Online Collaboration & Support in the Lung Cancer Social Media (#LCSM) Community

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#LCSM Chat (lcsmchat.com)

Abstract

The Lung Cancer Social Media hashtag #LCSM fosters collaboration across all stakeholders in the lung cancer community. It focuses on using social media to educate, end the stigma, connect the community, enable advocacy, and facilitate successful treatments for lung cancer, the leading cause of cancer deaths worldwide.

Since the #LCSM hashtag was registered with Symplur.com in June 2013, it has been used by over 20,000 participants, tweeted over 185,000 times, and generated over 535 million impressions. Participating Twitter accounts include lung cancer patients, caregivers, family members, advocates, healthcare providers, hospitals, researchers, nonprofits, government agencies, journalists, pharma and the biotech industry. They use the hashtag to track new treatments, find patient resources, broadcast new research findings, develop advocacy activities, and connect with other lung cancer community members they might not find otherwise.
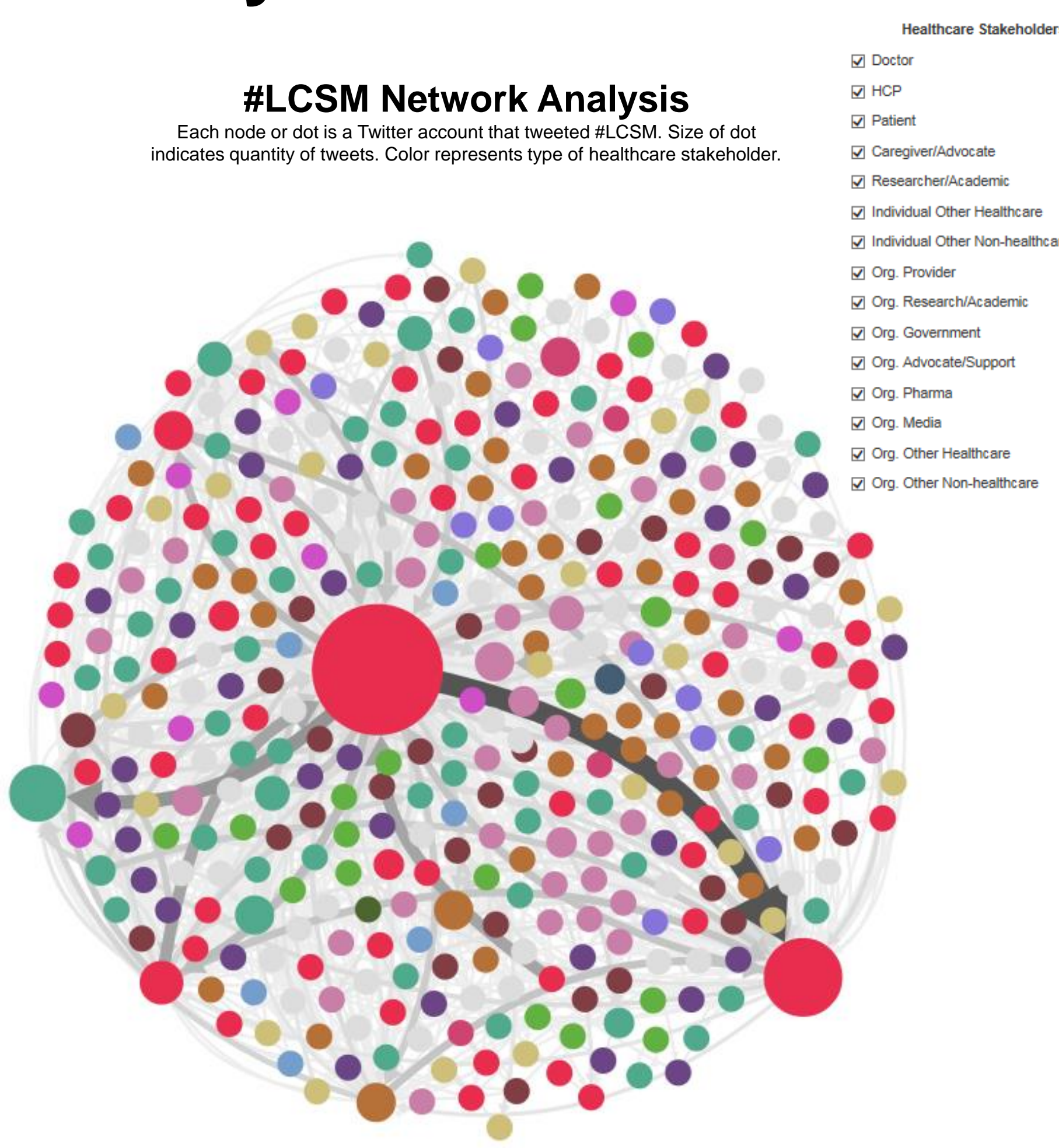
Biweekly chats on a wide variety of topics enable #LCSM stakeholders to share ideas, support research initiatives, coordinate advocacy activities, and address issues within the lung cancer community. Participants span the globe, yet are able to connect and collaborate across patient-clinician-researcher silos to share their common goal of defeating lung cancer.

The Core Team of #LCSM Chat have spearheaded several initiatives, such as curating lung cancer social media resources, a petition to gather signatures to support Centers for Medicare & Medicaid Services (CMS) coverage of low-dose CT screening, and participating in a Patient Centered Outcomes Research Institute (PCORI) Award titled "Empowering Patients and Their Families to Improve Outcomes That Are Most Important to Them after Surgery and Other Therapies for Lung Cancer."

Methods

- Data collected using Symplur Signals software .
- Represents Twitter activity between 00:00 AM 01-Jun-2013 and 23:59 AM 01-Apr-2016.
- We measured total impressions, tweets and participants during activity period.
- Example tweets were abstracted from top 100 most retweeted content during activity period.
- Example chat topics were taken from the chats with the highest participation during activity period.

#LCSM Engages Broad Variety of LC Stakeholders

#LCSM Network Analysis

Each node or dot is a Twitter account that tweeted #LCSM. Size of dot indicates quantity of tweets. Color represents type of healthcare stakeholder.

Healthcare Stakeholders
- ☑ Doctor
- ☑ HCP
- ☑ Patient
- ☑ Caregiver/Advocate
- ☑ Researcher/Academic
- ☑ Individual Other Healthcare
- ☑ Individual Other Non-healthcare
- ☑ Org. Provider
- ☑ Org. Research/Academic
- ☑ Org. Government
- ☑ Org. Advocate/Support
- ☑ Org. Pharma
- ☑ Org. Media
- ☑ Org. Other Healthcare
- ☑ Org. Other Non-healthcare

#LCSM Informs & Inspires

Patient and Caregiver Support

Janet Freeman-Daily @JFreemanDaily

HOPE: More new #lungcancer drugs became available in past 4 years than in previous 4 decades. Thank you researchers! #lcsm

Education

Matthew Katz, MD @subatomicdoc

New @astro_org guideline: Curative radiation in locally advanced non-small cell #lungcancer bit.ly/1ER2F38 #lcsm #radonc Pls share!

Advocacy

Faces of Lung Cancer @LungCancerFaces

Lung Cancer is the #1 cancer killer of women. 20% NEVER smoked. It's time to Rethink Lung Cancer. #lcsm #SXSW #SXSW14

Research

National Cancer Inst @theNCI

The #LungMAP trial will profile tumors to match patients & treatments: lung-map.org #cancer #genomics #lcsm

#LCSM Chat Facilitates Communication Across Silos

Example Chat Topics

- Precision medicine in lung cancer (joint with the National Cancer Institute)
- How can we fight the rising cost of cancer care?
- How can we overcome hurdles in clinical lung cancer research?
- Living metastatic– common experiences across cancers
- How do we move the needle on lung cancer?

What Chat Participants Say

Anita Figueras @scifixritter + Follow

T1: A place where patients, medical professionals, caregivers and advocates meet as equals to share information and support #lcsm

Robert West PhD @westd + Follow

#LCSM T3: An intelligence community available 24/7 to serve the needs of #lungcancer patients in ways docs and other HCP resources can't.

Dr. David Tom Cooke @DavidCookeMD + Follow

T2: These chats have led me to change my approach in some situations as a care provider, in a more #patientcentered way #LCSM

Doug @LungDocDoug + Follow

I love that patients talk about advances I read about in current peer-reviewed literature. SoMe accelerates dissemination of science #lcsm

American Lung Assoc. @LungAssociation + Follow

The thoughts shared in these chat help us learn about the needs of #lungcancer pts. #LCSM

Sara Whitlock @jqwhitlock + Follow

#lcsm I hope by learning from each other we can increase number of folks who participate in trials

H. Jack West, MD @JackWestMD + Follow

T3: Over past 2 yrs, have met many ppl participating in #LCSM. Love when you meet someone & feel like you already know them.

Bob Steele @steele_bob + Follow

I get recharged & recommitted with every Lung Cancer Social Media chat session I sit in on. Great & far reaching benefits... #lcsm

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586,225,661 Impressions

197,386 Tweets

21,277 Participants

Tweet Activity on #LCSM