

## BACKGROUND

A growing number of clinical guidelines recommend expansion of multidisciplinary care to include supportive/palliative care and survivorship care for oncology patients.

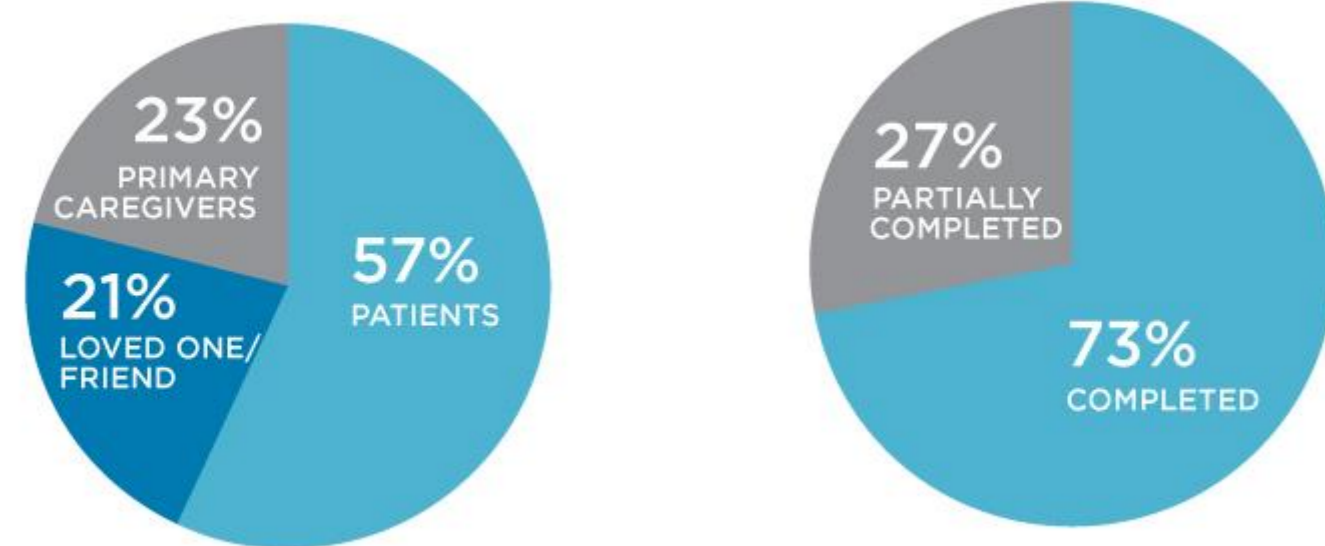
Health care delivery systems vary and lung cancer patients may not have the education, awareness or ability to access these recommended services.

Our goal was to assess treatment and care planning from the patient and caregiver perspective and to determine whether lung cancer patients are receiving the recommended high quality care.

## METHODS

A "Lung Cancer Community Needs Assessment" anonymous online survey was developed by Lung Cancer Alliance (LCA) and was open to both patients and caregivers from 11/9/2015 to 2/8/2016. The survey was promoted primarily electronically through social media (Twitter and Facebook) and electronic newsletters. The survey URL was also posted twice to the Inpire patient community. In addition, 15 long-term survivors known to be without internet access were called by a LCA staff member and 10 of them completed the survey by phone.

820 people responded, including 471 patients/survivors and 349 caregivers, 181 of whom were the primary caregiver.



The overall completion rate was 72.6%.

Demographic information was asked to identify whether patterns of care varied with geographical or socioeconomic factors. Demographic questions were optional and the number of respondents is indicated.

## DEMOGRAPHICS

The following demographic data reflects the 471 survey respondents who identified as patients. Demographic questions were optional and the number of respondents is indicated.

<b>Sex</b>	(n=407)	
Male	68	16.7%
Female	339	83.3%
<b>Race</b>	(n=365)	
White	342	93.7%
Black/African American	7	1.9%
American Indian/Alaskan Native	2	0.5%
Japanese	1	0.3%
Chinese	8	2.2%
Other Asian	2	0.5%
Other	3	0.8%
<b>Ethnicity</b>	(n=302)	
Hispanic/Latino	6	2.0%
Not Hispanic or Latino	296	98.0%
<b>Residential Setting</b>	(n=411)	
Rural	96	23.36%
Suburban	235	57.18%
Urban	80	19.46%
<b>Household Income</b>	(n=363)	
Less than \$20,000	27	7.4%
\$20,000 - \$39,999	41	11.3%
\$40,000 - \$59,999	74	20.4%
\$60,000 - \$79,999	53	14.6%
\$80,000 - \$99,999	50	13.8%
\$100,000 and over	118	32.5%

357 patients (87%) reported having Non-Small Cell Lung Cancer (NSCLC). Of those cancers, patients reported the following characteristics at diagnosis:

<b>Subtype of NSCLC</b>	(n=356)	
Adenocarcinoma	283	79.5%
Squamous	39	11.0%
Large Cell	1	0.3%
I Don't Know	33	9.3%
<b>Stage of NSCLC</b>	(n=356)	
Stage I	78	21.9%
Stage II	43	12.1%
Stage III	82	23.0%
Stage IV	147	41.3%
I Don't Know	6	1.7%

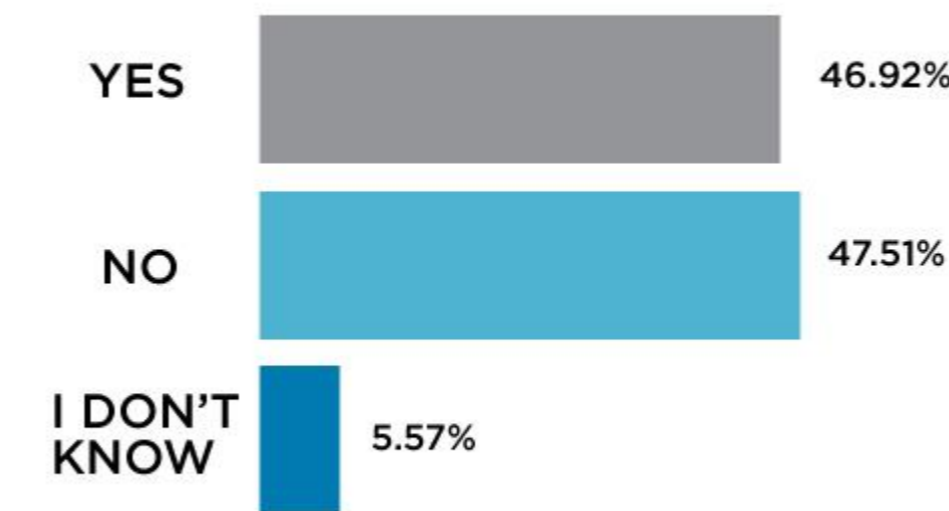
Caregiver-reported patient demographics represented a different population:

- 51% male, 48% female
- Majority 40-60 at diagnosis
- 91% white, 96% not Hispanic
- 34% never smoker, 41% former, 22% current smoker
- Cancers diagnosed later stage
- NSCLC: 68% Stage IV, only 10% Stage III
- SCLC: 64% Extensive, 27% Limited
- 55% said the patient they cared for is no longer alive

## RESULTS

**Less than half of patients reported having a conversation about their values and care goals with their treatment team before determining their treatment plan.**

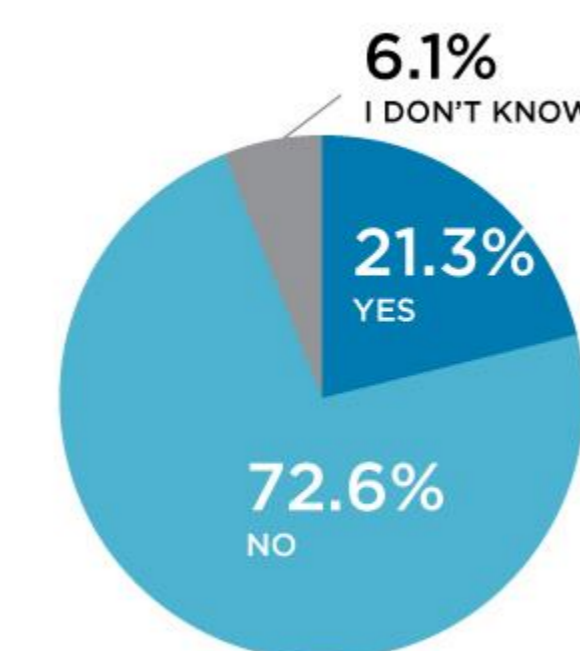
Before starting treatment, did you have a discussion with your doctor/care team about your personal goals for your treatment and what you valued most? (n=341 patients)



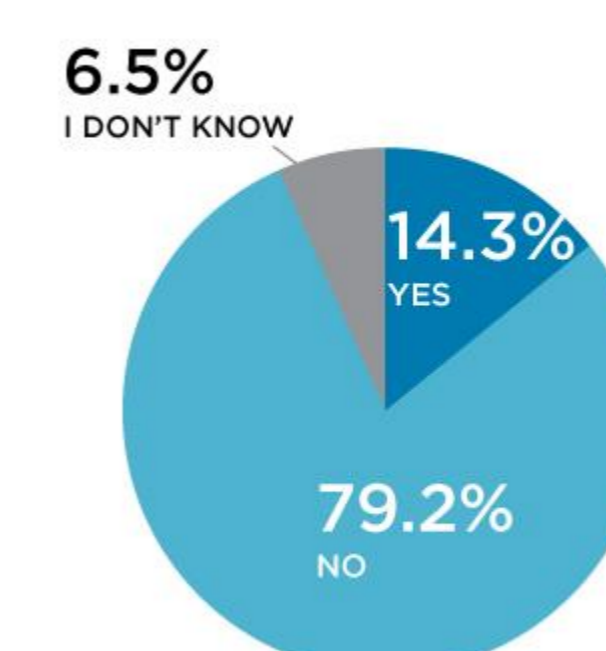
**Palliative care was not often discussed or received, despite data in lung cancer showing its potential survival benefit. (Temel et al, NEJM 2010)**

Only 26.9% of active patients had discussed it and 20.13% reported receiving palliative care. For all patients surveyed (n=376):

Was palliative care discussed?



Was palliative care received?



None of the patients (n=79) who were 5+ year survivors reported a palliative care professional being on their team at any point in their treatment or survivorship.

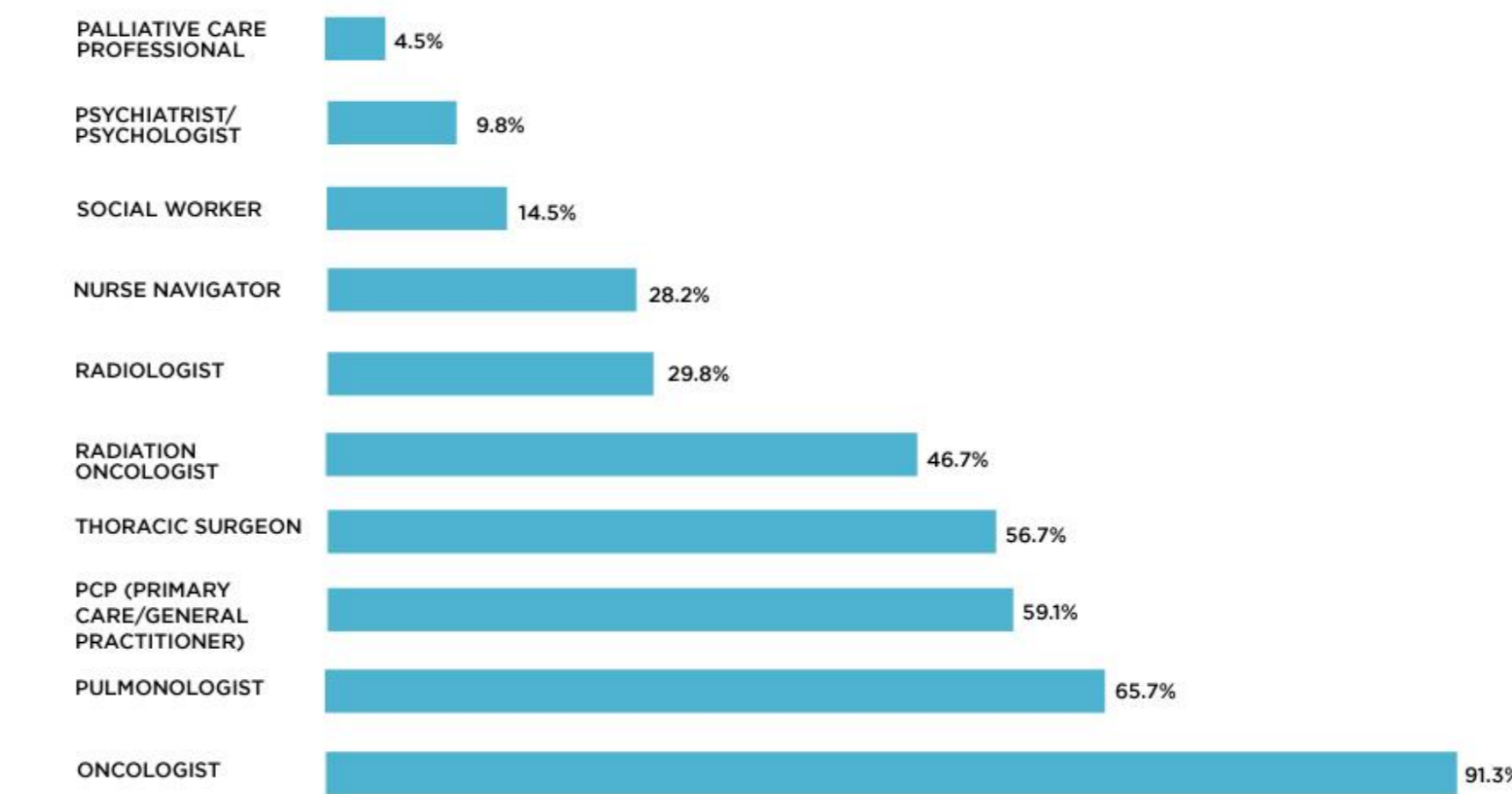
Caregivers reported a higher percentage – roughly 50% reported both palliative care discussions and care receipt. However, for caregiver-reported data, the patients receiving care generally had more advanced cancer and had often not survived.

## RESULTS

**Patients are lacking psychosocial support and complete multi-disciplinary teams**

Less than 30% of patients reported having a psychiatrist/psychologist, social worker or nurse navigator as part of their care team in any time period – treatment or survivorship.

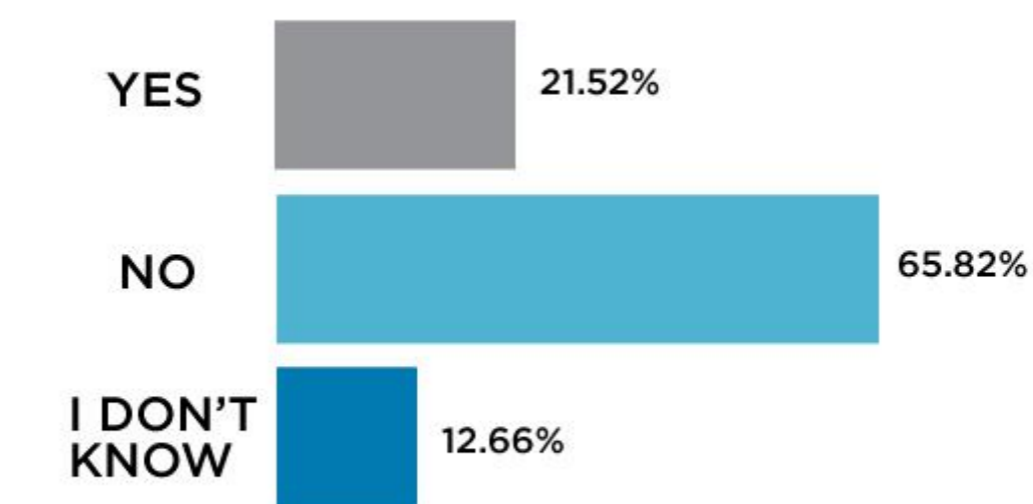
Care team during active treatment (n=379):



**Survivorship care planning is not common in the lung cancer community**

A survivorship care plan was defined in the survey as: a record of the patient's cancer history and recommendations for follow-up care. The plan should define responsibilities of cancer-related, non cancer-related, and psychosocial providers

Did you/do you have a survivorship care plan? And if so, was it helpful? (n= 79 patients who were >5 year survivors)



**Was it helpful? 100% said Yes**

n=11 patients who responded to open-ended question

Only 15% of caregivers of long-term survivors reported having a survivorship care plan.

## LIMITATIONS

The Needs Assessment was carried out completely online and therefore does not represent the entirety of the lung cancer community. However, this is concerning since there were large gaps in care in this population, which tends to be a more educated and health-literate segment of the community.

There was also poor ethnic and racial diversity in the survey population.

The majority of the respondents were women (although women caregivers responded about male/female patients in equal numbers) which may bias the results.

## CONCLUSIONS

Despite recommendations and guidelines for incorporation of palliative care, survivorship care plans, values based care planning and appropriate psychosocial support into lung cancer treatment, the majority of lung cancer patients and caregivers surveyed reported not receiving these services.

Respondents were technology-enabled and generally health-literate indicating that these problems could be more widespread in rural, lower socioeconomic areas where lung cancer is common. Addressing these problems in health care delivery could positively impact lung cancer patients and their families.

## FUTURE DIRECTIONS

Future directions for this work should include:

- A broader study of a more fully representation population of the lung cancer community
- Implementation research around incorporation of survivorship care planning and palliative care
- Provider education on values-based care planning and incorporation of psychosocial support into multidisciplinary teams

## CONTACT

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