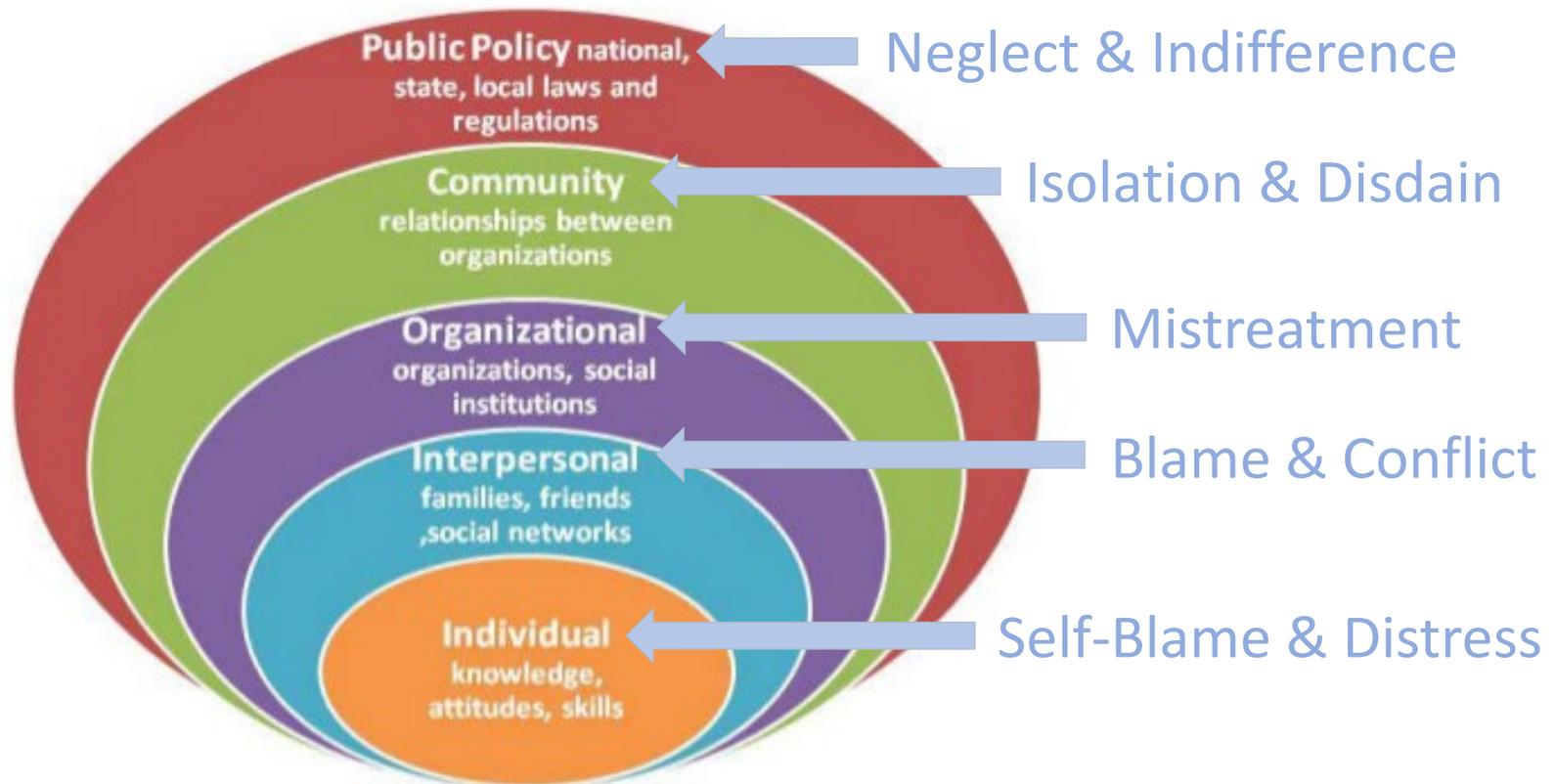
Comfort



Study II: Lung Cancer Stigma (N = 143)



Lung Cancer Stigma & the Socioecological Model



Where does lung cancer stigma come from?

- High disease mortality
- Perceived futility of treatment (nihilism)

“I’m 62 years old. I mean, you know, if I have lung cancer...basically, I just don’t want to know about it.”

- Heightened fear
- Need to distance self from perceived risk
- Lack of survivor visibility

Where does lung cancer stigma come from?

- Association with smoking
 - Intensified by the effectiveness of hard-hitting tobacco control public health campaigns.
 - Seen as self-induced.

Stephen [REDACTED]

Great !!

And if you continue to smoke after knowing the health risk there should not be any Medicare benefits.

8 hours ago · Like ·  4 · Reply



Courier-Journal

Tuesday at 10:30 AM · 

71 percent of Kentuckians support a law to ban smoking in most public places, according to a recent poll.



Support grows for smoke-free law in Kentucky
courier-journal.com

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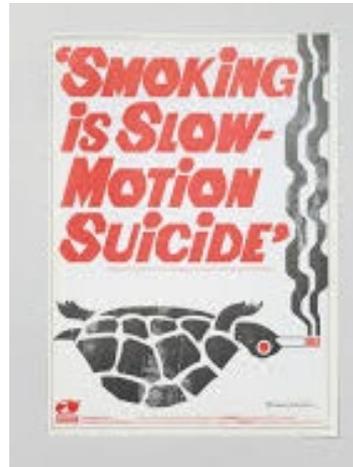
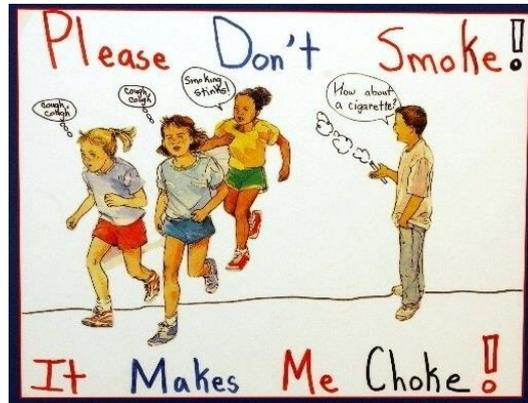
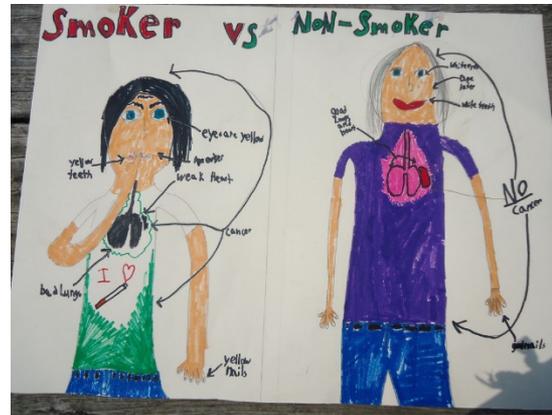
101 Comments 10 Shares

TIPS™ Campaign from the CDC

- The *Tips*™ campaign profiles real people who are living with serious long-term health effects from smoking and secondhand smoke exposure.
 - Since 2012, the *Tips*™ campaign has motivated an estimated 500,000 tobacco smokers to quit for good.
 - In 2016, the average weekly call volume to [1-800-QUIT-NOW](https://www.cdc.gov/tobacco/campaign/tips/) was 92.7% higher than the average call volume during the two-week baseline period, representing almost a doubling of call volume.
- What has been the impact of the *TIPS*™ campaign on individuals suffering from tobacco-related illnesses?
 - Was this considered during message design?
 - What might be non-stigmatizing messages?



Youth Tobacco Prevention



TOBACCO INDUSTRY'S Poster Child

CIGARETTES CONTAIN NICOTINE — A DRUG THAT'S MORE ADDICTIVE THAN HEROIN.
DON'T BECOME A TOBACCO INDUSTRY POSTER CHILD.

ADDICTION
Nicotine is a powerful drug that can be as addictive as heroin and other hard-to-beat narcotics.

WRINKLES
Smoking increases blood flow to the skin. This leads to earlier wrinkling, skin, and increased sunburning.

CATARACTS
The more you smoke, the greater your chance of cataracts — eye problems that can cause blindness. Quitting smoking before you're 50 can cut your risk of developing a cataract.

MOUTH CANCERS
Smoking is the most common preventable cause of oral cancer in both tongues and throats. Smoking makes it harder for your cells to remove poisons in your mouth. That's how it can lead to cancer and higher chances of poor disease — even if you're young.

SKIN DAMAGE
For those without visible skin, your lungs get hurt and cause your respiratory.

THROAT CANCER
That's not to worry because 85 percent of all throat cancers are due to smoking. It's possible to cure your throat cancer causing chemical cancer in your mouth and throat.

PSORIASIS
Smoking can make it likely to see psoriasis to develop psoriasis — a skin disease that can cause sores on your body.

HEART DISEASE
Smoking is a major cause of heart disease. Within one minute of your first puff on a cigarette, your heart begins to beat faster. The blood vessels begin to narrow, raising your blood pressure and forcing your heart to work harder.

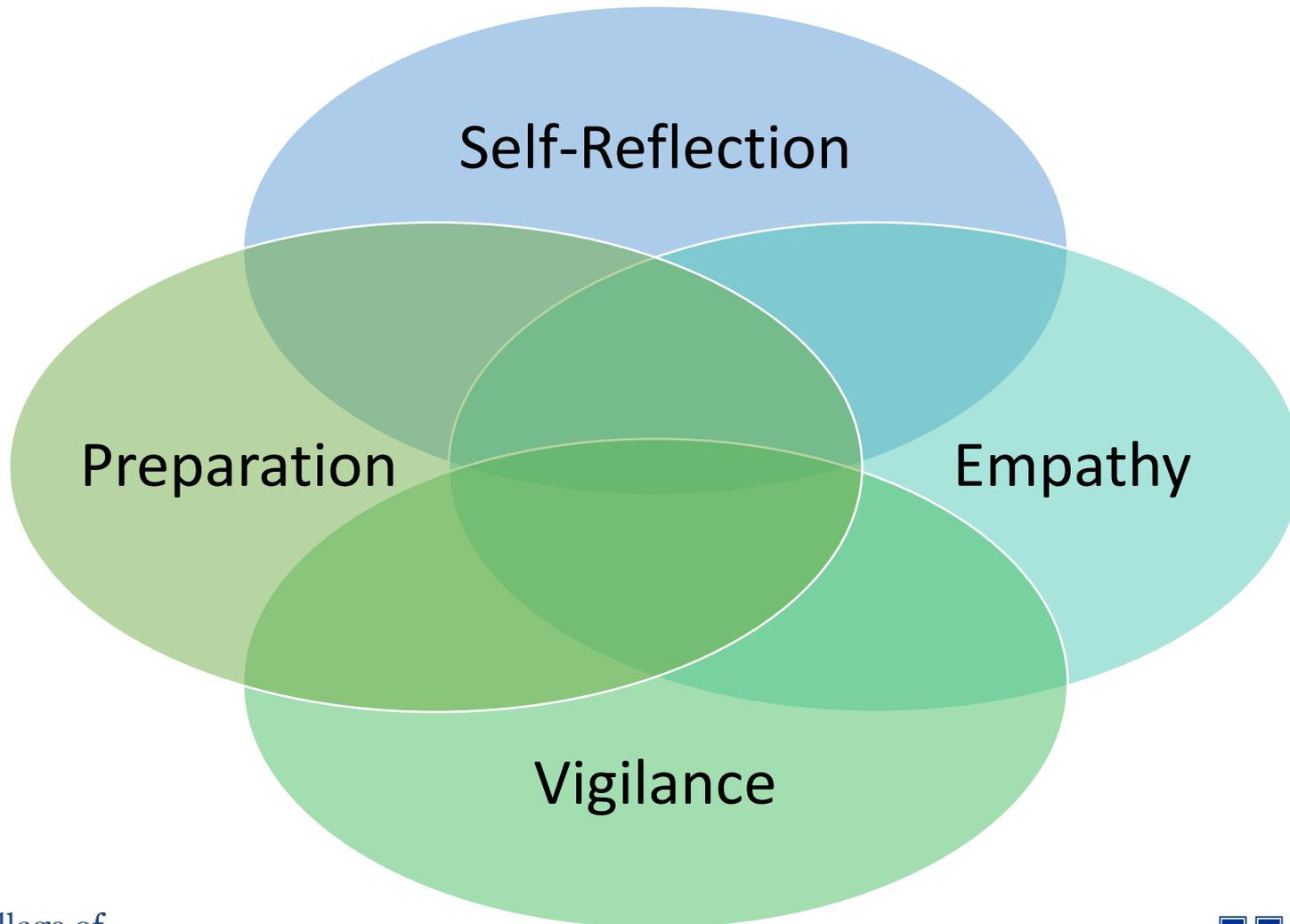
LUNG DISEASE
If you smoke, you're more likely to die of lung cancer. But lung disease isn't just about lung capacity decreasing. You may develop asthma and, if that doesn't stop you, emphysema — when the air sacs of all organs are caused by smoking.

STOMACH ULCERS
Smoking can harm people in upper stomach. You don't feel it until it's advanced and then it's more likely to cause stomach ulcers, peptic ulcers, and stomach cancer. Smoking also increases the risk of stomach, breast disease.

PREVENT CIGARETTES
Ministry of Health

© 1998-2011. Adapted and printed with permission from the University of British Columbia by CTR Association of Researchers, Chemists, and Scientists of California's anti-smoking.

Countering Lung Cancer Stigma



Countering Stigma

- Society
- Systems
- Clinicians
- Family & Friends
- Survivors
- At-Risk Individuals



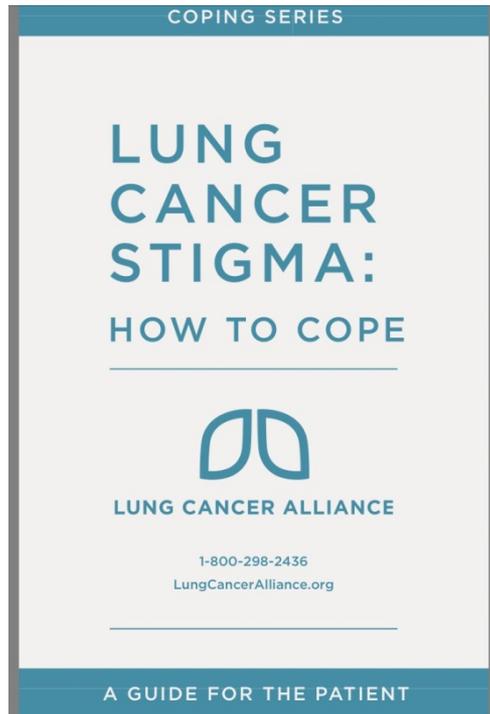
Self-Reflection

Regardless of your role as clinician, advocate, researcher, caregiver, organizer, or other, it is worth some time to reflect on your personal thoughts, attitudes, and actions related to tobacco and lung cancer.

- How do I think, feel, and act with regard to...
 - Individuals using tobacco?
 - Individuals using tobacco in restricted areas?
 - Individuals diagnosed with other stigmatized conditions?

Preparation: Countering Stigma

Empowering Survivors



Advice from lung cancer survivors on
the ever common question...

“DID YOU SMOKE?”

DON'T TAKE IT PERSONALLY

RISE ABOVE

EDUCATE

IGNORE

DOES IT MATTER?

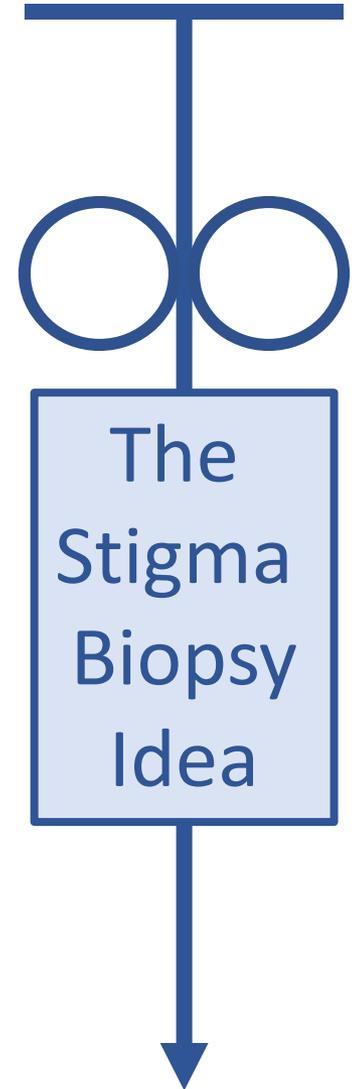


LUNG CANCER ALLIANCE

Stigma-Free Principles

Could we develop stigma-free principles for implementing & delivering health care services?

- Could be used to inform care pathways
- Could be used to train clinicians
- Could be used to design clinics and hospitals
- Could be used to inform clinic and hospital policy
- Could be used to guide community engagement and education



Stigma-Free Lexicon

Can we create a stigma-free game-plan for how to talk about tobacco, lung cancer, lung cancer risk, and other aspects of lung cancer care?

- Could be used to guide awareness & media campaigns
- Could be used to educate & train clinicians & caregivers
- Could be embedded in early health education efforts
- Could be provided to patients and survivors

Empathic Communication

- As clinicians, advocates, researchers, and caregivers, how we talk about tobacco, lung cancer risk, and lung cancer is extremely important and influential.
- There is ongoing research into how we can be more empathic in discussing tobacco use and other stigmatizing aspects of care.
- There is also work considering how we communicate publicly about tobacco and lung cancer.



Empathic Clinical Communication Skills

- 1) Agenda setting
- 2) Questioning and history taking
- 3) Recognizing or eliciting patient's empathic opportunities
- 4) Working towards a shared understanding of the patient's emotion or experience
- 5) Empathically responding to the emotion or experience
- 6) Facilitating coping and connecting to social support
- 7) Closing the conversation

Reframing the Conversation



The Contact Hypothesis

Intergroup Contact Theory

- ***Under certain conditions, interpersonal contact could be an effective manner of reducing prejudice between group members***
- **Positive Contact/Interaction**
 - 1) Equal Status
 - 2) Common Goals
 - Superordinate Goal
 - 3) Intergroup Cooperation
 - 4) Acknowledge Authority
- Reconceptualizing groups, reducing generalizations and prejudice
- **Caring**
 - With compassion and embracing lung cancer survivors during care
- **Championing**
 - Lung cancer survivors throughout survivorship
- **Creating**
 - Easy opportunities for lung cancer survivors to engage advocacy
- **Confronting**
 - Bias and stigma when identified, de-normalizing
- **Conversing**
 - About lung cancer, accepting and normalizing

Marketing & Communication Approaches

KEYTRUDA
(pembrolizumab) Injection 100 mg

Immunotherapy for Lung Cancer

Learn About KEYTRUDA 

Side Effects

Financial Assistance 

Patient Story

Get Patient Support 

Sign up for Updates



Actor portrayal of a real patient from the clinical trial.

KEYTRUDA is a pre cancer (NSCLC). KE spread (advanced N

A CHANCE FOR A LONGER LIFE.

IT'S TRU. KEYTRUDA.

KEYTRUDA does not work for everyone. Results may vary.

For advanced non-small cell lung cancer that has high levels of PD-L1, KEYTRUDA could be your first treatment option instead of chemotherapy.

[See Clinical Trial Results](#)

TRU STORY TOLD BY

OPDIVO
(nivolumab)
INJECTION FOR INTRAVENOUS USE (10 mg/mL)

Home

About OPDIVO 

Financial Resources

Patient & Caregiver Support 

OPDIVO.with You 

Sign Up for More Information and Support >



WATCH The TV Commercial

OTHER INDICATIONS > This site is intended for U.S. residents 18 years of age or older. 1-855-OPDIVO-1 **SIGN UP** > **CHAT**

For U.S. Healthcare Professionals > U.S. Full Prescribing Information  Medication Guide  Full Indication 

A CHANCE TO LIVE LONGER™

If you have a type of advanced-stage lung cancer, **THIS IS BIG.**

Advanced Non-Squamous NSCLC Trial
In a clinical trial of 582 patients whose advanced non-squamous NSCLC had spread or grown after treatment with platinum-based chemotherapy, 292 were treated with OPDIVO®, and 290 were treated with chemotherapy (docetaxel). OPDIVO was shown to reduce the risk of dying by 27% compared to chemotherapy (docetaxel). Half of the patients on OPDIVO were still alive at 12.2 months, compared to

Advanced Squamous NSCLC Trial
In a clinical trial of 272 patients whose advanced squamous NSCLC had spread or grown after treatment with platinum-based chemotherapy, 135 were treated with OPDIVO, and 137 were treated with chemotherapy (docetaxel). OPDIVO was shown to reduce the risk of dying by 41% compared to chemotherapy (docetaxel). Half of the patients on OPDIVO were still alive at 9.2 months, compared to 6 months with chemotherapy (docetaxel).

[See Additional Clinical Trial Results](#)



NATIONAL LUNG CANCER ROUNDTABLE



- The *National Lung Cancer Roundtable (NLCRT)* is a national coalition of public, private, and voluntary organizations, and invited individuals, dedicated to reducing the incidence of and mortality from lung cancer in the United States, through coordinated leadership, strategic planning, and advocacy.

- **Task Groups (10)**

- 1) Advanced Imaging
- 2) Lung Cancer in Women
- 3) LCS Implementation Strategies
- 4) Policy Action
- 5) Provider Engagement and Outreach
- 6) Shared Decision Making
- 7) State-Based Initiatives
- 8) Survivorship, Stigma, and Nihilism
- 9) Tobacco Treatment in LCS
- 10) Triage for Appropriate Treatment

2019 Annual Meeting

Date: December 9-10, 2019

Location: Capital Hilton, Washington DC

Conclusions

- 1) Lung cancer stigma is a pervasive and destructive aspect of American culture and health care.
(Patently: lung cancer stigma kills)
- 2) Research is necessary to develop, evaluate, and inform the development of evidence-based interventions at multiple levels.
- 3) Advocacy is desperately needed to promote empathy, compassion, and support for individuals at-risk for lung cancer as well as individuals and families who have experienced a diagnosis.
- 4) Lung cancer stigma can be addressed, reduced, and eliminated with wisely applied data, compassion, and persistence.
- 5) How can we work together to confront lung cancer stigma and reduce the burden of lung cancer?