

the value of
CO-CREATION
in health care

2016 ABIM Foundation Forum
Summary
by Tim Lynch





At this year's ABIM Foundation Forum, physicians, patients, medical students, residents, quality improvement experts, and other leaders learned about “co-creation”—the shared creation of value between the consumers and providers of a service—and how some leaders are applying its principles to health care. Alongside this learning, they practiced using co-creation techniques to address challenges to health and health care, exploring how they could employ the concept in their own workplaces. Through this move from the conceptual to the practical, participants began to experience a “mind shift” and develop skills that can lead to positive transformation of the health care system.

Introducing the Concept

The Forum opened with a conversation between Richard Baron, MD, President and CEO of the American Board of Internal Medicine (ABIM) and ABIM Foundation, and Holly Humphrey, MD, the Dean for Medical Education at the University of Chicago Pritzker School of Medicine and the Chair of the ABIM Foundation's Forum Planning Committee. Dr. Baron discussed the “important transition” inherent in co-creation from “doing for to doing with” and described how ABIM has employed the concept. He described ABIM's “deep and storied roots in American health care” and its long-held belief that its authority derived from the “luminaries and leaders” who held positions of power at the organization. Physicians, however, empowered by modern technology that enabled them to connect more easily with one another and changing mores that were undermining this traditional authority model, were increasingly disputing the Board's authority in recent years. ABIM's leaders decided that this changed climate required them to adopt a new,

far more collaborative approach. As an example, Dr. Baron described how last year, all diplomates were for the first time asked to comment on the “blueprint” that defined the particular topics to be covered on ABIM exams. “The blueprint changed some, not a lot, as a result of the comments, but the sense of participation, ownership and engagement was critical in creating relationships for us,” he said.

Dr. Humphrey described the challenging context her institution has faced in recent decades. The closure of a number of community hospitals on the South Side of Chicago, an economically disadvantaged area, reduced the number of available hospital beds from 5,200 to 2,000, causing chronic overcrowding of the university system’s emergency room and inpatient units. The system responded to the frustrations of the community, and its own personnel, by launching the Get CARE (community, access, reliability, excellence) initiative. The initiative brought together a coalition of local leaders, which included community hospitals, faith leaders, community organizers, first responders and others, and university hospital leaders. This coalition’s leaders traveled together to Springfield, Illinois, and obtained unanimous approval for a new Level I trauma center and the addition of 188 beds from the state hospital facilities review board, which had been hostile to previous requests.

These remarks were followed by three speakers who delivered TED Talk-style remarks about their own experiences with co-creation:

- Samantha Kennedy, a medical student, described how her life changed when she developed ulcerative colitis as a teenager. As a college student, she became an active member of the Improve Care Now network that fosters collaboration among physicians treating inflammatory bowel disease and patients and families living with the disease. “Engagement is an attribute of all patients and some patients will engage at a higher level to shape the system,” she said, just as Wikipedia is fueled by the small number of

users who contribute to and edit entries. She was an active network member and became co-chair of the patient advisory council at age 20. “The network invested in us as patients and parents, and respect begets respect,” she said. “As a medical student, I want to foster different groups bringing value to the health care system and respect them as I’ve been respected.”

- Kathy Kirkland, MD, is a professor of medicine and interim section chief for palliative care at the Geisel School of Medicine at Dartmouth-Hitchcock Medical Center. She was an infectious disease specialist for two decades before entering palliative care practice four years ago and discovering “a world that embodies co-creation.” In this world, each day begins with a team meeting that brings together physicians, nurses, social workers, a chaplain, a fellow, residents and students, and a healing arts therapist. They pause to mourn any patient who has died since the previous day and then discuss their current roster of patients, seeking input from one another about any whose cases are challenging. The team then conducts rounds together and tries to help patients facing the end of life formulate achievable goals and “reconstruct [their] agency in the face of an unwanted diagnosis.” “Each day we find, or co-create, joy in our work,” Dr. Kirkland said. She attributed this to three important elements: (1) their work is about closing the gap between patients’ hopes and what is medically achievable, with the care team and patients agreeing on shared goals; (2) their work is “grounded in narrative” and includes the privilege of co-authoring patients’ next chapters; and (3) their work is deeply collaborative.

- After Natasha Gajewski was diagnosed with a rare connective tissue disease, she said she “encountered wonderful clinicians and amazing science, but also a health care system that foundered in ways [she] couldn’t have anticipated.” For example, she narrowly avoided a duplicative test when the results were not forwarded from one health system to another. She said the experience inspired her to take a more active role in managing her care. So when a medication proved to be financially burdensome, she worked with her doctor to craft an alternative treatment plan. Ms. Gajewski was tasked with accurately reporting her symptoms in clinic, to ensure that the alternative medication was working. This responsibility marked an important shift for her. “My symptoms became evidence that I was responsible for collecting,” she said, and this responsibility shifted her thinking. “After burdening my family for so long, I suddenly realized that I wasn’t the problem; the disease was the problem. And I became part of the team working to defeat it.” To facilitate regular observations, she looked for an app that would efficiently record symptoms over time. When she couldn’t find one, she built her own, called Symple Health, which became one of the 10 most-downloaded medical apps.

“We normally think of learning as something additive. But when things change, we have to uninstall the old map to install the new one, and we are not used to unlearning,” said Dr. Bonchek.

Kimball Lecture

These stories were followed by the Kimball Lecture, the Forum keynote address that honors former ABIM and ABIM Foundation President and CEO Harry Kimball, MD. This year’s address was delivered by Mark Bonchek, PhD, the Chief Epiphany Officer of Shift Thinking, who focused his remarks on how to think about co-creation. “‘Change is hard’ is a truism, but I have found that’s not necessarily the case,” he said. He drew an analogy to hanging from a trapeze with fraying rope and no net; we will hang on to the rope for as long as we can until an alternative appears, and then will jump to that alternative. “Change is hard when there’s no model to jump to,” he said.

One of Dr. Bonchek’s major themes was the necessity of ‘unlearning.’ “We normally think of learning as something additive,” he said. “But when things change, we have to uninstall the old map to install the new one, and we are not used to unlearning.” To illustrate the point, he showed a video of a man who took eight months to learn how to ride a “backwards bike” that was re-engineered so that its steering system was the opposite of a regular bike.

Dr. Bonchek suggested that we always “see the new through the lens of the old.” He reminded participants that automobiles were called “horseless carriages” when they were first introduced; he then argued that “patient-centered care” is the horseless carriage of health care. He said the first level of co-creation is the two-way flow of information, and patient-centered care represents the opening of lines of communication, which is critical. The next level of co-creation, however, is connection and collaboration between and among patients, clinicians and institutions.

To achieve this next level, he said shared purpose—“absolutely the cornerstone of all work in co-creation”—was critical. He described different kinds of shared purposes, and said real power comes from moving to the “purpose with.” The test of whether an entity has moved to that level is if its mission also describes the mission of its consumers; in other words, if the users of the product or service would feel included



enough in the mission to wear it on a t-shirt. He also said reciprocal relationships are a hallmark of co-creation, pointing to new economy outfits such as ride-sharing company Lyft, which advertises itself not as a taxi service but as friends driving one another.

Moderator Christine Sinsky, MD, asked Dr. Bonchek how health care could look different under a co-creation model. He said the first step is to think differently about what we mean by health care. In his conversations with health systems, he said their missions always involve “doing to” or “doing for” and that institutional leaders see themselves as delivering care, not creating health. He suggested a mind shift toward creating health was essential. When asked how a system might go about doing that, he proposed sitting down with groups of patients and asking them the role they would like their clinicians to play in promoting health.

Dr. Bonchek was also asked how co-creation differs from teamwork. “I think the difference is scale,” he said. “Co-creation is like teamwork at a scale of thousands or millions of people. But where you have teamwork, you have co-creation going on.”

Applying Co-Creation to Health Care: Part One

After the Kimball Lecture set the conceptual stage, participants heard from two leaders who have been involved in implementing co-creation in health care. Zoe Radnor, PhD, Professor and Dean at the University of Leicester, shared her experiences improving care in the United Kingdom’s National Health Service (NHS). She began with a story. She was standing in an NHS hospital and noticed that people were signing a book. She asked them about the book, and learned that anyone who bicycled to work signed it. She asked what was done with the information, and the cyclists said they didn’t know. She found out that the Personnel department received the books, and promptly put them on a shelf. When the shelf became full, old books were sent to storage. No use was ever made of the information in the books. She then learned that the books had been collected continuously since 1948, when the cycling information

“What might be required to improve the value of the contribution that health care services make to health?” asked Dr. Batalden.

was used to allocate rations. To Dr. Radnor, the story illustrated the system’s blind attachment to business as usual and the need to re-examine our practices. (You can hear Dr. Radnor tell the story in this [BBC podcast](#).)

She shared how heavily the NHS relied on Lean principles in its attempt to improve the quality of care, and faulted that effort for an overreliance on figuring out how to improve care processes without first ensuring that the system is designed to meet patients’ needs. Even though health care is a service, she said, “We’ve designed our system based on manufacturing logic.” She called for actively engaging patients throughout their experiences with the health system. “True co-production is not doing a patient survey at the end of an appointment,” she said.

Paul Batalden, MD, Professor Emeritus at The Dartmouth Institute, talked about his work applying the theories of social scientists Victor Fuchs and Elinor Ostrom to health as he sought to answer the question: “What might be required to improve the value of the contribution that health care services make to health?” He pointed to a number of opportunities for using co-production in health care, including in the education of clinicians, the design of systems, and measurement, while acknowledging challenges such as the wide diversity of people involved in the health care system and “sturdy professional cultures” that may not naturally accommodate this new way of thinking. Overcoming such challenges is essential, he argued. “Neither health nor learning can be outsourced,” he said. “We’ve pretended we can have a conversation about quality within the professional domain alone, and then just tell the public they were well-served. We can’t do that anymore.”

After their remarks, participants discussed at their tables the challenges presented by co-creation. Time and a fear of lost control were frequently mentioned barriers. “To be relational takes time to establish and maintain the relationship,” said Lewis Sandy, MD, Executive Vice President for Clinical Advancement at UnitedHealth Group. “There needs to be a way to create more time, perhaps through networks.” Others expressed concern about how less sophisticated users of health care services could be incorporated in co-creation efforts. “Are we truly co-creating if everyone is not involved?” asked Robert Siegel, MD, Hematology Oncology Program Director at Bon Secours St. Francis Hospital. “Often this discussion is held among sophisticated people who articulate what their needs are. I’m not sure we understand the needs of disenfranchised groups.”

Summarizing Day One

Susan Edgman-Levitan, PA, the Executive Director of the John D. Stoeckle Center for Primary Care Innovation, offered closing remarks on the Forum’s first day. She reminded the audience that the concept of patient-centered care was developed in the late 1980s out of concern that the health care system “viewed patients as either imbeciles or inventory.”¹ She said that although we have made much progress in partnering with patients to meet their needs, it is still a “horseless carriage” in some places. She described resistance, fear and myths around the concept of co-creation. She said patients worry they won’t really be listened to, and clinicians worry that patients will see their “dirty laundry,” and that only angry patients would choose to participate in co-creation activities. In reality, she said, it rarely works out that way. She also suggested that clinicians should stop engaging in “magical thinking” by assuming that their instructions to patients are automatically followed without any exploration of patients’ priorities. She encouraged changing the clinical paradigm from “What is the matter?” to “What matters to you?”²

Ms. Edgman-Levitan also said that using co-creation does not require reinventing the wheel; rather, there are hundreds of health care organizations and practices where this is the way of doing business. For example, she said Massachusetts has required every hospital to maintain patient/family advisory councils and to report on them each year. “People were terrified when we started, like we were letting the Huns in,” she said. “Now many organizations can’t imagine how to work differently.”

The failure to co-create care can lead to dangerous pitfalls, she argued, relating a story about Partners’ effort to redesign diabetes care. Partners decided to create a series of centers for patients to go to learn how to start insulin injections for diabetes. The group responsible for the redesign vetted the idea with people who had diabetes, who, to a person, said they would not go to them and much preferred learning how to give themselves insulin in the practice where they received the rest of their care. In response, Partners abandoned the idea. “If we had built those centers, we would have wasted millions of dollars and blamed the lack of use on patient resistance,” she said.

Applying Co-Creation to Health Care: Part Two

The Forum’s second day featured presentations from clinicians and others who have used co-creation principles to improve care. The first presenter was Peter Margolis, MD, PhD, the Co-Director of the James M. Anderson Center for Health Systems Excellence at Cincinnati Children’s Research Foundation and a professor at Cincinnati Children’s Hospital Medical Center. Dr. Margolis believed the health care system was not working for physicians treating children with Crohn’s disease (who had limited access to information about what treatments worked best for particular patients) or for the children and their families (whose participation was not facilitated). He sought to create a better system for chronic illness care by building a network that would allow patients and physicians to share information, collaborate and use their collective

1 Beatrice DF, Thomas CP, Biles B. Grant making with an impact: the Picker/Commonwealth Patient-Centered Care Program. *Health Affairs* 17, no. 1 (1998): 236-244.

2 Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med*. 2012 Mar 1; 366(9): 780-1.

creativity. “Networks are so important in health care, because it’s a complex system beyond the capacity of a single place or person,” he said.

The network he founded, Improve Care Now, has grown to include 90 gastroenterology centers in the United States and abroad over the past 12 years, encompassing 25,000 pediatric patients—40 percent of children with the illness—and 780 physicians. The network offers extraordinary value for research, with registry data updated daily and employed to reduce variation and identify gaps that can be closed through research. For example, a researcher is currently using data from Improve Care Now for a Patient Centered Outcomes Research Institute study, and was able to recruit 30 study sites in two weeks and obtain 50 percent of the needed data from the registry.

The network also enables patients to play an active role in enhancing the care they receive. Patients develop and publicize ideas for care improvements and have formal advisory roles. For example, one group connected and empowered by the network developed an “ostomy toolkit.” Patients also contribute to research, including studies of individual patients.

The network’s life has coincided with a meaningful improvement in the treatment of Crohn’s disease; Dr. Margolis reported that since 2007, remission rates have increased from about 50 percent to about 80 percent. The network concept has been replicated for other diseases and conditions. Dr. Margolis pointed to four design principles that those interested in replication should be attuned to: a focus on outcomes, building a community, using technology effectively, and creating a learning system.

He said challenges included a “shifting power dynamic [between patients and clinicians] that can become uncomfortable” and limited bandwidth to operationalize great ideas that the network produces. Overall, however, he said, “the network has provided a sense of solidarity, mastery and friendship. It has inspired a relentless focus on outcomes and taught us about the importance of design.”

Benjamin Heywood, Co-Founder and President of Patients Like Me (PLM), spoke about his company’s efforts to enable patients to form networks and improve their health. He said that PLM’s network includes approximately 400,000 patients who use it to share information and engage with one another about approximately 2,500 conditions.

As an example of PLM’s potential, Heywood discussed its epilepsy community. He said that one-third of its members had never interacted with someone who had epilepsy before joining, and that 23 percent of group members reported visiting the emergency room less often after becoming part of the group. He said PLM partnered with the American Academy of Neurology to disseminate its standards of care on epilepsy, which recommend patients’ seeking treatment from an epileptologist, and that many network members had until then been unaware of the existence of such a specialist.

Heywood cited the medical community’s resistance to the introduction of home pregnancy tests as an example of how dramatically the balance between clinician and patient has shifted over the last half century. He then predicted that patient empowerment would increase exponentially in the coming decade and called upon the group to consider what it will mean when patients come to them “fully digitized.”

“Networks are so important in health care, because it’s a complex system beyond the capacity of a single place or person,” said Dr. Margolis.



After these presentations, meeting participants chose among small group “innovation sessions” in which they could learn more about efforts to use co-creation to improve care. Many of these sessions featured projects described in the background paper for this year’s Forum. Other examples included:

- **Co-Production of Cystic Fibrosis Care:**

Bruce Marshall, MD, the Senior Vice President for Clinical Affairs at the Cystic Fibrosis Foundation, described the foundation’s effort to create a “co-production dashboard” at the point of care to enable symptom tracking, self-management and communication during and between physician-patient encounters, and informed decision-making at the point of care. A pilot project was launched in 2015 at three care centers, and testing thus far suggests that use of the dashboard results in productive and interactive encounters, facilitates pre-visit planning and post-visit documentation, and enables patients and clinicians to annotate outcome measures.

- **Open Notes at Kaiser Permanente Northwest (KPNW):**

Robert Unitan, MD, the Director of Optimization and Innovation at KPNW, discussed how in April 2014, KPNW made the visit notes recorded by nearly all of its clinicians available to its more than 250,000 patients. Patients receive emails directing them to where in the online patient portal they can see the visit note as soon as the encounter is complete. Patients surveyed eight months after the project launched reported high satisfaction with the positive impact on their care and improvement in their relationship with their clinician.

- **From Voice to Voices: A Dynamic, Web-based Patient Presence:**

Meg Gaines, JD, the Director of the Center for Patient Partnerships (CPP) at the University of Wisconsin, led a discussion of an effort by the CPP and its network of

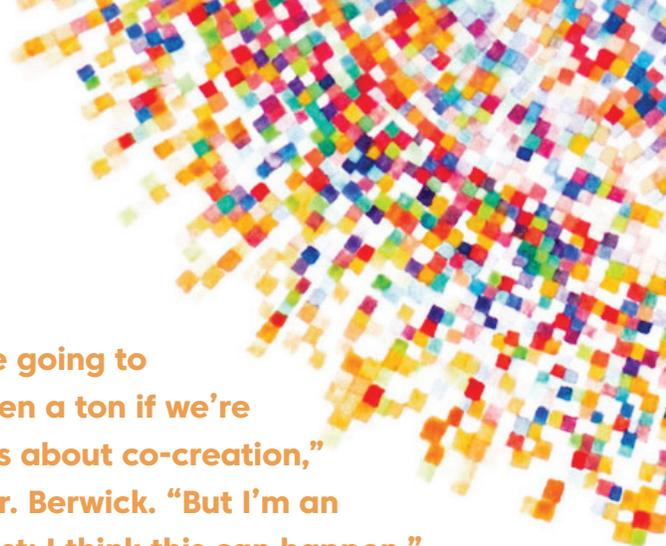
partners to “move from patient voice to patients’ voices” by combining rigorous qualitative patient experience studies and Web-based presentation of collected data to produce multimedia summaries of patients’ experiences with particular conditions. She demonstrated the first Web-based module, which illustrates young adults’ experiences with depression.

Summarizing Day Two

The day closed with remarks from Don Berwick, MD, President Emeritus and Senior Fellow at the Institute for Healthcare Improvement and former Administrator of the Centers for Medicare and Medicaid Services. He discussed the different levels where positive disruption can happen: individual interactions with patients, microsystems, mesosystems, and the environment of regulation and payment.

To explore the individual level, he told two contrasting stories about disruption. In the first, a very close friend of his was undergoing complex heart surgery and completed an affidavit enabling Dr. Berwick to review his record on a daily basis. When Dr. Berwick tried to pick up his friend’s chart on the hospital ward, he was stopped and reprimanded by several nurses and a security officer. It turned out that the affidavit had been lost, and the staff refused to believe Dr. Berwick’s assertion that he had the patient’s permission. After much interrogation, he was allowed to review the chart, but only in the presence of a nurse “to make sure you do not alter the record.” Dr. Berwick’s second story was about a moment that he called “one of the deepest experiences I have had as a clinician or a patient.” Another close friend of Dr. Berwick’s was seriously ill, and the diagnosis was proving elusive. In this case, the attending physician approached Dr. Berwick and asked him for his help to review the record and offer ideas. The attending physician asked Dr. Berwick “What do you think?” before turning each page in the record. “We co-created whatever future we could,” Dr. Berwick said. “What a disruptive world it would be if we asked that question, ‘What do you think?’ time after time.”





He then reflected on Dr. Kathy Kirkland’s remarks about her palliative care team as an example of positive disruption at the microsystem level. “I heard a passionate, committed, open-minded, poetic physician describe her work, but not her work only—the work of the team,” he said. “The team allowed dialogue and productivity that would never have been possible otherwise.”

At the mesosystem level, Dr. Berwick speculated about what it would be like to have Patients Like Me as a mainstay in the support systems created by large health systems.

Regarding the environment of care and the cultures of today’s micro- and meso-systems, Dr. Berwick then discussed challenges that those interested in advancing co-creation will have to overcome. For example, he said we have created a regulatory structure where sharing information is practically impossible (HIPAA, for example has serious flaws), and that structure is deeply embedded in rules, habits and beliefs. He also argued that co-creation more generally represents a giving up of control by powerful actors. “We’re going to threaten a ton if we’re serious about co-creation,” he said. “But I’m an optimist; I think this can happen.”

Co-Creation at the Community Level

The Forum’s final day featured presentations from Elliott Fisher, MD, MPH, and Laura Landy, MBA, about their ReThink Health initiative, which seeks to reinvent care at the community level. “It is hard to change a complex, dynamic system,” said Landy, the President and Chief Executive Officer at the Fannie E. Rippel Foundation and ReThink Health. “It requires getting outside of the current conversations in health, and asking how we co-create a process that helps us understand how to do that.”

In launching the initiative, Landy convened a group of experts from within the health system (e.g., Don Berwick, Fisher) and outside it (e.g., economist Elinor Ostrom, community organizer Marshall Ganz, alternative energy guru Amory Lovins). They engaged a group from MIT to create an interactive model of a regional health system and help create strategies

“We’re going to threaten a ton if we’re serious about co-creation,” said Dr. Berwick. “But I’m an optimist; I think this can happen.”

that could save lives and money and reduce inequality. The project’s leaders came to believe there were three requirements for reform that need to be pursued simultaneously: (1) achieve higher-value care, with better coordination and advanced planning to help avoid unnecessary hospitalizations; (2) address upstream determinants of health; and (3) develop new financing mechanisms and business models.

Landy said that ReThink Health has worked directly with about 70 regional coalitions to attempt to achieve these goals, and has not yet seen the desired results. However, she said interest in community-wide projects to improve health and health care continues to build, reporting that about 250 community organizations responded to a recent ReThink Health survey, and 64 percent had formed since 2010.

Dr. Fisher, the Director of the Dartmouth Institute for Health Policy and Clinical Practice, talked about the regional effort in the areas of New Hampshire and Vermont surrounding Dartmouth. He said the project got off to an excellent start. After General Electric CEO Jeffrey Immelt spoke at a forum at Dartmouth, the CEOs of the two largest local for-profit employers (King Arthur Flour and Hypertherm) engaged in the work. Project leaders interviewed a cross-section of people from the community, asking them “What matters to you?” and “If this were a wonderful place, what would it look like?” Among other things, respondents said they wanted to live in a wonderful place to raise a family and grow old, with a health system that made care accessible to the uninsured.

Hundreds of people attended community meetings about the project, Dartmouth and the involved businesses contributed funding, and small signs of change appeared, such as a focus on healthy food and an increase in advanced care planning. Funding, however, is now in danger, and Dr. Fisher is uncertain of the effort's future prospects.

He described barriers to progress in this and other community efforts as a lack of sustained leadership from organizational leaders who ultimately delegate their involvement, a lack of state and federal support, and a lack of infrastructure to undergird the work. However, Dr. Fisher believes the voice of the community is essential to achieving progress. "Incumbents don't want to change; it's going to take voices of the community to hold them accountable," he said.

Both Dr. Fisher and Ms. Landy talked about the importance of working at multiple levels ("nested structures") to achieve reform. "There are multiple levels where work has to happen if we're going to achieve a healthy system," Dr. Fisher said. "What do people in their households need to do? They need to be engaged in co-design of care for themselves, and in how to help people in their neighborhood get exercise. Getting your town to put in a sidewalk and lights requires the next level up of nested structures. Regional organizations need to work with payers. The state and federal governments need to make it possible. We're not thinking enough about how we build co-creation that engages all levels."

"Incumbents don't want to change; it's going to take voices of the community to hold them accountable," said Dr. Fisher.

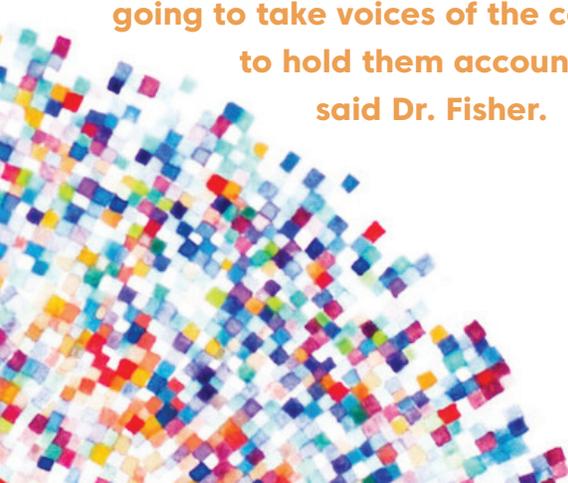
Reactions

A reactor panel then discussed their impressions from the Forum. C. Todd Staub, MD, the Chairman of ProHealth Physicians, who practices primary care in Connecticut, said his practice is currently engaged in a transformation effort and that he will now be "very intentional about getting end users to sit with us and reinvent the care platform." Moderator Jackie Judd asked what he would ask his community's residents. "Let's look at what we have and how we can re-imagine it in some other way that meets your needs," he said.

Jeanne Marrazzo, MD, the Director of the Division of Infectious Diseases at the University of Alabama at Birmingham School of Medicine, commented on how co-creation applied to the HIV research she conducts. "What has really resonated with me is how to reach healthy people, and not thinking of them as patients," she said, referring to her work to prevent HIV infection among young people in the South. "They don't come to the buildings we've erected to deal with health care." She also said it was critical to solicit and listen to disempowered community voices.

Meg Gaines, JD, responded to the concerns expressed about clinicians' ability to find time to engage in co-creation. "Co-creation is a process that takes time in the making, but once it becomes the new normal, it saves time and increases quality," she said. "There is an enormous untapped army of patients. Clinicians fear that this is something new, that they're not trained to do it, that the bicycle feels backward. We are holding on to this fraying trapeze so hard."

The group discussed the fear that physicians may believe that co-creation devalues their expertise. "It's a shift in expertise," Dr. Staub said. "When I came out of training, I had a lot of knowledge in my head that patients didn't have. Today, my patients may know more about their condition than I do. My role has changed to guide. How can I guide you if I don't know what matters to you?"



Co-Creation in Action

For part of each day at the Forum, participants worked in groups to develop their own co-creation idea. Fifteen ideas were developed, and three were recognized by a vote of the participants as the most promising. Representatives from each of the three winning groups discussed their ideas on the Forum's last day. The ideas were:

- **Unleashing Health-Making Capabilities of People Living in a Place:** Charles Kilo, MD, MPH, Vice President and Chief Medical Officer of Oregon Health & Science University, said the animating principle behind his group's concept was to foster the ability of people in low-income housing to co-create health in their community. He suggested that people in the community would begin walking together as a way to build health and "recapture community." Organizers would work with community members to develop health-generating activities, but the residents would determine which activities to pursue, after determining what resources were available and where gaps existed.
- **Educating Better Together:** Vineet Arora, MD, Assistant Dean for Scholarship and Discovery at the University of Chicago, described a co-created virtual learning community with the purpose of developing expertise about co-creation among the health care workforce. Such a network could begin with all Forum participants, each of whom could invite five colleagues. Initial content could include videos made by presenters at the Forum; other participants would be challenged to provide content as well.

- **The Ideal Primary Care Visit:**

Elizabeth McGlynn, PhD, Director of the Kaiser Permanente Center for Effectiveness and Safety Research, discussed a project to co-create a primary care system that works for patients, physicians and teams, health systems and payers, and reinvent how people interact with their primary care providers. The first part of the project would be an engagement phase, to elicit ideas from each group about what they would like to see from primary care. That would lead to an implementation phase of experimenting with designs and testing reactions from the constituent groups.



Conclusions

Robert Wachter, MD, the Interim Chairman of the Department of Medicine at UCSF, offered concluding remarks. He said that over the course of the Forum, he heard both moral and pragmatic arguments for embracing co-creation and believed both are critical. “If it’s all a moral case, I worry this won’t happen,” he said. “The forces fighting it are fairly powerful. This has been talked about for 20–30 years and not all that much of it has happened.”

He suggested, though, that changes in the environment have increased the appeal and practicality of co-creation, with digitization first among these changes. “In the last five years, we’ve gone from an industry that’s all about information but with a backbone of paper and pencil to one whose backbone is digital,” he said. “It’s a different conversation now.” Eventually, he suggested, the increasing role of information technology in health care would lead to connections between hospitals’ electronic systems and consumer-driven apps. “When the system becomes totally wired, you enable consumer engagement,” he said. “It will be a huge enabler of co-creation. For those of us in legacy organizations, co-creation is the most benign outcome. Another outcome could be replacement.”

Using co-creation to improve the system, however, must avoid certain pitfalls. Dr. Wachter said that he shared concerns about devaluing expertise, and believed that any approach designed to increase consumer input had to grapple with the fact that “the crowd is sometimes not wise.” He cautioned that appeals for greater co-creation should be evidence-based—advocates will need to prove that it is working to improve care.

Finally, he issued a multi-part challenge to participants: choose one level at which to advance co-creation (the clinician-patient level, within an organization, or between the organization and its stakeholders/consumers), develop moral and pragmatic arguments on behalf of their chosen co-creation project, embrace co-creation in an aspect of their personal work, use a technology with which they’re uncomfortable, and spread the word.

The ABIM Foundation endorses this challenge, and hopes that the Forum provided the content and experience necessary for participants to appreciate how co-creation might influence their own work. The ABIM Foundation would be very interested in learning from participants about any stories of co-creation that arise in the coming year; we look forward to hearing from you. ■



510 Walnut Street | Suite 1700
Philadelphia, PA 19106-3699
215.446.3530 | 1.800.441.2246 x 3530
www.abimfoundation.org

