



LAUNCH

L.A.U.N.C.H. Senior Leadership Think Tank
Exploring the Future of Connected Cancer Care
in Rural America and Beyond

Summer 2019

Federal Communications
Commission

Washington, DC



L.A.U.N.C.H. Senior Leadership Think Tank

Exploring the Future of Connected Cancer Care in Rural America and Beyond

MEETING SUMMARY

In 2017, the National Cancer Institute of the National Institutes of Health and the Federal Communication Commission's Connect2Health Task Force joined forces to catalyze a multi-stakeholder collaborative – the L.A.U.N.C.H. initiative (Linking & Amplifying User-Centered Networks through Connected Health: A Demonstration of Broadband-Enabled Connected Health and Community-Based Co-Design). L.A.U.N.C.H. seeks to address one of the key challenges of rural cancer care: quality symptom management. The goal is to leverage connectivity and advanced technology to improve the lives of cancer patients living in rural areas, who bear the double burden of having the highest cancer mortality rates and lowest levels of broadband access and adoption.



Other Collaborators:

University of Kentucky Markey Cancer Center
University of California San Diego Design Lab
Amgen

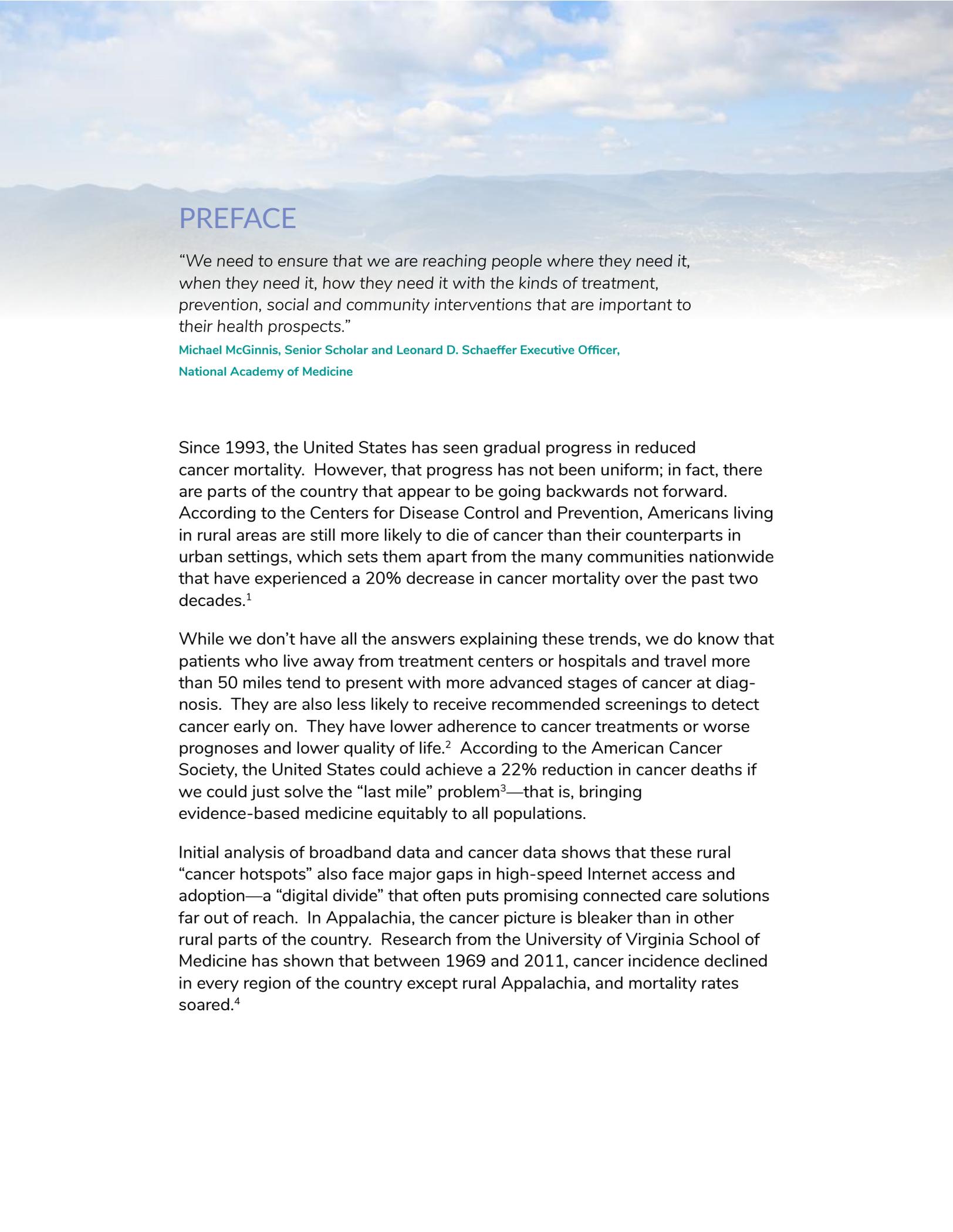
More information about the L.A.U.N.C.H. initiative is available at
www.LaunchHealth.org and www.FCC.gov/health/cancer

*Cover photo: The mountain range depicted on the cover is of the Middlesboro View from Pinnacle Overlook in Kentucky.

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PREFACE

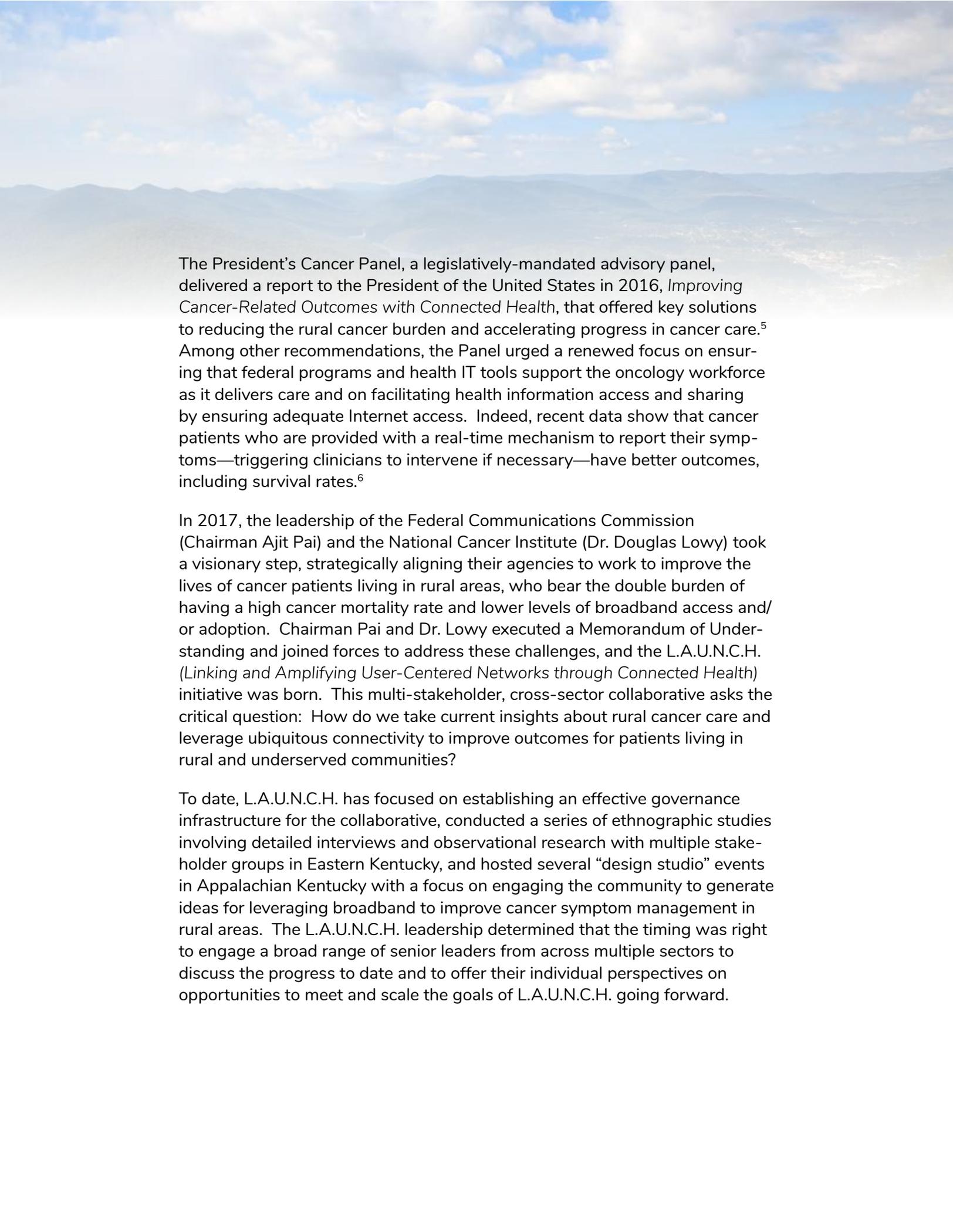
“We need to ensure that we are reaching people where they need it, when they need it, how they need it with the kinds of treatment, prevention, social and community interventions that are important to their health prospects.”

**Michael McGinnis, Senior Scholar and Leonard D. Schaeffer Executive Officer,
National Academy of Medicine**

Since 1993, the United States has seen gradual progress in reduced cancer mortality. However, that progress has not been uniform; in fact, there are parts of the country that appear to be going backwards not forward. According to the Centers for Disease Control and Prevention, Americans living in rural areas are still more likely to die of cancer than their counterparts in urban settings, which sets them apart from the many communities nationwide that have experienced a 20% decrease in cancer mortality over the past two decades.¹

While we don't have all the answers explaining these trends, we do know that patients who live away from treatment centers or hospitals and travel more than 50 miles tend to present with more advanced stages of cancer at diagnosis. They are also less likely to receive recommended screenings to detect cancer early on. They have lower adherence to cancer treatments or worse prognoses and lower quality of life.² According to the American Cancer Society, the United States could achieve a 22% reduction in cancer deaths if we could just solve the “last mile” problem³—that is, bringing evidence-based medicine equitably to all populations.

Initial analysis of broadband data and cancer data shows that these rural “cancer hotspots” also face major gaps in high-speed Internet access and adoption—a “digital divide” that often puts promising connected care solutions far out of reach. In Appalachia, the cancer picture is bleaker than in other rural parts of the country. Research from the University of Virginia School of Medicine has shown that between 1969 and 2011, cancer incidence declined in every region of the country except rural Appalachia, and mortality rates soared.⁴



The President's Cancer Panel, a legislatively-mandated advisory panel, delivered a report to the President of the United States in 2016, *Improving Cancer-Related Outcomes with Connected Health*, that offered key solutions to reducing the rural cancer burden and accelerating progress in cancer care.⁵ Among other recommendations, the Panel urged a renewed focus on ensuring that federal programs and health IT tools support the oncology workforce as it delivers care and on facilitating health information access and sharing by ensuring adequate Internet access. Indeed, recent data show that cancer patients who are provided with a real-time mechanism to report their symptoms—triggering clinicians to intervene if necessary—have better outcomes, including survival rates.⁶

In 2017, the leadership of the Federal Communications Commission (Chairman Ajit Pai) and the National Cancer Institute (Dr. Douglas Lowy) took a visionary step, strategically aligning their agencies to work to improve the lives of cancer patients living in rural areas, who bear the double burden of having a high cancer mortality rate and lower levels of broadband access and/or adoption. Chairman Pai and Dr. Lowy executed a Memorandum of Understanding and joined forces to address these challenges, and the L.A.U.N.C.H. (*Linking and Amplifying User-Centered Networks through Connected Health*) initiative was born. This multi-stakeholder, cross-sector collaborative asks the critical question: How do we take current insights about rural cancer care and leverage ubiquitous connectivity to improve outcomes for patients living in rural and underserved communities?

To date, L.A.U.N.C.H. has focused on establishing an effective governance infrastructure for the collaborative, conducted a series of ethnographic studies involving detailed interviews and observational research with multiple stakeholder groups in Eastern Kentucky, and hosted several “design studio” events in Appalachian Kentucky with a focus on engaging the community to generate ideas for leveraging broadband to improve cancer symptom management in rural areas. The L.A.U.N.C.H. leadership determined that the timing was right to engage a broad range of senior leaders from across multiple sectors to discuss the progress to date and to offer their individual perspectives on opportunities to meet and scale the goals of L.A.U.N.C.H. going forward.

MEETING OVERVIEW AND PURPOSE

On May 28, 2019, the Federal Communications Commission's (FCC) Connect2Health Task Force (C2H Task Force) and the National Cancer Institute (NCI) of the National Institutes of Health convened a groundbreaking meeting at FCC headquarters in Washington, DC, with senior thought leaders from both the public and private sectors and across the country. The broad expertise included representatives from government, academia, industry, healthcare systems, public health, biotechnology, design and innovation, and telecommunications. The more than 6-hour meeting was designed to usher in the next phase of the L.A.U.N.C.H. initiative by gathering information and individual expert input related to the initiative's efforts to date. Additional meetings with senior thought leaders may be planned in order to obtain additional expert input on the L.A.U.N.C.H. initiative and to provide opportunities for other interested stakeholders to participate in these important discussions.



Background – About L.A.U.N.C.H.

L.A.U.N.C.H. is a multi-year national project led jointly by the FCC's C2H Task Force and NCI, and in conjunction with their strategic collaborators: Amgen, the University of California San Diego Design Lab, and the University of Kentucky Markey Cancer Center. This public-private collaborative has been engaged in ongoing efforts to demonstrate the power of broadband-enabled health technologies and solutions—especially when coupled with user-centered design methodologies—to positively transform the future of connected cancer care throughout the country, especially in rural areas. The collaborative is currently working on pilot studies in the Appalachian region of Kentucky focused on developing and delivering connected solutions for patients to be able to better manage their cancer symptoms.

The plan is to ultimately scale this effort nationally, by distilling and applying the learnings of the pilots to other areas of the country (i.e., those with low broadband access and/or adoption and high cancer rates) and making the resulting “blueprint” of that effort available to cancer centers in the United States that are interested in implementing the same.

In terms of the overall approach for the project, the L.A.U.N.C.H. initiative has five key guiding principles or goals. They are listed and described below:

- 1. Cutting-edge symptom management enabled by broadband.** This demonstration project is focusing on how ubiquitous broadband connectivity can be leveraged to improve symptom management for rural cancer patients, one of the key priorities of the 2016 Blue Ribbon Panel. Early deliverables will include a Platform for Agile Development (the “L.A.U.N.C.H. PAD”) to help communities co-design better cancer symptom management tools and practices enabled by connectivity.
- 2. Robust cross-sector collaboration.** In the 2016 President’s Cancer Panel report, *Improving Cancer-Related Outcomes with Connected Health*, cross-sector collaboration was viewed as essential to the future of cancer care. Harnessing the power of the collective, this unique coalition combines government, academia, and private sector entities and multidisciplinary experts who each bring a unique perspective and skillset to bear on solving this difficult problem.
- 3. User-centered design methodologies.** Who better to solve health problems in rural communities than rural residents... provided they are supported with the right tools and are empowered to act? This human-centered way of thinking is what sets this project apart. Empowering rural communities is not just about the deployment of new technologies; to be successful long term, this effort must include a process of ground-level inquiry and listening. What are the self-identified and last-mile problems that patients, providers, and communities face? What solutions have already been tried, and what made those successful or unsuccessful? The L.A.U.N.C.H. project is coupling this type of field-based, empirical inquiry with a bold, imaginative vision of the future of connected cancer care.

4. **Sustainability and scalability.** By thinking nationally and acting locally, we can find sustainable, scalable methods for solving local health challenges through the power of connectivity and engaged communities. By succeeding in Appalachian Kentucky, the project aims to show that connectivity can extend access to needed healthcare services with improved outcomes anywhere in the country.
5. **Improved broadband access and adoption for health.** The L.A.U.N.C.H. project is focusing on areas that face the dual challenge of higher cancer mortality rates and lower levels of broadband access and adoption.

Meeting Goals and Objectives

With these guiding principles in mind, L.A.U.N.C.H. leaders sought to bring additional expertise together in a think tank format to facilitate a cross-sector discussion. The goals and objectives for the meeting were to:

- **Recap L.A.U.N.C.H. learnings** from Year 1 and place them in the broader context of other national efforts, including the National Academy of Medicine’s *Vital Directions for Health and Health Care* concepts and the President’s Cancer Panel Report on *Improving Cancer-Related Outcomes with Connected Health*;
- **Gather individual input and perspectives** from healthcare, public health, technology, communications, and other senior thought leaders on a range of relevant issues that can serve to inform the ongoing work and next steps for the L.A.U.N.C.H. initiative, particularly as they relate to setting the stage for national scale and reach in the future;
- **Identify shared interagency and public-private synergies and interests**; discuss opportunities for potential collaboration with L.A.U.N.C.H., in both the near term and in the future; and
- **Explore and catalyze greater cross-sector engagement** in the L.A.U.N.C.H. project, including a shared and detailed understanding of the power of connectivity (i.e., high-speed Internet access) to be transformative in cancer care—especially rural cancer care—and to support stated goals.



Meeting Themes and Findings

In general, participants discussed the basic concepts important to the L.A.U.N.C.H. project, as well as more specific points and views, such as: the need to move knowledge not people, the trend of shifting care to the home, the need to believe in people, empowering rural communities, customizing care to the individual, leveraging citizen-science evidence, adopting principles of equity and inclusion, ensuring a regulatory environment that will not inhibit progress, and the need for stakeholder cooperation to achieve mutual goals. In addition, participants agreed that broadband is key to providing patients (especially rural residents) with access to healthcare providers and the information they need to get well and stay healthy. But, at the same time, participants also recognized that technology and access are not enough on their own; that there also needs to be meaningful engagement with patients.

Attendees identified several issues related to technology solutions contemplated under L.A.U.N.C.H. that are also applicable to telehealth solutions in general. For example, some participants urged the creation of a predictable and stable financing system for telehealth, which is different from the current system where telehealth services generally are considered nonequivalent to face-to-face services and thus may not enjoy adequate funding. Others contended that the current regulatory environment still reflects barriers to telehealth. For example, the state-based licensure system makes it difficult to provide telehealth within certain geographic regions that cross state boundaries. Participants also emphasized that social services sometimes play an important role in an individual's overall well-being, and that evidence is emerging demonstrating the impact of broadband as a social determinant of health.

Moving forward, participants all commented that creating a successful demonstration project for telehealth—such as the one being developed for L.A.U.N.C.H.—is essential for moving telehealth forward, and that iterative learning is important to success. Some participants also emphasized that patients are a vital voice in creating community partnerships and, therefore, need to be included in future meetings and discussions about the L.A.U.N.C.H. initiative.

A detailed summary of the meeting follows.



WELCOME FROM THE CONNECT2HEALTH^{FCC} TASK FORCE

(as prepared for delivery)

Welcome to the Federal Communications Commission. I'm Michele Ellison, a Deputy General Counsel here at the FCC, and the Chair of the FCC's Connect2Health Task Force.

On behalf of the staff of the Task Force and the Co-Chairs of the L.A.U.N.C.H. initiative, Dr. Brad Hesse and Dr. David Ahern, I want to thank each of you for joining us today—especially on the day after a long holiday weekend. And we extend a special thank you to our strategic partner, Dr. Douglas Lowy and the National Cancer Institute, for their continuing support, as well as to our collaborators: the University of Kentucky Markey Cancer Center, Amgen, and the University of California San Diego Design Lab. We are grateful to all of you for linking together to make this groundbreaking project a reality.

Today's meeting is about a vision, a big, shared vision—a vision of transforming rural cancer care in Kentucky and beyond by leveraging the power of broadband connectivity and human-centered design. Simply put a vision of: everyone, everywhere connected to the people, services and information they need—when and where they need them—to get well and stay healthy. That vision is more than aspirational to us; we believe it is, indeed, a moral imperative. In pursuing this vision, we recognize that we stand on the shoulders of the President's Cancer Panel and the efforts of many of you in this room. Here at the FCC, we are delighted to be in the trenches with you, and we are incredibly excited about what we can accomplish together.

Before we go any further—and because we have assembled such a unique, multidisciplinary group—government, industry, non-profits and academia, representing the health, research, technology, and communications sectors, I'd like to go around the table and have you briefly . . . very briefly . . . introduce yourselves by name and the organization or company you represent before I introduce the Chairman.

(introductions)

Thank you all . . . such an impressive group!

I now have the distinct pleasure of introducing the Chairman of the Federal Communications Commission. Few can speak as eloquently, passionately, or intelligently about telehealth as the gentleman now sitting beside me.



He comes by this naturally. He had a bird’s eye view of the practice of medicine while growing up in Parsons, Kansas. His mother, an anesthesiologist, and his father, a urologist, treated patients in the nearby county hospital. He’s seen first-hand the challenges and experienced the transformative power of broadband in health. While overseeing our nation’s communications, he has consistently championed the cause of closing the digital divide in this country, especially in the context of rural health care. We hope his parents have now forgiven him for not going to medical school. We are certainly grateful that he found his way to law school and then to us. Please join me in welcoming the Chairman of the Commission—Ajit Pai.

Before we launch the first session, I am reminded of something a judge once taught me while I was a fledgling lawyer. I clerked for the revered judge Damon Keith in the Sixth Circuit who passed away a few weeks ago. In mentoring his law clerks, Judge Keith would often say: “Learn to Listen and Listen to Learn.” That’s really what we are here to do today—“Listen to Learn” because each of you brings a unique perspective, experience, skill, and expertise to the table. And then based on our collective learning, we will be better able to chart the broadband and health future of tomorrow.



OPENING REMARKS FROM FCC CHAIRMAN AJIT PAI

(as prepared for delivery)

It’s a real pleasure for me to welcome you to the FCC and to briefly join you in this great endeavor. We are incredibly proud of our strategic partnership with the National Cancer Institute and the collaboration with the University of Kentucky Markey Cancer Center, the University of San Diego Design Lab, and Amgen. All of you are our nation’s thought leaders, the folks we rely on to get connected health policy right. And, we’re excited that you’re here at the FCC today.

It’s also nice to see some familiar faces, as I had the opportunity to meet several of you while in Boston for the Connected Health conference last October.

For me, LAUNCH isn’t just about technology; it’s about people and their ability to get the care they need to lead healthier and longer lives. Growing up in small-town Kansas, I often saw my dad, a urologist, hit the road in the early mornings. He drove long distances across southeast Kansas to make sure that patients in even smaller surrounding communities could get help from a specialist.



Decades later, physician shortages are even more acute. Many rural hospitals have closed, and others are struggling to stay afloat. So rural Americans are often forced to spend a lot of travel time and money to access essential care, if they are able to access it at all. And, specialty care—like oncology care and all the support services involved—can be hard to access, bringing real stress and anxiety to families.

That's why it's so important to gather together in fora such as these to discuss how connected health can change the narrative. How can next-generation telehealth deliver on its promise of overcoming many of the barriers that stand between rural Americans and cutting-edge healthcare solutions? I believe that broadband has a critical role to play in these efforts to help bridge the digital divide and reduce inequalities in health and healthcare.

In fact, I get re-energized every time I have the opportunity to see connectivity in action for health. Take Allen County, Kentucky, an economically-challenged rural area near the Tennessee border that I visited recently. The school system there has over 3,000 students—but not one pediatrician. The nearest one is a decent drive away in Bowling Green. But now, thanks to broadband, local students can see a pediatrician simply by walking down to the school nurse's office. There, they can be seen virtually by a top-notch physician from Vanderbilt University's Children's Hospital, which has a partnership with the school district. Think about what a difference all this makes: students are healthier, parents worry less and don't have to take time off work, and teachers can focus on teaching.

I strongly believe that connecting communities and health systems through deployment of high-speed broadband is essential to improving our nation's health. And, I'm convinced that cancer represents a particularly compelling use case for the power of connectivity to reduce the burden of disease in our rural communities.

Last October the FCC announced that it is seeking public input on how best to design a [“Connected Care Pilot Program”](#) to support pilot projects demonstrating the impact and value proposition of broadband-enabled solutions.⁷ This program has a proposed budget of \$100 million and we welcome your input as we strategize and put the rules of the road in place.

The FCC is also committed to promoting investment in 5G networks. One promise of 5G is the opportunity to deliver more coordinated and timely care over these high-speed networks.



So, what does this mean for you? It means that our work and your work on LAUNCH are strategically aligned. Our successes are your successes. I've been encouraged by the work LAUNCH has done thus far and I look forward to the great work to come in Kentucky and beyond.

After introductions and welcoming remarks from Ms. Ellison and Chairman Pai, the meeting was turned over to Dr. David Ahern and Dr. Brad Hesse, Co-Chairs of the L.A.U.N.C.H. initiative, to begin the substantive segments on the agenda. Included below is a summary of statements, substantive discussions, and key points or takeaways for each segment.

L.A.U.N.C.H.: The Big Vision; Where are We?

Brad Hesse, NCI and L.A.U.N.C.H. Co-Chair, painted a compelling picture of the “tyranny of distance” facing rural cancer patients. He noted that cancer-related mortality is decreasing overall, but not everyone is equally benefitting from recent advances in cancer treatment.⁸ He said that Eastern Kentucky was chosen as the region of focus for L.A.U.N.C.H. because it is an area lacking continuity of care for patients with cancer and survivors, and research suggests that cancer-related mortality is increasing in these regions.⁹ Areas with high mortality and low Internet access have a “dual burden” — that is, higher than average cancer mortality rates and lower broadband access. Dr. Hesse reminded the group that to address these “double-burden” areas, the L.A.U.N.C.H. project established five core major goals:

1. Co-create cutting-edge digital tools for patient empowerment
2. Foster robust cross-sector collaboration
3. Deploy user-centered design
4. Plan for sustainability and scalability
5. Increase broadband access and adoption and thereby reduce the digital divide for health and health care

Dr. Hesse noted that the next step in the L.A.U.N.C.H. project will be the piloting phase later in 2019. This pilot work aims to be a successful demonstration in Kentucky with documented data showing the benefits of implementing technologies and workflows that improve patient empowerment, both pre- and post-cancer treatment. Through the L.A.U.N.C.H. project, a blueprint will be created that can serve as a roadmap for other regions to replicate these benefits across the country. The idea is that successful projects will come from a bottom-up approach to create platforms that will work in each unique area. Consideration will also be given to new payment models in alignment with other funding agencies.



L.A.U.N.C.H.: In Broader Context

National Academy of Medicine, Vital Directions for Health and Health Care

This segment framed the meeting in terms of the broader national context surrounding L.A.U.N.C.H. It included a featured presentation about the National Academy of Medicine's *Vital Directions for Health and Health Care*.¹⁰ The presentation was followed by cross-sector perspectives from several members of the collaborative about their respective views for improving health and health care.

Michael McGinnis, Senior Scholar and Leonard D. Schaeffer Executive Officer, National Academy of Medicine (NAM), provided critical context and background on the *Vital Directions for Health and Health Care* report published by the National Academy of Medicine in 2017.¹¹ He emphasized that the healthcare share of the federal budget was 18% in 2017, and will become an increasingly large share of federal spending over the coming decades. Life expectancy rises with income and income-related disparities are increasing nationally.¹² Since the 1970s, the risk of mortality in lower-income populations has increased, and this has driven a decrease in life expectancy for these populations.¹³ A variety of factors drive individual and health status, well beyond access to health care, but also genetics, behavior, social, and environmental factors, and in fact, for most people the influence on health status of the other determinants overshadows the influence of medical care.

“But more importantly, these factors interact in a connected fashion and to address them effectively we have to act in a connected fashion. It’s absolutely essential to progress.” Across the globe, countries that spend more on social services and prevention than delivery of health care have higher life expectancies than in the United States.¹⁴ “We need to ensure that we are reaching people where they need it, when they need it, how they need it with the kinds of treatment, prevention, social and community interventions that are important to their health prospects.”

Dr. McGinnis also shared that the *Vital Directions for Health and Health Care* report was created to guide the change in political administrations during the election of 2016. The steering committee created four action priorities: pay for value, empower people, activate communities, and connect care. Four essential infrastructure needs were also identified as key priorities: measure what matters most, modernize skills, accelerate real-world evidence, and advance science. The NAM has created four stakeholder partnerships in



informatics, evidence, financing, and culture to understand the dynamics at play in each of these areas and to identify how to bring about change. Several areas were identified to target, including facilitating how people, communities and technologies interact to enhance person and community health.

Cross-Sector Perspectives

Paul Jacobsen, Associate Director, Division of Cancer Control at the National Cancer Institute, presented the NCI perspective as the premier cancer research organization in the United States on improving cancer outcomes. He said that NCI's main objective is to provide guidance and support for developing a cancer-related evidence base for policy and practice. NCI's interests span the cancer continuum—from etiology and prevention to survivorship and end-of-life care—and intersect with the translational research continuum. NCI has a number of data resources and research infrastructure, including enhancements to NCI's Surveillance, Epidemiology, and End Results (SEER) Program that create new research opportunities—opportunities to conduct cancer-care delivery research through NCI's Community Oncology Research Program (NCORP), and implementation science centers for cancer control. NCI's current research priorities are to support time-sensitive policy and program evaluations and research on optimizing care and outcomes for cancer survivors. NCI has plans to fund initiatives for cancer control in rural communities, with interests in research for telemedicine and other technology-enabled forms of care. There are also plans to fund initiatives to improve the management of symptoms and study cancer survivorship, with an emphasis on rural communities. Additional areas of interest are applications of artificial intelligence (AI) and machine learning to cancer-care delivery, the impact of value-based reimbursement on quality of care, application of digital health to monitoring of patients under active cancer treatment, development of science on team-based care and care coordination, and the use of learning health systems to conduct rapid, responsive, and relevant cancer-care delivery research.

Lisa Nugent, Executive Director Customer Experience at Amgen, discussed patient-centered design. She shared that Amgen is creating partnerships with community leaders to prioritize problems and co-create solutions. Amgen applies this information to make scalable solutions, use the right technologies, and implement the solutions in a way that is meaningful to the patient. It is important to look at specific situations in a way that is “technology agnostic,” and without preconceived notions of what might work in a given community. Amgen has an innovation strategy called Beyond-the-Molecule, which seeks to understand the things that will be important to the people taking their medicines. Recent lessons include the realization that early



molecule-design decisions impact the drug in important ways such as how it is administered (daily pill versus continuous IV infusion, etc.). However, understanding patient goals and motivations should inform the design of the molecule and the formulation. Manufacturers should work together with patients to determine the optimal design of the drug to minimize not only side effects, but route of administration, monitoring technology, community support, and how to measure effectiveness. Partnering with patients is important to increase not only survival rate, but also to help people live the lives they want.

Karen Onyeije, Chief of Staff of the Connect2Health^{FCC} Task Force and Associate General Counsel at the FCC, elaborated on the mission of the Connect2Health^{FCC} Task Force, emphasizing that the Task Force is motivated by the “transformative power of connectivity” and is focused on the intersection of broadband, advanced technology, and health. In her comments, Ms. Onyeije made three main points. First, she compared the “tyranny of distance” for patients with cancer that live in rural communities with the tremendous opportunity that broadband presents to address this issue. It is these opportunities to leverage connectivity to transform rural cancer care that drive the Task Force’s work in L.A.U.N.C.H. Second, after engaging with hundreds of stakeholders across the country, it has become increasingly clear to the Task Force that health is a compelling use case for broadband adoption. The FCC often hears that there is a lack of deployment and adoption of broadband technologies in rural communities. Health is one way to make broadband more relevant to rural consumers and to potentially change the “rural” business model for broadband. The analytics and experiential data all support this conclusion. Third, Task Force research and data analytics have also established that broadband connectivity is a “super-determinant of health,” a construct of particular importance to public health. In this regard, the Task Force has found a persistent relationship (albeit not causal) between diabetes prevalence (a health outcome) and broadband connectivity, even controlling for potentially confounding factors like income, age or rurality; and the Task Force continues to work closely with the Centers for Disease Control and Prevention to further explore this connection. The L.A.U.N.C.H. collaborative is a unique opportunity to use these insights to transform rural cancer care. Connectivity allows us to create an “ecosystem of care,” not just around the clinic encounter (i.e., connecting a patient with cancer to a specialist), but also leveraging cutting-edge technology platforms like artificial intelligence (AI) to help predict and better meet the needs of rural communities in novel and cost-effective ways.



Overview and Meeting Objectives

Kevin Patrick, University of California San Diego, and Lisa Klesges, NCI, on behalf of the L.A.U.N.C.H. collaborative, provided an overview of the four “deep dive” sessions that comprised the bulk of the meeting, described the discussion format, and identified the objectives for each session.

The remainder of the meeting was divided into four “deep dive” sessions structured around NAM’s *Vital Directions for Health and Health Care* action priorities to inform the L.A.U.N.C.H. implementation. Within this framework, the L.A.U.N.C.H. collaborative also sought specific input on whether the plan for Kentucky has the right framework, models, and terminology or whether changes are necessary for a successful demonstration.

Deep Dive Session 1:	Empower people—democratize action for health
Deep Dive Session 2:	Connect care—implement seamless digital interfaces for best care
Deep Dive Session 3:	Activate communities—collaborate to mobilize resources for health progress
Deep Dive Session 4:	Pay for value—deliver better health and better results for all

Some key objectives for the sessions included:

- The need to work together in creating a successful demonstration project in Kentucky (with documented impact);
- Strengthening the L.A.U.N.C.H. collaborative’s “Blueprint” with input from key stakeholders as a way to improve the project’s scalability; and
- Aligning funding/action across sectors to achieve national impact together over time.



Deep Dive Session 1: EMPOWER PEOPLE

How can we democratize action for Health? Through the design of systems that meet people where they are, that empower patients to take life-saving action, and that embrace reinvention to serve needs at scale?

Key Observations:

- The United States has enormous capabilities for combining technologies with a reconfigured workforce to move health care outside of conventional institutional settings and closer to people in their communities.
- There is often misalignment between patient goals and the care-delivery system. Broadband is key to providing patients with the access to providers and information they need. Technology and access are not enough on their own, however; there also needs to be meaningful engagement with patients, families, and communities.
- Co-design/participatory design actively involves all stakeholders in the innovation process to help ensure that the results meet their needs and are usable.
- There needs to be a shift to “point of need” in addition to “point of care.” The L.A.U.N.C.H. program will help to determine how to disseminate information and care to those who need it in a timely fashion.
- What is particularly concerning is that the number of cancer survivors grows at a faster rate than the number of healthcare providers.
- There is a lack of access to psychosocial oncology services and palliative care. Telehealth could also help reduce the stigma associated with psychosocial services by allowing access from the privacy of the home.
- We must also address healthcare disparities; addressing geographic disparities is a good way to address healthcare access.
- Meeting people where they are is understanding their views of the healthcare system, their views of their role in health care and how they manage their own health, as well as their perceptions of the healthcare system.

**Elijah Aronoff-Spencer, Director, Center for Health, UCSD Design Lab,**

moderated this session and discussed prior examples of connectedness and health care. An example of how broadband can transform a community was described. An initiative in Mozambique concentrating on medical education and health system strengthening was co-designed by local physicians. Broadband connectivity was brought to the hospital and surrounding area. Medical technologists were able to leverage technology to create their own company called Braveheart Productions. This company was able to create a 911 service along with ambulance service with funding from the primary telecom company.

Connected technologies are rapidly evolving and how this will apply to health care is still uncertain. In human-centered design, it is important to listen, co-design, and co-create solutions. Results from the Kentucky demonstration project are beginning to show what a community needs to do to be able to design solutions for themselves. The collaborative envisions an “evolving platform that creates an ecosystem of people, technology, linked by broadband.” A core principle of this project is to allow the community to become the experts and create the solutions necessary to succeed.

Susan Dentzer, Visiting Fellow, Duke-Margolis Center for Health Policy,

discussed the [Health Care Without Walls report](#).¹⁵ The United States has enormous capabilities for combining technologies with a reconfigured workforce to move health care outside of conventional institutional settings and closer to people in their communities. Most of healthcare delivery does not involve direct “laying on of hands,” but rather, exchanges of information. The report offered hypothetical scenarios that involved using technology that already exists to support telehealth delivery. Telehealth has been around since the 1960s, but is underutilized by modern medicine. The report identified four obstacles that must be addressed to move telehealth and other forms of more “distributed” health care forward:

- Payment models that move away from visit-based and fee-for-service care and encourage new modes of care delivery
- Regulations, including licensure; availability of nationwide broadband and 5G
- Workforce issues, including training and education
- Human factors, including proclivity of providers and patients to take up and use technology effectively; need for human-centered design



L.A.U.N.C.H. has an exciting opportunity to make headway in all these areas and set a standard for the rest of the nation. However, the solution must be sustainable. The Duke-Margolis Center for Health Policy is undertaking a Patient-Centered Outcomes Research Institute (PCORI)-funded effort to determine additional aspects of “health care without walls” that will lend themselves to future PCORI-funded, patient-centered, comparative-effectiveness studies. The L.A.U.N.C.H. initiative is an embodiment of the kinds of solutions envisioned by the report.

Katherine Kim, Assistant Professor, School of Medicine and Betty Irene More School of Nursing, University of California Davis, elaborated on the science of design. “Patients need tailor-made opportunities to participate in the design of patient-centered care. Because what they primarily want is engagement in life, in family, and in community.” Engagement with health and health care should only support those goals. To solve this design challenge, you must believe that people can contribute and are the experts in their lives and their communities. One solution is to design opportunities with which patients can elect to engage. To do this, we must consider “citizen science”-based evidence to co-design help for points of need. “Citizen science involves the co-creation of research among citizens and professional researchers in substantive aspects of scientific inquiry, including equitable contributions to governance, to the development of research questions, data collection, analysis, application of findings, and dissemination in order to deliver knowledge and community action.”

For example, the Karuk tribe of Northern California was given a grant to train the youth of the tribe to become citizen scientists based on training and developing leadership skills. Their work led to interventions that the tribe undertook on behalf of the community such as building community gardens and launching hikes designed to help families identify acorns, collect, process, and cook them. The study also led to changes in the school lunch program, another area of priority, that altered the sourcing and production of food in the school lunches. This experiment demonstrated the selection of priorities that were relevant to the community, which led to sustainable change.

Co-design/participatory design “actively involves all stakeholders in the design process to help ensure that the results meet their needs and are usable.” This requires empathizing with the community and understanding their needs and what’s going to work.

“Point of need” in care or care coordination is any time and place where health-related conversations occur and choices and decisions are made among individuals, clinicians and healthcare staff, families and caregivers, and



community resource teams. There is no single solution on how to engage communities; and individuals will select different opportunities at multiple levels. We must “build the opportunities that are tailored to how people want to engage with us as we design solutions.”

Deborah Mayer, Professor, School of Nursing, University of North Carolina,

spoke about empowering cancer-care teams, noting that the factors facing cancer-care teams in rural communities also relate to all cancer-care teams in all locations. What is particularly concerning is that the number of cancer survivors grows at a faster rate than the number of healthcare providers.¹⁶ The L.A.U.N.C.H. program will help to determine how to disseminate information and care to those who need it in a timely fashion. There needs to be a shift to “point of need” in addition to “point of care.” To facilitate co-designed implementation strategies, we need key stakeholders, including survivors, healthcare administrators, oncology, and primary care teams. To democratize community assessment of needs and priorities, consider partnering with State Health Departments (which also include their state cancer control plans through the [CDC](#)) to develop statewide assessments designed by stakeholders based on existing evidence-based approaches.¹⁷ Participatory agenda-setting should include all of these stakeholders. Creating a database that all stakeholders can access that includes existing resources is important as not all resources are located within a single institution and many are in the community. Information should be as public and as disseminated as possible for everyone who wants access.

Dr. William Pirl, Vice Chair for Psychosocial Oncology, Dana-Farber Cancer Institute,

brought up the lack of access to psychosocial oncology and palliative care. Lack of access to this kind of care exists everywhere, not just in rural areas. These types of services don’t need to be delivered in person and can include creating repositories of self-management interventions that people could access on their own. Telehealth could also help reduce the stigma associated with psychosocial services by allowing access from the privacy of the home. There are two types of organizations that could help provide access to psychosocial services: the cancer support community and patient advocacy organizations. These groups have been involved in telehealth for many years and could provide perspectives on best practices. Primary care doctors in the region could identify patients that could help with purposeful sampling—that is, to have them identify some patients who may be skeptical about using technology-enabled solutions as well as patients who are more savvy, thereby getting both perspectives. Patient-reported outcomes must be part of the metrics and could also be implemented without the “laying on of hands.”



Dana Wollins, Division Director for Health Policy, American Society of Clinical Oncology, discussed the need to address healthcare disparities. Addressing geographic disparities is a good way to address healthcare access. Rural caregivers also lack access to education. We should encourage the use of educational tools such as [project ECHO](#) and virtual tumor boards and grand rounds.¹⁸ The community care setting is changing rapidly, and nurse practitioners and primary care physicians may be treating patients with cancer and are also in need of educational resources and support.

Teresa Zayas Cabán, Chief Scientist, Office of the National Coordinator for Health Information Technology (ONC), U.S. Department of Health and Human Services, spoke on making electronic health data easily accessible. ONC issued a notice of proposed rulemaking that will help make these data more accessible and usable to both patients and caregivers. She said that care delivery is still not completely patient-centered, and empowering patients is vital to achieving this goal. There is often misalignment between patient goals and the care-delivery system. Broadband is key to providing patients with the access to providers and information they need. Technology and access are not enough on their own, however; there also needs to be meaningful engagement with patients. Many patients still view the clinician as overseeing their health. “Meeting people where they are means understanding their views of the healthcare system, their views of their role in health care and how they manage their own health, as well as their perceptions of the healthcare system.” Implementation science will be important to determining what will work in these communities and what developments are scalable.

Deep Dive Session 2: CONNECT CARE

What are some of the new ways of leveraging connectivity and health technology to facilitate and expedite the goals of L.A.U.N.C.H. and the future of connected care?

Key Observations:

- L.A.U.N.C.H. needs to be a coalition that brings both health care and the telecom industry together, rather than having them operate in silos.
- Humans are driven by competitiveness that coexists with a need to collaborate and cooperate. Harnessing and balancing these two factors is important to achieving our goals.



- Digital health is more than just apps. Useful digital health tools and solutions include wearables, sensors, and implantable devices, enabled by machine learning and AI. For example, autonomous vehicle technology is being tested to transport patients from their homes to their physician’s offices. And deep-learning models are testing the accuracy of lung cancer detection algorithms.
- 5G networks will be important to improving the speed of connectivity. More broadly, consideration should be given to how spectrum is allocated to ensure that healthcare delivery needs are met.
- The satellite industry has been investing in telehealth capabilities and sees it as an area of growth and opportunity.
- Telehealth can improve the health and outcomes of patients with cancer and reduce overall costs, but we need to ensure we are using the right metrics, for example, physicians’ efficiency through reduced paperwork and efficient workflows.
- Telehealth visits are being piloted to identify specific patients that need an in-person surgical oncology consult to essentially recreate the home visit, so that patients receive care where they are.
- [Based on Task Force analytics of 2016 broadband data](#), there is a very strong correlation between areas with lower broadband access/Internet adoption and high lung cancer incidence and mortality.¹⁹ More than 70% of counties with the highest lung cancer incidence and mortality have rural broadband access below 50% and nearly 90% have Internet adoption levels below 50%. This is one example of the digital divide in health that the L.A.U.N.C.H. initiative seeks to address.

Chris Gibbons, Senior Advisor on the FCC’s Connect2Health Task Force, moderated this session, framing the discussion in terms of a big vision developed by the Connect2Health^{FCC} Task Force: “Everyone connected to the people, services and information they need to get well and stay healthy,” noting that social connectedness is essential to our health and wellbeing. We are used to connection being in-person, but we can now connect through technology. We can also connect people to things (e.g., car-sharing services). He emphasized that “the patient’s healthcare team is not just the clinical healthcare team. It includes all the other people and resources that they rely on outside



the clinical encounter and in between clinical encounters.” Connecting patients to what they need, whenever they need it, wherever they are is part of our goal. Connectedness will allow the creation of personal digital health ecosystems.

Chip Pickering, former U.S. Congressman, and now CEO of INCOMPAS, discussed the perspective of the communications industry. Industry is facing the challenge of taking current technological advancements and moving them to new wireless telecommunications networks from older infrastructure (analog). Humans are driven by competitiveness that coexists with a need to collaborate and cooperate. Harnessing these two factors is important to achieving goals as a society. The FCC has initiatives to help expand networks in a manner that is cheaper and faster. There is also an initiative to identify areas that lack broadband access and to encourage use of existing networks in areas not currently using it. The FCC’s digital opportunity fund is directing funding to underserved communities to encourage the deployment and up-take of broadband access. Increasing the standard speed of access will also help to meet communications needs.

Thomas Power, Senior Vice President and General Counsel, CTIA, discussed the perspective of the wireless industry. 5G networks will be important to improving the speed of connectivity. Robotic surgery is a good example of the importance of high-speed connectivity. There is a need for highly-detailed imagery in real time, and 5G will be able to provide this kind of connection. Consideration should be given to how spectrum is allocated to ensure that healthcare delivery needs are met. The FCC can help make infrastructure to rural areas more affordable, but it is difficult to build wireless networks in areas that do not have population density. Past successes have proven the need for collaboration with community leaders to drive the right solutions for underserved populations.

Rene Quashie, Vice President of Policy & Regulatory Affairs of Digital Health, Consumer Technology Association (CTA), spoke about the promise of digital health. Digital health is more than just apps. Useful digital health tools include wearables, sensors, telehealth, AR/VR, and implantable devices. For example, Best Buy Health is creating a system to install sophisticated remote monitoring devices connecting patients at home with caregivers and healthcare providers thereby facilitating opportunities for aging Americans to stay at home instead of moving to a facility. Autonomous vehicle technology is being developed to, among other things, transport patients from their homes to healthcare facilities, including their physicians’ offices. A recently published study showed that a deep-learning model could accurately detect



lung cancer.²⁰ He also noted that privacy and data stewardship are significant regulatory issues that need further consideration and analysis. In that regard, CTA has developed its own privacy principles regarding personal health data. In addition, a lack of uniform standards pertaining to digital health has led to confusion among both clinicians and consumers regarding the trustworthiness of digital health solutions. CTA has taken on the challenge and is developing best practices for virtual care solutions. Coverage and reimbursement will also play a large role in determining what digital products consumers ultimately use. In looking to the future, CTA has formed a work group on AI health care made up of industry leaders as well as leading healthcare and public interest associations and stakeholders. The group is looking at the definitions and characteristics of AI health care, including trustworthiness and data stewardship.

Tom Stroup, President and CEO, Satellite Industry Association, discussed satellite broadband. Satellites play an important role in providing broadband connectivity and there are two companies currently providing service to the United States with FCC-defined broadband speeds. The service they offer is ideal for providing the connectivity sought for needs identified for the connected health pilots. Currently, there are over 2,100 satellites in operation. Over the next five years, there is expected to be a 10-fold increase in satellite broadband capacity. Broadband access is still very expensive for many users, and perhaps subsidies could help offset these costs. The industry has been investing in telehealth capabilities and sees it as an area of growth and opportunity.

David Finley, Director of the Comprehensive Thoracic Oncology Program at Dartmouth-Hitchcock Norris Cotton Cancer Center, discussed challenges in connected care. When patients are more than 30 km from a cancer center, they end up having, on average, more diagnostic imaging and laboratory tests than similar patients who live closer to the center; this distance also leads to delays in seeing a specialist, which increases the risk for mortality in certain types of cancer. The fee-for-service model of medical care promotes in-person visits and discourages the use of telehealth technologies. One example of telehealth was a voluntary exercise program that gave patients a fitness tracking device to remotely monitor exercise. Most of the patients performed voluntary exercise, which resulted in better patient-reported outcomes. Telehealth visits are being piloted to identify specific patients that need an in-person surgical consult that can essentially recreate the home visit, so that patients receive care where they are. Providers and patients need education on the issues surrounding telehealth. Payments for telehealth visits are lower



than in-person visits, which needs to change for more physicians to adopt it. Telehealth can improve patient health and outcomes and reduce overall costs, but we need to ensure we are using the right metrics, for example, physicians' efficiency through reduced paperwork and efficient workflows.

General Discussion and Comments for Deep Dives 1 and 2

- The technology for telehealth exists, but it's not readily accessible. The next step should be figuring out how to coordinate the efforts of the community to support increased access to telehealth services.
- The L.A.U.N.C.H. project should focus on the specific aspect of telehealth that the collaborative wants to pilot. There have been suggestions to expand and evolve clinical practice, but also about how to understand patients and communities. Airbnb (as an example) looked closely at the ideal travel experience and used that prototype to scale the ideal with technology. Could this approach work for L.A.U.N.C.H.?
- The L.A.U.N.C.H. blueprint needs to outline an iterative process and needs to look forward to the long term and not compromise with short-term solutions.
- L.A.U.N.C.H. needs to be a coalition that brings both health care and the telecom industry together, and not have silos.
- A barrier to social services in the United States is the lack of an efficient way to find the services that exist. Currently, patients and caregivers can't find the solutions that may already exist.
- Randomized controlled trials are not useful in determining optimal technology because technology changes too quickly.
- One participant suggested creating an open platform that would allow anyone to build what they need.



Deep Dive Session 3: ACTIVATE COMMUNITIES

How might collaboration mobilize resources for health progress? Through co-designing implementation, assessing community needs and priorities?

Key Observations:

- “Participation” must be considered along with “connection.” How can we think about participating in the experiences of the people living in rural Kentucky as part of connecting care?
- L.A.U.N.C.H. can help to create grassroot efforts to drive demand for smart-connected systems.
- Communities that build strong multi-sector connections can achieve sizable reductions in preventable morbidity and mortality, reduce costs, and lower the life expectancy discrepancy between low- and high-income populations.
- The American Cancer Society affirms the need to form a connected health system to monitor a patient’s healthcare needs through predictive and prescriptive analytics and to take care of that individual’s physical, psychological, and social function. This system must also remotely monitor survivors’ and caregivers’ outcomes to assess intervention success and ongoing needs.
- Community networks are an important aspect of public health. Communities actively participate in these programs because they trust them and understand that they are a permanent service, and not just a short-term research project.
- One of the big issues currently facing primary care physicians who provide oncology care in rural areas is the difficulty in communicating with specialists on behalf of their patients.
- The outcomes of L.A.U.N.C.H. have to show that we are eliminating “pain points” for both patients and clinicians. Data from successful care redesign in Europe suggest that demonstrating solutions for pain points is what convinced the rest of the system to change.
- Physicians not participating in telehealth feel no perceived need for telehealth. The infrastructure exists, but the implementation is lacking.



- Connected technologies can be used in a variety of ways, including public health, not only for delivery of oncology care but also for prevention.
- It is important to create an evidence base specific to rural settings because programs that are developed in urban settings do not necessarily translate.

Robin Vanderpool, Professor, University of Kentucky College of Public Health; and Associate Director for Community Outreach and Engagement, University of Kentucky Markey Cancer Center, discussed the Eastern Kentucky cancer experience. Building trust is essential in our rural communities. The community often uses the term “the cancer,” which means a universal, holistic experience to which all (Appalachian Kentucky) patients and caregivers and communities can relate. Contextually, each community is different and has a unique perspective. To activate communities, we need to identify the key gatekeepers, such as pastors, public safety officials or educators, to work with patients. “It needs to be as personal to you (the researcher, collaborator, outside agency) as it is to each one of those community members.” Partnering with communities happens through shared priorities and commitments and being in it for the long haul through mutual trust and respect.

Glen Mays, Professor and Chair, Department of Health Systems, Management and Policy, Colorado School of Public Health, discussed activating communities through programs and people that are already embedded within the communities. Communities that build strong multi-sector connections through joint initiatives can achieve sizable reductions in preventable mortality, reduce costs, and lower the life expectancy discrepancy between low- and high-income populations. Open and transparent governance structures are vital to multi-structure health improvement networks. Organizations are strengthened by diversity and need to actively recruit all community partners to achieve optimal gains. Good networks cannot rely on one-time funding; there is a need to find a way to sustain the investment through shared resources.

Catherine Alfano, Vice President of Survivorship, American Cancer Society, discussed ways to support cancer survivors. The American Cancer Society (ACS) affirms the need to form a connected health system to use predictive analytics to monitor survivors/caregivers for physical, psychological, functional, financial needs; support survivors/caregivers and clinicians in shared decision-making about care; and use prescriptive analytics to connect



survivors and caregivers to interventions that will work best for them. This system must also remotely monitor survivors' and caregivers' outcomes to assess intervention success and ongoing needs. These prescribed interventions ought to vary with need (stepped care). We need to shift cancer care from the “point of care” to the “point of need” through telemedicine and community programs wherever possible. Patients need to be supported to self-manage their own wellbeing. L.A.U.N.C.H. can help to create grassroots efforts to drive demand for patient-driven and smart-connected systems. We need to build demand for home-based telemedicine approaches and community approaches. Educational programs aimed at clinicians to drive referrals to telemedicine options will also be necessary. The outcomes of L.A.U.N.C.H. have to show that we are eliminating “pain points” for both patients and clinicians. Data from successful care redesign in Europe suggest that demonstrating solutions for pain points is what convinced the rest of the system to change.

Karen Rheuban, Professor and Senior Associate Dean, and Director of the Karen S. Rheuban Center for Telehealth at the University of Virginia, discussed efforts to create a connected healthcare ecosystem in Virginia. A community partnership with Southwestern Virginia was formed to create a blueprint. There have been over 100,000 patient encounters with services offered in over 60 subspecialties. The community actively participates in the program because they trust the program and understand that this is a permanent service, and not just a short-term research project. A remote monitoring program for patients with diabetes demonstrated reductions in hemoglobin A1C levels within six months. An online learning program called [Telehealth Village](#) was created and provides continuing medical education credits for healthcare providers as well as a consumer platform.²¹ Several partnerships with local and governmental agencies enable data sharing and provide telehealth services.

Lisa Richardson, Director of the Division of Cancer Prevention and Control in the National Center of Chronic Disease Prevention and Health Promotion at the Centers for Disease Control and Prevention (CDC), discussed the public health perspective. Three points were highlighted: (1) leadership buy-in for telehealth needs to happen early in the process; (2) the technologies under discussion can be used in a variety of ways, including public health, not only for delivery of oncology care but also for prevention; and (3) communication can be enhanced by technology, but the personal touch is important to remember. Citizen-science evidence at the individual level is an important concept, and a way to keep individuals engaged and involved in



their own health and health care. Community networks are also an important piece of public health. Nonprofit healthcare policy organizations should not be overlooked in this process for promoting a culture of health.

Tom Morris, Associate Administrator for Rural Health Policy, Health Resources and Services Administration, U.S. Department of Health and Human Services, discussed the focus on community in rural health. It is important to develop cross-sector lines when building community programs. It is also important to create an evidence base specific to rural settings because programs that are developed in urban settings do not necessarily work well in rural areas. One of the big issues currently facing primary care physicians who provide oncology care in rural areas is the difficulty in communicating with specialists on behalf of their patients.

Ian Hargraves, Lead Designer, Shared Decision Making National Resource Center, Mayo Clinic, spoke on participatory design. Participation should be thought of along with connection. To participate is to become part of something, so researchers and clinicians should become part of the communities for which they are working and providing care. Clinicians ought to consider how to participate in the suffering, problems, experience, and the potential of these environments. And most important, how do we think about participating in the dignity, pride, and overall humanity of the people living in rural Kentucky as part of connecting care.

General Discussion and Comments

- One participant mentioned a research study that reported that only a small portion of physicians were using telehealth, and those that were using it were not connected to other specialties.²² Physicians that were not participating in telehealth felt no perceived need for telehealth. The infrastructure exists, but the implementation is lacking.
- It was emphasized that, in rural areas, other people from the community are providing a lot of care for their neighbors for not only health care but paying bills and other services. One example is [Kentucky Homeplace](#).²³ We need to take advantage of existing networks in the community and of federally qualified health centers, rural health clinics, and local health departments. These places are thought of as only primary care, but they could also be useful as a base of operations for remote monitoring or telehealth. Never underestimate the pride the



community has in local institutions such as state universities, which could serve as gateways for encouraging participation.

- One participant mentioned that education is essential to informing physicians about how to use telehealth to their advantage.
- One participant spoke to the fact that many rural communities feel isolated in struggling with population health issues, not only with respect to cancer, but other chronic diseases and the opioid epidemic. This suggests that we need different ways of defining the problem and delivering solutions. Technology can change the questions that are asked as well as the answers themselves.

Deep Dive Session 4: PAY FOR VALUE

How can our mobilized communities deliver better health and better results for all? Through the design of more efficient and human-centered systems, by measuring what matters most, and by reimbursing for care that improves value for all?

Key Observations:

- Human-centered design has substantially informed CMS’s approach to various improvements. Transitions in care is a particular “pain point” and warrants significant focus.
- Culture and incentives are important to networks, and we need to re-evaluate these domains through scientific inquiry and research to promote collaboration.
- The metrics and value-drivers that will be created by L.A.U.N.C.H. are essential to proving success of the program.
- Path dependence is critical; picturing the end goal will help direct the L.A.U.N.C.H. project.
- The hope is to use functional monitoring of patient-reported outcomes and physiological data to provide care without the patient having to physically go to the clinic.



Tim Mullett, Medical Director, University of Kentucky Markey Cancer Center, moderated this session and discussed the opportunity technology presents. Dr. Mullett shared a compelling analogy: there is now an app that will analyze pool water, recommend the necessary chemicals to treat the pool, and allow the consumer to order the supplies through the app. This kind of end-to-end approach could work with health care and could facilitate distress-monitoring of patients. In addition, the Commission on Cancer introduced standards for navigation, distress-monitoring, and survivorship, and also developed a distress-monitoring tool. However, patients will answer differently depending on whether the tool is administered in person or via technology.

Data monitoring is moving to the home as patients shift from the hospital setting to a home-based setting. The hope is to use functional monitoring of patient-reported outcomes and physiological data to provide care without the patient having to physically go to the clinic. An informal trial of remote monitoring indicated that patients were not sure how to use it, suggesting that implementation will require a lot of patient education.

Kate Goodrich, Director of the Center for Clinical Standards and Quality and also Chief Medical Officer, Centers for Medicare & Medicaid Services (CMS), talked about the role of the payer in the telehealth environment. CMS is changing the culture of how they provide care to Americans. The agency has adopted human-centered design and agile development, and is working to become a “learning organization.” They also started creating journey maps to understand stakeholders, including clinicians and beneficiaries. These journey maps helped the agency understand “pain points.” This approach of human-centered design has substantially informed the agency’s approach to improvements of the “Health Plan Finder” and “Compare” sites.²⁴ For beneficiaries, we heard that transitions in care is a particular “pain point”; consequently, we focused on this area and developed scenarios and personas to help beneficiaries navigate the various transitions of care such as from hospital to home and provider to provider. From this work, we realized we can improve our other websites, tools, and resources for our beneficiaries.

William Dalton, Founder and Executive Officer of M2Gen, a national biotechnology subsidiary of the Moffitt Cancer Center, discussed data sharing between a network of cancer centers for the purpose of collaborative research. The Oncology Research Exchange Information Network ([ORIEN](#)) is in the early phases of development. It was formed in response to a common protocol, where patients can share their lifetime health records and tissue without having to be re-contacted after the initial consent. A detailed patient-reported outcome tool was developed to identify, meet, and predict



patient needs. There is a single, centralized source to access and host the data. Over 250,000 patients have consented to be part of the protocol. The goal is to create a searchable database to allow clinicians to compare treatment decisions for patients, thereby informing clinical decision making. The database can predict an appropriate clinical trial for a high-risk patient. Patients also want to understand the data and have been included in the project. Culture and incentives are important to networks, and we need to re-evaluate these things in medical science to promote collaboration.

Dan Sullivan, Executive Director, US Value Based Partnerships, Amgen, spoke on value-based health care. Value-based or outcomes-based contracting aims to align the value that exists in health care to the payments provided for the services rendered. For example, if a patient were compliantly taking an osteoporosis medication and nevertheless suffered an osteoporotic fracture, the manufacturer of the medication would pay back the cost of the drug or event under an outcome-based contract. Amgen is a national leader in this area and is committed to this concept. However, currently it is very challenging to harmonize the relevant data elements supporting this process and the analysis of the data to determine appropriate payment because of siloed data sets and organizational complexities. It is also very difficult to create value-based metrics and to implement them at scale. The metrics and value-drivers that will be created by L.A.U.N.C.H. are essential to proving the success of the program.

David Bates, Chief, Division of General Internal Medicine, Brigham and Women's Hospital, spoke about path dependence. Picturing the end goal will help direct the L.A.U.N.C.H. project. However, the steps in between are still unclear. Currently, patient needs are not well defined and there is still a lot to learn.

General Discussion and Comments

- One participant commented that patients feel that they are a burden and are reluctant to reach out to physicians. Patients need to be empowered to take care of their own health. Patient engagement from the payer perspective is important. We need incentives to change behavior for patients.
- It was mentioned that the L.A.U.N.C.H. project needs to have a detailed discussion on creative ideas for the payment system.



- One participant noted that people appreciate opportunities to communicate. There have been other projects that produced good data, such as the University of Virginia telehealth project, and these examples can be used to strengthen L.A.U.N.C.H. The project needs to demonstrate the potential for telehealth.
- A representative from the telecommunications industry suggested having a task force within L.A.U.N.C.H. to target the public policy side to complement, coordinate, and integrate the different pieces. The various government agencies involved should be aligned to create a new regulatory framework to create a new model of medicine.
- It was observed that, in order to show immediate impact, we should build on existing evidence such as enhanced recovery after surgery or palliative care. Demonstrating reduced emergency department visits and hospitalizations would provide noticeable results in a short time frame. Targets should be challenges that are difficult to implement in a rural setting and where technology might help.
- One participant emphasized the need to reduce the perception of risk from the provider perspective and also mentioned that user-centered design must be central to L.A.U.N.C.H.
- It was stated that we also need to find ways to better engage the tech community in this initiative.
- One participant cautioned that short-term wins could prevent the achievement of the bigger vision. Start with the bigger picture and work backwards to get there.

L.A.U.N.C.H.: Where Do We Go from Here?

Donald Berwick, President Emeritus and Senior Fellow at the Institute for Healthcare Improvement, and former Administrator of CMS, summed up the comments and discussions as the designated Chair and Facilitator for this Senior Leadership Think Tank meeting.

The goal of L.A.U.N.C.H. is to align technology with clinical science and with co-design—three concepts that are not normally associated with one another. Indeed, he noted that much of the discussion challenged some of the underlying assumptions in health care. It is clear that the regulatory environment needs to be reshaped to better meet the needs of the health of Americans. The organizational architecture for L.A.U.N.C.H. is therefore the most important aspect to consider. The design/innovation concepts will be the basic operating procedures for L.A.U.N.C.H.



Dr. Berwick observed that there was high-level agreement on some basic concepts, including the need to:

- Move knowledge, not people
- Shift care to the home
- Believe in people
- Expand the workforce, i.e., change the status quo of who does what
- Promote customization to the individual
- Embrace citizen-science evidence
- Consider the principles of equity and inclusion
- Make it easy; ensure a regulatory environment that is not inhibitory to progress
- Cooperate

He also observed that some participants identified potential barriers facing the goals for L.A.U.N.C.H. and telehealth services generally:

- Funding – Money will have to be allocated or reallocated. There is still a lot of hesitation among hospital administrators on telehealth. It is necessary to create a stable financing system that is different than what exists.
- Regulatory chasm – State-based licensure system must be reviewed and changed because telehealth will cross state boundaries.
- Boundary between health care and social care – As just one example, housing can be an important determinant of overall health and well-being, but is not considered part of health care in the United States.
- Private sector and government action may be a friction point.

So where do we go from here? Dr. Berwick suggested the following concrete roadmap:

- “Double-down” and make Kentucky work as a demonstration of a novel approach
- Project results need to happen quickly and be shared (A traditional 5-year randomized controlled trial will not work for this demonstration.)
- Use iterative learning as the evaluative process
- Clarify the values framework
- Get patients in the room as part of shared discussions

Thereafter, the meeting was adjourned.



POSTSCRIPT: As L.A.U.N.C.H. collaborators, we are indebted to the Think Tank participants for their valuable input and insights. We also continue to be inspired by the vision and leadership of FCC Chairman Ajit Pai and NCI Acting Director Douglas Lowy. In addition, we are mindful of the powerful words of the Vital Directions framework—“[a]t this vital inflection point in health and health-care, the challenges are great, but so are the opportunities and knowledge to direct change”—words which capture the incredible promise and potential for L.A.U.N.C.H. We recognize the critical urgency of this work to rural cancer patients and their caregivers and intend to put forth maximum effort toward a successful end. Of course, we welcome ongoing input from relevant stakeholders and other potential collaborators.

More information about the L.A.U.N.C.H. initiative is available at www.LaunchHealth.org and www.FCC.gov/health/cancer

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