

Social Media Can be Used as a Qualitative Research Tool in Surgical Patient-Centered Outcomes Research

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²#LCSM Chat: Lung Cancer Social Media

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THORACIC SURGERY



Disclosures

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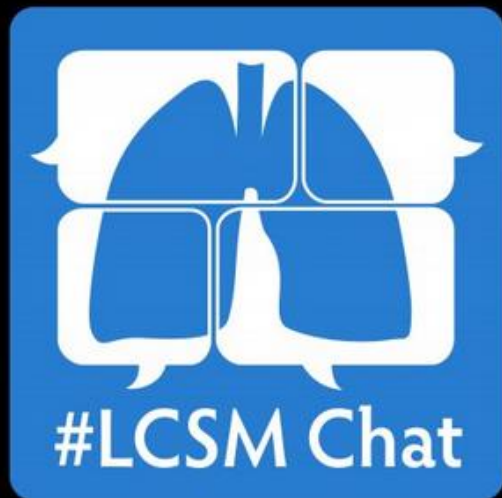
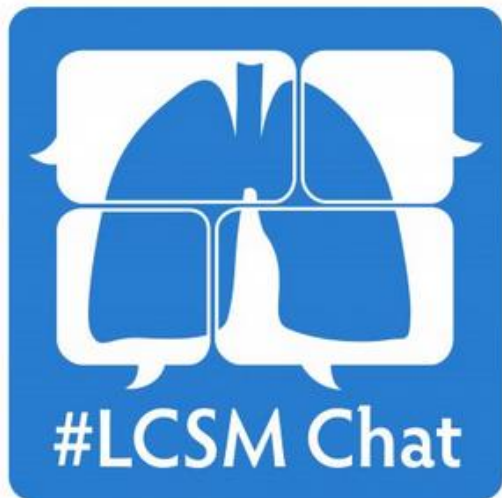
Patient-Centered Outcomes Research Institute
(PCORI) Tier I and II Pipeline to Proposal Award

Financial Relationships:

None (Will reference private companies, i.e.
Twitter and Symplur, but no relationships)

Background

- Focus groups in patient-centered outcomes research may lack diversity in patient demographics and experience, and have associated costs.
- To achieve a diverse study population and obtain outcomes information stakeholder-identified as important (Sii), we evaluated a Twitter based patient-engagement platform as a potential new qualitative surgical research methodology.



[Home](#) [About #LCSM Chat](#) [To Participate in #LCSM Chat](#) [What Is #LCSM?](#) [Schedule and Transcripts](#) [Lung Cancer Resources](#) [#LCAM Lung Cancer Facts](#)

Schedule and Transcripts

#LCSM Chats occur on Twitter every other Thursday at 8 PM Eastern Time (5 PM Pacific). Below is the schedule for past chats and the next few chats in reverse chronological order. Past dates are linked to chat transcripts (transcripts courtesy of Symplur, a website dedicated to following and tracking social media trends in healthcare). Topics are linked to our blog posts about that topic.

[August 27, 2015: TBD](#)

[August 13, 2015: TBD](#)

[July 30, 2015: What's the Role Today of Whole Brain Radiation for Lung Cancer with Brain Metastases?](#)

[July 16, 2015: Happy 2nd Birthday #LCSM Chat!](#)

[July 2, 2015: NO #LCSM CHAT \(have a nice break!\)](#)

Recent Posts

[#LCSM Chat 7/30 8pm ET: What's the Role Today of Whole Brain Radiation for #LungCancer with Brain Metastases?](#)

[#LCSM Chat topic 7/16 at 8pm ET: Happy Second Birthday to Us! NIH invite to #LCSM: join NIH tweekchat on Precision Medicine Initiative 6/30 1pm ET using #PMINetwork hashtag](#)

[#LCSM Chat Topic 6/18: "What I wish I'd known before my #LungCancer treatment."](#)

[#LCSM Chat Topic 6/4 8pm ET: Moving Ahead with Immunotherapy for Lung Cancer--Biomarkers,](#)

<http://lcschat.com/>

Community Stakeholder Partnership: Core Governing Group

David Tom Cooke, MD (@UCD_ChestHealth)

Laronica Conway (@lousianagirl91)

Janet Freeman-Daily (@JFreemanDaily)

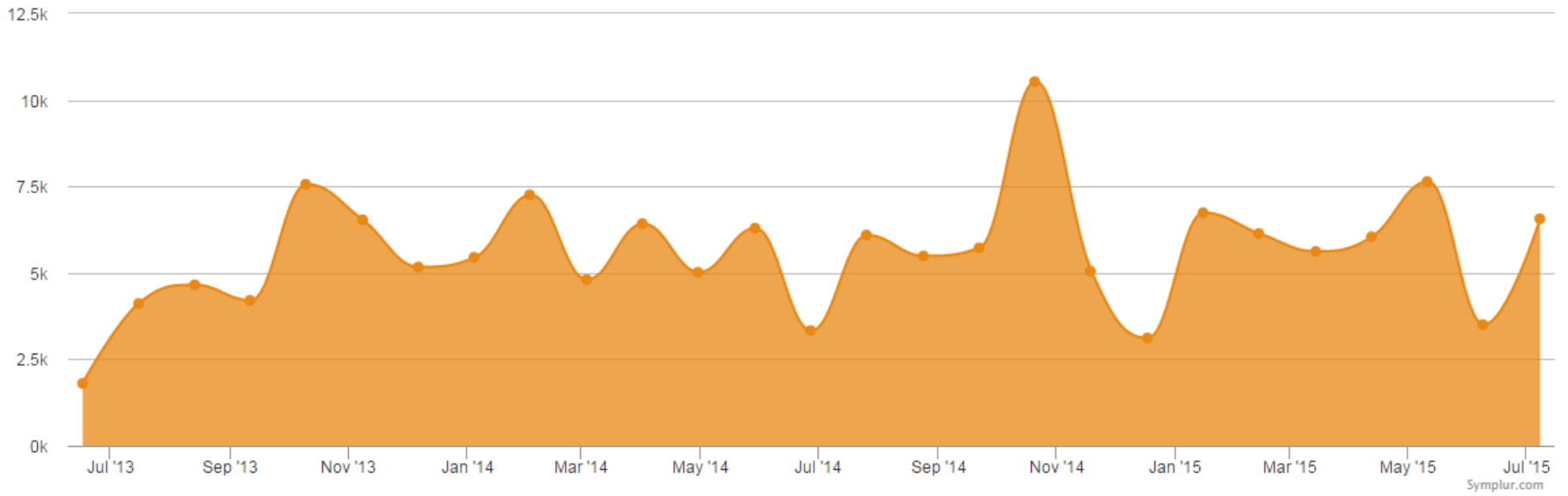
Deana Hendrickson (@LungCancerFaces)

Jack West, MD (@JackWestMD)

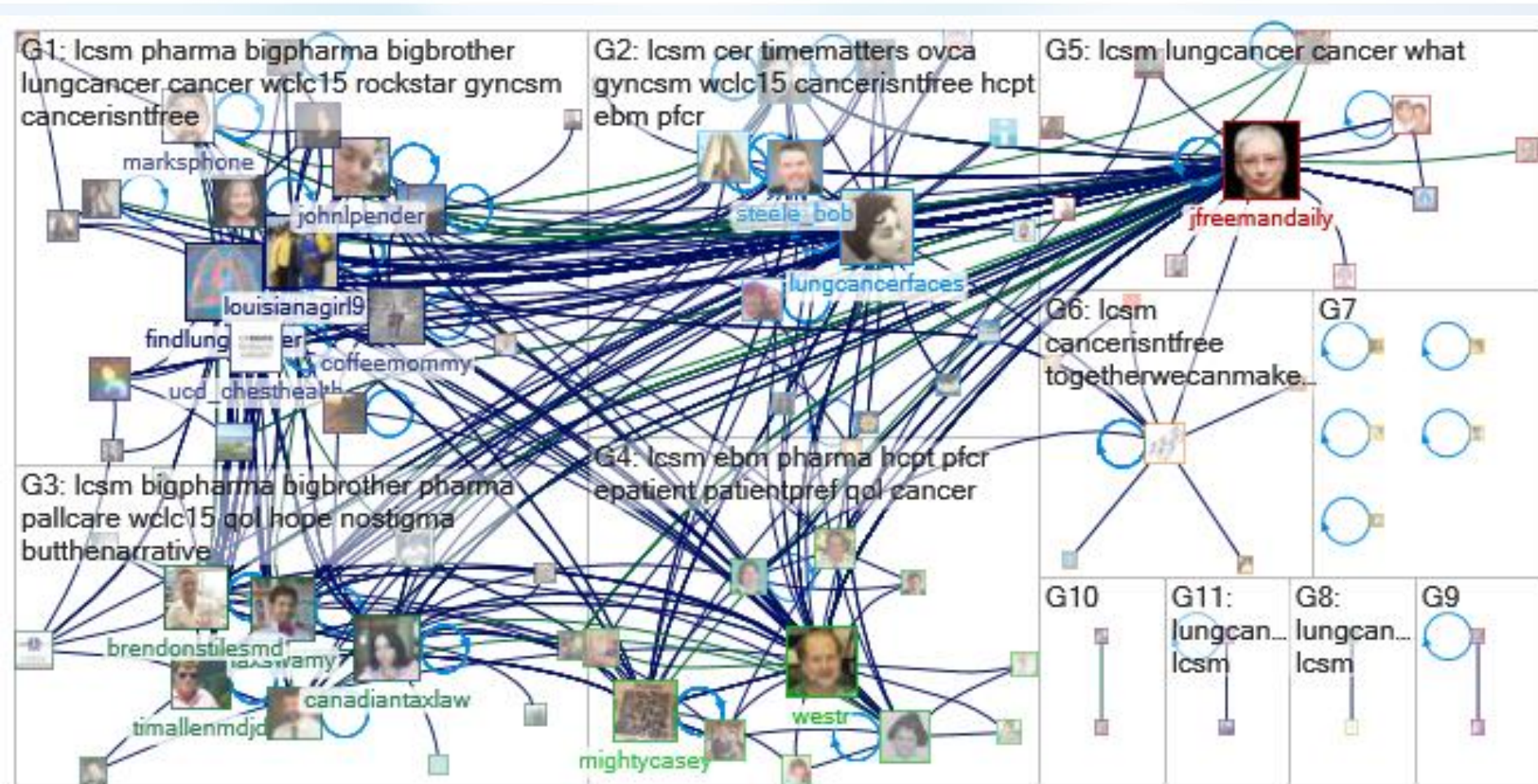
- #LCSM first use June 16, 2013 on Twitter
- Every other Thursday, one-hour tweetchats at 5 PM PT
- Focus: use social media in an innovative manner to educate, develop public support, end the stigma, and facilitate successful treatments for lung cancer
- As of August 5, 2015
 - 16,000 participants, ~151,000 tweets, >421 million impressions

#LCSM

Tweet Activity on #LCSM



Representative #LCSM TweetChat: Edge and Vertex Network Graph



Methods

- We prospectively compared a Tweet Chat with traditional Focus Groups
- Patients status-post lung cancer surgery & stakeholders were engaged through 2 in-person focus groups (**FG**)

In-Person Focus Groups: Post Lung Surgery Patients and Families

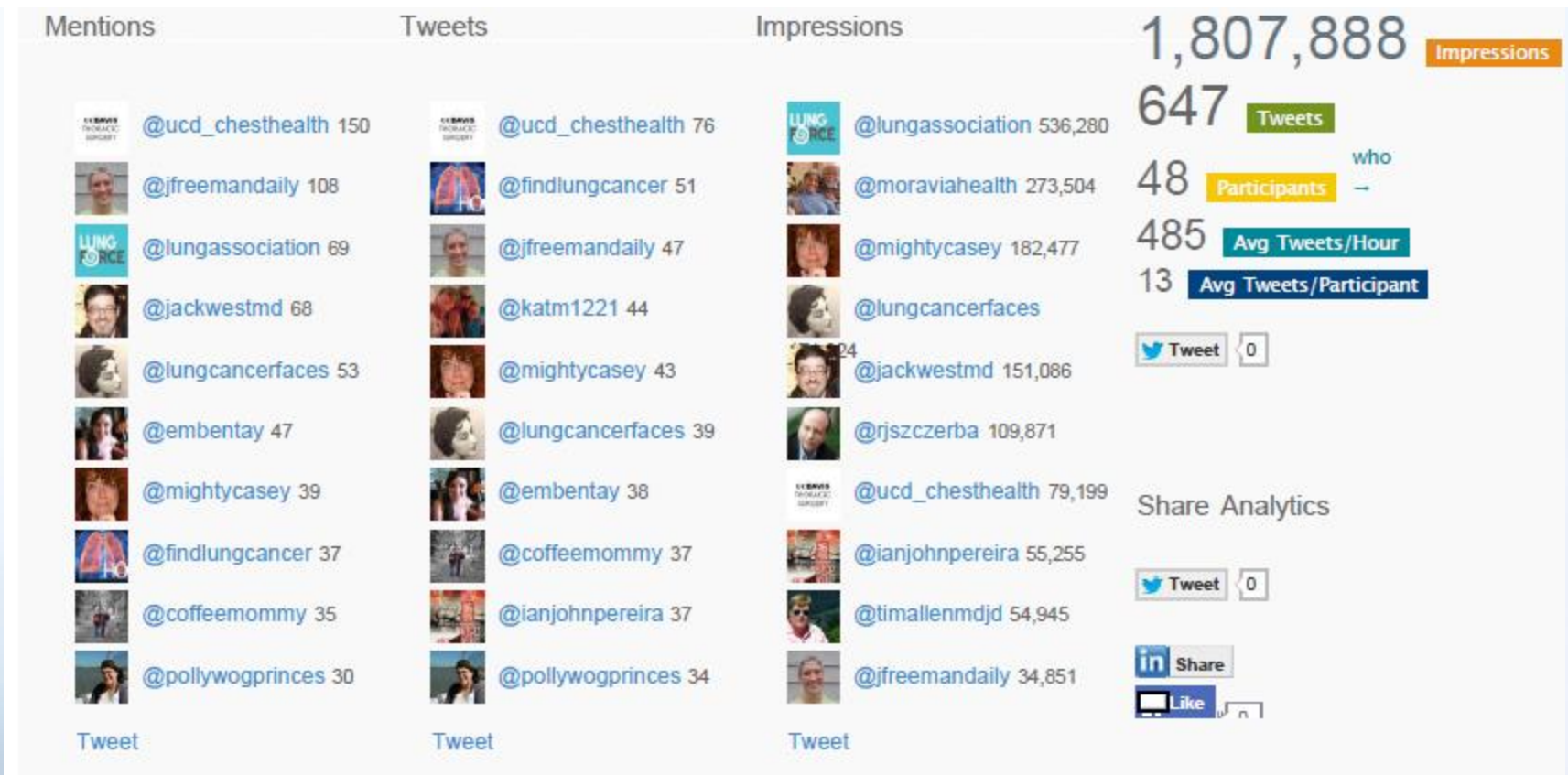


Which lung cancer surgery outcomes are most important to patients & families?

Methods

- We prospectively compared a Tweet Chat with traditional Focus Groups
- Patients status-post lung cancer surgery & stakeholders were engaged through 2 in-person focus groups (**FG**)
- ...and electronically via 1 Twitter “chat” (**TC**) using the social media platform Lung Cancer Social Media (#LCSM)

#LCSM June 19, 2014 Which lung cancer surgery outcomes are most important to patients & families?



Methods

- **FG and the TC Forum addressed the questions:**
 1. What Postoperative Clinical and Functional Outcomes are Most Important to You?
 2. What are Your Views on Communication Between Patients and Families and Physicians?
 3. What was the most beneficial thing to you postoperatively for your well being?

Methods

- We measured **online persona (TC)** and personal information **(FG)** **demographics...**
- ...and performed content analysis of session transcripts **to determine most mentioned patient outcomes self-identified as important (Sii)** by patients and their stake-holders.

Results

	Focus Group n = 22 (%)	Tweet Chat n = 47 (%)
Type of Participant		
Patient	20 (90.9)	10 (21.3)
Family Member	2 (9.1)	5 (10.6)
Clinician/Researcher	N/A	13 (27.7)
Advocate/Other	N/A	8 (17.0)
Medical Center/Org	N/A	11 (23.4)
Sex		
Male	11 (50.0)	9/36 (25.0)
Female	11 (50.0)	23/36 (63.9)
Unknown	N/A	4/36 (11.1)
Race		
White	19 (86.4)	22/36 (55.6)
Non-white	3 (13.6)	5 (13.9)
Black	2	
Asian	1	
Unknown	N/A	9 (25.0)
Costs		
	\$1,434.02	0
<i>Participant Stipend</i>	\$1,100	
<i>Food</i>	\$334.02	

Twitter Chat Content Analysis

1. T1: What post-operative clinical and functional outcomes are most important to you (patients & family) after surgery for lung cancer?
2. T1: What outcomes other than cure of lung cancer? Example, avoiding need for long term oxygen treatment or a stay in a rehab, etc...
3. T1: What unforeseen circumstances affect lung cancer surgery outcomes/goals? For example transportation, expenses, etc...
4. T1: Did Lung Cancer surgery affect other dimensions in your lives?
5. T1: Did you identify key lung cancer surgery outcomes yourself, or discuss with family or other stakeholders?

Themes	Mentions
Pain control	13
Avoiding O2 dependence/Pulmonary function	12
Cancer Free	11
Cost	11
QOL	10
Doctor Availability	7
Help with Treatment Decisions/Decision Tools	7
Perioperative survival	6
Physical therapy	6
Travel	6
Activities of Daily Living	2
Familial Support System	2
Infection	1

Twitter Chat Content Analysis

1. T2 Talk about communication between the patient, family & health care providers after your operation and during your hospital stay. Were there problems. How could the process be improved?
2. T2: Was there communication with your primary care provider &/or oncologist or other referring HCP after surgery?
3. T2: Were you able to get the information you needed after lung cancer surgery?

Themes

Mentions

Clear communication	29	Teach Back - 10
Communication with PCP	11	
Layperson communication/Health literacy	10	
Doctor availability for discussions and updates	6	
Patient feels intimidated	5	
Graphic (picture) communication	3	
Trustworthy source (media) of information	3	

Twitter Chat Content Analysis

1. T3: What changes in lung cancer surgery care process are needed to achieve clinical/functional goals important to patients & family?
2. T3: For example healthcare providers team “huddles” with patient and family, handouts, nurse navigators, etc?
3. T3: If you could choose one thing that was helpful in the after surgery care process, what was it?
4. T3: Are there things that were helpful in managing the physical issues after surgery, & how to add to care process?
5. T3: Was there instruction on how to stay well after surgery, like nutrition, physical activity, stress?

Themes	Mentions
Doctor availability	20
Peer to Peer support	9
Surgery outcomes transparency	4
Follow up coordination	3
Team Huddles with Family/staff	2
Tumor board participation	2

In Person Focus Group Content Analysis

1. What Postoperative Clinical and Functional Outcomes are Most Important to You?



Themes	Mentions
<i>Avoiding O2 dependence/Pulmonary function (Not major theme in in-person focus groups, but important in Twitter Chats)</i>	<i>(12 From Twitter Chats)</i>
Pain control/Management (Both peri/postoperative & longitudinally)	6
HCP communication/Doctor Availability	6
Perioperative survival	6
<i>Physical therapy (Not major theme in in-person focus groups, but important in Twitter Chats)</i>	<i>(6 from Twitter Chats)</i>
Importance of patient participation	5
Perioperative survival	4
QOL/Return to Baseline/Return to Home (Realistic expectations on length of recovery)	4
Pathology anticipation anxiety/Scanxiety	3
Familial Support System/Support systems ("Do you have the support you need?")	3
Acknowledgement, respect and help with Emotions	3
Knowledge of available resources (Cancer center/hospital)	1
Discussion of probabilities and odds in regards to outcomes	1

In Person Focus Group Content Analysis

2. What are Your Views on Communication Between Patients and Families and HCPs [Physicians]?

Themes	Mentions
<i>Clear communication</i>	<i>(29 Teach Back – 10 in Twitter Chats)</i>
<i>Communication with PCP</i> <i>(Not major theme in in-person focus groups, but important in Twitter Chats)</i>	<i>(11 In Twitter Chats)</i>
Stigma of lung cancer	5
Familial Support System/Support systems	
- Patient Advocates/Navigators	
- Navigators important to some but not everyone	
- Must understand lung cancer	3
Have someone with you to hear info	2
Lists FAQ/Video from patient	1

In Person Focus Group Content Analysis

3. What was the Most Beneficial Thing for you Post-operatively to your Well Being?

Themes	Mentions
Encouragement/Family	
Support/Support for Family	4
Exercise Information/Keeping Active	3
Access to my MyChart	2
Dealing with Scanxiety	1
Pain Management	1

Results: Summary

What Postoperative Clinical and Functional Outcomes are Most Important to You?	
TweetChat Sii	In-Person Focus Group Sii
1. Pain control	1. Pain control
2. Breathing without difficulty	2. Clear healthcare provider communication
3. Being cancer free	3. Perioperative survival
What are Your Views on Communication Between Patients and Families and Physicians?	
TweetChat Sii	In-Person Focus Group Sii
1. Clear communication is important	1. Important to discuss stigma of lung cancer
2. Need for health literacy	2. Importance of familial support systems
3. Need for provider availability for follow up discussions	3. Having a family/friend at clinic visit

Sii = stakeholder-identified as important

Summary

- Twitter Chats can provide experiences and opinions from a diverse population of patients and stakeholders
- Low cost qualitative research tool
- Difficult to validate participant demographics
- Inability to control who participates

Conclusions

- Twitter Chats should not replace focus groups
- Can help refine questions to take to focus groups
- Can help review questions and simple problems from patient-centered perspective
- Identify areas for process and quality improvement

Thank You

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lcsmchat.com