MEETING SUMMARY
PRESIDENT'S CANCER PANEL
CANCER COMMUNICATION IN THE DIGITAL ERA: OPPORTUNITIES AND CHALLENGES

June 13, 2014
San Diego, California

This workshop was the first in the President's Cancer Panel's (the Panel) 2014-2015 series, *Cancer Communications in the Digital Era: Opportunities and Challenges*. During this workshop, representatives from the academic research community, government agencies, advocacy organizations, and nonprofit organizations convened to discuss ways to organize a series of meetings focused on the potential of new media, especially social and participative media technologies, to improve the control of cancer. Participants were encouraged to live-tweet at #NewComm4Cancer during the workshop.

President's Cancer Panel

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Owen Witte, M.D.

National Cancer Institute, National Institutes of Health

Abby Sandler, Ph.D., Executive Secretary, President's Cancer Panel

Meeting Co-Chair

Bradford W. Hesse, Ph.D., Chief, Health Communication and Informatics Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute

Participants

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Shannon Stokley, M.P.H., Associate Director for Science, Immunization Services Division, Centers for Disease Control and Prevention

Eric Topol, M.D., Director, Scripps Translational Science Institute; Chief Academic Officer, Scripps Health; Professor of Genomics, The Scripps Research Institute

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WELCOME AND INTRODUCTIONS

Dr. Rimer welcomed invited participants and other attendees to the meeting on behalf of the Panel. She introduced Panel members, provided a brief overview of the history and purpose of the Panel, and described the aims of the current series of meetings. Dr. Rimer also introduced the meeting co-chair, Dr. Bradford Hesse, and the workshop facilitator, Robert Mittman.

APPROVAL OF WORKING GROUP RECOMMENDATIONS

Dr. Witte reported that the President's Cancer Panel Working Group on the HPV Vaccine met on July 24, 2012; September 13, 2012; November 16, 2012; and January 9, 2013, to discuss policy, research, and program recommendations for the 2012-2013 report to the President. Dr. Witte moved to accept the recommendations made by the Working Group on those dates. Dr. Rimer seconded the motion, and Drs. Rimer and Witte voted to accept the recommendations.

OPENING ROUNDTABLE

The goal of the current workshop is to provide input to the President's Cancer Panel on the 2014-2015 workshop series *Cancer Communications in the Digital Era*, including possible topics, key questions to address, and potential participants. Participants introduced themselves and were asked to describe a cancer-related problem for which emerging digital media may be able to provide a solution. Participants cited the potential for digital media to facilitate communication and coordination across scientific disciplines, as well as across sectors (e.g., government, private sector, academic institutions). Social media could be used to promote healthy behaviors, and also could support patients and their families across the cancer continuum, including prevention, screening, diagnosis, treatment, and survivorship. Digital media may be able to help improve patient compliance and help patients weigh evidence and make decisions. There also are opportunities to more efficiently connect patients to appropriate clinical trials and collect information from patients on their clinical trial experiences. Data collected via digital media could help refine clinical trial processes and behavioral interventions. There are opportunities to learn from what people are saying on social media and to interact with people in settings in which they already are engaged. Digital media could be used to address myths and inaccurate information. One suggestion was to utilize modern communication tools to inform the public, providers, and adolescents about the human papillomavirus (HPV) vaccine. Consideration should be given to how social media should be used to reach people across the lifespan, as well as populations with limited resources.

DR. ERIC TOPOL

NEW MEDIA: OVERVIEW AND APPLICATIONS ALONG THE CANCER CONTINUUM

Background

A practicing cardiologist at Scripps in La Jolla, California, Dr. Topol is well known for leading the Cleveland Clinic to become the leading center for heart care. While there, he also started a new medical school, led many worldwide clinical trials to advance care for patients with heart disease, and spearheaded the discovery of multiple genes that increase susceptibility for heart attacks. Since 2006, he has led the flagship National Institutes of Health (NIH)-supported Scripps Translational Science Institute in La Jolla and is a professor of genomics at The Scripps Research Institute. He is chief academic officer of Scripps Health and a co-founder of the West Wireless Health Institute. Dr. Topol pioneered development of many medications that are used routinely in medical practice, including t-PA, Plavix, Angiomax, and ReoPro, and he was the first physician to raise safety concerns about Vioxx. He has published 1,100 peer-reviewed articles and over 30 medical textbooks. In 2009, along with Drs. Francis Collins and Harold Varmus, Dr. Topol was named one of America's 12 "Rock Stars of Science" in *GQ* magazine. In 2011, the University of Michigan, where he had served on the faculty, initiated the Eric Topol Professor of Cardiovascular Medicine to recognize his contributions. The University of Rochester, his alma mater medical school, awarded him the Hutchinson Medal, the University's highest honor. In 2012, he was voted the most influential physician executive in the United States in a poll conducted by *Modern Healthcare*. Dr. Topol was elected to the Institute of Medicine of the National Academy of Sciences and is one of the top ten most-cited researchers in medicine. His book, *The Creative Destruction of Medicine* (Basic Books), was published in 2012.

Key Points

- Dr. Topol encouraged meeting participants to become active on Twitter in order to gain a better sense of the power of social media.

- Popular media and cancer center advertising often create false hope about cancer cures despite the fact that cancers often recur, even with excellent therapies. For example, a *Time* magazine cover included the headline "How to Cure Cancer," and an MD Anderson Cancer Center publication stated, "Together, We Will End Cancer."

- Messages about curing cancer mislead the public. An advertisement for the Knight Cancer Center announced, "One Down. We've already taken down one cancer. Help us take down the rest" in reference to advances in treatment for chronic myeloid leukemia (CML). This message was offensive to CML patients who cannot be cured with current treatments.

- An article in *Annals of Internal Medicine* analyzed cancer center advertising to the public and found that cancer centers evoke hope for survival, focus on innovation, and use fighting language, among other things.

- Social media can be used to spread more accurate messages and help patients have more realistic expectations.

- A survey by the Huntsman Cancer Institute found that 34 percent of respondents would not seek genetic testing to predict the likelihood of developing a hereditary cancer. This is troubling because genetic testing for cancer can be beneficial.

- An article in *The New York Times* included an infographic illustrating a small decline in cancer mortality over time compared with a much larger decline for heart disease death rates. Cancer death rates declined by 2 deaths per 10,000 people between 1958 and 2010 while death rates for heart disease fell by 38 deaths per 10,000 people over the same time period.

- Better messages about cancer have been included in magazines such as *Wired* and *Consumer Reports*. *Consumer Reports* rated cancer screening tests and concluded that approaches to screening often are based on a 1960s view of the disease.

- Some screening tests are still widely used even though they have been shown to cause net harm. Making screening decisions on an individualized basis would be more appropriate than conducting mass screening. For some people, annual screening may cause more harm than benefit. The general public does not know about research that has called some screening practices into question.

- Personalized medicine can be effective, but many physicians do not know what tests and treatments they should be using. One study found that only 6 percent of U.S. patients with lung cancer are screened for *EGFR* mutations that predict responsiveness to drugs like erlotinib. Many women with breast cancer do not undergo testing for the mutations that predict responsiveness to Herceptin.

- Current communication strategies directed to consumers and doctors are suboptimal, as are messages from academic medical centers. The public should be educated about important cancer-related issues so that they can discuss these issues with their doctors, who may or may not be aware of the care they should be offering patients.

DR. BRADFORD HESSE

CANCER COMMUNICATION IN THE DIGITAL ERA: OPPORTUNITIES AND CHALLENGES

Background

Dr. Hesse received his degree in social psychology from the University of Utah in 1988 with an accompanying internship in the nascent field of medical informatics. After completing his degree, he served as a postdoctoral fellow within the Department of Social and Decision Sciences at Carnegie Mellon University. For more than 20 years since, Dr. Hesse has been conducting research in the interdisciplinary fields of social cognition, health communication, health informatics, and user-centered design. He was recruited to the National Cancer Institute (NCI) in 2003 and has since focused his energies on bringing the power of evidence-based health communication to bear on the problem of eliminating death and suffering from cancer. He continues to direct the Health Information National Trends Survey (HINTS), a biennial general population survey aimed at monitoring the public's use of health information during a period of enhanced capacity at the crest of the information revolution. He also serves as program director for the Centers of Excellence in Cancer Communication Research, a cutting-edge research initiative aimed at expanding the knowledge base underlying effective cancer communication strategies. Dr. Hesse has authored or co-authored over 160 publications, including peer-reviewed journal articles, technical reports, books, and book chapters. In 2009, his co-authored book titled *Making Data Talk: Communicating Public Health Data to the Public, Policy Makers, and the Press* was named book of the year by the *American Journal of Nursing*.

Key Points

- A 2005 article in *The New York Times* described the experience of a cancer survivor named Meg Gaines. As she was being treated for cancer, she struggled with the doctor-centric world of medicine in which it was difficult to get answers to questions. She faced cloistered knowledge, fragmentation

of care, and inaccessible medical records. She felt that she had limited support as she worked to navigate this world. Many people today struggle with these same challenges.

- Billions of dollars are spent looking for better treatments and effective prevention and early detection interventions. However, the benefits of this research will not be realized if effective interventions are not available to patients. It is important that system supports be created in order to get these interventions to patients.

- There has been longstanding interest is using technology to facilitate communication. In 1984, the National Science Foundation and National Library of Medicine were investing in work focused on how networking information technology might influence the behavior of practicing professionals. These influences were thought to be realized through impact on the environment, time, and people. For example, telemedicine and other mobile technologies have allowed care to be delivered at the point of need, which is not necessarily in medical settings. Also, asynchronous communication via email or through electronic medical records can increase efficiency. Communication tools also may be able to help overcome some of the social constraints that have affected minority populations. In order to achieve the potential of digital tools, it is important to create a reliable interface to connect health care systems and patients.

- Data from the 2012 HINTS indicate that 80 percent of people in the United States had access to the Internet at that time. This exceeds goals set by both *Healthy People 2010* and *Healthy People 2020* and represents an approximately 16 percent increase since 2003.

- Males and females access the Internet at similar rates despite early predictions that there would be lower uptake among females.

- Individuals with lower incomes are less likely than those with higher incomes to have Internet access, but these differences have decreased over time. Mobile access to the Internet may play a role in reducing differences between socioeconomic groups.

- Individuals with less education are less likely than those with more education to have access to the Internet. Differences by education have decreased somewhat over time but remain notable. In 2012, more than 90 percent of college graduates had Internet access compared with about 70 percent of those with less than a high school education.

- Younger people are more likely than older people to have Internet access. In 2012, more than 90 percent of 18- to 35-year-olds had access to the Internet compared with about 60 percent of people over 75 years old. Younger people also are more likely than older people to use social media. Although Internet use has increased among older people in the United States over the past ten years, new technologies may not be the best way to reach this population.

- Among people who have Internet access, social media use is higher among racial/ethnic minorities than among non-Hispanic whites. About 30 percent of non-Hispanic white Internet users participate in social networking compared with more than 40 percent of Hispanic and African-American Internet users.

- There was concern that availability of health information on the Internet would erode people's trust in physicians. Although people commonly use the Internet as their first source for cancer information, physicians have become an even more highly trusted source. This is thought to be in part because people often need assistance in understanding information they find on the Internet. People also are beginning to use email to communicate with their physicians.

- Cancer survivors prefer their physicians to be their first source of health information. Physicians are most often the first source of information used by survivors in the first year after diagnosis, but survivors are more likely to turn first to the Internet when they are between two and ten years post diagnosis.

- HINTS data indicate that people can find cancer information more easily now than in the past.

- People with chronic conditions are less likely to use the Internet than are those without chronic conditions, in part because those with chronic conditions tend to be older. However, once people with chronic conditions are online, they often become actively involved in social networking and start paying attention to reliable web-based information.

- The concept of the "social life of information" emphasizes the need to think beyond technology when considering information dissemination.

- The digital era poses many challenges but also many opportunities. The cancer community needs to understand how to take advantage of digital media and how to counter myths propagated through these outlets. There are opportunities across the cancer continuum to improve care. There also are opportunities to support cancer research and bring together stakeholders from across the cancer community.

QUESTIONS AND KEY POINTS OF DISCUSSION

- Many people do not trust the American Cancer Society (ACS) or NCI. It is unclear whether the Internet is going to help or hurt the credibility gap of these organizations from the perspective of the general public.

- Social media do not negate the need to address the social and environmental contexts that influence health. Recent activities in the Middle East often are referenced as an example of the power of social media, but the failings of the Arab Spring illustrate that social media alone cannot solve problems.

- Low-income populations have greater access to technology than in the past, but this does not necessarily mean that they are consistently connected. In a recent field experiment of working poor populations with cell phones, 30 percent of participants could not be reached for follow-up. This population goes on and off the grid for a variety of reasons; for example, their phones may be disconnected because they cannot pay their bills.

- Cancer centers have an economic incentive for emphasizing cures and positive messages.

- The first precision trial will soon be launched through the National Clinical Trials Network. This is a new way of doing research and it likely will be difficult to explain to the general public.

- The viral spread of information via digital media is a double-edged sword. Trust can be enhanced if there are consistent messages provided within context. However, there is also a chance that people will become rapidly polarized and begin identifying with extreme points of view. It is important to keep in mind the roles of long- and short-term feedback loops and systems-level factors.

- People should be taught to weigh evidence and make decisions. For too long, communications research has focused on convincing people to adopt certain behaviors that public health professionals think are best. Problems arise when subsequent evidence suggests that those behaviors are not optimal. Organizations that have promoted those behaviors then feel that their credibility is at risk and lash out at those with contradicting messages.

- The changes taking place in the digital era cannot be ignored. These changes create challenges for the academic and research communities in terms of how to engage people and how to take control of and optimize messages. It can be difficult to try to put issues into perspective if they have been distorted by other parties.

- A study was done to compare the quality and credibility of information on the ten most costly medical conditions on Wikipedia versus in the peer-reviewed literature. Cancer was one of the conditions studied. Significant discordance in quality and credibility was found between the two sources.

- Consideration needs to be given to how to reach people who are influential in target communities. The federal government issues press releases and provides some facts, but these facts then move into the social media sphere. It would be a good idea to engage with influential people who can strengthen

messages and help them reach target communities. The U.S. Food and Drug Administration has had some success using this approach for diffusion of data.

BRAINSTORM: TOPICS AND FOCUS AREAS

Participants were asked to brainstorm about potential topics and ways to organize these subjects for the upcoming Panel series of meetings on cancer communications in the digital era.

Key Points

- One option would be to hold workshops on the following topics: (1) New media as a tool to address traditional problems in cancer control, (2) new opportunities created by new media, and (3) new problems that have been created by the existence of new media. Problems that need to be addressed include developing strategies for responding to the more rapid diffusion of myths and ways to be pre-active instead of reactive.

- One potential organizing framework for the Panel series would be to focus on local, regional, and national considerations for and/or examples of cancer communications. For example, San Diego has achieved some success related to obesity via Community Transformation grants and Putting Prevention to Work grants, largely through the work of community-based organizations and local tactics. The series also could focus on unique issues that affect different regions of the country; for example, the Southeast is very different from the Southwest. Consideration also could be given to strategies that could be used by national organizations such as NCI and ACS.

- One Panel workshop could focus on communication challenges across the cancer continuum—from prevention through end-of-life care. A second workshop could focus on target audiences, such as patients and families, providers, and health care systems. A third workshop could focus on opportunities created by new media. Another workshop that could fit into this framework would be one that focuses on types of technology. Specific brands (e.g., Facebook, Twitter) would not be the focus; rather, the discussion would focus on the types of interactions supported by different types of media.

- Workshops could be organized by target audiences, including patients and families, providers, professional organizations, support groups and advocacy groups, and health care systems. There needs to be consideration of how messages should be tailored for these various constituencies. For example, consideration could be given to how to communicate with health care professionals about making the best recommendations for their patients. It will be important to learn more about what is being done by patient groups such as PatientsLikeMe and Cancer Commons.

- Target populations could be defined based on desired behaviors or behavior change. One framework that could be used is healthy people, patients undergoing cancer treatment, and patients whose cancer is in remission. The desired actions for these groups are somewhat different. Healthy people should be encouraged to adopt healthy behaviors and avoid unhealthy behaviors. People who have been diagnosed with cancer could be encouraged to consider a clinical trial or share their experiences via social media.

- There are many crosscutting issues that should be addressed at all of the Panel workshops. All workshops should include broad representation from multiple sectors, including the private sector, advocates for the underserved, and others. Each workshop should consider local, regional, and national examples and issues. All of the workshops should consider multiple platforms and technologies, including but not limited to social media, and all should include representation of diverse populations.

- Taking the mentioned crosscutting themes into account, workshops could be held on the following topics: (1) research; (2) prevention, screening, and early detection; and (3) cancer care and survivorship. The research workshop would focus on discovery science and clinical trials and could

include discussion of trial enrollment, biorepositories, informed consent, and other issues. The second meeting would address topics such as health behavior, behavior change, and screening uptake. The third workshop would focus on issues such as providing support for patients, integrating care, answering patients' questions, ensuring continuity and coordination of care, and defining the role of communications in the delivery of patient- and family-centered care.

- Workshops could be organized around outcomes, quality, cost/value, and privacy. There needs to be a deeper understanding of the outcomes associated with technology use. One randomized clinical trial of Internet access found that quality of life was lower among cancer patients with Internet access.

- The Panel series should address the need for research on issues related to digital communications, including the impact of social media and how messages spread. The concept of "circles of influence" should be incorporated into the study of social media.

- Panel meetings could focus on examples in which social media have played a role in propagating misinformation. Some examples include myths about cancer and skepticism about vaccination.

- Panel workshops could focus on ways technology could be used to make a difference. The impact of technologies on outcomes should be measured. One example would be how technology could be used to reduce and contain costs associated with cancer, including but not limited to the costs of care. Another application would be looking at ways to increase the ability of patients and families to make good decisions.

- The Panel should learn from the for-profit sector about ways to use information to improve health. Entrepreneurs, including people who work with Google Analytics and others, have developed ways to leverage social movements and fads for commercial purposes. Some of these approaches could be applied to health.

- Consideration should be given to systems that need to be in place to facilitate communication about emerging science to the public. The future will bring tremendous developments in cancer-related science. This new knowledge will undoubtedly be misinterpreted, misrepresented, and reinterpreted. Systems need to be in place to guide the dissemination of information in these situations. These systems need to take into account the fact that the landscape of communication is changing and will continue to change.

- Evidence changes rapidly, but the rules for judging evidence do not change nearly as rapidly. Public health professionals would be better served by instructing the public about how to judge evidence than by simply disseminating facts.

- Social media and participatory platforms can facilitate partnerships and communication among different sectors, including the public sector, commercial entities, and various parts of the health care system.

- Organizations with an interest in cancer should work in a coordinated way to use new media. For example, organizations could agree to use a certain hashtag to communicate about important topics of common interest. Organizations also should work together behind the scenes before launching campaigns to facilitate unified and coordinated messaging. The Office of the National Coordinator for Health Information Technology (ONC) has been using this approach for its Blue Button initiative, which is focused on promoting access to health data. ONC is working with ACS, the Centers for Medicare and Medicaid Services (CMS), Aetna, United Healthcare, and others on this campaign. All of the organizations will use the same symbol. Coordination of activities among organizations also has occurred related to the Lung-MAP trial, a new protocol being launched for lung cancer.

- Consideration should be given to how to capitalize on hot-button issues to disseminate messages of interest. For example, the e-cigarette phenomenon has brought tobacco control back to the forefront. This provides an opportunity to focus media attention on this topic.

- As new media rapidly evolve, adequate resources need to be made available and strategies should be developed to keep pace with this evolution.

- It is difficult to reconcile the slow pace of research with the rapid pace of innovation and advancement of technology. Research methods must evolve to be able to more rapidly inform development and optimization of messages and interventions.

- Communication, including communication about cancer, should be considered as being part of an ecosystem rather than as discrete interactions or activities of individual people or organizations. Different people and groups use technologies in very different ways. It would be beneficial to understand some of these differences.

- Digital technology may support systems science by facilitating the collection of various types of data by geographic area (e.g., county, neighborhood). This would facilitate tracking and correlation of health outcomes by different variables, identification of areas that are over- or underperforming with respect to health outcomes, and transfer of lessons learned in high-performing areas to other areas.

- The intersection of telecommunications policy and health policy should be considered. In South Korea, virtually all households have access to the Internet because of policies in that country.

- Panel workshops should include consideration of global issues. Modern communication is not limited by borders. The U.S. can learn from other places in the world and can also share what we know.

- Technology has potential to impact health in many settings outside of the health care system; for example, providing lighting in parks so that people can jog at night.

SENSE-MAKING AND PRIORITIZATION

The following seven potential workshop structures were considered and discussed. Participants acknowledged that the potential series structures are not mutually exclusive. Any structure selected likely would incorporate components from other structures as crosscutting themes. Additionally, regardless of the series framework, invited participants should represent a spectrum of disciplines and interests. Following discussion, participants prioritized the proposed structures (order of list does not reflect outcomes of prioritization).

Structure 1

1. New media as a tool to address traditional problems in cancer control.

2. New opportunities created by the existence of new media.

3. New problems created by the existence of new media.

4. Integrative workshop

Key Points of Discussion

- This framework acknowledges that there are problems created by new media. It would be useful to articulate these problems and discuss how to avoid or minimize them.

- Other proposed structures could be incorporated into this structure. For example, different target audiences and parts of the cancer continuum could be considered at each workshop.

- This framework has a broad scope, which might create challenges in planning and formulating recommendations.

Structure 2

1. Patients and families

2. Providers

3. Professional organizations

4. Support groups and advocacy groups

5. Health care systems

Key Points of Discussion

- One benefit of this structure is that it facilitates organization of issues and recommendations by responsible stakeholders. It makes it easy to articulate who should be doing what.

- The workshops listed for this structure could be condensed. Support and advocacy groups could be combined with patients and families. Providers and health care systems also could be combined.

- Community members should be added as a target audience.

- It would be helpful to gain a better understanding of the target audiences to be reached via new technologies.

- Considering various target populations separately may not be optimal since integration of all of these players is needed to make progress in cancer control.

Structure 3

1. Local

2. Regional

3. National

Key Points of Discussion

- New media are not geographically limited, so this is not a preferable organizing framework.

Structure 4

1. Cancer continuum

2. Target audiences

3. Technologies

4. Challenges and opportunities created by new media

Key Points of Discussion

- This structure encompasses many of the other proposed frameworks, including Structures 2 and 5.

- For the workshop on technology, it would be interesting to hear from technologists how they are addressing some of the challenges associated with technology in other domains. Discussions of challenges and opportunities in the fourth workshop should include consideration of policy and data.

- This structure creates a good framework for actionable recommendations.

- Modern technologies are disruptive. For example, using Twitter allows people to engage with the discussion at this meeting even if they are not in attendance. It makes sense to consider technologies as a separate topic because this allows an opportunity to consider the current state of technology and what is expected to develop in the future.

- All of the topics in this structure are very broad. It is difficult to envision who would be invited to participate in these workshops.

Structure 5

1. Discovery science and clinical trials
2. Prevention and early detection
3. Cancer care
4. Survivorship

Key Points of Discussion

- This framework provides focus and defines domains in which actions could be taken. This approach has potential to promote advancement in areas in which progress has lagged.
- If this framework is adopted, target audiences could be considered at each workshop.

Structure 6

1. Outcomes
2. Quality
3. Cost/value
4. Privacy

Key Points of Discussion

- This structure is likely to lead to actionable recommendations.
- This structure addresses several major societal issues.
- If this framework is adopted, it will be necessary to think more about what outcomes should be considered (e.g., mortality, quality of life). Outcomes are defined differently by different people and disciplines.
- There has traditionally been hesitation about discussing costs associated with cancer. However, cost should be discussed and addressed. There are opportunities to reduce waste.

Structure 7

1. Players/target audiences
2. Technologies
3. Data

Key Points of Discussion

- Digital technologies are not limited to social media. They include tools that facilitate data collection (e.g., mobile apps, wearable technologies), which creates opportunities to capture new and additional data related to cancer and cancer risk. Data can be utilized at multiple levels and in multiple ways to support systems-level study of cancer.
- The ultimate goal is to improve lives of patients. Improving technology and data collection are important, but only because of their roles in improving the lives of patients.
- The nature of data is changing. In the past, researchers had control over generation and dissemination of data, but new technologies are shifting this power to community stakeholders.

- It is important to try to anticipate the types of technology that will emerge in the future. This is something the Institute for the Future has done well.

PUBLIC COMMENT

- There was no comment from the public.

INPUT INTO WORKSHOPS: POTENTIAL TOPICS AND QUESTIONS

Informed by the discussion and prioritization exercise, Panel members identified the following structure as the focus of the remainder of the workshop.

Workshop 1. New media as a tool to address traditional problems in cancer control.

Workshop 2. Problems and new opportunities created by the existence of new media.

Workshop 3. Integrative workshop focused on a systems perspective.

Participants were asked to brainstorm about questions that should be addressed and potential participants for each workshop.

Key Points

- Several participants advocated for identifying specific problems for discussion at the workshops. If the workshops attempt to address a broad array of topics, it will be difficult to identify participants and define questions. It also will be difficult for the Panel to develop a high-impact report. One proposal is to focus on four discrete problems in cancer control for the first workshop.

- There are a number of problems in cancer control that potentially could be addressed in the workshop. The challenge is to identify appropriate and representative examples of work in these areas. One drawback of structuring the series around exemplars is that some people or organizations may feel excluded.

- One way to identify topics for workshop 1 would be to find exemplary work focused on each of the identified target audiences (e.g., patients and families, providers, professional organizations). For example, a representative of PatientsLikeMe could be invited to talk about the work that organization is doing and the problems it has been able to address.

- One approach would be to look at different cancer types, keeping in mind the populations that are most affected by each type. There are significant differences in how men and women communicate. It would be a mistake to assume that strategies that work for women with breast cancer also will work for men with prostate cancer.

- HPV-associated cancers would be an interesting topic for discussion because digital and social media have facilitated dissemination of misinformation about the HPV vaccine. In addition to addressing HPV vaccination, the series could include discussion of the need to inform clinicians about the increasing proportion of head and neck cancers that are caused by HPV and issues facing survivors of HPV-associated cancers. Another benefit of this topic is that it would build on the most recent Panel report.

- Prostate cancer screening may be a topic of interest. Many experts have concluded that prostate-specific antigen (PSA) screening results in net harm. Many men who are treated for prostate cancer deal with permanent life-changing side effects. However, there are many people who continue to think that foregoing PSA screening is irresponsible. This may be an area for continued research.

- Most experts agree that colorectal cancer screening has value. A new campaign is focused on increasing colorectal cancer screening by 2018. It might be interesting for the Panel to convene a

discussion about how to use new media to help achieve this. This topic is timely and has potential for actionable recommendations.

- Sun safety and indoor tanning are other potential workshop topics. There is opportunity to change people's perceptions and social norms in this area. Another potential topic is weight management, both for cancer prevention and cancer survivors. There are many user-generated interventions (e.g., Instagram) that people are using to support their weight loss efforts. Other topics include the digital divide, uptake of advance directives, facilitation of end-of-life discussions, lung cancer screening, e-cigarettes, and clinical trials accrual. There have been examples of patients influencing who does and does not participate in clinical trials.

- It may be difficult to identify the exemplary programs. There are many ongoing activities in this area. The challenge will be to identify the best examples that also have evidence of positive impact. Most activities have not accrued evidence of impact. The exemplars do not necessarily need to focus on the selected problems in cancer control (e.g., tobacco, HPV vaccination, colorectal cancer screening uptake); they could be from other areas of health or from the business sector, but they need to have lessons applicable to cancer control.

- Crowdsourcing or other new media strategies could be used to solicit ideas for problems in cancer control that could be addressed by new media. Once potential problems are identified, examples of efforts to address these problems using new media could be found.

- Creating a formal challenge or prizes may help attract people from different disciplines to identify examples of evidence-based activities or to develop solutions for pressing problems in cancer control. This approach has worked in both the private and public sectors.

- When selecting topics for the workshop, consideration should be given to points of engagement that would have the biggest impact on public health.

- In selecting cancer control problems to address, it is important to ensure that communication processes and dynamics are a central part of the problem.

- One question that could be addressed is how new media could be used to facilitate use of evidence-based information by community stakeholders in order to promote cancer control in various ways.

- More research is needed on applications of social media in cancer, but social media research has been conducted in other areas (e.g., marketing). Lessons learned in other fields need to be identified and adapted for cancer control. It is important to identify what is known in order to determine what needs to be done to advance the use of new media for cancer control.

- Ideas for new media strategies should be gathered from other fields and sectors. For example, if adherence to treatment is an issue of interest, input could be solicited from the television industry, which has strategies for increasing the likelihood that people remain engaged with programming.

- Analysis of big data might identify potential topics. Legacy conducted an analysis of ten years of data for QuitNet, one of the most successful and longstanding self-help smoking cessation programs. The analysis showed that there were a few thousand key individuals who formed the foundation of the millions of interactions and contacts that took place through QuitNet. Without prompting or guidance, these individuals remained engaged for years after they quit smoking and formed a densely connected core for the social network. This may be a lesson about how to sustain a social network while ensuring that it remains a product of and for the community, not something done to the community.

- It will be very important to gather the right balance of participants at the first workshop. It should include broad and diverse representation, but there must be some focus.

- Some questions that could be asked in the first workshop include: What new technologies are people using? What are they doing with those technologies? Are they having an impact? What do people not yet using new technologies want to use them for?

- The second workshop could include discussion of how new media might be able to help address cancer health disparities as well as the risk that these disparities will increase with the emergence of new media.

- The second workshop could also focus on issues related to value and privacy. For example, new technologies may create ways to better communicate with patients about the costs and potential value of treatments. There also is a lot of concern about privacy; it would be of interest to address misconceptions about privacy and discuss ways to ensure that privacy is adequately protected.

- Experts in online marketing and banking were suggested as potential participants for the second workshop. The banking industry has dealt with issues of privacy.

- It would be interesting to learn more about how norms and consensus are established within social networks. A sentiment analysis published in the recent special issue of the *Journal of the National Cancer Institute* found that people in social networks with a positive view of the use of CHANTIX for smoking cessation were more likely to use and adhere to the treatment.

- Workshop 2 could include discussion of new research methods and possibilities. New media create opportunities to collect continuous longitudinal data and integrate different types of data (e.g., genomic, microbiomic, behavioral, environmental). Rich information can be generated, even from studies of a single person. However, the possibility of continuous and long-term data collection raises issues related to informed consent.

- Workshop 3 provides an opportunity to consider systems-level issues, including context and feedback loops that may come into play.

- The third workshop could focus on how to measure success in the area of cancer communications in the digital era.

- The third workshop could also be used as an opportunity to identify stakeholders responsible for implementing recommendations. In its recent report on HPV vaccination, the Panel identified the Centers for Disease Control and Prevention (CDC) and other stakeholders responsible for implementing each of its recommendations. CDC has taken this charge seriously and is actively working to move this issue forward.

- In addition, the third workshop could focus on policy and practical implications of the issues discussed and recommendations generated during the first two workshops. It will be necessary to make policy decisions about some of these issues even if there is not comprehensive supporting evidence.

- One option for the third workshop is to engage a broad array of cancer-related organizations (e.g., ACS, LIVESTRONG, Komen) to solicit their input. Many organizations are struggling with the issue of new media. The workshop could model many of the concepts that will be discussed during the series, such as facilitating broad online and offsite engagement. Bringing many stakeholders together would serve as a catalyst for dissemination of the report and, hopefully, implementation of recommendations.

- The third workshop should include representation from cancer-related groups already actively engaging with social media. For example, there is a widely used breast cancer social media hashtag, and LIVESTRONG has some robust networks.

- The Panel could solicit ideas for innovative ways to use new media to address issues raised during the first and second workshops. Ideas could include things like apps, systems, or services. The most interesting ideas could be selected for presentation at the third workshop.

- The third workshop should include representation from global organizations. The World Health Organization (WHO) is doing interesting work in this area. WHO representatives recently spoke with Harvard researchers about building capacity for risk communication science. A distinction must be

made between personal health information and other types of information that may be less sensitive. Considerations related to Health Insurance Portability and Accountability Act provisions will need to be taken into account as people share or are asked to share their data.

- There should be at least one high-risk workshop in the series that brings together experts from outside the cancer field to brainstorm about how technology could be applied to improve cancer control. However, the external perspective needs to be balanced by an awareness and understanding of the rigor and evidence needed to apply new technologies to clinical and public health problems. One option would be to have cancer experts present problems in cancer control during the first half of the workshop and then have outside technology experts discuss innovative ways to address these problems.

- One workshop could be structured as a cancer control "hackathon" with experts from various fields coming together to brainstorm solutions to a specific cancer control problem (e.g., colorectal cancer screening uptake). Although a central feature of this type of meeting is promoting creativity, the importance of evidence cannot be forgotten. There should be discussion about how to go about evaluating new media-based approaches to address cancer.

- A recent meeting used an innovative approach to brainstorm about new ways to treat addiction. Approximately 30 participants were invited to the meeting, but only 2 were from the addiction treatment field. The rest were technologists, biomedical engineers, nanotechnologists, and other technology experts. Two addicts and two children of addicts gave detailed presentations about their lives. Participants then broke into groups, each one with consumer representation, and designed a technology-based addiction treatment. The results were fascinating.

- A high-level definition of new media should be developed. Several related terms have been used through the course of discussion (e.g., new media, social media, new technology, social technology), but the definitions of these terms are unclear. One option would be to use the framework put forth in the recent President's Council of Advisors on Science and Technology report on envisioning a digital future. It was suggested that any definition should include technologies that are social, mobile, and cloud based. Social media include things like Twitter, Facebook, Pinterest, and Instagram. These tools are important, but attention also should be paid to the ability to capture information using other types of tools. One term that was suggested for consideration is "the social-technical ecosystem." Inclusion of the word "ecosystem" acknowledges that various components are in play. Another definition that was suggested is "user-generated content and user-generated interaction."

- There was discussion of whether the series should focus only on communication in the traditional sense (i.e., exchanges among two or more entities) or whether it also should include consideration of how to capture and utilize data generated through digital technologies.

- The book *The Unpersuadables* by Will Storr argues that many people look only to select information sources that reinforce their current opinions. It is possible that social media reinforce polarized thinking. It may be useful to conduct research on how to reach people who are entrenched in their opinions. Even if some people hold extreme views, there also are a number of people in the "persuadable middle" who can be targeted with positive health messages. One strategy is to find ways to become credibly integrated into discussions or social networks that perpetuate misinformation about cancer and health.

- The consumer perspective should be represented at the workshops. Patients should be asked to tell their stories, and these experiences should frame the discussion.

- It may be helpful to clarify the desired outcomes of the workshops and/or new media interventions. Some cancer control efforts aim to change behavior while others mainly focus on education and decision-making.

- Two dimensions of new media need to be considered. First, there needs to be recognition of the social networks and online activities that have developed naturally among cancer patients and other

stakeholders. It is important to understand these activities so that lessons can be learned and applied. Secondly, new media provide opportunity to develop and implement new types of interventions that can improve cancer control. Public health professionals tend to focus on creating interventions, but it also is important to learn from ongoing grassroots efforts.

- The slow pace of traditional research cannot address many of the questions surrounding new media. Consideration needs to be given to new ways to generate and use data in order to more rapidly accumulate evidence. There inevitably will be tension between the desire to robustly evaluate interventions and the need to quickly measure outcomes.

- The Panel should recommend that steps be taken to ensure that all or nearly all people in the United States have access to high-speed Internet.

- The Panel may want to consider the "two-lane" Internet issue that is being considered by the Federal Communications Commission. This may have important implications for the digital divide and other issues of interest to the Panel.

- The general public needs to be able to understand public health concepts in order to make informed decisions. Emphasis should be placed on increasing numeracy and literacy skills among K-12 students and other age groups.

- It may be helpful to look at the participants and outcomes of other meetings related to health and technology that are not necessarily focused on cancer (e.g., Health Datapalooza, Health 2.0, mHealth Summit).

- One potential participant for the third workshop is Phil Bourne from the University of California, San Diego. Dr. Francis Collins called on him to help with issues related to the Human Genome Project.

- The Panel should think about how it will measure the success of the workshops and consider the risks of the framework that has been discussed.

- Stronger partnerships are needed between the public and private sectors. The private sector often is able to move from research into practice more quickly.

- New media are not going to provide easy or quick solutions to problems in cancer control. These tools are constrained by the larger context in which they exist.

PUBLIC COMMENT

- There was no comment from the public.

CREATION OF A PANEL WORKING GROUP

Dr. Witte proposed a motion to establish a Panel Working Group for the communications series. Dr. Rimer seconded the motion. Drs. Witte and Rimer voted in favor of the motion.

CLOSING REMARKS

Panel members and staff will take the input provided into account as they develop a framework for the series. Panel members thanked the participants for their valuable contributions. Dr. Rimer asked the participants to submit any additional input via email.

CERTIFICATION OF MEETING SUMMARY

I certify that this summary of the President's Cancer Panel meeting, *Cancer Communication in the Digital Era: Opportunities and Challenges*, held June 13, 2014, is accurate and complete.

Certified by: _____   Date: ___August 29, 2014___

                 Barbara K. Rimer, Dr.P.H.
                 Chair
                 President's Cancer Panel