Crowd-Sourced Focus Groups on Twitter: 140 Characters of Research Insight

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Abstract

Researchers have traditionally relied on in-person focus groups to test and obtain feedback regarding behavioral and technology-based interventions for specific disease processes. An increasing generation of engaged and connected patients turn to Twitter, a popular microblogging service, to discuss health related topics. Regularly scheduled Twitter-based chats (tweetchats) can potentially function as an additional source of input and information from a diverse, global group of engaged participants. We report the first use of a "tweetchat focus group" to explore data collection issues using this methodology. The speed at which tweetchat conversations occur, coupled with the ability to pursue multiple streams of conversation both in real time and in a delayed fashion, make tweetchat data collection particularly challenging. We discuss important considerations and preparation that should be undertaken by the researchers prior to initiating a tweetchat focus group, consider facilitation challenges and issues of confidentiality.

1. Introduction

Twitter, a popular social media and microblogging service that allows users to post short 140 character messages (tweets) has gained popularity among physicians and patients as a vehicle to connect, discuss and disseminate information. Publicly available Twitter data can identify and predict changing patterns of health treats, including infectious disease, substance abuse and disaster response.[2,3,10] Social media outlets like Twitter are also increasingly used by connected patients (e-patients), to engage with each other and with health care providers.[8,12,14]

Healthcare oriented chat groups on Twitter (aka tweetchats) have emerged as models to connect physicians, patients and other stakeholders around specific disease states.[1] Multiple regularly scheduled health care oriented tweetchats exist centered around a range of topics, form specific disease states (c.f. #lcsm—lung cancer social media, #dwd—dying with dignity) to health care infrastructure and leadership (c.f. #hcldr—healthcare leaders, #bioethx—bioethics, #hcsm—healthcare communications and social media). By aggregating tweets from regularly scheduled tweetchats using hashtags (#), users can respond to structured questions posed by tweetchat moderators in real time, and/or read compiled transcripts.

Traditionally, formative health intervention research relies on qualitative data collected via focus group sessions or individual interviews.[13] Twitter is an attractive platform to access and gather formative health attitudes and beliefs from a wide variety of individuals. Marketing researchers have leveraged Twitter to gather individual opinions on advertisements and increase engagement with potential users.[9] No data exist on techniques to analyze or gather qualitative data through Twitter. In this study, we explored whether and how tweetchats can be a supplement or an alternative to local focus groups. Tweet chats have the potential advantage of reaching larger groups of diverse participants with variable experiences. Tweetchat focus groups may provide an opportunity for researchers to receive directed feedback regarding health interventions from a diverse and geographically disseminated group of users. While there are recommended guidelines for conducting and analyzing qualitative focus groups to refine behavioral interventions, little experience exists in translating relevant moderating techniques into global

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tweetchat-based data collection.[4,6,7,13] In this paper, we describe the methods of what is, to our knowledge, the first tweetchat focus group. We also describe the adaptation of traditional qualitative analytical techniques to the analysis of tweetchat focus group results, and technical challenges that face researchers who seek to conduct tweetchat focus groups.

2. Materials and Methods

We partnered with a weekly tweetchat, healthcare communications & social media (known as #hcsm) to create a pilot focus group session.[5] #hcsm is a 7-year-old weekly tweetchat that attracts several dozen participants each week in a 60 minute chat to discuss various topics related to healthcare's intersection with social media (Figure 1). During a standard #hcsm tweetchat, the #hcsm moderator account tweets out three related "topics" at approximately fifteen minute intervals for participants to discuss. Topics are created by the #hcsm moderator or submitted by users the week prior to the tweetchat. This format, first used by #hcsm, is now standard for most healthcare-related tweetchats.

For this pilot tweetchat focus group, we designed a special session focusing on the overarching perceptions of and facilitators/barriers to a formal research tweetchat. Our study was deemed exempt by one of our hospital's institutional review board (IRB), and approved by the other hospital's IRB.

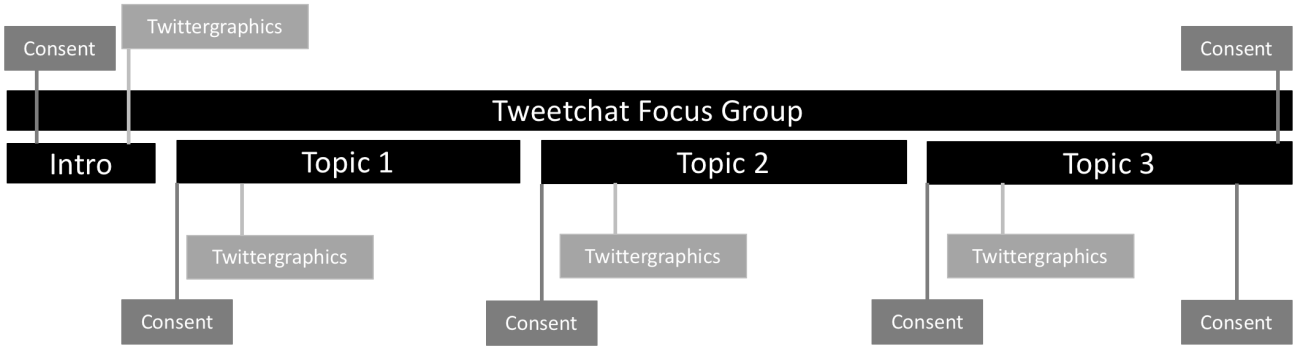
2.1. Topic selection.

Concepts for the tweetchat were initially developed in conjunction with the #hcsm moderator, and piloted among the study group. Our goal was to demonstrate the principles of tweetchat focus group design, facilitation and analysis with a conversation regarding the Twitter based research process. From these pilot sessions, we developed three topics (T1-T3) which the #hcsm moderator refined and condensed to fit the 140-character limit of composed tweets, as well as the style of the #hcsm tweetchat (Table 2).

2.1. Participant recruitment.

We developed structured tweets for the tweetchat focus group in order to describe the study and notify #hcsm participants of the study (Appendix 1). These pre-tweets contained links to the #hcsm blog where a standardized blog post described the purpose, risks, and benefits of the study, the waiver of informed consent, and options for #hcsm users to opt out of the study, both before and after the weekly tweetchat.

These pre-composed advertisement tweets were posted by the official #hcsm Twitter account (@HealthSocMed) after the #hcsm chat the week prior to our tweetchat focus group, and approximately every other day from our personal Twitter accounts (@meganranney, @peterrchai, @toxinnewengland, @rklrosen, @danamlewis) on Twitter at regular intervals for the week prior to the scheduled session of #hcsm. We have a combined 46,389 followers on Twitter, a large majority of whom participates in health care related tweetchats. The official #hcsm account (@HealthSocMed) has 31,800 followers. We were available through Twitter-based direct messaging



Consent: Please note your tweets in #hcsm tonight may be used in a research study. To opt out & for more details, read here: (LINK)
Twittergraphics: If you're joining us for #hcsm tonight, let us know a little about yourself: (LINK)
Topic 1: What is difference in researchers using tweets from tweetchat for research; vs creating a tweetchat *for* research purposes? #hcsm
Topic 2: Would you be comfortable participating in a tweetchat for health research? What would you be comfortable sharing vs. not? #hcsm
Topic 3: Twitter=public; research=bound by confidentiality. How do these concepts impact opportunities for research in tweetchats? #hcsm

Figure 1: Overall structure of tweetchat focus group.

throughout the study for potential participants with specific questions.

2.2. Conducting tweetchat focus groups.

The tweetchat focus group was conducting after a week of general recruitment through tweets composed from the #hcsm account. Structured tweets introducing the tweetchat, reminding users that this session of #hcsm would be analysed for our study, and methods for opting out of the study were tweeted both at the start of the tweetchat and after every major topic was introduced through the official tweetchat account (@HealthSocMed) (Table 1).

Structured tweets introducing tweetchat focus group and reminding participants of the study in sequential order (from the @HealthSocMed account):

- Welcome to (#hcsm) healthcare communications & social media. If you're joining tonight, please introduce yourself! (@danamlewis moderating)
- We will assume all tweets within #hcsm during following hour are your own & not those of your employers (unless specifically declared).
- Please note your tweets in #hcsm tonight may be used in a research study. To opt out & for more details, read here: (LINK)
- Welcome, everyone, to #hcsm! Special hi to any first-timers joining tonight :), and of course our friendly lurkers.
- We'll get started with topic 1 (T1) in just a few minutes. Remember if you jump in to #hcsm later to introduce yourself!
- Again, a reminder that your tweets from tonight's #hcsm may be used in research; but you can opt out. Details: (LINK)

Table 1: Introductory tweets to the tweetchat focus group from @healthsocmed.

Three topics were tweeted through the #hcsm account and tweetchat participants were discussed each topic for approximately 15 minutes at which time a new topic was tweeted. Due to the nature of tweetchats, where staying on topic is encouraged but not enforceable, participants had the option of continuing to discuss previous topics or the current tweeted topic. Tweets containing a link to an optional secure, online survey collecting demographics was provided to tweetchat participants prior and just after each topic was tweeted (Table 2).

Topic Tweets from @HealthSocMed:
TOPIC 1: What is difference in researchers using tweets from tweetchat for research; vs creating a tweetchat *for* research purposes? #hcsm
TOPIC 2: Would you be comfortable participating in a tweetchat for health research? What would you be comfortable sharing vs. not? #hcsm
TOPIC 3: Twitter=public; research=bound by confidentiality. How do these concepts impact opportunities for research in tweetchats? #hcsm

Tweet notifying tweetchat participants of the study:
Please note your tweets in #hcsm tonight may be used in a research study. To opt out & for more details, read here: (LINK)

Tweet asking study participants to complete a survey for demographics:
If you're joining us for #hcsm tonight, let us know a little about yourself: (LINK)

Table 2: Composed tweets of topics 1-3 (T1-3), tweets notifying tweetchat participants of the study, and tweets asking for participant demographics.

The regular #hcsm facilitator/moderator, co-author Dana Lewis, moderated the tweetchat as she would a regular HCSM group from the @HealthSocMed account. However, the topics for the chat were on the topic of using Twitter for research focus groups. The specific topics were suggested by the research team and finalized in partnership with Lewis so that they would be formatted and presented in a manner that would be discussable by all stakeholder groups (patients, providers, etc.) in the conversation. Co-authors were present and participated in the tweetchat only to guide or redirect the discussion as needed.

2.3.Tweetchat aggregation and analysis

Tweets occurring during the scheduled hour of the tweetchat were compiled and downloaded verbatim, using an online, open-source hashtag aggregator (Symplur Analytics, Upland, CA). Transcripts were scrubbed of identifiers (participant Twitter handle, timestamps, participant names, and location). Tweets were ordered to reflect ongoing conversation "threads" between #hcsm participants. Retweets (tweets re-posted by participants) were removed from the transcript. We accessed #hcsm participants' public Twitter profiles in order to gather Twitter-based demographics (Twittergraphics).

We adapted the technique of applied thematic content analysis to interpret the tweetchat focus group,

and adhered as closely as we could to the consolidated criteria for reporting qualitative research (COREQ).[11] Codes were developed both deductively (based on the *a priori* tweetchat questions) and inductively (based on themes that emerged from the data) Transcripts were read independently by three team members, a list of inductive codes were developed, and tweets were then assigned specific thematic codes by each investigator. After coding, coded tweets were read in aggregate and discussed by the group. We independently coded tweetchat focus group transcripts and compared codes to ensure inter-rater reliability.

3. Results

A total of 29 unique Twitter users [excluding moderators] participated in the tweetchat focus group (TABLE 3). Together, the tweetchat generated 652 discrete tweets.

Male	54% (N=13)
Female	31% (N=11)
Not Reported	14% (N=5)
Primary role	
Physician	28% (N=10)
Patient	17% (N=6)
Organization	8% (N=3)
Healthcare Affiliate	20% (N=7)
Other	14% (N=5)

Table 3: Twittergraphics of Tweetchat focus group participants

3.1. Moderation techniques

While not traditional tweetchat moderators, we were able to function as more traditional focus group facilitators during the tweetchat to guide the discussion as needed.

Facilitator guiding discussion (A):

Participant	Tweet
Participant 1	A2. I am selectively open about my lived experiences. If researchers want to know more, DM in private is A LOT better for me! #hcsm
@peterrchai	Participant 1, so would you be more open if there were a private tweet chat aimed at a specific topic? #hcsm

Facilitator redirecting discussion (B):

Participant	Tweet
Participant 3	T2: Understand your patient's motivation to participate in research first rather than moving to another channel. #hcsm
@meganranney	Indeed. What motivations have you heard (or had) re: research? altruism? wanting a cure? something else? #hcsm

Table 4: Sample tweet from a co-author (@peterrchai) guiding discussion (A), and redirecting discussion (@meganranney) (B).

3.2. Introduction.

The first 10 minutes of the tweetchat focus group served to introduce tweetchat participants to each other and welcome them to #hcsm. As most tweetchat participants knew each other from prior participation of #hcsm, this section consisted of social tweets akin to interactions among focus group participants prior to the start of a focus group (Table 5). Most of the tweets in the introduction served to establish social relationships between tweetchat participants. Participants responded positively to the concept of a tweetchat focus group ("Ohhh—this is going to be fun! Tweetchats for research is a great idea!"/ "Will participants in this receive a copy of the report it engenders? That would be cool and a fair trade").

Participant	**Tweet**
Participant 1	Hi everyone! Looking forward to tonight's chat #hcsm
Participant 2	@ Participant 1, Hi! Welcome to the chat this morning #hcsm
Participant 3	@ Participant 1 and 2, Any chance that hashtag stands for "healthcare sarcasm"? #hcsm
Participant 2	@ Participant 1 and 3, ☺ #hcsm

Table 5: Sample social/introductory tweets during #hcsm introduction.

3.2. Topic 1: What is difference in researchers using tweets from tweetchat for research; vs creating a tweetchat *for* research purposes?

The first topic centered around the use of a tweetchat as a focus group in comparison to researchers mining searchable tweets on Twitter for their own research. Major themes in this section included the reputation and authenticity of study investigators, and the ethics of using participants tweets for research purposes (Table 6). Multiple tweetchat participants echoed concerns

with the ethics of using a tweetchat for the purposes of a researcher in comparison to those of the participants.

Participant	Tweet	Theme
1	For me to want to participate in tweetchat for research, need to understand how this will benefit patients rather than researchers.	Ethics
2	When your tweetchat is for research purposes, you might encourage ppl (people) to act in an unnatural fashion. They might tweet to the test.	Authenticity
3	I perceive investigators creating a Twitter chat for research purposes as transparent.	Believable

Table 6: Sample tweets during topic 1.

3.3. Topic 2: Would you be comfortable participating in a tweetchat for health research? What would you be comfortable sharing vs. not?

The second topic focused on the use of a tweetchat for health research. Some participants were wary of sharing personal health details on a tweetchat, but described alternatives of direct messaging on Twitter, or private Facebook groups as methods in which individuals with similar disease states could gather and discuss their health (Table 7). Participants reported an expectation that their privacy be protected even in the public arena of a tweetchat. Participants that were motivated to share their health information in a tweetchat reported having previously participated in tweetchats, or having passionate feelings towards the use of social media in health care.

Participant	Tweet	Theme
1	Consumers/patients not likely to share intimate details in public forum. Also HIPAA implications.	Privacy
2	I wouldn't say one damn thing without you asking consent and warning each person.	Privacy
3	I am selectively open about my lived experiences. If researchers want to know more, DM (direct messaging) in private is A LOT better for me!	Privacy

Table 7: Sample tweets during topic 2.

3.4. Topic 3: Twitter=public; research=bound by confidentiality. How do these concepts impact opportunities for research in tweetchats?

The third topic explored the translation of confidentiality in research to tweetchats. In an inherently public forum (Twitter), we wanted to understand how participants viewed protections of identity in Twitter based focus groups. Participants described the need to protect sensitive information on Twitter, while others recognized that true privacy found in protection of participants during in-person focus groups was unlikely to occur in a tweetchat focus group (Table 8).

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Participant	Tweet	Theme
1	People will perceive Twitter as a more public forum than it really is. That said, privacy of sensitive data must be assured.	Privacy
2	I'm being seen by a research team for XXX. I signed away some confidentiality to be in the program. Same could be done.	Protection in Research
3	Research like medicine will start to learn that humility goes a long way in collaboration.	Authenticity

4	Researchers reveal their medical history before asking others to do the same. Begin w/ public gesture of vulnerability.	Authenticity

Table 8: Sample tweets during topic 3.

4. Discussion

Our data shows that Twitters users are interested in online tweetchat focus groups. We were able to effectively recruit participants to join our tweetchat focus group by partnering with an existing tweetchat. Earning trust of participants through participation in previous tweetchats helps establish a "Twitter rapport" that may improve researchers' reputations prior to conducting a tweetchat focus group.

Our respective IRBs had conflicting opinions regarding the use of a tweetchat as a research focus group. While Twitter is inherently a public medium with tweets easily discovered through conventional search engines, one IRB was concerned regarding the protection of participants despite implied consent from the act of composing tweets. We note that individuals who wish to protect their privacy could have enabled the privacy feature within Twitter to prevent us from aggregating their tweets. Additionally, we had difficulty reconciling the participation of children (users <18 years old) in the tweetchat. While the topic and nature of #hcsm does not tend to attract individuals under the age of 18, the ability to remain anonymous on Twitter prevents us from truly confirming the age of participants. Ultimately, our IRBs recognized the inherent limitations of conducting traditional informed consent through Twitter. Despite the implied consent in this study simply from tweeting during #hcsm, we provided participants with an IRB-approved factsheet that described the study, and provided our contact information for individuals who wanted to opt out of the study. Despite this, we did not receive any requests for participants to opt out of the study during or after the chat.

Deidentifying the tweetchat focus group transcript and protecting the privacy of participants was difficult. Unlike traditional focus groups, there are an entirely different group of identifiers on Twitter: time stamps on tweets, location of tweets, Twitter handles and names of participants in composed tweets. Scrubbing tweetchat focus groups of these identifiers required multiple readings of the tweetchat transcript. We discussed our intention to deidentify the tweetchat during the focus group and we received multiple tweets indicating that participants were willing to be identified as the composers of tweets. Participants may have been more open about their willingness to share their identities and tweets due to the nature of our focus group, but confidentiality of tweets likely would have changed if our topic were different.

We found that Tweetchat focus groups differ from in person focus groups due to the fluidity of participants, multiple streams of simultaneous conversation, and speed of the focus group. Recognizing these factors and preparing for them prior to the initiation of a tweetchat focus group should be a goal of researchers seeking to conduct Twitter-based focus groups.

Most participants joined the tweetchat during the initial introduction period, but due to the open nature of tweetchats, participants could leave and return at any time during the tweetchat. We also found new tweetchat participants entering the chat at later periods. We tried to obtain demographics on tweetchat participants through a simple online survey that was tweeted to #hcsm participants with the introduction of each topic, but we only received 6 responses. Instead, we turned to Twitter based demographics (Twittergraphics) which were gathered from Twitter profiles of users participating in #hcsm.

During the tweetchat focus group, we sought to act as faciliators following the model of in person focus groups, but quickly realized that facilitating a tweetchat focus group was substantially different from in person focus groups. First, the #hcsm tweetchat already has an established moderator and participants are experienced with this type of moderated session. Additionally, at any time during the tweetchat, there were multiple simultaneous streams of conversation and each of these could spin off comments both related and unrelated to the initial conversation. Following these streams of conversation proved difficult as tweets are displayed in chronological order. Facilitating a tweetchat with a solo researcher as would be done an in-person focus group would have been impossible. Decoding and understanding streams of conversation in real-time required facilitators to click backwards in time in order to follow a thread of tweets, a time consuming process that would frequently leave the facilitator behind the conversation in the overall tweetchat focus group. Tracking the pace and direction of conversation during a tweetchat required multiple facilitators, in addition to the tweetchat moderator.

Additionally, unlike traditional focus groups, comments and discussions made in the beginning of the tweetchat may be revisited by participants at any time during the tweetchat. Therefore, traditional facilitation models do not apply to tweetchat groups. While key topics can be raised for participant feedback, clarifying questions and probing for more in-depth understanding of a comment is not always possible. This lack of

temporal adherence to topics also presented difficulty during analysis, as it was not always possible to identify which main topic a participant was discussing.

In contrast to traditional focus groups or interviews, our tweet chat did not produce extensive interaction between participants. There was the natural back-and-forth of forwarding and responding that is common part of Twitter interaction, but this does not provide much opportunity for participants to compare, contrast or explain their opinions in detail. Tweetchatting does provide ample opportunity for people to give brief opinions, but it does not allow either detailed description of participant experiences or reasons for these opinions.

Based on our tweetchat data collection and analysis experiences in this study, we do think that tweetchats are a viable adjunct to traditional focus groups and interviews. We do not think, however, that they are likely to replace them, especially in research contexts where detailed personal experiences or the understanding of meaning making behind individual opinions or behaviors is needed.

In our future research we hope to further explore the commonly used 'like' function in tweet chats. In conventional focus groups, there are research protocols which track nodding and other nonverbal agreement and disagreement in order to understand participant reactions to one another's opinions. The Twitter 'like' function effectively tracks which participants like other participants comments. We'd like to better understand for Twitter-based research: what exactly does 'like' mean. Is it tantamount to agreement? Does it simply mean 'take a look at this'? This function could be effectively used in seeking feedback for a variety of behavioral health intervention, but better understanding and coding of its use is needed. The same considerations and questions are needed for understanding and coding the use of the "retweet" function.

This study had several limitations. First, we conducted our focus group leveraging a tweetchat with an established record and reputation; participation in de novo tweetchats may be different depending on the "Twitter reputation" of researchers and the moderator. Second, our tweetchat focus group was centered about conducting research on Twitter; variable participation may occur depending on the topic researchers are studying. Third, we had previously been members of #hcsm, and participated in tweetchats in the past. This (in addition to the chat moderator being a co-author and researcher) may have increased the acceptability of participants in our tweetchat focus group, and contributed to the number of participants in our tweetchat focus group.

5. Conclusion

Tweetchat focus groups are a useful adjunct to traditional in person focus groups. Although tweetchat focus groups cannot provide the detailed information that is collected via in person interviews and focus groups, they are an excellent venue for collecting broad feedback from a diverse group of engaged participants. Conducting a tweetchat focus group requires careful coordination with a moderator and planning of topics and multiple facilitators to track, facilitate and redirect discussion. Researchers who seek to conduct tweetchat focus groups should understand the limitations of the types of data obtained through tweetchat focus groups and recognize the unique issues with privacy and consent on Twitter.

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