Proceedings of a Symposium

USING VIRTUAL PLATFORMS TO ENGAGE STAKEHOLDERS IN RESEARCH

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CONTENTS

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Executive Summary

The Data Science to Patient Value (D2V) Initiative at the University of Colorado Anschutz Medical Campus held a symposium in March 2018 entitled, "Using virtual platforms to engage stakeholders in research." The purpose of the symposium was to describe the characteristics, strengths, and weaknesses of using virtual platforms, such as social media and Internet-based technologies, for developing relationships with those who are responsible for, or affected by, health research. The intended audience was clinical and translational health researchers interested in engaging patients, practitioners, and other stakeholders in health and health care in the design, conduct, and dissemination of research.

Topics Covered

The symposium's speakers, who were from the University of Colorado and across the United States, explored with the audience the **ethics and principles** underlying stakeholder engagement in research as well as the **methods and tools** that could be used to engage stakeholders in research using virtual platforms.

Discussion of the ethics and principles centered on whether concepts and issues foundational to traditional in-person engagement do or should apply to the virtual setting (see page 24). Protecting privacy and confidentiality, ensuring the voluntariness of participation, empowering individuals to contribute, and promoting representativeness of stakeholders and the inclusion of vulnerable groups, for example, all seem relevant to virtual settings, but perhaps in different ways when compared to in person ones.

Speakers shared different methods and tools, such as storytelling (page 13), group facilitation, and brainstorming techniques (pages 12 and 35), which could be extended to virtual settings. In addition, virtual platforms can be used not only to engage research participants but also to conduct research itself (e.g., via recruitment and data collection). Whether some methods or tools could be uniquely suited to virtual settings, whereas others might be inappropriate or even manipulative, was an unresolved issue.

Insights for the Future of Virtual Engagement

Using virtual platforms to engage various stakeholders in health research appears to be at a crossroads (see page 45). On the one hand, virtual platforms hold the potential to reduce some barriers to effective engagement, including time, expense, and geographic distance. This holds the promise of engaging more people in research. On the other hand, skepticism exists regarding whether virtual platforms can be adequately aligned

Executive Summary (cont.)

with the core principles of authentic, bidirectional, longitudinal engagement. To some, virtual platforms may complement – but can never replace – traditional in-person engagement methods. If a middle ground is possible, it can perhaps be reached by further analysis of the ethical foundations and principles of engagement, by ongoing innovation in virtual methods to overcome their potential limitations, and by the collection of evidence comparing in person and virtual methods.

Introduction and Overview

SYMPOSIUM OBJECTIVES

The purpose of this symposium was to describe the characteristics, strengths, and weaknesses of using virtual platforms for engaging stakeholders in health research. The 1-day symposium convened speakers with expertise in stakeholder engagement, the use of virtual platforms in research, virtual platform development, data analysis, and ethics on March 19, 2018 at the University of Colorado Anschutz Medical Campus in Aurora, Colorado. Attending the symposium were 74 individuals, comprised mostly of researchers at the University of Colorado Anschutz Medical Campus in addition to attendees from Kaiser Permanente, Denver Health, the Colorado Department of Public Health and Environment, and the US Department of Veterans Affairs.

Speaker topics included

- regulatory and ethical issues in the use of virtual platforms for stakeholder engagement;

- issues in the collection, validation, and analysis of data obtained via virtual platforms;

- weaving traditional engagement considerations into the virtual arena; and

- current projects that have used virtual platforms to engage stakeholders, or projects that will soon expand to using virtual platforms for the purposes of stakeholder engagement.

DEFINITIONS AND BACKGROUND ON THE SYMPOSIUM

The Stakeholder Engagement Core at the CU Data Science to Patient Value (D2V) Initiative has developed a working definition of "stakeholder engagement" that builds on the definitions provided by Concannon et al. in their paper A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research.[1] This paper provides the following definitions:

- **Stakeholder:** *An individual or group who is responsible for or affected by health- and healthcare-related decisions that can be informed by research evidence.* Following the Patient-Centered Outcomes Research Institute, PCORI, the D2V initiative specifically notes that health research stakeholders include groups like payers, practitioners and policy makers as well as patients, families and communities.

- **Engagement:** *A bi-directional relationship between the stakeholder and researcher that results in informed decision-making about the selection, conduct, and use of research.* Bi- or multi-directionality is an important feature of the D2V definition, since some methods of communication and marketing, though valuable, do not comprise engagement because they are information delivery mechanisms that do not include opportunities for meaningful reciprocal relationships to form and to generate new insights for all parties.

Additionally, the D2V initiative has defined engagement as a **longitudinal** activity. That is, stakeholder engagement means engaging at least some of the same stakeholders more than once during the engagement period (e.g., from planning to dissemination/implementation or throughout one or more phases of a study).

With regard to virtual methods of stakeholder engagement, a growing volume of research appears to be including virtual components in studies (for participant recruitment, data collection, etc.),[2] but the utility of virtual platforms for the purposes of conducting stakeholder-engaged research, as defined above, is not yet well-explored in the literature. For the purposes of this symposium, we defined **Virtual Platform** as *a system that allows users to access information and/or communicate via the internet (e.g. social media such as Facebook and Twitter, patient portals, websites and chat platforms such as Basecamp).*

In April and May of 2017, researchers from the D2V Engagement Core held interviews about stakeholder engagement with D2V's pilot project awardees. (D2V funds 1-year grants for researchers who have projects that contribute directly to our program's mission to bridge the disciplines of data science and health outcomes research.) During these interviews with pilot project awardees, we found that stakeholder-engagement—as defined above—is not something researchers are necessarily comfortable with, budget for, or know how to do. Since some have proposed that using virtual platforms for engagement might reduce budgetary and knowledge barriers to stakeholder engagement,[3] the topic for this symposium was selected based on the perceived need on our campus for better information on how to use these platforms most effectively and ethically.

As our team began the planning process for the symposium, we found that many researchers are turning to virtual platforms as components of their studies,[2] yet it took our team considerable time to identify researchers able and willing to discuss the pros and cons of using virtual platforms for the purposes of conducting stakeholder-engaged research. It appears that formal studies on the use of virtual platforms to engage stakeholders are uncommon today, despite the widespread recognition that certain audiences may prefer communications via virtual platforms[4] and that other audiences are becoming increasingly comfortable with virtual communications.[5] Given shifting trends

toward the use of virtual communications[6] and the relative dearth of existing research in this domain, we came to realize that our campus symposium might hold appeal more broadly. We therefore entered the symposium with the aim of exploring what virtual platforms can add to the literature on in-person stakeholder engagement efforts, as well as identifying whether there are some crucial components of in-person engagement that virtual engagement, in its current forms, might be unable to replace.

Matthew Wynia, MD, MPH, Opening Remarks

Matthew Wynia, MD, MPH, Director of the Center for Bioethics and Humanities at the University of Colorado Anschutz Medical Campus and Lead of D2V's Stakeholder Engagement & Governance Core, began the symposium with an introduction to the importance of stakeholder engagement in research while tying in a discussion of the emerging trend of using virtual platforms in research.

FIGURE 0-1

Reasons for Focusing on Stakeholder Engagement, and How Virtual Platforms may be of Use

Why focus on stakeholder engagement?

Complex ethical and policy issues are common in health research, *as evidenced by too many high-profile missteps;*

- Virtual platforms could provide an effective means to address them, if done right.

Increasing demand for community-engaged research from funders, *but relatively little guidance on what this means or how to do it;* and

- Also relatively little funding, and virtual platforms can be efficient.

Increasing need for researchers to engage other stakeholders too, *if we want our work to have real-world impact.*

- Virtual platforms are ubiquitous and for many young people they ARE the real world, so we'd better learn to use them well.

Learning how to do effective stakeholder engagement is important, and major governmental funding agencies (e.g., PCORI, the National Institutes of Health, and the Agency for Healthcare Research and Quality) are increasingly expecting stakeholder engagement to be included in the research process. Yet, little guidance exists about what comprises excellent stakeholder engagement. Additionally, the institutional infrastructure necessary to support engagement activities (virtual or otherwise) is not yet well described in the literature.[7] In particular, there is still much to be learned about the most effective ways of engaging a *variety* of stakeholders, including those identified by PCORI;[8,9] patients, clinicians, researchers, purchasers, payers, industry, hospitals and health systems, policy makers, and training institutions. Nor is there a large literature on the most effective methods to achieve specific purposes of engagement.

Virtual platforms hold the potential to reduce barriers to engagement: they can be relatively inexpensive to use, can connect individuals who span wide geographic areas, and are increasingly being used for a wide variety of purposes amongst individuals in some demographic groups. However, whether such platforms are able to produce meaningful and valuable engagement for purposes related to health research requires further exploration. There are reasons to question whether virtual platforms can generate *meaningful* engagement – in particular, Wynia noted that a portion of online engagement is of the 'echo chamber' type, which generates positive feelings among like-minded individuals, but no new insights. Another portion comprises 'flame war'-type interactions, which rapidly degenerate into personal vitriol that is similarly unhelpful in generating novel insights. The relative proportion of virtual interactions that can be labeled as useful or meaningful engagement is, perhaps, relatively small, as shown in the cartoon diagram on the slide below.

Virtual platforms hold the potential to reduce barriers to engagement.

However, whether such platforms are able to produce meaningful and valuable engagement for purposes related to health research requires further exploration.

FIGURE 0-2
Flame Wars versus Echo Chambers

VIRTUAL PLATFORMS, MEANINGFUL ENGAGEMENT

- Virtual platforms dramatically reduce numerous barriers to engagement, but...

- Can virtual platforms really produce valuable engagement?

POLITICAL DISCUSSION ON FACEBOOK

LOTS OF LIKES

THE VALLEY OF OPEN-MINDEDNESS

LOTS OF COMMENTS

ECHO CHAMBERS

FLAME WARS
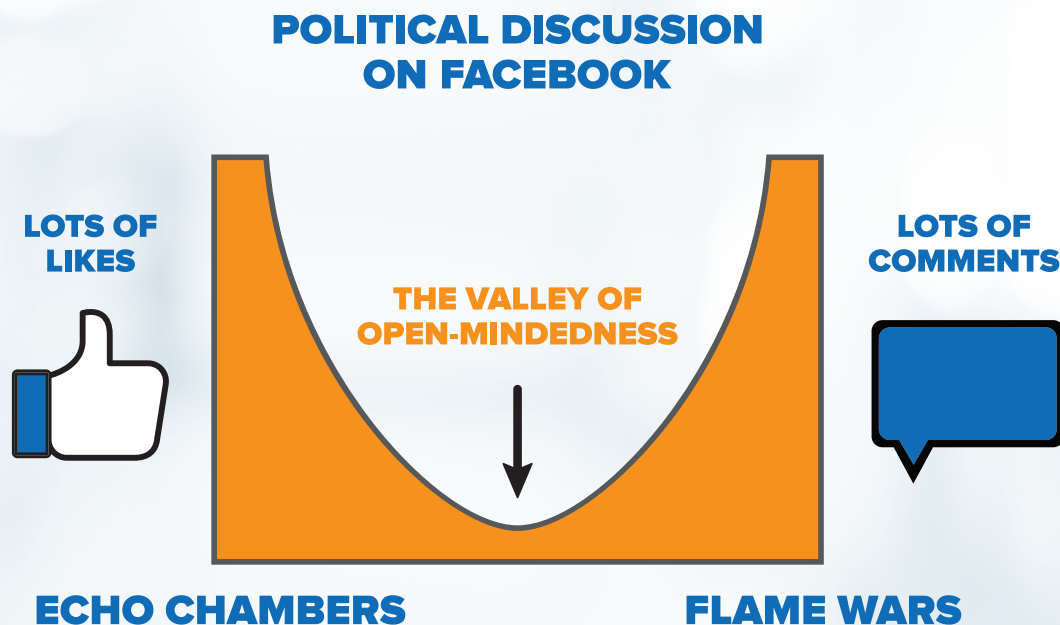
The fundamental cause of the trouble is that in the modern world, the stupid are cocksure while the intelligent are full of doubt.

Bertrand Russell, 1933
The Triumph of Stupidity

Use of Virtual Platforms to Engage Stakeholders

The first talk during this session was by Kim Kimminau, PhD, Associate Professor at the University of Kansas Medical Center. This presentation discussed the value of Liberating Structures to engage stakeholders, both in person, but also via virtual platforms. Kathleen McTigue, MD, MPH, MS, Associate Professor of Medicine, Epidemiology, & Clinical/Translational Science at the University of Pittsburgh then described the MyPaTh Story Booth Project, focusing on the value of virtual storytelling to facilitate and increase stakeholder engagement.

HIGHLIGHTS AND MAIN POINTS FROM THE SESSION

- Storytelling—whether conducted in person or virtually—can be a great way of engaging stakeholders and eliciting key insights to improve research (McTigue & Kimminau).

- Liberating Structures may be powerful tools to break down pre-existing hierarchies and foster effective engagement between stakeholders (Kimminau).

- Researchers are very intrigued by and interested in stakeholder-engaged research, but many have no idea how to identify, interact with, and engage stakeholders (McTigue).

Storytelling—whether conducted in person or virtually—can be a great way of engaging stakeholders.

Kim Kimminau, PhD, Using Liberating Structures to Unleash Stakeholder Engagement Potential – A Stone Soup Approach

Dr. Kimminau began by asking the audience if anyone had ever used Liberating Structures for engagement. No one in the audience raised their hand. Liberating Structures are easy-to-learn alternative frameworks for interaction that are designed to boost participation and enhance creativity[9]. Kimminau and her colleagues have been asking different stakeholder groups from community members, to patients, to local hospital organizations, to healthcare systems, what they want and need with regard to engagement methods that serve to shift interactions and help them become better engaged. Among those items identified, some of the most important takeaways for researchers are to become less dependent on PowerPoint, become more comfortable with listening to stakeholders, become more comfortable with silence, utilize activities that shift existing social hierarchies, and to not underestimate the importance of using fun activities to engage stakeholders.

Liberating structures have eight attributes (see Figure 1-2 on page <u>12</u>), each of which address feedback Kimminau has received from stakeholders about what they want and need in order to be effectively engaged.

FIGURE 1-1
Methods that Shift Interactions

- Stories versus PowerPoint
- Listening, silence
- Big questions
- Improvising
- Diversity of formats: pairs, small groups, large groups
- Focus on Purpose
- Inviting participation, minimizing status differences
- Rapid learning and prototyping cycles
- Feedback loops
- Innovative ways to harvest output
- Natural environment
- Movement, fun
- Social elements, mixing participants
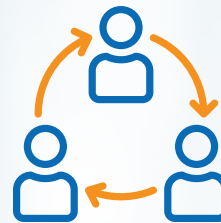
FIGURE 1-2
Attributes of Liberating Structures

1. **Expert-less:** requires only a few minutes to introduce; novices can succeed after a first experience

2. **Results-focused:** likely to generate better-than-expected purposeful results

3. **Rapid Cycling:** fast iterative rounds are very productive

4. **Seriously fun:** boosts joy, freedom & responsibility

5. **Inclusive:** together, everyone is invited to shape next steps

6. **Multi-scale:** works for everyday solutions, projects, strategy, movements

7. **Self-spreading:** simple to copy without formal training

8. **Modular:** the parts can be combined & recombined endlessly

There are about 30 existing Liberating Structures techniques.[10] Kimminau has used seven of these methods via virtual platforms to engage rural and remote audiences (Wicked questions; Heard, seen, respected; What I need from you; TRIZ; 15% solutions; Celebrity interview; and User experience fishbowl). Not all Liberating Structures techniques are likely to work virtually, as some require convening stakeholders in-person, but Kimminau has used some Liberating Structures effectively with the help of virtual platforms. Kimminau then went on to describe the TRIZ Liberating Structures technique.[10] When using TRIZ, participants are asked to design failure. Stakeholders are asked to identify anything and everything that could possibly contribute to failure. Once perfect failure is identified, participants are then able to identify the underlying variables which contribute to such failure. This technique helps participants determine what they should do—or stop doing—in order to solve a problem.

Kimminau concluded this discussion by stating that Liberating Structures open up many opportunities for flattening hierarchies among stakeholders, both virtually and in person.

Kathleen McTigue, MD, MPH, MS, MyPaTH Story Booth Project: A digital engagement tool from the PaTH Clinical Data Research Network (PCORnet)

Dr. McTigue described the MyPaTH Story Booth Project, which is a resource for researchers to help them develop patient-centered research projects.[11] The MyPaTH Story Booth Project is an archive of digital audio-narratives from patients and caregivers about their experiences with "health, illness, and accessing the health care system". This project was developed in response to the challenges of conducting patient-centered research, such as conducting research that reflects areas of importance to stakeholders, engaging stakeholders while planning research, and creating avenues for stakeholders to partner with research teams.

FIGURE 1-3

Innovations from Patients that Shaped the MyPaTH Project

Patient & caregiver input shaped the project

- Patients contributed to the project design through PaTH's stakeholder engagement meetings, an in-person Steering Committee, & the PaTH IRB pre-review process

Their innovations include:

- An option for stories to be posted online

- The addition of phone-based interviews

- The inclusion of caregiver stories

- The need for patients to approve recordings or re-record prior to a story's inclusion in the archive

The MyPaTH Project was shaped by patient and caregiver input. Some notable innovations from stakeholders included the need for stories to be posted online so that they could not only be shared with other researchers but also with other patients and caregivers, the option to be interviewed by phone (as opposed to in-person), and the option for participants to approve recordings before they are included in the archive.

FIGURE 1-4
Lessons Learned from the MyPaTH Project

- Many patients and caregivers are interested in sharing their personal stories and insights about health, illness and navigating the health care system
  - Their stories focus on topics of importance to researchers
- A digital story archive can record patient/caregiver perspectives in a manner that is satisfactory to participants & accessible to researchers
- Narrative collection can facilitate stakeholder engagement; over half of participants are interested in learning of research opportunities
- A shared archive that supports many projects holds promise for efficient engagement practices
  - An archived story is not linked to a single project; multiple researchers can learn from it & it can lead to multiple engagement connections

The searchable MyPaTH Story Booth archive allows researchers to listen to patient and caregiver stories to in turn help inform the development of research questions addressing topics identified by stakeholders as important (leading to better patient-centered care). MyPaTH also facilitates connections between researchers and patients/caregivers interested in their research topic. By creating a virtual archive, multiple researchers can learn from stakeholder stories, instead of typical research in which data is collected and used for the purposes of a single research study. When stakeholders indicate that they are interested in participating in future research, virtual archives such as MyPaTH can also serve to facilitate multiple engagement connections.[11]

Session 1 Panel Discussion

The majority of questions from the audience during this panel discussion were about storytelling, including the advantages and disadvantages of storytelling (in person and virtually), disseminating via storytelling, and how to make storytelling effective for researchers who may be seeking more quantitative information. The audience also directed some questions to McTigue about the MyPaTH project, seeking information about MyPaTH's informed consent process, how her team differentiates opinion from evidence in the stories told, and how the search function for MyPaTH works.

The first question from the audience was directed at McTigue and asked how the informed consent process is framed for a project like MyPaTH. McTigue answered by explaining that the first paragraph of the informed consent document explains that these stories will be used for health researchers. Then a separate question allows them to either consent or not consent to be contacted by researchers in the future. This question reflects an ongoing issue with virtual platforms, which is that they may make content more easily accessible, but the use of content or allowed use of content may not always be clear or fully understood by all parties. An additional concern is how to handle existing data when someone later withdraws their consent from a study. Because digital data may have been reconfigured and used in ways that preclude the complete elimination of the data from all possible sites, it might not be realistic to promise participants that they can fully withdraw their from such studies.

Kimminau was asked why some other Liberating Structures techniques (besides TRIZ) work well virtually. She responded by explaining that Liberating Structures are generally useful for breaking down hierarchies and therefore tend to be good tools for allowing for dynamic, interpersonal communications (whether conducted in person or virtually).

McTigue was asked how she differentiates opinion from evidence when stakeholders tell their stories in the MyPath Story Booth. Another audience member added on an additional question by asking if this project was also created for patients, and not just researchers. McTigue responded by explaining that as part of the PCORnet, this project was created to foster patient-centered research. McTigue and her colleagues are currently working on how to make this project equally valuable to patients and researchers; however, it was originally created with researchers in mind. Her team found that researchers were very intrigued and interested in stakeholder-engaged research, but many had no idea how to identify, interact with, and engage stakeholders, so MyPaTH was originally created as a tool to bring people together. With regard to the question about how her team knows when a story is true, McTigue responded that they do not try to differentiate opinion from evidence. It is important to allow people to tell their story how they want to tell it, and just accept that the stories may not be 100% factual.

One audience member wanted to know if the panelists had measured the benefits of storytelling to individuals who aren't researchers, as well as if one can learn about dissemination of findings and innovations through this process. Kimminau discussed how storytelling can have a positively infectious nature. She described one rare disease researcher who originally designed a study with minimal stakeholder engagement. This researcher was told by PCORI that the original study seemed too superficial, so Kimminau stepped in and used a Liberating Structures technique with 15-20 stakeholders of this rare disease. Instead of asking how the data looked, she asked the stakeholders what was missing. The stakeholders quickly identified two key components of their disease that weren't noted anywhere in the data presented to them. This instance led to important changes to the proposed research, and the researcher is now a major proponent for using engagement techniques like Liberating Structures and storytelling to gather information that will enrich research.

The panelists were asked by another audience member if they could comment on any potential disadvantages of storytelling. They were also asked if there are important differences between storytelling that happens in person versus virtually. McTigue responded that storytelling does have limitations: it is one person's story, reflecting one person's perspective, which means it might not be generalizable to others. Yet, people tend to overgeneralize from stories. Their tremendous persuasive power may be the biggest risk of using stories. The virtual stories on MyPaTH may be more like casual stories one might hear in passing than stories told in an artificial arena like a formal qualitative interview, which has both positive and negative implications. Further, Kimminau noted that when one moves to virtual settings using written language, one loses intonation and visual cues. Still, she added, though one might tend to think stories are best used for patients and caregivers, they are also useful for clinicians. Whether written or verbal, virtual platforms can encourage storytelling, and perhaps honesty, in ways that in-person discussions cannot. One member of the audience commented that researchers don't always understand stories, and sometimes need stories to be interpreted for them. It was noted that re-framing questions could be a useful tool to help researchers listen to stories while also collecting the specific information they are seeking. The audience also expressed some concern about a lack of opportunities for bi-directional engagement through storytelling.

> Whether written or verbal, virtual platforms can encourage storytelling, and perhaps honesty, in ways that in-person discussions cannot.

Strengths and Weaknesses in the Use of Virtual Platforms

The first talk of this session was by Katja Reuter, PhD, Associate Professor of Clinical Preventive Medicine at the University of Southern California's Keck School of Medicine. This presentation discussed the capabilities of the Web-based tool Trial Promotor and the challenges of collecting data from virtual platforms.[13] Matthew Baumer, PhD is a Data Scientist with Facebook Analytics led the second talk of this session, describing recent Facebook efforts to build engaged communities and ensure the authenticity of user experiences.

HIGHLIGHTS AND MAIN POINTS FROM THE SESSION

- There is a need for standardized reporting guidelines of metrics across the many social media platforms and in the scientific literature to develop evidence-based communication methods in the digital age (Reuter).

- With regard to virtual platforms—including social media platforms— transparency is key if researchers want to be able to leverage these for research purposes. It is critical that researchers are clear about the purposes of their research and how the data collected will be used (Reuter).

Katja Reuter, PhD, Trial Promoter: A Web-based Tool to Test Stakeholder Engagement in Research on Social Media

Dr. Reuter discussed Trial Promoter, a tool that has been developed to enable more rigorous evaluative research for health communications.[13] Reuter and her team are focused on developing digital, evidence-based clinical research recruitment and health promotion interventions. Trial Promoter allows researchers to run multiple experiments simultaneously. For instance, researchers can test different characteristics of messages (e.g., psycholinguistic aspects, different types of images and hashtags) based on how effective each is in engaging their target audience online (i.e., Do stakeholders click on the link, go to the website, read about the study, contact the study team, and/or enroll in the study?). The messages and characteristics are randomized by the Trial Promoter tool to reduce selection bias.

FIGURE 2-1

Trial Promoter has the ability to support and collect data on multiple experiments simultaneously.

Trial Promoter collects data on primary outcome variables (e.g. click rates, numbers of surveys completed) and secondary outcome measures (e.g., number of retweets and shares, time spent on webpage).

COLLECTING DATA FROM MULTIPLE EXPERIMENTS

TRIAL
PROMOTER
SANDBOX

Experiment 1   Experiment 2   Experiment 3   Experiment 4

Messaging strategies to be tested

Automated distribution across multiple platforms
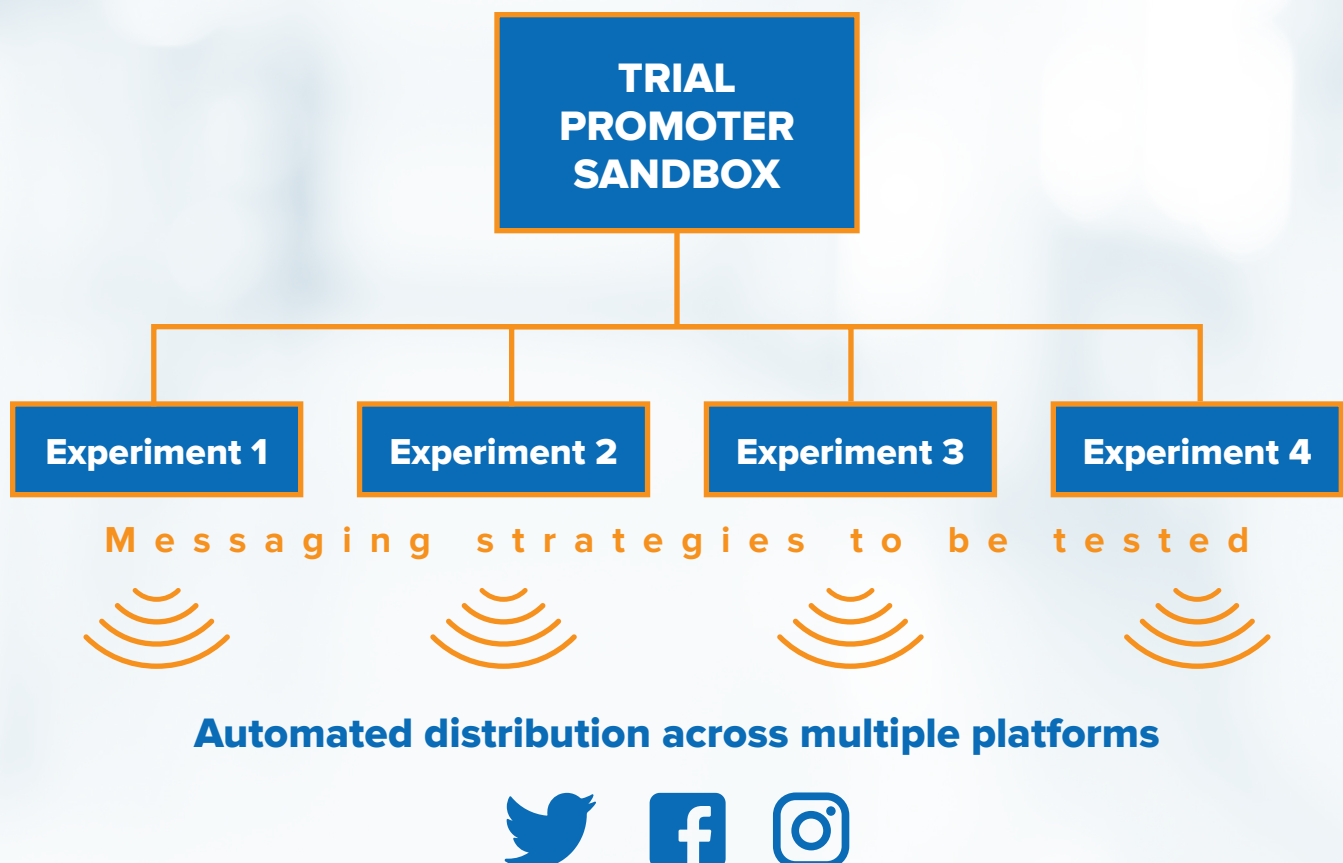
FIGURE 2-2

Primary and secondary data collected by Trial Promoter

SOCIAL MEDIA

WEBSITE

CONVERSION

Social media user clicks on link in social media message

Social media user completes carries out asked behavior

PRIMARY OUTCOME VARIABLES

- Impressions
- Clicks

- Clicks on website links
- Number of sessions (visits to landing page)

- Number of surveys completed
- Number of contact requests
- Number of people enrolled

SECONDARY OUTCOME VARIABLES

- Retweets, Replies, Likes (Twitter);
- Shares, Comments; Likes (Facebook);
- Reposts; Comments; Likes (Instagram)
- Cost

- Number of website pages viewed (pageviews)
- Time spent on webpage

Reuter described a number of the issues and challenges in collecting and validating data obtained via virtual platforms, including a lack of reporting standards for social media-related research; metrics across platforms use different definitions (e.g., Twitter uses "likes", Facebook has "reactions", etc., and it is difficult to compare these across platforms); different platforms have different policies of use (e.g., Twitter requires that researchers obtain a pre authorization from Twitter before they can place paid advertisements for clinical trials and Twitter also requires additional time to review ads);[14] data must be collected in different ways, depending on one's needs (e.g., organic engagement data is cumulative and should be manually downloaded daily); and time calculations of advertisements can vary between platforms (e.g., one's budget may be exhausted on one platform long before reaching the end of the study period). Reuter also explained that it is crucial to find the right third-party application to help collect the data one needs.

Reuter closed her talk by informing the audience that her team is looking for collaborators and partners to help further test and develop Trial Promoter.

While it is arguable whether Trial Promoter is being used for longitudinal and bi- or multi-directional engagement as defined by the D2V initiative (while information is being both delivered and collected, there is no guarantee that the same individual or group is engaged more than once, for example), this virtually-based tool—and others like it—are intended to improve researchers' ability to communicate with and engage stakeholders.

Matthew Baumer, PhD, Building Engaged Communities with Facebook

Dr. Baumer then gave a presentation about using Facebook's platform to build engaged communities. Employees at Facebook are generally not able to give recorded talks or share slides, so by prior agreement this talk was not recorded and slides were deleted from our records after the presentation. As a result, we will not summarize Baumer's talk is this report, but we are thankful to him and Facebook for coming to our symposium and presenting about this emerging topic.

Session 2 Panel Discussion

The audience began by asking Baumer a few questions about his presentation. Questions from the audience included: How does one know if someone is displaying their "authentic identity"? How does one navigate the tension of people displaying an online persona versus their true selves? What metrics is Facebook developing to distinguish meaningful or "authentic" engagement? Does Facebook make efforts to engage people with disabilities (e.g., visual disabilities)? Facebook's Transparency Report for 201815 addresses several of these questions, including a section specifically regarding the identification of fake (i.e., not authentic) accounts.[16]

Baumer and Reuter were then asked if virtual platforms serve as democratizers, and whether they more commonly divide or bring us together. They were also asked if participatory engagement on virtual platforms might marginalize some groups rather than working to reduce marginalization. Reuter replied by saying that academic research does not take enough advantage of the opportunities provided by social media. This being said, social media only reach the populations that use them, which can be considered a limitation. But in her view it is not an argument for not using virtual platforms, including social media, in ways that complement more traditional approaches.

A member of the audience described a recent survey about privacy from the NIH's All of Us research program. This survey asked people what they are willing to share. The majority said they would share blood, urine, environmental data, but only about half of those surveyed were comfortable sharing their social media data. This audience member went on to say that as researchers consider using virtual platforms and social media, they should consider how to define health data in these arenas since users might be particularly concerned about privacy of online data. Reuter responded by saying there are no defined guidelines (outside of the HIPAA Privacy Rule, which doesn't apply to most online platforms because they are not "covered entities") and each online entity can therefore determine their own privacy policies. This raises a question: should there be explicit and unique standards to govern the use of social media in research? Or, should social media, whether used for data collection or study recruitment, be subject to the same standards as other research (as proposed by Gelinas et al, 2016 as part of their "non-exceptionalism" framework?)[17] Presumably, non-exceptionalism would mean, for example, that instead of treating social media-driven recruitment approaches as something entirely different from traditional recruitment practices, one could look for commonalities. What should be the differences, if any, between receiving a request to join a real-world patient group to collect data vs. joining a Facebook group in which some data collection will also occur? It was also noted that many IRBs probably have little or no experience examining such issues as yet.

Session 2 Panel Discussion (cont.)

In response to a question from the audience, Reuter explained that automated, virtual strategies for recruiting can be a particular boon to junior researchers, who often receive less research funding and attention from institutional communication teams than more senior researchers. Reuter also reiterated the privacy concerns that arise when using virtual platforms, and that investigator transparency about their research goals is critical when engaging audiences on social media.

Another audience member asked Reuter and Baumer if there are strategies for finding leaders in outreach via virtual platforms, and once identified, whether researchers could then use a snowball technique to establish more relationships. Reuter responded by discussing Symplur, an analytics company that analyzes healthcare social media Twitter data.[18] Symplur aggregates specific Twitter conversations and influencers based upon disease keywords and hashtags such as #lupus.[18] It can display how many people talked about a specific topic, how they talked about it, and what resources they shared, among other things.[18] Reuter suggested using the free version of Symplur as a way to identify relevant disease communities, conversations and individuals on Twitter.

One audience member made a comment about trustworthiness and transparency, noting that the work to develop and test the Trial Promoter presumably had to go through an IRB (which likely posed some challenges and may have influenced its design, functionality and other characteristics), while Facebook may have a very different, and less transparent, ethics review process.

The session was concluded by Reuter thanking Facebook for advertising clinical trials on their platform. She went on to say that Facebook's moderation process allowed her team to learn a few things about advertising which helped their study. Reuter also said she wished there were more opportunities for collaboration between Facebook and the academic enterprise.

Ethical and Legal Issues in Virtual Engagement

This session began with The Ethics of Virtual Engagement, a discussion by Matthew DeCamp MD, PhD, Assistant Professor at the Johns Hopkins Berman Institute of Bioethics and the Johns Hopkins Division of General Internal Medicine. The talk established a proposed framework for engagement, to which common ethics language might then be applied, including engagement via virtual platforms. In the second part of this session, Drs. DeCamp and Wynia facilitated a live audience poll of the audience which posed various questions on the topic of ethical uses of virtual platforms for research purposes.

HIGHLIGHTS AND MAIN POINTS FROM THE SESSION

- There is a need for the evaluation of engagement activities, and to do so researchers need to develop more rigorous and valid process and outcomes measures (DeCamp).

- Many of the same ethical questions that arise in traditional engagement will arise in virtual engagement methods; however, there may be additional questions specific to engagement via virtual platforms (DeCamp).

- Stakeholder engagement should build relationships, and the jury is still out about whether or not virtual platforms can build and maintain relationships. Researchers should be asking stakeholders themselves if they want to be engaged virtually or in person (audience members).

Matthew DeCamp MD, PhD, The Ethics of Virtual Engagement

Dr. DeCamp's presentation focused on the ethics of virtual engagement. DeCamp began by describing a conceptual model of engagement, which looks at the connection between "why?", "how?", and "how well?", and then noted that common ethics language and concepts can inform each of these steps. The "why" of engagement has been frequently considered, and includes goals often connected to common ethical principles such beneficence/non-maleficence, respect, and justice.

FIGURE 3-1
The "Why" of Engagement

ETHICAL PRINCIPLE	ETHICAL GOAL
BENEFICENCE/ NON-MALEFICENCE	Ensure scientific quality
	Protect individuals or communities from harm or exploitation
	Enhance benefits for individuals or communities
	Increase potential for long-term research impact
RESPECT	Demonstrate respect (e.g., for cultural differences)
JUSTICE	Involve vulnerable or marginalized groups
	Ensure that burdens and benefits are equitably distributed
	Share responsibility
	Build legitimacy for the research project
	Improve trust in the research project or enterprise
	Set research priorities

Adopted from Table 1 in MacQueen et al. BMC Med Ethics. 2015; 16: 44 with inclusion of trust from Yarborough M et al. Acad Med 2009; 84:472-477 and priority setting from Pratt et al Social Science & Medicine 2016;151:215-224.

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> Different methods are presumably more or less effective for achieving different goals.

DeCamp went on to discuss the "how" of engagement. There are wide array of different methods used for engagement, and the "how" of engagement (i.e., selecting which method to use) is or should be connected to the "why." That is, different methods are presumably more or less effective for achieving different goals. In addition, different methods of engagement fall onto a spectrum of power sharing, as shown in the "ladder of engagement" reproduced in Figure 3-2 on page 27.

DeCamp then noted that some ethical challenges to virtual engagement are new, but a number of challenges related to engagement are not new when moving to engagement using virtual methods. In particular, he said that researchers using virtual platforms for engagement still must pay attention to power dynamics, even though some commentators have asserted that virtual platforms are inherently more "equalizing" compared to in-person methods.

FIGURE 3-2

A Ladder of Citizen Participation and the Importance of Breaking Down Power Dynamics

OF POWER & CONTROL
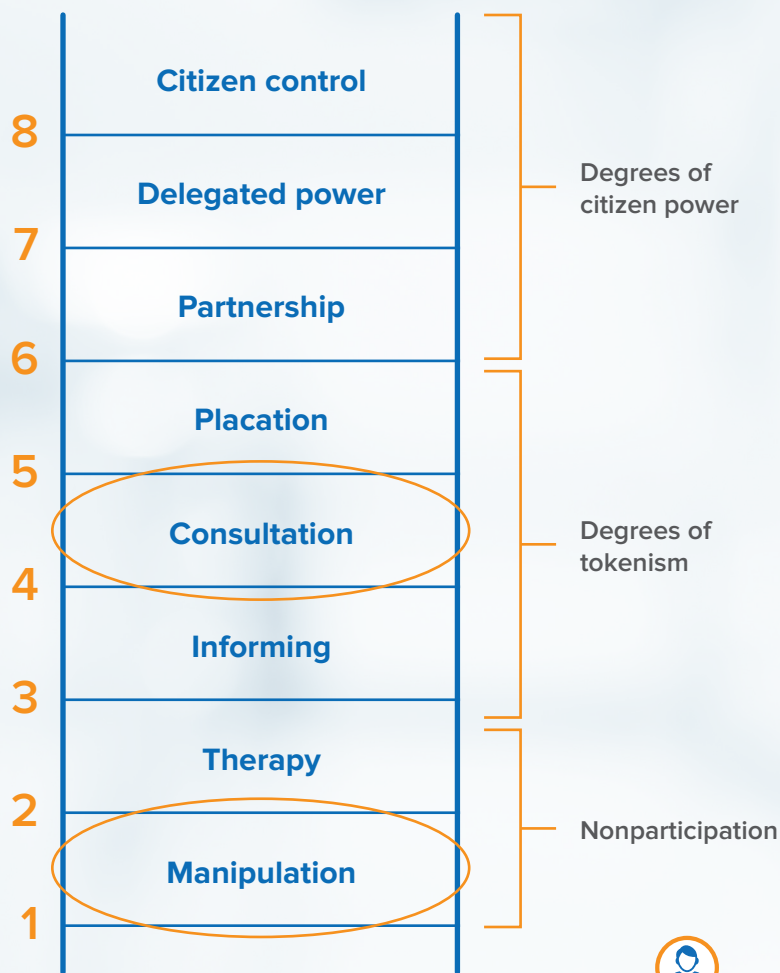
Eight Rungs on a Ladder of Citizen Participation

Rung	Label	Category
8	Citizen control	Degrees of citizen power
7	Delegated power	Degrees of citizen power
6	Partnership	Degrees of citizen power
5	Placation	Degrees of tokenism
4	Consultation	Degrees of tokenism
3	Informing	Degrees of tokenism
2	Therapy	Nonparticipation
1	Manipulation	Nonparticipation

Here, traditional ethics concepts need to be supplemented with sociology and political theory — in part because of their greater attention to power dynamics.

At the same time, we must keep in mind that some believe **virtual** methods are uniquely "equalizing" regarding power.

Arnstein, Sherry R. A Ladder of Citizen Participation. Journal of the American Planning Association, 1969;35: 4, 216 — 224

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DeCamp then discussed what he called the "how well" of engagement, an area which he said needs the most work with regard to what it means to conduct stakeholder engaged research, whether using in-person or virtual methods. He showed a slide from PCORI's We Enact toolkit, which asks stakeholders questions such as "how much influence did you have" on various aspects of the project, and "how much did you feel trust, honesty, transparency, shared-learning, and give-and-take relationships while working on this project"? DeCamp also showed a slide referencing an online conceptual model for community-based participatory research (CBPR), which includes clickable evaluation domains (e.g. contexts, group dynamics, etc.) that link to outcome measures for each domain.[19] The discussion of the "how well" aspect of engagement was concluded by calling the evaluation of engagement approaches an ethical obligation, and one which should eventually be linked to the "why" and the "how" of engagement.

FIGURE 3-3
Ethical Questions Considered with Regard to the Use of Virtual Platforms

SOME QUESTIONS ETHICS WILL ASK

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GENERAL QUESTION	SPECIFIC QUESTION IN VIRTUAL SETTINGS
Who should be included (or excluded) in the engagement?	Is the process inclusive of vulnerable, marginalized, or other excluded groups (e.g., those with limited technology access)?
What should be the goal of the engagement?	Can a virtual method (and if so, *which* virtual method) achieve the stated goals?
When should different stakeholders be engaged?	Was the virtual engagement process open and fair (i.e., no constrained agenda from the outset)?
How will power imbalances be mitigated?	How can all the stakeholder participants be empowered to foster a process with true dialogue?
How do we know we are achieving our goals?	What evaluation outcomes should we use?

The conclusion of DeCamp's talk included a brief discussion of how ethical engagement practices can and will need to be applied to engagement via virtual platforms. In short, the same ethical principles will apply; however, these principles may require extra care with regard to new and evolving considerations that arise with the use of virtual platforms.

Questions from the Audience & Audience Survey using Poll Everywhere

This session was structured differently than the prior sessions. Instead of having a panel at the end, DeCamp and Wynia facilitated a phone survey of the audience (results from the audience survey are described below and can also be found in the appendix on pages 48-49 of this paper). Before the survey, a couple of minutes were given to the audience to ask DeCamp questions.

One audience member discussed focus groups and how focus group moderators are typically trained to deal with group power dynamics. She wanted to know if moderation, and moderator training, would be a factor if stakeholders were engaged virtually. DeCamp responded that moderation may or may not be a factor, depending on which approach to engagement was being used. Technology may make it possible to "train" virtual moderators to keep an eye on group power dynamics and intervene to address power imbalances. In his view, there will probably continue to be reasons to include a human moderator in certain engagement cases. Wynia noted that some research suggests that when people use a Virtual Reality (VR) headset to talk to a fake, computerized psychiatrist, these users tend to be more honest and enjoy the relationship more than they would if they were talking to a real person.[20] He went on to say he could picture the possibility of development of virtual, algorithmic moderators that can watch conversations and make sure stakeholders are being respectful, everyone is prompted to participate, etc.

The audience survey began with some basic demographic questions, such as asking about the ages of audience members. Among those who participated, 17% were less than 30 years of age, 77% were between the ages of 31-50, and 7% were between the ages of 51-70.

The audience was asked to type a response to the question "What is the most important ethical issue to address in using virtual platforms for engagement in health research?" Poll Everywhere created a word cloud of audience responses (n=41). "Privacy" was the largest word in the cloud. Other large words included "diversity", "consent", "trust", "inclusion" and "inclusivity" and "inclusiveness", and "representativeness" and "representation".

FIGURE 3-4

Word cloud from audience responses to the question "What is the most important ethical issue to address in using virtual platforms for engagement in health research?"

What is the most important ethical issue to address in using virtual platforms for engagement in health research?

The audience was then asked "Are any of these ethical issues NEW, compared to ethical issues in traditional stakeholder engagement methods"? Among audience members who responded to this question (n=31), 52% said "no", 29% responded "not sure", and 19% said "yes". While audience members were responding to this question, there were a few comments from the audience. One member of the audience said she (and likely other audience members) was becoming antsy about how thus far the symposium had discussed engagement in the absence of a discussion about relationship building. For many, stakeholder engagement is relationship building and one cannot have engagement without true relationship building. This audience member was not sure that virtual platforms would be able to serve the function of relationship building. There are plenty of virtual communities that form around an issue or topic and support bidirectional exchange of ideas and information. Questions remain, however, about how these communities are/will be accessed for research purposes and the extent to which researchers will allow for virtual communities to shape the research itself. Wynia and DeCamp responded in agreement

For many, stakeholder engagement is relationship building and one cannot have engagement without true relationship building.

with this concern, noting that this was an important driver for having the symposium, and especially the session on the ethics of virtual engagement. In particular, there appears to be a need for further exploration into whether, when, where, and how virtual platforms might or might not be able to build relationships that can meaningfully and ethically inform the research process.

Another audience member discussed the difference between "engagement" for the purposes of data collection versus engagement which builds actual relationships. She then went on to say that it might be best to ask intended stakeholders how they want to be engaged and what types of tools they would prefer to use and that would support ongoing engagement.

Many times one cannot even begin to engage virtually until one has built solid relationships.

Another audience member went on to say that researchers need to ask "are there purposes for which virtual engagement is well suited", as well as "are there purposes for which virtual engagement is not well suited"? She also added that many times one cannot even begin to engage virtually until one has built solid relationships.

Wynia and DeCamp then asked a couple questions intended to explore some of the ways in which virtual platforms might be similar to or differ from typical engagement methods used as part of human subjects research. The first asked, "Should health research that mines data available from virtual platforms (e.g., Facebook, Twitter, Google searches) be subject to human subjects review (e.g., via Institutional Review Boards)"? This question was verbally clarified by Wynia, who explained that the question was asking whether employees at companies like Facebook, Twitter, and Google who want to use the data they have collected on a health topic should have to undergo human subjects review. (At the moment, they do not need to do so, since they are not covered under the "Common Rule" governing human subjects research using federal funding, just as they are not "covered entities" with regard to the HIPAA Privacy Rule.) Of the audience members who responded to this question (n=31), 58% said "yes", these companies should be required to put their research protocols through formal human subjects review, 32% said "no", these companies should not have to undergo human subjects review, and 10% responded "not sure".
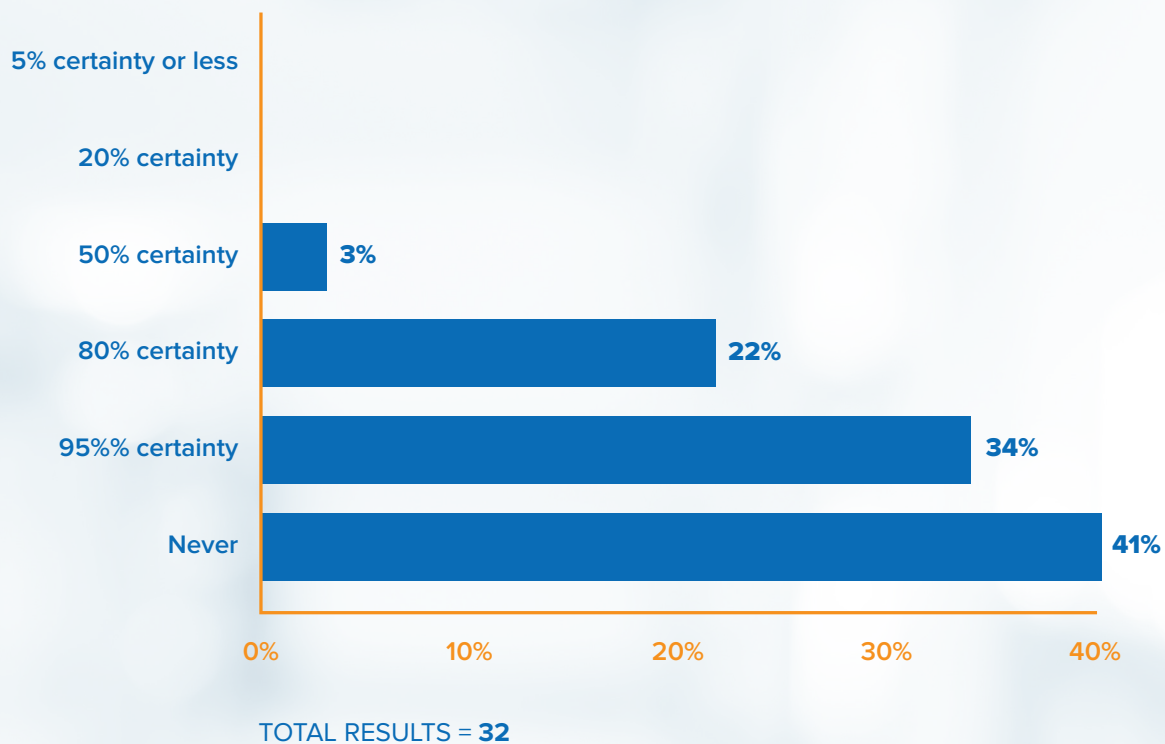
The next question posed to the audience was "Is Google morally obliged to notify a person whose searches suggest s/he has a serious illness"? Among respondents (n=33), 58% said "no", 21% said "yes", and 21% said "not sure". One audience member wanted to know how Google could be sure that the person searching wasn't searching on behalf of someone else. She also posed a comment that this could create all types of ethical issues (for instance, a person who has been identified by an algorithm as exhibiting signs of needing psychiatric help being targeted advertisements about psychiatric hospitals).

This question about the moral obligations of Google was followed by another question; "At what percentage of certainty about the diagnosis should Google be obligated to notify a person that they may have a serious illness"? Among audience members who responded to this question, 41% responded "never", 34% responded "95% certainty or more", 22% responded "80% certainty", 3% responded "50% certainty", and no one (0%) responded "20% certainty" or "5% certainty or less".

FIGURE 3-5

Survey responses from the audience about how certain Google would need to be before notifying users they may have a serious illness

At what percentage of certainty about the diagnosis should Google be obligated to notify a person that they may have a serious illness?

Certainty	Percentage
5% certainty or less	
20% certainty	
50% certainty	3%
80% certainty	22%
95%% certainty	34%
Never	41%

TOTAL RESULTS = **32**

Weaving it all Together

The first presentation during this session was by Consuelo Wilkins, MD, MSCI, Associate Professor of Medicine at the Vanderbilt University Medical Center and Meharry Medical College. Her talk addressed the need for strategies to measure and monitor the effectiveness of various engagement methods. The second presentation in this session was by David Grande, MD, MPA, Assistant Professor of Medicine and the University of Pennsylvania School of Medicine. He discussed the complexities of using social media as a tool for engaging policy makers with research.

HIGHLIGHTS AND MAIN POINTS FROM THE SESSION

- Researchers need common measures and metrics of various engagement strategies to ensure engagement is meeting the needs of those being engaged (Wilkins)

- While engaging groups of people, it is crucial to be aware of power imbalances and to take steps to minimize these imbalances (Wilkins).

- As technology evolves, researchers should not be thinking about replacing in-person engagement with virtual engagement, but considering how technology can be leveraged to serve different engagement purposes (Wilkins).

- The timing at which research findings reach politicians is crucial, and social media may be particularly useful for re-publicizing research results at moments of particular political relevance (Grande).

- When disseminating research findings, researchers may want to place more focus on the policy life-cycle rather than the research life-cycle, to ensure dissemination is as effective and relevant as possible (Grande).

Consuelo Wilkins, MD, MSCI, Stakeholder Engagement to Enable Consensus Building and Decision-Making

Dr. Wilkins began her talk by thanking everyone who had presented thus far, especially DeCamp for his slides demonstrating that engagement is not something new, and that scientists have been doing engagement work for decades. She then went on to say that she rarely gets groups of people together for the purpose of generating consensus, which is a common purpose of engagement methods outside the research setting (e.g., in deliberative democratic or civic engagement processes). In fact, Wilkins considers consensus to be the antithesis of engagement in some circumstances, particularly when consensus building results in the exclusion of marginalized voices or minority opinions. In her view, engagement should serve the purpose of eliciting and hearing multiple voices, not getting everyone to agree on one thing. In addition, Wilkins expressed discomfort with calling the use of predictive analytics a type of "engagement." Strategies such as following users on their virtual applications without consent, or counting clicking a button as informed consent, and tracking behaviors and data for the purpose of getting users to do what researchers want them to do is, in her view, not engagement; it is manipulation (see also Figure 3-2 on page 27).
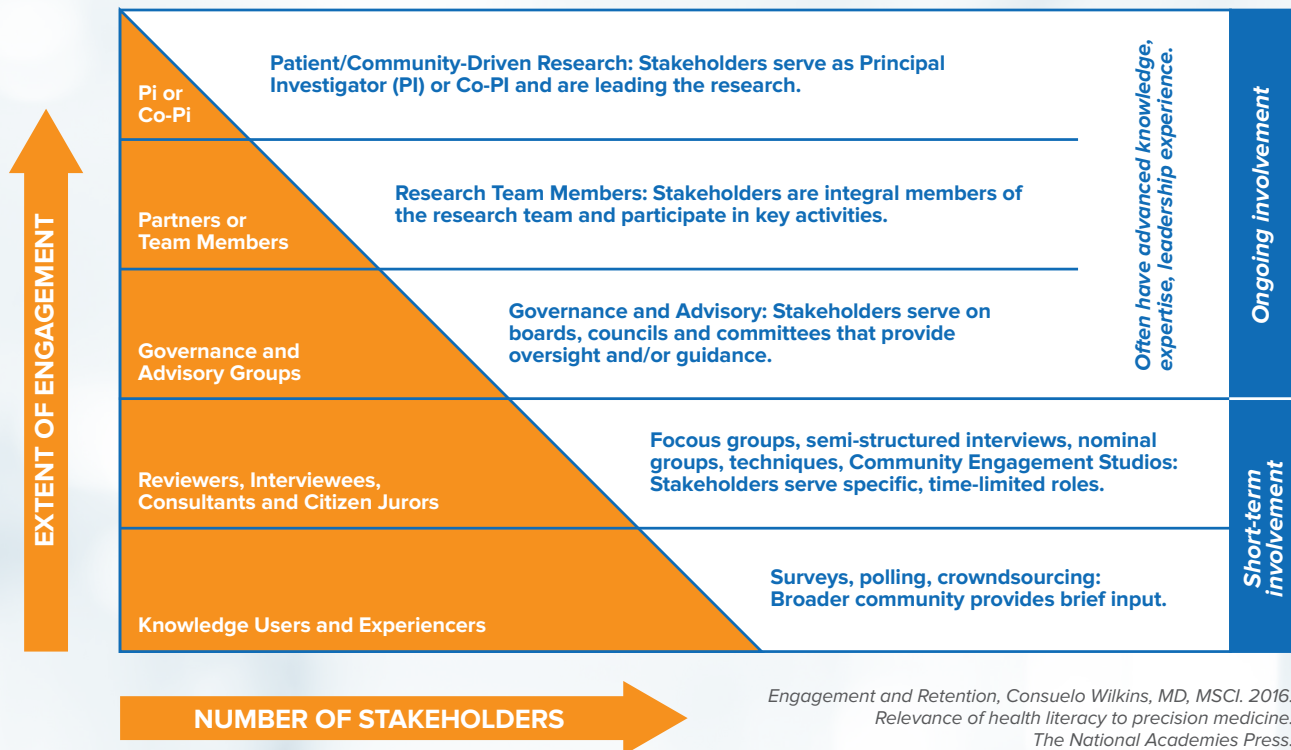
Wilkins went on to say that researchers need strategies to ensure that any methods used for engagement are effective in achieving their intended purpose(s). In addition, it is critical to be aware of power imbalances and to ensure that these imbalances are minimized during engagement processes, as others speakers have noted. While agreeing with others' concerns in this regard, Wilkins emphasized that perpetuating, exacerbating or ameliorating power imbalances is an outcome of engagement processes that can and should be evaluated.

When groups of people are truly engaged, they are the ones driving change, rather than waiting for researchers to come to them and ask them their thoughts. Wilkins showed a slide containing a continuum of engagement that she and her colleagues developed. She went on to say that she rarely conducts a project that does not include at least three levels of engagement from this continuum.

> When groups of people are truly engaged, they are the ones driving change, rather than waiting for researchers to come to them and ask them their thoughts.

FIGURE 4-1
The Continuum of Community (Stakeholder) Engagement in Research

Engagement and Retention, Consuelo Wilkins, MD, MSCl. 2016. Relevance of health literacy to precision medicine. The National Academies Press.

Wilkins also showed a slide of various consensus-building approaches to engagement that have been used online (including variations of Delphi, Concept Mapping, and crowdsourcing). As technology evolves, she said, researchers should not be thinking about replacing in-person engagement with virtual engagement, but considering how specific technologies and platforms can be leveraged to serve specific engagement purposes.

Researchers should not be thinking about replacing in-person engagement with virtual engagement, but considering how specific technologies and platforms can be leveraged.

FIGURE 4-2
Consensus building methods that can be effectively conducted via virtual platforms

NEWER APPROACHES TO CONSENSUS BUILDING

- Online Delpi
- Concept Mapping Policy Delphi
- Conensus-Based Crowdsourcing
- Crowdsourced Delphi
- Deliberative Polling
- Public Consultations

Domain   **Scope (time horizon)**   **Intervention Title**   **Intervention Rationale**   **View/Add Comments**

Primary Domain	Scope	Title	Rationale	Comments
▼	▼			💬
Primary Domain	Scope	Title	Rationale	Comments
▼	▼			💬
Primary Domain	Scope	Title	Rationale	Comments
▼	▼			💬

Coleman S, Hurley S, Koliba C, Zia A, Crowdsourced Delphis: Designing solutions to complex environmental problems with broad stakeholder participation. Global Environmental Change; **45***: 111-23.*

Klenk, Nicole L., and Gordon M. Hickey. "A virtual and anonymous, deliberative and analytic participation process for planning and evaluation: The Concept Mapping Policy DFelphu." International Journal of Forecasting 27.1 (2011): 152-165.

MEHARRY VANDERBILT ALLIANCE
SINCE 1999

Wilkins continued her presentation by emphasizing that engagement takes time, and if researchers do not include stakeholders in the planning of engagement activities, they should not expect the findings from subsequent engagement activities to be of much use. She also spent a little time discussing Community Engagement Studios, an engagement strategy developed by her team. Wilkins and her team compared input from community members to input from researchers. The responses can be drastically different, which underscores the importance of engaging stakeholders from a variety of backgrounds. Wilkins then went on to show a scale intended to measure the extent to which a given research project is person-centered.

FIGURE 4-3

Tool to measure the person-centeredness of research

Engagement in development of person-centeredness of research scale

PERSON CENTEREDNESS OF RESEARCH SCALE
1. There is evidence that **beliefs** relevant to the population of interest are included or addressed in the research.
2. There is evidence that **attitudes** relevant to the population of interest or to patients/community members are included or addressed in the research.
3. There is evidence that **concerns** relevant to the population of interest or to patients/community members are included in the research.
4. Person/community-centered **goals and/or outcomes** are included or addressed in the research.
5 . Research **priorities** of interest to the patient/community are included or addressed in the research.
6. The **needs and preferences** of the patient/community are included or addressed in the research.
7. Individuals representing patients and/or communities are **engaged in the research as stakeholders,** advisors, consultants, or team members (beyond serving as research volunteers).

5-point scale: Strongly Disagree, Somewhat Disagree, Neither, Somewhat Agree, Strongly Agree
Wilkins, Wallston et al 2017.

Wilkins also noted that the symposium had thus far been discussing the extent to which virtual platforms might be able to expand engagement opportunities; however, researchers also need to consider that some populations could be excluded from engagement if one were to limit projects to virtual engagement only. For example, by choosing to engage virtually one might be excluding individuals who did not complete high school, individuals who do not speak English, deaf or blind stakeholders, rural and remote populations, tribal populations, or the homeless.

> Researchers also need to consider that some populations could be excluded from engagement if one were to limit projects to virtual engagement only.

Wilkins concluded her talk by providing some of her own "best practices" guidance for using virtual platforms to engage stakeholders. She emphasized the importance of making sure that any strategies used do not overlook the important foundations of engagement, including attending to balancing power dynamics and ensuring efforts are representative, inclusive, and based on the needs of the study and of the population(s) being engaged. Researchers should also think carefully about how best to present stories to stakeholders, whether these stories occur in person or virtually, since learning through narrative is such a powerful method. Wilkins concluded by re-emphasizing the point with which she began, noting that engagement methods are often used to achieve some version of consensus, and that researchers using engagement for this purpose should be very certain that consensus is really needed, because achieving consensus might result in limiting the options and stifling the voices of stakeholders with less power.

David Grande, MD, MPA, Research to Policy – Can Social Media Bridge the Divide?
Dr. Grande next gave a talk about the relationship researchers have with policy makers, and exploring how virtual platforms can be used to extend the influence of research within the policy-making process.

While exploring the question "can social media help bridge the gap between research and policy?", Grande showed findings from a study his group conducted by surveying researchers. Overall, the researchers surveyed thought social media could be effective at reaching and influencing policymakers; however, the researchers tended to not be confident in their ability to use social media for research purposes and in general tended to be nervous about engagement via social media. Additionally, researchers noted that conversations via social media can be noisy, professionally risky, and that the efficacy of engaging via social media is uncertain. Perhaps reflecting this discomfort, several years ago Grande and his group surveyed researchers and asked which dissemination methods they had used, and social media was at the very bottom of the list.

FIGURE 4-4

Survey of researchers asking which dissemination methods they had used in the past year

They were using traditional dissemination methods

Method	Percentage
Directly Contacted Policymaker	74.4%
Interviewed by Reporter	69.7%
News Media Covered Your Study	65.1%
Contacted Interest Group	63.2%
Published Policy Brief	33.5%
Published Editorial with Policy Recs	30.7%
Blogged about Research Policy	20.9%
Updated Facebook Friends about...	19.1%
Tweeted about Research	14.4%

Respondents were asked to self-report whether they had used any of the above communication methods in the past year.

Grande went on to explain that while it is fairly well known that researchers distrust politicians or the political system, his group also found that politicians distrust researchers, often believing that they are subject to bias, institutional conflicts of interest, or seeking continued funding for grants that are not really of service of the public. In a survey of state legislators, his group found that these politicians do not want to be treated as the students of researchers and are instead seeking relevant and timely information about topics they need to address in the immediate future.

Grande went on to describe that he and his group have looked at congressional staff with health-related responsibilities and reviewed their top health sources on Twitter. Health information primarily reaches government officials from either traditional news media channels or official government agencies, and health news was only a sliver of the news these congressional staffers were following on Twitter. On the other end of this, when state legislators were asked where they get health policy information, social media was also at the very bottom of the list. Grande explained that he is not trying to discourage researchers from disseminating findings via social media; instead, he is emphasizing that both researchers and politicians have been slow to adopt social media as an information channel.

Sources from which state legislators reported getting most of their health policy information

STATE LEGISLATORS
"Where do you get most of your health policy information?"
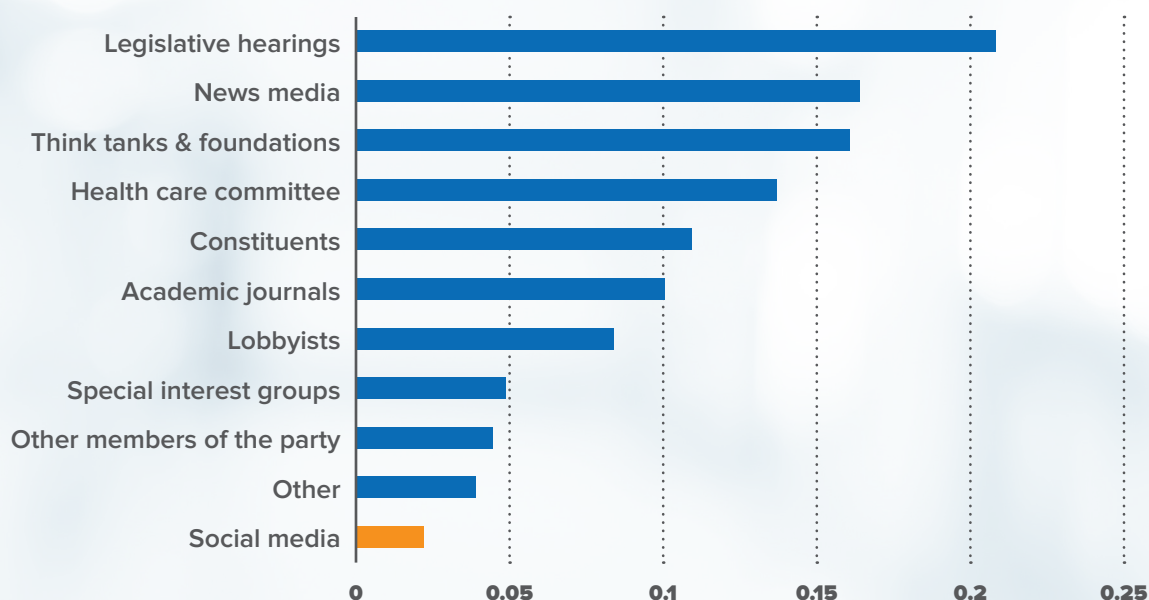
Source: unpublished analysis of 2017 data

Grande concluded his talk by discussing whether using social media is worthwhile for researchers. When it comes to health research and how information about it gets to policymakers, Grande's data shows that social media is not (yet) disrupting traditional information channels, though it may move information around more quickly than traditional information channels. Researchers and institutions are still trying to solve various problems related to communicating via social media, such as being concerned about over-generalization or over-simplification of findings in social media messages, which are typically very brief; being embarrassed by the appearance (or reality) that posting items on social media is self-promoting; concern about getting something wrong in a social media post; and concerns about whether and how researchers could be incentivized to promote their research findings using social media. When discussing the use of social media by researchers, one should recognize that these platforms comprise social communities of individuals and that effective users of these platforms need to be comfortable developing a social media personality. Grande also noted that social media may be particularly useful for rapidly re-publicizing prior research results at moments that are of particular political relevance. He gave an example of research that had been published months or years prior to a social event arising that was related to the research; social media was found to be very effective at raising awareness of the research findings, which had become newly relevant to the public. With this in mind, researchers may want to place more focus on the policy life-cycle rather than the research life-cycle as they use social media to disseminate their findings, using social media to ensure dissemination is timely, effective and relevant.

Session 4 Panel Discussion

One member from the audience emphasized the idea that narratives are very powerful and described anecdotes that suggest researchers presenting data may or may not convince legislators to vote one way or another, but when researchers bring a patient in to tell their story, legislators are more likely to be moved to vote in favor of what the researcher is asking. This audience member commented that researchers should first be bringing patient voices to politicians, and then should use data to further support the point. Wilkins responded by saying this can be a very useful strategy and that some researchers have already begun doing this. In addition, she noted, researchers shouldn't present more than one page of information, and what they present should begin with a story if they want representatives to pay attention. Grande reiterated that narrative is an extremely effective mechanism of delivery, saying that research suggests that when messages are packaged as stories, all audiences (not just politicians) tend to be more responsive. Grande also emphasized that, as researchers, we must be responsible for ensuring that the stories and anecdotes we use are actually backed up with rigorous evidence; it is critical that the stories we tell must convey truthful messages.

Another member of the audience asked for an example of how one might use social media to tell stories in an effective and engaging way. Wilkins responded in part by saying she was unaware of any projects in which social media platforms were used to engage from the beginning through to the end of the project. She continued by saying that at some point in a project, the level of engagement and the relationships built need to be stronger than they would likely be if engagement was conducted exclusively via social media. To illustrate this point, Wilkins suggested a thought experiment: for those in the audience who are researchers, she asked that they consider whether they would ever collaborate with another researcher on a study exclusively via social media. "Exclusively" means the researchers would have found each other on social media, communicated exclusively through social media, conducted the research, and then developed plans for dissemination, all only via social media. She concluded with posing the question: what would be lost by communicating exclusively via social media? When it comes to our stakeholders, she concluded, researchers must value the people—their input, the resources they bring, their stories—and not just convince them that the data they provide is of value.

Another audience member continued this discussion by saying she found a major take home point from the day to be that virtual engagement may be among the many approaches to engagement, but that it will never replace face-to-face engagement. Researchers still have to answer questions regarding how virtual engagement should be used and in what circumstances it works best. Wilkins responded that it is not clear

where technology will take us in the future, so as new platforms and technologies evolve, researchers should think of how they can use certain platform functionalities to create specific types of relational interactions. Grande noted that he has seen people recognize individuals they have never met in person because they had been in contact via Twitter at one point or another. In these circumstances, meeting in person can serve to deepen these relationships.

Wynia noted that he has colleagues he knows only from Twitter, and he considers these individuals to be trustworthy sources of information, though he wonders whether these relationships would be changed in important ways by meeting in person. Wynia added that Grande's talk caused him to think about the capacities of virtual platforms to engage other audiences (beyond patients and the public) such as payers, clinical communities, professional associations, or policy-makers. If someone has little or no trust of the health system, can one garner new trust via social media? Grande responded that there are numerous opportunities for research to affect the decision-making of health care delivery organizations. One aspect of Twitter, for example, is that it has many micro-communities with highly specialized interests. These are important communities to tap into, and one way to do so is to identify the key influencers in these communities and get them to distribute pertinent messages or ask relevant questions. When thinking about dissemination, he noted, it is useful to ask researchers about who the stakeholders are that might be interested in the findings from a given study, and then think about how to crack into the networks of these stakeholders. Wilkins added that she isn't sure clinicians are forming the same kinds of communities on social media that other stakeholders are.

One audience member asked Wilkins how she differentiates marketing from engagement. Wilkins responded that this is an important distinction. Often people say the word "engagement", when in fact they mean "outreach" because no bi-directionality is planned. Wilkins also noted that superficial changes in language and communication can actually result in the opposite of engagement (i.e., dis-engagement) by making certain groups of people feel as if they are not welcome.

Another audience member posed a question in reference to Grande's presentation about the relationship between researchers and policy makers, asking how one might address barriers to getting evidence into the policy making process when receiving the information might be blocked by policy makers' implicit or explicitly held values. Grande acknowledged that this is a tough question, but added that in reality, it is very unlikely that any information derived from research will fundamentally change anyone's political belief system. It can, however, bring greater visibility and exposure to issues, and this can sometimes yield results in unexpected ways. Furthermore, even if research data don't

have the power to change underlying beliefs, Grande emphasized that this does not mean that researchers should not, as scientists, continue to push.

Wynia closed this final session of the symposium by thanking both audience members and speakers, especially for the speakers' very thoughtful and provocative presentations and for the audience members' probing and robust discussions during the question and answer parts of the day. There remains plenty of work ahead, as evidenced by the energetic conversations of the day, and he noted that the D2V initiative can begin to take some important next steps based on the many ideas raised during the symposium. For instance, Wynia suggested that this might include putting together a library that compiles instances where social media is being or has been used to engage various stakeholder groups in health research; exploring a set of ethical norms to guide this work; and developing and promoting an understanding of engagement that includes notions of bi- or multi-directionality and concerns about power dynamics raised by several of the speakers, as well as other possible directions for future work on using virtual platforms to achieve effective stakeholder engagement in health research.

Summary and Next Steps on the Use of Virtual Platforms for Stakeholder-Engaged Health Research

Virtual methods have potential for engaging diverse stakeholders throughout the research lifecycle. For instance, virtual methods could make engagement activities more efficient by reducing costs associated with in-person engagement, more responsive to real-time research needs because of their capacity for rapid communication, and more inclusive of diverse groups. Realizing this potential will not happen by accident, however. Presenters and audience members at this symposium identified several critical issues and questions that ought to be addressed for virtual methods to reach their full potential in engaging stakeholders in health research.

First, achieving progress in virtual engagement will be difficult if there is lack of agreement about the overall goals and values served by stakeholder engagement in research, inadequate resources to support it, or inadequate understanding of how to do it. Symposium speakers and audience members suggested that more work is needed to clarify the core goals and values of stakeholder engagement in research, whether in traditional or virtual environments. Only then can one ask important questions like which of these goals and values might be served best, or more efficiently, using virtual means, and how can unintended consequences (e.g., exclusion of those with limited technology access) be managed?

Breaking down pre-existing hierarchies and power imbalances was emphasized throughout the symposium as a key goal of stakeholder engagement. Whether through liberating structures that intentionally level the playing field or deliberative methods that encourage participation among all voices, this may be a key to effective engagement. Are virtual platforms able to serve this function? When might they be better than in-person engagement, and when might they be worse? In sum, symposium attendees were clear that whether researchers engage stakeholders in person or virtually, engagement is relationship building, and one must always remain mindful of power dynamics in relationships.

Storytelling also emerged as a promising theme when the group discussed means of engagement. Widely accepted and recognized as particularly powerful in the "in person" setting, stories can also be told and shared in virtual settings. At the same time, stories have limited generalizability, are dependent on whose story gets told, and may be interpreted differently by different listeners. How does virtual storytelling compare and

contrast with more traditional methods, and when is virtual storytelling an appropriate means of initiating or advancing and engagement effort?

Symposium speakers and attendees who had used social media for research purposes referred to social media (particularly Facebook) as a very helpful tool. There are, however, issues that arise when collecting data from social media platforms. For instance, the metrics across platforms are not standardized, it can be tricky to plan data collection when obtaining data externally, and there is a lack of reporting standards for research that uses social media. Additionally, it was suggested during the symposium that at this point in time, most IRBs would not know how to handle the concepts that emerge around using social media in research. Despite these challenges, social media may provide a lot of opportunities from which health research could benefit.

There is a crucial and urgent need for process and outcome measures to evaluate the effectiveness of engagement activities, whether virtual or not. As noted above, a necessary first step in developing outcome metrics is being clear about the goals and values of engagement. Once this is done it should be possible to develop measures based on these goals and values and to comparatively evaluate different methods of engagement (virtual versus in-person, as well as different virtual methods or in-person methods compared to each other) in regard to achieving different aims.

Although virtual and traditional engagement methods share many ethical issues in common, some ethical concerns are particularly relevant in the virtual setting. Symposium participants identified privacy, diversity/inclusion/representativeness, consent, and trust as critically important for using virtual methods to engage stakeholders. What are the best ways to manage these issues in a rapidly changing technological environment? Might technology provide solutions to help address these concerns (e.g., by implementing dynamic, real-time consent processes for the mobile setting, or by developing virtual discussion moderators who can mediate power dynamics and ensure all voices are 'heard')? One observation is clear following the discussions at the symposium: one should not discuss virtual engagement without carefully considering ethics as well.

Appendix

Results from Audience Survey:

How old are you?	% (n=not available)
<30	17%
31-50	77%
51-70	7%
>70	0%

Are you more "conservative" or more "progressive"?	% (n=not available)
Very conservative	2%
Somewhat conservative	15%
Somewhat progressive	46%
Very progressive	37%

What is the most important ethical issue to address in using virtual platforms for engagement in health research? (n=41)

Privacy	Trust
Representation/Representativeness/ Representation	Respect
Diversity	Consent
Inclusion/Inclusiveness/Inclusivity	Power
Informed	Benefits
Electronic	Goals
Measurement	Value
Rules	Social
Safety	Justice
Balancing	Confidentiality
Authenticity	Meaningful

Appendix (cont.)

Are ANY of these ethical issues NEW, compared to ethical issues in traditional stakeholder engagement methods?   % (n=31)

Yes	19%
No	52%
Not sure	29%

Should health research that mines data available from virtual platforms (e.g., Facebook, Twitter, Google searches) be subject to human subject review (e.g., via Institutional Review Boards)?   % (n=31)

Yes	58%
No	32%
Not sure	10%

Is Google morally obligated to notify a person whose searcher suggest s/he has a serious illness?   % (n=33)

Yes	21%
No	58%
Not sure	21%

At what percentage of certainty about the diagnosis should Google be obligated to notify a person that they may have a serious illness?   % (n=33)

5% certainty or less	0%
20% certainty	0%
50% certainty	3%
80% certainty	21%
95% certainty or more	33%
Never	42%

Should Google's obligation change if the condition is NOT treatable?   % (n=30)

Yes	7%
No	73%
Not sure	20%

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