LARRY CHU, MD, MS (EPI), MS (BCHM)
Executive Director

Medicine X 2016 sessions of interest to the Pharma and Life Sciences Industries

This document contains a selection of the 250+ presentations at Stanford Medicine X 2016 (Sept 16-18, 2016) that may be of particular interest in the following domains:

- SPECIAL SESSIONS
- DATA, DEVICES AND THE PHARMA ENTERPRISE
- DIAGNOSTIC TESTING
- DESIGN IN HEALTH CARE
- TECHNOLOGY AND HEALTH CARE
- PATIENT AND PROVIDER COMMUNICATION/OUTREACH
- PATIENT PARTNERSHIP AS A DRIVER OF HEALTH CARE INNOVATION
- CLINICAL RESEARCH INNOVATION
- HEALTH CARE PROVIDER EDUCATION AND OUTREACH
- HEALTH CARE SYSTEM IMPROVEMENT
- ORGANIZATIONAL INNOVATION IN HEALTH CARE

SPECIAL SESSIONS

Opioid Crisis

The Opioid Crisis Special Session will be moderated by Joanne Kenen Executive Editor, Health at POLITICO. It will focus on engaging different perspectives surrounding the opioid crisis and address questions such as: What are the issues surrounding medical access and opioid abuse? What is the role of technology and design in addressing these questions? What are the opportunities and obstacles to changing the culture?

Changing Cancer Care: The Medicine X and Astellas C3 Prize Live Pitch

Recognizing the need to move big ideas in health care innovation into real world solutions, Medicine X is excited to feature the Changing Cancer Care: The Astellas and Medicine X C3 Prize Live Pitch this year. This innovation challenge was created to uncover new tools and resources that can change cancer care by potentially helping patients with cancer, their caregivers and loved ones live better today. Five C3 Prize finalists will pitch their ideas to change cancer care live at Medicine X to a panel of judges, including Robert Herjavec, star of ABC's hit television show Shark Tank, and Michael Seres, Medicine X ePatient-in-Residence, and founder of 11health.

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Executive Director

DATA, DEVICES AND THE PHARMA ENTERPRISE

Extracting adverse drug events from Twitter messages in real time using Naive Bayes classifier

Dimitris Spachos

Background
Traditional reporting systems for adverse events (AE) have been slow in adapting to online AE reporting from patients. In the meantime, the growth and popularity of social media turned many patients and drug users to share their experiences with drugs online. Twitter is a social media service with increasing adoption and, although is limited to 140 character messages, can be a valuable source of AE related information. In this study, we describe the development and use of a real time system, that gathers AE information from users tweets. We compare the collected AE frequencies with those referred in the clinical trials of the drug and examine the results: are they a reliable source of information?

Method
The system uses Twitter Search API to retrieve Tweets that contains a specific drug name, e.g. Xanax. We carefully choose up to 25 tweets to create a training set for use on the Naive Bayes (NB) classifier. NB classifier is fast and requires only a small amount of training data to estimate the parameters necessary for classification. Thus, is suitable for a real-time application. The software can run on a mid-size server making it fast and cost-effective.

The system periodically collects new messages. In each message, we apply the NB classifier and get a value between 0 and 1. This number represents the probability this message to refer to an AE. Finally, messages having values over a threshold create a set of AE incidents items.

Results
Using the above described method, we searched for a specific drug word (Xanax) and extracted around 320 AE incidents, for a threshold of 0.6. Within these tweets, we counted the frequency of specific words (e.g. drowsiness, insomnia) coming from AE reported in placebo-controlled trials of the drug. Comparing the two frequencies gives us a glimpse on how reliable are the collected information: although there is a recognisable pattern between the two frequency tables, there are differences in the percentages of the observed AE.

Conclusion
This study proposes an innovative way to use well-known techniques, such as NB classification, to build a fast and cost-effective real time system for collecting AE incidents from social media platforms, such as Twitter. The system can automatically collect and report messages with information related to AE. A comparison between the frequencies of the AE in the messages and those reported in clinical trials, shows that although there are differences on the percentages (and, thus, the data cannot be considered as reliable), there is a pattern that indicates a possible correlation. Future work includes research for more drugs and AE as well as improvements on the NB classifier.

Securing the internet of health care – effective strategies for medical device security

Christopher Campbell

The modern clinical ecosystem has become dependent upon a complex environment of medical devices, from the simplest consumer glucose meters to the largest imaging devices. The interactions of patients and clinicians, and the sharing of data among devices, is crucial for accurate diagnoses and effective outcomes. However, medical devices typically have the worst relative security profile, and this fact is too often overlooked. Medical devices have the most vulnerabilities of any hardware, IT or otherwise, functioning within the hospital.

Most healthcare security experts agree that medical device security vulnerabilities have reached the tipping point at which the risk to integrity of data is becoming eclipsed by the compromise of patient safety.
Given the criticality of data sharing and analysis from this Internet of Healthcare, what can be done to address medical device security issues without creating obstacles to patient care?

In this presentation we will:

- Discuss how to identify and target the devices with the most critical security vulnerabilities – from those in use by consumers to those within hospital settings.
- Learn how to address these issues through a layered risk management approach of IT security best practices and vendor analysis that creates checkpoints for patients, clinicians and IT staff.

How to maintain innovation in development of medical devices and applications while adhering to security best practices.

Revolutionizing the flow of data to improve every patient's care

Jim Hollingshead, PhD

Digital health cannot succeed if siloed systems impede the flow of data. As the global leader in connected health devices, ResMed has a unique understanding of what it takes to connect the healthcare world. ResMed has built its success in the space through its history in understanding and creating therapies designed to improve chronic respiratory conditions, including sleep apnea and COPD.

As the first to commercialize CPAP therapy for sleep-disordered breathing, ResMed has been revolutionizing care delivery and medical devices for decades. Looking forward, it looks to revolutionize how best to learn from patients as to how and why they are using prescribed devices.

In this talk, Jim Hollingshead will discuss how ResMed has evolved from a medical device manufacturer to the global leader in connected care with more than 1.3M connected health devices today, and how, in the process, the company has singlehandedly built a scalable infrastructure to diagnose, treat and monitor tens of millions of patients with life-threatening conditions, and what that means for patients, payers, providers, and the future of medicine.

How to use open healthcare data to empower patients

Fred Trotter

The industry has taken to calling medicine the new "MoneyBall" which makes the implicit analogy that healthcare is like baseball. We love the idea of evaluating the data of providers as teams, rather than as individuals, but Healthcare is nothing like baseball.
Instead, healthcare used to be a sport like Golf, played in a solitary man-vs-man fashion where teams did not matter too much. Now it is becoming a sport like Rugby or Frisbee Golf… and we have the data visualizations to prove it!

MHealth and big data are catalysts for personalized patient care

Ravi Komatireddy

The intersection of widespread mobile adoption, cloud computing and healthcare will enable patient-reported outcomes to be used to personalize care, draw insights and shorten the cycle from research to clinical implementation. Today, patient-reported outcomes are largely collected as part of a regulatory shift to value-based or bundled care. When patients are

able to record their experiences in real-time and combine them with passive data collection from sensors and mobile devices, this information can inform better care for each patient and contribute to the growing body of health data that can be used to draw insights for all patients. This session explores the current limitations of patient reported outcomes and how mobile health and big data analysis unlocks their potential as a valuable tool to deliver care.

At the end of this session, participants will understand the evolution from today's static patient-reported outcomes to fully patient-driven outcomes that enable personalized care based on each patient's situation and life goals. They will be learn strategies for how to apply to their own situation, whether they are patients, providers, or healthcare administrators.

Leveraging econometric theory to detect adherence patterns in digital health social networks

Trevor van Mierlo

Background

Digital behavior change interventions have shown much promise. However, many programs that are successful in experimental conditions suffer from high attrition in the general population. This presentation leverages two economic models to help illustrate how digital patients engage with online support groups.

Methods

Two periods of activity (July 25, 2008-August 7, 2012; Nov 15, 2005 – June 6, 2014) of actor and network-level data were extracted from AlcoholHelpCenter.net, a free-to-consumer, self-guided, patient-centric intervention designed to assist individuals cut down or quit drinking. In study period one, demographic characteristics and social network usage patters of 2584 registrants were analysed. Study period two assessed social network engagement patterns of 830 actors.

Results

In period one, when comparing actors (n=449) to non-actors (n=2135), there were no observable differences in gender, age range, occupation, or level of education. However, there were statistically significant associations between social network use and engagement with tailored exercises ($P<0.01$). In period one, social network contributory patterns resembled a power curve, with a high R2 values (.962) and a statistically significant spearman correlation (.987, $P<.001$). In period two, social network patterns of engagement were analysed over 34 quarters. Number of actors (Mean=43, SD=89) and posts (Mean=507, SD=368) varied, however the Gini coefficient, an economic measure of statistical dispersion used to measure income distribution, remained surprisingly consistent (Mean=.29,

SD=.02).

Conclusions
In this digital health program, it was not possible to detect usage patterns based on demographic characteristics. However, engagement in the social network strongly resembled a power law, and the Gini coefficient was consistent. These results suggest that it is possible to predict and stratify individual engagement patterns. Based on these findings, it may also be possible to develop algorithms that can intervene with specific users who are in the process of disengaging with treatment.

DIAGNOSTIC TESTING

The rapid adoption and evolution of liquid biopsy technology in oncology diagnostics

Helmy Eltoukhy

The pace of adoption of liquid biopsy by the U.S. oncology community has few peers in the history of cancer care. This rapid adoption has sparked a wave of investment and interest in similar technology from large biotechnology companies, venture capitalists, and numerous startups.

Liquid biopsies were originally introduced as a tool to help match advanced cancer patients with an appropriate targeted therapy, while sparing them the discomfort and risk of an invasive tissue biopsy. But the greater promise lies in the ability of a blood test to surveil for cancer and assuage the concerns of high-risk populations, whether they have inherited cancer risks, environmental exposures, or are cancer survivors.

As genomic sequencing costs drop, technology improves, and test sensitivity increases, new applications will emerge.
In this session Guardant Health CEO Helmy Eltoukhy will discuss:

- The rapidly evolving liquid biopsy commercial landscape
- The potential for new applications beyond what has already been commercialized today

The process of building and iterating a digital-molecular product in a regulated environment.

The Economics of Diagnostics: Disrupting the Health Care Industry Through Near Patient Testing

Cary Gunn, PhD

The current laboratory testing system is broken and costly. It sends patients

to off-site collection sites, and then transports their samples in fleets of economy cars and cargo jets to large central laboratories for testing which takes days or weeks to generate results. This delays medical decisions and adds significant additional costs to physicians, patients and the health care industry as a whole. The industry is long overdue for change.

The past six months have brought intense scrutiny of the diagnostics world from industry leaders, investors and media alike. This has led many to question the ability of the diagnostics industry to make the necessary changes and transform the way in which we operate. It is imperative in this time of great upheaval, that we look at successful, innovative models in diagnostics as proof positive our system is ready for great change.

For too long diagnostics have played a tangential role in the patient experience by being absent from that critical time when a physician and patient are in consultation. Centralized laboratory testing virtually ensures that a physician will not be able to interpret test results contemporaneously with an exam. Instead, when he/she finally receives test results the doctor is forced to interpret them in the context of an exam that happened days or weeks ago. And the results still have to be communicated to the patient by phone or in a follow up appointment. All of these delays are not only costly, but negatively impact quality of care and patient satisfaction.

Genalyte's approach brings diagnostics into the physician office, allowing for point-of-care testing that delivers results in under 15 minutes. Genalyte can embed itself in the health care system and digitize blood samples from a finger-stick. Then it harnesses the massive efficiency of cloud technology for data analysis, quality control, and communication.

Near-patient testing presents a $75 billion opportunity for our industry. A single specialty such as rheumatology alone presents a $1 billion opportunity, highlighting the myriad specialties within health care where this approach can be implemented.
Genalyte's business model and proprietary technology will improve the patient experience as well as bring significant savings to the healthcare system as a whole.

- Machines are placed directly in clinics eliminating the need to send patients off-site or to transport samples saving millions of dollars on transportation alone.
- Results are generated and communicated to the physician within 15 minutes allowing test results to be interpreted with the patient present for examination allowing earlier intervention and improved outcomes.
- Patients will leave an appointment with their test results eliminating the need for costly follow up appointments or unreimbursed phone calls.
- Genalyte owns the testing platform, operates the lab and oversees

billing so there is no cost to the clinic.

Proprietary technology must be thoroughly vetted for the sake of the patient as well as the physician. Health care is not an industry that you can disrupt by breaking things and going back to remedy them later on. There are no do-overs. You must lead with fundamentally sound, proven technology.

As evidenced by the growing scrutiny on verifiable results, the watchwords for companies transforming diagnostics must be "scientific rigor." The science backing this change must be the highest priority; anything short of that will disrupt the disruptors and hinder needed improvements to healthcare that can mean a better quality of life for patients around the world.

The vision of our approach is simple: in an age when information can be transmitted at the speed of light, it makes no sense to maintain a diagnostics system that involves patients traveling to far-flung labs and then waiting days or weeks for results. Rapid test results that provide physicians and patients with the confidence to make data-driven treatment decisions during a patient's initial visit should – and will – become the new standard of care.

How patients take control of their precision cancer care by accessing their own molecular profiling data

Martin Naley, MBA

Advancements in technology and science are making precision medicine more possible every day. However, these innovations remain just out of reach for so many patients. We built a new company based on the hypothesis that regular people, armed with their data, can effectively access treatment options that were otherwise unavailable to them. Cure Forward recently launched for cancer patients, giving them access to their molecular profiling test data from any lab. People can use that data to learn about their disease, participate in a clinical trials exchange, and meet matched patients to problem-solve together.

2016 is the year that we plan to validate our hypothesis. We will be monitoring patient activity on the website: data uploads, posts to the trial exchange, clinical trial matches, and stories where using one's data changed the course of their care. We will be collecting data to understand the impact we are having on patient's lives and to improve to make an even bigger difference.

In this presentation, we will share the story of Cure Forward and our progress to-date with hard metrics and activity-based insights. We believe that a movement is underway for citizen science and patient-powered medicine, and we want to contribute our experience to the dialogue.

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Diagnostic testing brought into the home increases Telemedicine usage: The Strep Club

Rob Lapporte, MD

Patients are longing for convenient, high-quality care for low acuity conditions like sore throat, flu and urinary tract infection. Ideally, patients could get diagnosed and treated for such conditions without leaving their homes, for less than the cost of a co-pay. Although the telemedicine explosion has offered a partial solution, most services are rudimentary and lack diagnostic testing, which leads to underutilization of telemedicine, and in-person follow up visits.

Due to decreasing reimbursements and increased demands on medical providers, they too are in the market for an evolution in efficiency of patient care. They need a telemedicine system that allows them to diagnose and treat a patient, document the encounter, and write prescriptions within minutes, while minimizing liability. There is currently no comprehensive system that increases value, by increasing quality, saving time and reducing cost.

What if there was a home-strep test? Or a home flu test?

Just as easy to use as a home-pregnancy test, this one-step test tells you with near certainty whether your sore throat is viral (needing grandma's chicken soup and perhaps a prescription for comfort measures) or bacterial (requiring antibiotics.) If you do need antibiotics, you don't need to call your physician and make an apt or go into the ER or urgent care. Simply log in to the website listed on the box, upload a photo of your positive test, and a prescription will be waiting for you at the pharmacy. Still want to talk directly to the board certified physician? Not a problem!! That is always an option, for a small additional fee. But your entire encounter costs less than an average insurance copay.

Forty-five percent of people surveyed said they would trust a virtual diagnosis less, while 29.3 percent said they wouldn't trust a virtual diagnosis at all. That means approximately 75 percent of people either wouldn't trust a diagnosis made via telemedicine, or would trust it less than one that was made in-person. This leads to underutilization of telemedicine services.

48% of execs say they are more concerned with convincing doctors about the credibility of the telemedicine. 41% of respondents said they are not reimbursed at all for telemedicine services and 21% are receiving lower rates from managed care companies for telemedicine than in person care.

Lack of reliable physical exam, objective diagnostic testing and credibility lead to under reimbursement. We solve this problem.

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DESIGN IN HEALTH CARE

Patient designed, directed, and controlled health care

Marc Braman, MD

The big missing ingredient in health care and in the United States is an effective voice and representation of patients. Healthcare is supposed to be all about patients, and it is anything but that. The primary reason for this is that patients have no representation, voice, or negotiating power at healthcare system design tables. Efforts being done with patient participation at end-user levels are great, but we need patient control at the highest levels.

The obvious solution is an organization that pulls together many pieces and dynamics to take control healthcare at the system level, become the market and directing force for what patients require of those who will deliver health care to them. This involves everything that would be normal in well run business (which is completely not the case in our current non-system). This understanding and approach goes well beyond "patient participation" and employers taking control of payment processes of healthcare (such as in "The Grassroots Healthcare Revolution", by John Torinus, Jr). It is akin to a well run business designing and defining what they require and putting our RFPs and engaging those who best deliver what is required.

Design and business elements are key and very strong, as is excellence in execution and growth. Patients United is the core non-profit entity, which will have several related entities rounding out the spectrum of necessary functions for a highly effective change movement to take control of health care.

Made with Meaning: Patient-Driven Innovation in the Age of Consumerization

Stuart Karten

Technology is changing how people experience healthcare. Driven by connectivity that has put information at people's fingertips and forever changed our expectation for convenience, healthcare is in the midst of "consumerization." In a world where patients have increased decision-making power and more responsibility for their health outside of clinical settings, the patient's role is increasingly important in determining health outcomes. Engaged, confident patients are motivated to stick to treatment regimens and make often-difficult behavioral changes to achieve and maintain health. Despite their growing influence, few solution providers systematically engage patients in their product innovation and design process. This results in

negative experiences, and frustrated, fearful patients. Stuart Karten believes that looking at the patient experience can reveal new opportunities for innovation. In this presentation, Stuart will introduce best practices for developing differentiated health solutions that empower and engage patients.

He will discuss how to understand the needs of patients, caregivers, and health consumers on a deeper level, and how to translate such insights into meaningful health experiences that will boost engagement, capturing people's hearts and minds through emotional connection. Attendees will learn from real-world examples where incorporating patient insights has driven innovation.

Attendees will learn:

- Social, economic, and cultural forces that elevate the role of the patient in the innovation process
- Examples where incorporating patients into the product development process has led to a better patient experience in both traditional and non-traditional healthcare solutions
- An expanded definition of who patients are and what insights they can contribute to product innovation
- A framework for understanding patients' holistic needs to drive engagement
- A vision for the future of healthcare delivery

Designing health care that delivers more health, delight

Dave Sanders

It's no secret that the healthcare system is inefficient and, more often than not, confusing to patients. Research indicates that the number one contributor to health is access to good healthcare, yet traditional healthcare models often limit access. What if we reimagined healthcare in a way that puts patients' need first? What if instead of incremental change to a legacy system, we build it from the ground up?

Imagine incorporating technology seamlessly into the patient experience and responding to the needs of the most demanding generation that is underserved by healthcare today: millennials.

This resulting experience would be more personalized, less institutional and designed for everyday use. It would be more accessible in neighborhoods and via smartphone, and more transparent, with prices for services clearly posted and accessible. It would offer more personalized healthcare, instead of taking a one-size-fits-all approach, and it would integrate exercise, healthy eating and mind-body medicine into the clinic, as ways to prevent chronic

disease and achieve better health.

To accomplish this, two physician entrepreneurs assembled a team of leading designers, technologists, and brand experts with a principal goal: to redesign a well-established network of retail urgent care clinics into a full stack of medical services for millennials, complete with tightly integrated insurance. This generation gets messages, movies, and massages on-demand. They also seek to learn how their bodies work, and how combining food, medicine and relationships can help them go beyond basic wellness. They are accustomed to designed experiences, such as the look and feel of an Apple store. What if healthcare was designed in this way? To fully realize the benefits, they envisioned a mobile-first approach, integrated UX design and on-demand retail-style service.

The result is a complete care system that launched in 2015. It offers primary, urgent and advanced specialist care, and insurance people can use every day, like a gym membership, to access a network of neighborhood-based retail clinics for all needs. The system includes emergency care, as well as red-carpet admission to local hospitals when needed, delivered as part of a tightly integrated, technology enabled program. For example, patients and their specialists have an ongoing engagement via text message, email and video that lasts until the patient is satisfied with the outcome.

Dave Sanders, co-founder and CEO of ZOOM+ can discuss the design and creative thinking that went into this model of what healthcare might look like in the future. He can discuss examples of cost-savings gained through an innovative approach to triaging 80% of what emergency rooms treat at a significantly reduced cost. He can also provide examples of how applying a design mindset has influenced all aspects of care delivery within the system ZOOM+ has created, which includes 31 neighborhood clinics in the Portland and Seattle metropolitan areas.

Designing for core needs

Erica Savig

As human beings, we each have core needs that must be understood and satisfied: like a sense of belonging, connection, understanding, autonomy and control. These core needs and our desire to have them met are heightened in times of difficulty, as is often within medical contexts. For patients and their loved ones, being diagnosed with a new disease, undergoing intensive medical treatment or facing death can be one of the most profoundly challenging and vulnerable circumstances in life. It is at once the greatest challenge and opportunity in healthcare. Tending to a person’s emotional and psychological needs is a fundamental component of “caring” for them. It is also the crux of providing optimal patient experience, offering the best perceived and real care to patients, and creating truly deep relationships between patients, their families and a health care organization.

For administrators, determining common superficial needs of patients and families is a challenge, but uncovering these core needs requires a different approach. Not only is it very difficult to ever reach that emotional space, it takes time for staff to get to know their patients and families, especially on a very personal level, and time is particularly constrained in a clinical setting. It also requires clinical staff and caregivers to have specialized talent and training to effectively connect with people and determine their deeper needs while operating within a fast-paced and highly regulated clinical environment.

However, the opportunities created by understanding these core needs and directing efforts, investments, or other resources towards them, could be significant.

At Lucile Packard Children's Hospital, in the Bass Center for Childhood Cancer and Blood Diseases, we have designed and tested an effective and efficient method for capturing the core needs of patients and family members who have undergone treatment. The methods build on principles of design thinking and needfinding, and use clinically adapted design probe tools that help participants reflect deeply and communicate their core needs and feelings. We have been able to facilitate serious, yet often fun and personally satisfying, discussions with patients and their family members. The sessions have identified numerous immediately addressable issues, areas for future development in providing patient and family support, and other insights for improving hospital experiences and care. Interestingly, the process itself was also intrinsically rewarding and therapeutic. According to a survey completed, the sessions made participants feel inspired and excited, a deeper sense of purpose in life, like they were working with people who genuinely cared for them, and offered the opportunity to begin to relieve deep emotions, fears and traumas unknown to the care team and even among family members. The method and tools can be adapted to other clinical and design contexts.

Developing tools for improving quality of life with people living with Parkinson's

John Dean

Developing tools for improving quality of life with people living with Parkinson's
Parkinson's disease is the second most common neurological disease in the world, with as many as 10,000,000 people currently living with the diagnosis. This figure is expected to double by the year 2030 largely due to improvements in medical treatment and care that will allow individuals to longer (Dorsey, et al, 2007).

In the recent past, there have been a number of projects that have been undertaken in order to better understand aspects of the disease. From startups and venture backed projects to multinational initiatives in the

European Union with budgets in the millions of euros, technologies have been developed to monitor symptoms in order to optimize medication timing (Lakshminarayana, 2014), improve physical performance (Ginis, 2015) and quantify disease progression and potentially segment the disease into different phenotypes (Sama, et al., 2012; Serrano, et al, 2015).

Parkinson's disease provides a number of symptomatic components that make it a particularly attractive target for technology and innovation. Some of the most prominent features of Parkinson's lend themselves well to monitoring and analysis via technology. Tremor, for example, can be quantified with accelerometry (Daneault et al, 2013); in addition, it is typically responsive to dopaminergic medications used to treat the disorder (Buijink, et al, 2012), which provides a mechanism for assessing efficacy of novel compounds and other treatments including surgery as well as nonpharmacological approaches. Other aspects of the disease such as changes in gait (Ginis, 2015), axial mobility (Horak, et al, 2015), vocal volume and quality (Arora, 2015), fine motor control (Stamatakis, 2013) and changes in sleep function (Maglione, 2013) also lend themselves well to identification, assessment and ultimately, quantification via currently available technologies.

Despite this, the technological landscape within the Parkinson's community is littered with false starts, incomplete ideas and poor implementation. People with Parkinson's present with a unique set of challenges that can have a significant impact on their ability to interact with various technologies including issues with fine motor control, visuospatial deficits including decreased contrast sensitivity as well as cognitive changes that can significantly impact the ability to interact with different technological devices.

Developing a product that truly helps people live with the disease requires inclusion of the people living with the disease (the true "experts") as well as their care partners, healthcare providers and others in every step of project design. It is only the consideration of these multifactorial symptomatic influences alongside elements identified by individuals living with the disease that will ultimately lead to design of a successful product that will truly improve quality of life for people living with Parkinson's.

Human-centered design for quality of life in cancer care

Kavitha Ramchandran, Erika Tribett

Background

Care for people experiencing chronic and serious illness should focus as much on quality of life as on the treatment of disease. However, the current system is not designed to address these needs. Further, what does "quality

LARRY CHU, MD, MS (EPI), MS (BCHM)
Executive Director

of life" mean for patients, families and providers? How do we equip our healthcare teams, our system, and families with the tools to assess and support quality of life? Our team is focusing on tailoring and applying a clear set of tools from palliative care (PC) to general practice so we might treat the whole person and improve a range of outcomes. We are utilizing human-centered design methods to rebrand PC (from an end of life service) and develop novel interventions that bring quality of life central to cancer care.

Project detail
Our data collection to date has revealed need for improvements in:

- protocols and role definition for addressing patient distress,
- resources and tools to address needs,
- clinician education in palliative skills such as communication, symptom management and identifying patient goals,
- relationship-building to encourage interdisciplinary care,
- feedback mechanisms to track impact on quality of life and other outcomes over time.

In 2015, we convened a multidisciplinary group of 25 patients, family members, oncology clinicians and experts in patient experience and health services research to evaluate current data and generate ideas for optimizing support for symptom management and quality of life. Several themes were generated from the workshop and the group was engaged in small groups to work on pilot projects in these areas. Proposed solutions, such as a subspecialist "hub" that allows single referrals and streamlined access to supportive care, began testing and iteration at the Stanford Cancer Center in June 2015.

Workshop outline

During this workshop, participants will have the opportunity to utilize a rapid design process to explore and create for a specific theme around quality of life that we heard through work with patients and families. Together, we will discuss this theme and the cancer care experience. In small groups, participants will identify root causes and generate ideas to address them. Groups will converge around a single prototype and map the inputs and process required to ready it for testing. They will also create potential metrics for measuring success. At the end of the workshop, participants will have worked through the design process and generated a prototype to share with a small group of stakeholders. These prototypes will inform future work to improve quality of life care for patients and families.

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#WeAreNotWaiting – A revolution in patient-centered design

Amy Tenderich

Back in 2007, noted diabetes patient, blogger and patient activist Amy Tenderich wrote an open letter to the late Steve Jobs asking him to help design better diabetes devices. Since then, she has worked hard to amplify the voice of patient needs and bring innovation to diabetes via the DiabetesMine Innovation Project activities and events. These gatherings spawned the #WeAreNotWaiting movement – the ultimate grassroots patient-led innovation initiative, which has now gone global and is expanding even beyond diabetes.

Learn how the diabetes and other disease communities are taking matters into their own hands, with examples of products and platforms being created to help patients better utilize devices and health data for improved outcomes. Examples such as increased "time in glucose range" and quality of life improvements will be discussed, as well as ways that health care providers can and should engage in this movement.

TECHNOLOGY AND HEALTH CARE

Accelerating the promise of mHealth: the power of data, devices, and decisions for people living with chronic conditions

Matthew Jordan

The explosion of health and fitness wearables and the emergence of connected medical devices has enabled us to acquire more data about ourselves at an ever-increasing rate, however we have not yet figured out how to use the data to immediate benefits or lasting positive outcomes. At the same time, the number of people living with chronic conditions, and the individual and system cost of managing these conditions, continues to climb.

In this talk, healthcare design expert, Matthew Jordan will outline the opportunity presented by the proliferation of data and devices to create solutions that help people with chronic conditions understand and manage their conditions better. He will provide an overview of a conceptual vision for a cloud-based platform and mobile patient experience that integrates real-time environmental, connected device, measured biometric, and self-reported data from people with shared health factors. He will also highlight key design principles that will help make such a solution not only technically possible, but successfully adopted and implemented by patients and the healthcare system overall, finally delivering on the promise of mHealth.

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Smart aging: the impact of IoT on the elderly and caregivers alike

David Moss

The senior population in the United States is experiencing unprecedented growth. Since nearly 90 percent of seniors want to age in place, or stay in their own homes as they age, there is a significant need for technology solutions that can help seniors age independently. As such, health care is moving toward more coordinated, continuous health management monitored by new technology. These connected devices and mobile Internet-based technologies empower senior citizens to age independently while addressing the social, medical and functional needs of seniors and their caregivers.

In order to help improve quality of life, new technologies must provide both caregivers and patients with a simple way to communicate, generate emergency alerts and monitor medications, while still incorporating privacy and security. Ideally, these services should relieve some of the burden on caregivers while keeping seniors stay connected to relatives, caregivers, and healthcare providers. They should also be very easy to install and use for those with various health conditions.

People Power's recently launched Presence Pro Care software solution helps address one of the biggest challenges in society today: a rapidly aging population with a health care system that cannot keep pace with their needs. Comprised of a hub and sensors, this solution was created to help seniors live independently while giving relatives and caregivers a better balance between caretaking and their personal lives. With the ability to monitor whether a parent or grandparent opens their pill dispenser, leaves the house or deviates from their normal routine, Presence Pro Care allows caregivers to take better care of the people they love even when they're not present. It also helps seniors stay connected to their family members through two-way audio and video calling using the optional Presence video features, and photo sharing. With a focus on facilitating communication between people and their elderly family members and friends, this new technology will help shape connected health care and set a standard for senior living and caregiving.

David Moss, President and CTO of People Power, will discuss how connected devices empower senior citizens to age independently and how mobile Internet-based technologies, especially home monitoring, address the social, medical and functional needs of both seniors and their caregivers. He will also expand on Presence Pro Care, its benefits and differentiators, as well as why these types of technologies are necessary for the connected healthcare market.

By the end of this presentation, attendees will understand how to build a platform that embraces 3rd-party devices and sensors, and how the use of

sensor technology can lower senior care costs. They will also understand how caregivers can leverage IoT tools to shift their focus from reactive to preventative healthcare, as well as criteria to empower elderly populations living in their home to have safer, richer lives.

Fixing health information for ePatients and beyond

Tal Givoly

5% of all search is for health information. Google is now providing better information "ready made" when searching health information. Yet finding the proverbial needle in the haystack of millions of search result is still woefully inadequate. In recently published research at McGill University, 5 patterns of information seeking patterns for cancer patients have emerged. As it turns out, over 60% of the population are not fully satisfied with what they get in terms of health information – especially when coping with a serious or chronic illness. That's a huge problem. What's wrong with health information? How can it be fixed? Where are we going in this regard?

The speaker will share insights gained from this groundbreaking research as well as his personal experience both as a caregiver and an entrepreneur trying to transform health information to be the experience it should become. Additionally, key insights about the topic from a recent worldwide tweetchat comprised of patients, patient advocates, doctors and other medical professionals will be shared.

Set me free: The power of technology on the patient experience

Jessica Melore

When I was a 16-year-old high school senior, my life took a sudden, drastic turn. I suffered a near fatal heart attack and leg amputation, and later became a heart transplant recipient and two-time cancer survivor. As a healthcare professional, a national patient spokesperson, and a patient health advocate, I've seen both sides of the patient experience. I've found one of the hardest aspects of being a patient is the loss of control. Your schedule, your treatment regiment, and your life as you knew it is no longer your own, or at least how it feels at first. Having access to technology transformed my experience by connecting me with others and enabling me to define life on my own terms.

There were three forms of technology that had a major impact on my experience. The Heartmate LVAD (Left Ventricular Assist Device), a then-experimental implanted heart pump that kept me alive via battery power, enabled me to return to school after six weeks instead of waiting for months in the hospital like many other patients. My prosthetic leg empowered me to be active and mobile, to exercise and keep my body in good shape while I

waited with hope for a heart transplant. I sang on top of a desk in my school musical, went on a choir trip to Disney World, and danced the night away when I was named prom queen. The internet kept me connected with high school friends and new friends from college as they followed my wait for a transplant. It became a powerful tool for advocacy when I became a national guest blogger for organizations like Leukemia & Lymphoma Society, I Had Cancer, and Cancer Care. And it connected me with my heart donor's best friend, who finally found closure after the passing of her friend. As a professional in the organ donation field, I can also discuss ways that I've used the internet to facilitate discussions with donors, transplant recipients, and patients on the waiting list. For my Stanford Medicine X presentation, I will cover some of these areas.

Technology can offer mobility and freedom that allows patients like me to reclaim their lives. It inspires patients by giving us access to others' stories and helps us realize we're not alone. It allows us to stay engaged within our own networks even when we can't be physically present, and to make valuable connections through communities of support that can extend across the world. I would love the opportunity to share my story with the Stanford X community in hopes that it will show other patients how embracing technology can enhance their own lives, and inspire health professionals about ways that they can help facilitate access to technology and empower their own patients in this way.

The Human Side of Tech: Enhancing Digital Health Programs Using Technology to Complement Human Interaction

Margaret Laws, Eliza Gibson, Alex Drane, Wendy Sue Swanson

Given the increasingly ubiquitous role of cell phones and wearables in our everyday lives, we know that mobile tech holds a lot of promise in the digital health space. Technology follows us everywhere, opening up new opportunities to deliver effective healthcare interventions. However, technology cannot alone replace the important element of human interaction. We see the importance of and impact of face-to-face meetings and customized education on the quality of care. This poses the question: how might we effectively design a digital health program that combines technology with human touch? You'll hear from experts who have designed and implemented digital health interventions and learn about their success and what they've learned from failures. We will conclude with a robust audience discussion.

LARRY CHU, MD, MS (EPI), MS (BCHM)
Executive Director

High tech for high touch healing: using digital tools to blend conventional and complementary medicine for chronic disease patients

Bonnie Feldman, MD, Robin Berzin, MD, Lena Cheng, MD

The Precision Medicine Initiative and Vice President Biden's "moonshot in cancer" renew Federal focus on medical research. The convergence of healthcare and information technology—especially advances in data collection and analysis—is accelerating research in genomics, immunology, microbiomics, and systems biology. These developments are sparking unprecedented innovation in healthcare, enabling us to dream of a future where every person gets the right care at the right time, even before disease strikes.

Despite these new tools, chronic disease is epidemic, especially among young adults and children, who face a lifetime of suffering. Vague and debilitating symptoms are aggravated by confused and disconnected care. A major patient frustration is the lack of care coordination across medical specialists, even more so for complementary interventions like diet, exercise, and meditation. Results from our Stanford Medicine X 2015 survey of autoimmune patients reflect these cries for help, which are also shown in other patient communities.

"It took 7 years and 13 doctors to even TEST for autoimmunity. I feel cheated out of so many years of my life."

"I would like a team of healers working together, 'looking at the body as a whole system' to determine diagnosis and best outcome for each patient."

This panel is an opportunity for Stanford Medicine X's empowered patients to lead in the integration of complementary and conventional medicine to help reverse the accelerating growth of chronic diseases.

Inspirational entrepreneurs developing innovative delivery approaches will highlight how they are tackling chronic disease management in new and different ways.

Doctor on Demand gives consumers access to telemedicine consults at the push of a button.

Parsley Health focuses on prevention with a novel, subscription-based wellness practice that incorporates digital tools and coaching.

OneRing: automated parkinson's disease stage classification through random forest learning ensembles – an intelligent wearable ring for monitoring motor symptom progression

Utkarsh Tandon

This interdisciplinary study develops a wearable ring to automatically classify the stage and severity of Parkinson's disease through novel machine-learning based signal-processing. The algorithms presented in this study are trained to analyze passively collected movement data; automatically generating a quantified patient report that is critical to tracking disease progression, and optimizing its treatment. Current diagnostic procedures of Parkinson's – which affects millions worldwide – lack quantification, hence inhibiting a physician's ability to accurately prescribe medication. The developed ring utilizes power spectral analysis and deviation calculations as feature generation mechanisms to extract the principle components from movement data collected over an entire day. Random Forest (RF) classification then algorithmically identifies unique Parkinson's motor symptoms and uses the machine-learning ensemble to classify disease severity with 71% accuracy. The RF module, using stochastically trained decision-trees built from a labeled dataset of 30,000 examples, models movement patterns including Bradykinesia, Dyskinesia, and tremor to produce meaningful patient reports. Each report includes thousands of automated classifications resembling Hoehn and Yahr grading – therefore completely revolutionizing how physicians interact with their patients to prescribe medications. Overall, OneRing provides an entirely novel tool for monitoring Parkinson's, therefore potentially facilitating faster relief from motor symptoms for thousands of patients worldwide.

PATIENT AND PROVIDER COMMUNICATION/OUTREACH

Engaging the next generation of health care consumers

Michael Ruiz, John Englehart, Graham Gardner, Aaron Martin

For six years Clinical Observational Design Experience (CODE) has brought engineering students into active Emergency Departments where they discover problems in health care. This is a design course focusing nearly entirely on the discovery phase of design. Students spend 6-8 hours a week in multiple Emergency Departments where they begin to understand how healthcare is delivered and discover the problems faced by clinicians and patients.

Most clinical immersion programs have very limited time and limited access– essentially the students only see what their client wants them to see. In this course students see whatever happens in the Emergency Department – a place where healthcare covers broad ranges of demographics and clinical conditions. Extended periods of time for observation lets them understand the broader context of the problems. Collectively they see similar issues play out at different facilities and they see how the problems they identify affect different stakeholders. Extended opportunities to observe in the clinical setting enhance students' understanding of clinical problems.

Members of the panel will include faculty who have shaped this course and who work with students on biomedical design projects before and after their clinical experience.

The renaissance of patient education in the age of social media

Eran Kabakov

Our modern-day ability to exchange large amounts of information quickly and efficiently, through online platforms like social media, stands in stark contrast to the capacity of health care providers to share critical information with patients. This issue is best exemplified by the paper-based patient education that inexplicably continues to serve as the primary didactic tool in most clinics worldwide.

Historically, two main factors contributed to the knowledge sharing gap in health care: (1) lack of an intuitive and efficient information-delivery technology and; (2) the expense of creating didactic materials for patients. Whether causative or mutually exclusive, the vague US regulatory requirements, which simultaneously mandates the use of technology (HITECH Act) while insisting on highly misunderstood privacy regulations (HIPAA), further exacerbates these issues. Expecting busy healthcare providers to navigate this complex environment with the currently available tools is misguided.

As a result, healthcare is failing to provide an experience that mirrors the convenience and effectiveness of other knowledge-sharing services within information-heavy industries – services that have fundamentally altered huge segments of the economy and have seamlessly been integrated into our lives. This is not only a missed opportunity to improve user (read: patient) experience – it is literally a life-threatening rift in the provider-patient relationship.

With careful consideration of UI, UX and security, a standalone technology prototype was designed to specifically address patient education. This service was subsequently tested in 21 healthcare practices and amongst 57,000

patients in multiple locations across the United States. Patient education was limited to three specific, semi-elective surgical procedures. Prior to study commencement, these practices utilized face-to-face discussion and paper handouts as the primary educational tool (as none had knowledge or access to any applicable technology). At various points after implementation, patients (n=~32,000) and healthcare providers were rigorously surveyed. Patients reported significant satisfaction rates (≥98%), improved preparedness for procedures and/or follow up appointments (≥96%), and a high desire for repeat-usage (≥92%). Practices experienced improved utilization of clinical and ancillary staff members, and subsequent decrease in overhead costs related to patient education and communication. Additionally, clinic staff reported increased trust in the capability of technology to support patients with asynchronous education (≥95%). Overall, the prototype demonstrated the value in augmenting current treatment protocols with appropriate and thoughtful digital education solutions.

This presentation will review the history and evolution of patient education over the past three decades; discuss and differentiate between patient education versus engagement; clarify HIPAA and HITECH Act misconceptions (as they relate to this subject); and challenge current methodologies of patient education and engagement, demonstrating currently available strategies to substantially strengthen this experience.

The opportunities and challenges of connecting half a million health care professionals around the world

Joshua Landy, MD

Deep in the Peruvian rainforest, a single physician looks after a farming settlement just shy of two thousand people. There are no other health care professionals around; hospitals are expensive and far. But he is not alone. By using Figure 1, a secure digital platform for discussing and sharing medical cases, this physician is able to consult colleagues and specialists around the world.

With more than half a million users, WIRED magazine calls Figure 1 "the central nervous system of global health." The platform is connecting health care professionals around the world, allowing them to share their clinical knowledge on a global scale – and helping save lives.

Example: A 22-hour-old infant in Haiti presents with pustules over the scalp and shoulder. The registered nurse overseeing the infant's care has no access to laboratory testing and is concerned about the safety of 12 other infants sharing the same room. She shares the case on Figure 1, asking for help. Suggestions come within minutes and don't stop for days. In the end, 16,000 health care professionals sprang into action to help attend to one sick child. Paging cases such as this, where Figure 1 users can upload a case and

"page" relevant specialists for feedback, are typically responded to within three hours by a verified specialist. This is faster than many hospitals.

Health care professionals from almost every specialty connect on Figure 1 to help assess challenging cases, learn from differences in practice, and marvel at medicine in its many idiosyncratic forms. The platform reports more than 50,000 active users daily. While many users have helped improve outcomes for global cases, advancements are also being made on a local scale. American hospitals with large-scale clinical practices are using Figure 1 to share their expertise by virtually walking through interesting cases. What was typically restricted to one cohort of residents (and perhaps a few top-of-mind colleagues) is now easily shared.

As the Figure 1 community continues to grow and begins localizing in other markets, its co-founders are making constant adjustments to their strategy to sustain the quality of the clinical knowledge made available on the platform. This presentation will be led by Figure 1 co-founder, Dr. Joshua Landy. He will discuss how network effects apply to global medicine, the barriers to innovation and how to work around them, and what the future holds for connected health care.

Empowering Providers to Engage Patients

Russell Olsen

Despite all the advances introduced into healthcare over the last 20 years, the biggest X factor in successfully treating patients is still the patients themselves. If the patient is not engaged, then it is unlikely their condition will improve. This is especially true of patients with one or more chronic illnesses, which describes nearly 1 out of 2 adults in the U.S. according to the CDC.

In this presentation, "Empowering Providers to Engage Patients," Offering Lead for IBM Watson Care Manager, Russell Olsen, will briefly describe the vast need for improving patient engagement, and then discuss the analytics, tools and automation providers need to find and engage the right patients at the right time – on a population scale. At the heart of the problem is the need to make it exponentially simpler for providers to reach out and encourage the sickest patients to take better care of themselves. As Olsen will describe, the key is automating many of the care management tasks that are currently being performed manually by physicians, nurses and/or office staff.

Building on the theme of automation, Olsen will describe how IBM Watson Health's care management automation technology – used by 1 in 4 of the nation's largest health systems – has improved patient engagement for large physician groups across the country. One area where IBM Watson Health is making a significant impact is improving the health of patients with chronic

diseases. Here are three recent examples:

- Bon Secours Virginia Medical Group (BSVMG) used IBM Watson Health to drive nearly 31,000 extra visits to BSVMG from chronic disease patients with gaps in care during the 12 months ended August 2014. By meeting payer requirements for filling patient care gaps, BSVMG received $2 million in incentive bonuses from their ACO-like commercial contracts while improving the health of those patients. (http://bit.ly/1gogWqk)
- Arch Health Partners in San Diego wanted to raise the percentage of patients whose hypertension is under control from 63% to 70% by the end of a six-month trial period. Instead, using IBM Watson Health, the group achieved 77% control, leading Arch to create a new target of 80% for the next six months (http://bit.ly/18Yc4Lj).

Northeast Georgia Physicians Group used IBM Watson Health to build a patient cohort, risk-stratify patients, identify care gaps and send automated messages encouraging patients to make and keep appointments and providing digital diabetes education materials. As a result, the physician group was able to help 800 targeted patients lower their HbA1c scores by nearly 50 percent (http://bit.ly/1EUNqao).

Applying behavior change models to educate genetically at-risk celiac disease patients: a case study and workshop

Aimee Corso, Alice Bast, Daniel Leffler, MD, MS, Patrick McGovern, Kristin Voorhees, MA

Objective

This workshop will teach attendees how Beyond Celiac, a patient advocacy organization, is educating and empowering patients diagnosed with a serious, genetic disease to help advance diagnosis rates by encouraging those most at-risk to be tested: their biological relatives. Learn how qualitative patient-powered research that uncovered perceptions, barriers and knowledge gaps about disease risk and the testing process informed the design and launch of a national awareness campaign.

Unmet Need

When a health condition runs in the family, properly educating at-risk relatives is a critical tactic to improve diagnoses. To be successful, it's critical to first identify and understand the specific role those already diagnosed have in helping their biological relatives understand disease risk.
But this strategy represents only one piece of the puzzle. Those diagnosed cannot take action for their relatives and changing a person's health-related behavior is notoriously difficult. These more basic challenges are just half of the hurdles the celiac disease field must overcome in order to advance

diagnosis rates.

Enter "gluten-free." Now a common household word, its myths and food industry growth have obstructed understanding of celiac disease as a serious genetic autoimmune condition whose only treatment today is the gluten-free diet. The disease remains misunderstood and, as a result, is largely self-diagnosed. For the 83% of Americans left undiagnosed or misdiagnosed, their health is at stake and they are at risk for lymphoma, bone disease and other autoimmune diseases.

Solution
This workshop will examine how Beyond Celiac identified a creative solution to this uniquely complex problem by conducting primary qualitative research using an online community of patients and untested relatives. Rooted in the basics of verbal and non-verbal communication, a family member's likelihood of getting tested is determined by key factors including how and when we talk about disease risk and severity and the mindful balance of being both informative and caring.

Developed in collaboration with expert clinicians and a video production company, the Beyond Celiac campaign has reached over 642,000 people through online discussions, webinars, podcasts, views and downloads alone in 7 months. After using campaign resources, 95% of untested relatives surveyed said they are likely to ask their doctor for the celiac disease blood test.

Participants will benefit from interactive dialogue and valuable insights about:

- A creative approach in conducting primary patient-centered research
- How motivated patients can help influence diagnosis strategies
- When online health discussions become barriers to behavior change
- The application of theoretical behavior change models, including role modeling and the Health Belief Model, one of the most widely used conceptual frameworks in health behavior
- How clinicians can supplement these efforts and apply similar approaches to their care models

LARRY CHU, MD, MS (EPI), MS (BCHM)
Executive Director

PATIENT PARTNERSHIP AS A DRIVER OF HEALTH CARE INNOVATION

Creating movement in health care organizations through patient mobilization

Elizabeth Presson

ePatient Sarah Kucharski summed up a core theme of last year's Medicine X when she chanted, "I command changes in corporate philosophy that facilitate collaboration between pharma and patients. See me, hear me, feel me, and include me. We must find ways to work together. Even though it will not be easy." We heard it loud and clear: relationships matter—patient-to-patient relationships and relationships between organizations and patients.

We've heard, and understand, why patient communities are important to patients. In this talk, we'll shift the focus to why and how patient communities are helpful for organizations. We'll dive into the value of patient communities and what patient engagement looks like in practice with examples of initiatives by organizations like Oticon Medical and Eli Lilly.

Today, patients empower themselves by meeting others and finding information online. Less time with doctors and more investment in personal healthcare drives that desire more than ever. Organizations see the need to play a role in this connection, community and information sharing, but can become paralyzed by process and an unclear understanding of how it helps further business objectives.

As Jack Whelan said, "Business processes that have served this industry are so entrenched throughout that we fail to recognize their shortcomings. It's no secret this industry has become risk averse, reluctant to change and often gives its business processes priority over science."

Patients who practice self-disclosure and who have made it their own personal mission to inform others can help organizations overcome that paralysis. Understanding how to engage and create meaningful relationships—and most of all how to mobilize those relationships—can become access to otherwise closed conversations.

For organizations, patient communities serve the purpose of becoming more patient-centric, but these communities can also make a significant business impact. Organizations have the opportunity to connect advocates to patients, which gives organizations the opportunity to empower people to share messages in a much more casual, informal way. People trust other people more than companies, and they want to get as close as possible to

understanding what to expect from a product or process. Patient communities help people get there. Listening and observing conversations in patient communities helps companies create content that really moves people through the journey and/or decision process. These conversations take the guessing out of content creation—topics, questions, what will provide value—which is time consuming and costly. Communities act as built in R&D for organizations by helping to inform what's next.

For example, Oticon Medical, the company pioneering bone anchored hearing implant technology, needed to prioritize a number of new products for development, FDA approval and marketing. By creating a closed community for patient-to-patient discussions, Oticon Medical saw that current bone anchored hearing system users were finding many people who also wanted the device, but had an abutment that wouldn't allow for use of Oticon Medical's system. With that patient data in hand, Oticon Medical pushed the release of their abutment extender product. Today, the community has done most of the marketing for the new product, which has greatly increased interest and sales.

We'll also cover brass tacks, like:

- How to use technology to be a MORE human-centered company
- How and why connection needs context
- Why professionals want patient-centered content too

We'll dive into a 6-step engagement process that organization can utilize to build and use patient communities to move their organizations into the present and future—with each step showing live examples.

Breaking the medical cartel – patient ordered tests and treatments

Gregory Schmidt, MD

Since time immemorial, a small group of individuals has controlled medical knowledge. Be it the shaman, the medicine man, or the doctor, the practice of medicine has been restricted and secretive. The medical cartel, however, will come to an end this decade.

In this session, I will demonstrate why it is essential that patients be given the ability to order their own investigations and treatments. You are not alone in thinking such a proposal seems ill-conceived and a disaster waiting to happen. However, I will show why this is an essential step towards creating space for the development of new models of health care delivery.

The current system of physician-centered health care evolved to protect patients from nineteenth century quackery. Today patients continue to demand trustworthy care; however, there are new ways to verify

authenticity. I will show how the clash between the current medical model and potential future models will only be amplified once home diagnostic tests are more widely available and computer algorithms and machine intelligence has matured.

Many within healthcare anticipate that new artificial intelligence-aided diagnostic tools will be used only by qualified clinicians. However, this is akin to limiting Google Search to select university professors. In almost every field outside of medicine, access to knowledge and tools for implementation have been democratized and made almost free. Advances in diagnostics and machine learning will help do the same for medicine; but we must create a regulatory environment where this can happen.

In addition to new technologies, one can expect better personal relationships in health care. New 'para-physician' fields will emerge. Rather than studying for 15 years to become a physician, new specialists may train for a few years to become qualified in a specific domain – such as hypertension, diabetes, obesity, and lifestyle change. Such providers would cost significantly less than physicians, and provide more effective longitudinal care. The current system prevents such fields from emerging.

This presentation will address many unanswered questions. Where does this leave the physician? How do we help prevent patients from being duped by online scams? Is my headache a brain tumour? Will this system be fragmented and contradictory? Will antibiotic use skyrocket? Who is responsible for following up on test results? Who pays for this?

Explore the potential opportunities and risks that could result from fracturing the physician monopoly over health care and giving patients the ability to order their own tests and treatments.

Bringing a great consumer experience to healthcare: killing engagement and embracing empowerment

Jennifer Schneider

Chronic conditions are highly prevalent today, with about half of all adults – 117 million people in total – having one or more chronic health conditions, and one in every of four adults having two or more chronic conditions. Diabetes, a disease that affects more than 29 million people in the United States, is notorious for the development of co-morbidities and other problems. This creates an extreme threat to health and quality of life for people with diabetes. This is why it is so vital for people to take control of their disease and properly manage it. And, knowing you have to manage a disease simply isn't enough – people must feel empowered to manage their health.

Unfortunately certain technologies or devices can only add to that frustration and provide more of a burden, which leads to disengaged patients no longer active in care management. Disease management technologies must evolve to be seamless, non-disruptive, and personalized to align with a patient's lifestyle and goals.

In this insightful MedX talk, Dr. Jennifer Schneider and Dr. Tim Church will discuss why the theory of empowerment with chronic disease is so important and how programs need to map goals to chronic conditions and passively monitor for information, rather than relying on the patient to do more. Dr. Jennifer Schneider and Dr. Tim Church will provide insights on empowering the healthcare consumer and using new technologies with the consumer in mind to manage chronic conditions:

- Bringing a great consumer experience to healthcare
- Killing engagement and embracing empowerment: the new model of patient care
- Learning from employer-sponsored care: taking a new approach to diabetes management
- How a great consumer experience yields positive financial and clinical outcomes

The cost of traditional disease management: why business leaders must approach disease management from a new perspective – one that is designed with the patient in mind

The power of the caregiver: insights from Medisafe

Jon Michaeli, MBA

Greater social support has been shown to be associated with improved health outcomes and healthier behavior Non-adherence to chronic medications imposes a substantial clinical and financial burden on the US healthcare system. Research shows that social support using existing friends or family has been associated with greater medication adherence. A recent CVS Health report evaluated 50 peer-reviewed articles, which directly measured the connection between social support systems and medication adherence. There have been many medication reminder interventions aimed simply reminding patients to take their medications in order to increase adherence. In a new approach, Medisafe provides a personalized mHealth platform that uses its social support feature to enhance medication adherence beyond just reminders. This combination seeks to tackle the $290 billion problem of non-adherence by addressing all the major underlying causes of this complex problem, including lack of motivation and support through the app's Medfriend feature.

The Medfriend feature allows a family member and/or caregiver, to engage in

the medication adherence regimen of another user. This allows the Medfriend to assume an important role in supporting patients in managing their medication and health. When a Medisafe user adds and connects with a Medfriend, the designated caregiver receives alerts about missed medication doses and can view the user's history and schedule. This makes the patient more accountable, encourages positive behavioral changes and helps prevent serious health events that could arise from a missed dose. The Medfriend feature was integral within Medisafe from the beginning, since a double dose of insulin threatened the health of founders Omri and Rotem Shor's father.

The company released in the end of 2015 the results of a retrospective study demonstrating the positive effect of its Medfriend social support feature on medication adherence. The study showed that 40% of previously non-adherent users (taking their medications less than 80% of the time) became adherent (taking their medications at least 80% of the time) after adding a Medfriend. Medisafe's study looked at the impact of the Medfriend feature on both adherence and retention:

Group One – Adherence: 1,617 users who were non-adherent before adding a Medfriend and were active two weeks before and after adding a Medfriend. 71% improved adherence after adding a Medfriend (mean=+17% improvement), and 40% became adherent after adding a Medfriend.

Group Two – Retention: 4,000 users with a Medfriend and 4,000 users without a Medfriend, all of whom must have a) installed Medisafe during a two-month period between 5/29/15 and 7/28/15 and b) registered a medication dose at least once. After 90 days on Medisafe, users with a Medfriend were 59% more likely to have remained active.

Our study results indicate that adding social support to a medication adherence intervention can yield positive results.

Helpsy: an online marketplace and engagement platform for managing chronic conditions

Sangeeta Agarawal

As of 2012, 117 million adults in the US suffered from at least one chronic condition while 60 million adults suffered from at least two chronic conditions. Supportive care therapies such as physical therapy, nutrition, chiropractic, and yoga have been shown to be effective in improving chronic conditions and increasing overall health. It is unsurprising that 38% of Americans spend over $34 billion per year on complementary and alternative medicine (CAM) care to address their health issues. However, few resources currently exist for CAM patients to find effective therapies and trustworthy health experts. As a result, people experiment with multiple therapies and supplement regimens in desperate hope to find something that works. This

process can hurt them, and waste time and money.

The Helpsy online platform addresses these issues and provides a reliable and efficient way for sufferers of chronic conditions to find the supportive care modality best suited to treat their chronic condition and to get in contact with the best experts of that care modality. Helpsy was founded in October 2014 by software engineer, oncology nurse, and Ayurveda specialist Sangeeta Agarawal who was inspired to provide a comprehensive and easy-to-use solution for those suffering from chronic conditions. Current online supportive care solutions exist which provide either an online healthcare plan or access to supportive care practitioners and resources, but none exist which integrates the two in one product. At Helpsy, we are targeting the patients who need our care and the practitioners who can administer it through direct sales channels and through large institutions. At the moment, we are initially focused on the $2 billion out-of-pocket cancer symptom management market made up of over 14 million cancer survivors, 20 million cancer fighters, and over 1000 cancer centers within the US which must implement a cancer survivorship plan due to new Commission on Cancer accreditation requirements.

This talk will introduce the Helpsy online platform and will demonstrate our solution as an easy-to-use and cost-effective way to obtain supportive care for the treatment of chronic conditions.

Changing the conversation : How shared decision making can transform the physician-patient consult

David Cerino, Kristian Novakovic, Christopher Saigal

Shared decision making (SDM) – the collaboration of patients and physicians to make smarter, more confident treatment decisions – is not a new concept. In fact, decades of research have shown that this approach produces more satisfied patients, better adherence and outcomes, and lower costs. Despite this, SDM has often been tried and abandoned when it has failed reach broader adoption to multiple conditions and specialties. Despite the challenges of the past, we believe that SDM's time has come. As patients demand more involvement, and providers compete to deliver a better care experience in less time and at lower cost, SDM, when designed and deployed intelligently, offers a sustainable path to meeting these competing imperatives.

WiserCare believes that SDM has failed to catch on because for such an approach to scale, it must provide a two-way flow of insight and value to both patient and physician. Legacy approaches have often focused on simply better educating patients on their options. Rarely do they take stock of patient preferences and goals, and when they do, it is in a low-fidelity way that provides little or no value in a treatment decision. On the other hand,

traditional SDM has often left the physician in the dark, with no feedback loop as to the SDM "prep" the patient has done, and how that could impact their decision. Thus, SDM expands the patient's options and questions, rather focuses them. This means a longer consult (a non-starter today), spent at the surface, with little time for deep exploration and the more confident decisions that result.

WiserCare (WC) is an interactive SDM experience that solves the limitations that past SDM approaches have faced. Patients receive an invitation to use WC from their doc, and complete a thought provoking exercise that elicits their goals and preferences. Using a patented algorithm, WC combines these insights with high quality evidence and patient-specific clinical data to generate a "best fit" ranking that is shared with BOTH patient and doc prior to the consult. The doc can glance at the patient's one-page profile and in 15 seconds, know what matters most to the patient, and how that matches their treatment options. The patient arrives equipped for deeper discussion.

We are in use at 5 health systems (4 AMCs) with more coming. Our patient adoption rates range from 70-95% (about 4x traditional patient engagement adoption rates), and we have achieved unprecedented, statistically significant improvements in decision quality and patient satisfaction. Consult times have decreased, and physicians are delighted with their improved depth. Most importantly, both docs and patients report that WC transforms their time together, making it at once more meaningful and efficient, and yielding measurably happier, more confident patients. This panel includes WC's founder, as well as physician users, to reflect on how and why WC works, and how it has changed their practice and outlook.

Patient case study: my data. my research. my results. how I used my own data to create a precision medicine approach to my autoimmunity.

Julie Cerrone

I love my rheumatologist. She is caring, she's gentle, she takes the time with me to talk through any issues I need. But the problem is that the health system that she works in does not provide focused, individualized care for my specific needs. I'm ushered in, usually have to wait forever, and then given the basic drugs, blood tests and care the majority of the patients which walk into that office are given.

When I first started going to my rheumatologist, my CRP and SED rate levels were sky high! Methotrexate was shoved my way and a few months later Humira. These drugs were promised to help manage my inflammation and get my body calmed down.

Did they do that? To a certain extent. Sure, I started to feel a bit better, but

they didn't address my fatigue. My malaise. My nauseousness. My bone aching pain. My general ability to lead a normal 20-something life.

I'd go back into my appointments with my doctors and the same thing was always said. Oh you need to be more active, then you'll feel better. Just give the meds more time, then you'll feel better. You have autoimmune issues, you'll probably never feel 100% better.

I knew there had to be a better way. I knew there had to be more to the story than they were telling me.

This presentation would talk about my health journey and how having access to my data, using my data, and fielding my "dream team" or doctor has helped me get to where I am today. My case study proves that we need precision medicine to combat these complex health issues. My main objective would be to show the Medx audience what I used to help tailor my plan, how each and every patient needs someone on their side to help them do the same and end with the thought of "How might we offer our patients this opportunity?".

Revolutionizing health: Personal omics becoming a clinical reality

Lavinia Ionita

Introduction

Around 80% of chronic disease could be avoided through efficient preventative medicine. Yet, the fact remains that it is easier to sell someone a painkiller or a pill that treats a disease than it is to sell a vitamin or a lifestyle change to prevent that disease. Additionally, our culture and education have not been traditionally focused on prevention, the medical system and the healthcare industry have followed that lead, investing mostly in the production of drugs and treatments.

Today, however, two new emerging trends produce a paradigm shift from traditional medicine focused on disease and treatment towards medicine focused on health, prevention and, when needed, a personalized treatment: 1) the new medical technologies make prevention scientific, personalized and accessible: we can perform deep molecular diagnosis with a personal biomarker map, and we can create a "personal health blueprint" that is based on an integrated omics profile, microbiome and other phenotypic data; 2) increasing patients' & health consumers' demands for "empowerment", the desire to have more control over their health and be pro-active, which is noticed from a constant growth of using health trackers and sensors. This precious data become a digital biomarker when it is put in a clinical context, with other biological information.

Although several barriers still exist, the way is open for a new kind of medicine: data-driven, personalized, accessible, digitized, and importantly, caring and empathic.

This is why we created Omixy.

Omixy is a healthcare provider founded on the notion of "Healthcare on demand, personalized for you." Our company (https://www.omixy.com/) emphasizes genomics, metabolomics, microbiome, and telemedicine to create holistic health-oriented services. Omixy's goal is to bring personalized medicine into the daily lives of all people through our platform and mobile app. Omixy offers on-demand, complete medical check-ups, WGS (Whole Genome Sequencing), microbiome sequencing, and metabolomics analysis together with several other types of phenotypic data, with longitudinal and dynamic follow-up.

Method
Our comprehensive report covers a complete panel of clinical blood data-set, metabolomic, gut microbiome and genome analysis for the actionable diseases and pharmacogenomics. We are actively developing algorithms to integrate and correlate clinical variables and a panel of genetic variants, involved in phenotypes or pathways, to develop predictive tools for health outcomes.

Conclusion
At Omixy, we start at "Health" and use omics to predict, identify and most of all prevent the potential risk of a "disease" before the clinical onset of symptoms. If disease is already present, by using the same approach and looking at a molecular level of the organism combined with pharmacogenomics and with a longitudinal dynamic profiling, we believe we can provide truly personalized healthcare, helping both patients and specialists.

Use of a patient-facing interactive software platform to improve the quality of medical decisions in clinic

Christopher Saigal

Improving patient engagement in evidence-based decision making is a key tactic that has improved value in a variety of clinical settings. We evaluated patient 'decisional quality' in several common and expensive decision settings at our health system (treatment for benign prostatic hyperplasia, prostate cancer, low back pain, women's choice of birth control, and newborn delivery method). We found that while satisfaction was high, both decisional conflict and condition-specific knowledge after physician counseling were below expectations. Pre-implementation surveys found patients have significant knowledge gaps after physician counseling (e.g., most pregnant women

LARRY CHU, MD, MS (EPI), MS (BCHM)
Executive Director

erroneously believe that a Cesarean section is required for babies >9.5 lbs.; few women are familiar with birth control options such as the contraceptive sponge and tubal ligation; many patients with herniated discs are unaware that pain will improve without surgery and are overly optimistic about the expected level of pain 1 year after surgery). Many patients also had significant decisional conflict after treatment selection with their physician, which is associated with delays in care and greater chance of blaming physicians for bad outcomes. We also found evidence of inappropriate use, especially in regards to the use of caesarean section for routine childbirth. The decisions we evaluated were "preference sensitive," meaning patient values play a key role in identifying the optimal treatment choice.

We implemented an interactive software application ("WiserCare") prior to the physician consult. The software ingests patient clinical data relevant to a decision, interviews patients to determine the relative strength of their values for the decision, and performs an instantaneous decision analysis. The platform is used prior to the physician visit, and generates an educational report for patient use in preparation for the clinic visit and a summary version for physician review. The software generates a personalized report of the patient's preferences as well as which evidence-based treatments may best match the patient's clinical and personal situation. The summary report is emailed to the physician prior to an outpatient clinic visit, in order to center the discussion on patient values and improve the efficiency of the visit.

We analyzed clinic workflows to determine how best to integrate the program without disrupting care. We educated physicians about the current state and why they could benefit from participation in the program. We first implemented the prostate cancer module, and saw significant improvements in decisional quality. Patients to date (N=125) that underwent the software intervention demonstrated higher satisfaction with care (98.4%), higher satisfaction with decision making (99.2%), and increased disease-specific knowledge (81.6%), compared to baseline measurement of these variables after the physician visit.. 30% of patients chose to provide qualitative written feedback about the application. 86% of these comments were uniformly positive, with most feedback indicating the tool was "helpful" "informative" and that the "overall process was good"

We are now scaling up the program by implementing the other conditions. Early qualitative analysis also shows that these patients continue to indicate that the tool is "helpful". We are learning that implementation needs to be responsive to clinic contexts. We are collecting data on impact on decisional conflict, disease specific knowledge, satisfaction, and utilization patterns.

LARRY CHU, MD, MS (EPI), MS (BCHM)
Executive Director

Patient-centric social media for outcomes and pharmacovigilance considerations: The time has come.

Brian Loew, Greg Powell

Patients and caregivers use social media to share health and medication experiences, as well as to seek advice and support. Healthcare providers are increasingly turning to social media (Doximity, Sermo), to gain insights from their colleagues about how to best care for patients. Other interested parties, pharmaceutical and research companies working to deliver better and safer tools to the healthcare team, are regularly searching to better understand from patients and providers how to make a meaningful difference while keeping safe and effective products on the market.

Through the use of de-identified Big Data from online patient forums open to healthcare providers, the pharmaceutical industry may glean useful insights into both the safety of existing products as well as future needs of patients. Post-marketing safety surveillance for pharmaceuticals currently relies on data from adverse event reports to companies or regulatory authorities, medical literature, and observational databases. Together these sources provide some insight into everyday product safety or risk, but the unique insight the patients themselves can offer is also highly desirable.

Using insights from a 2016 research project involving Inspire, GlaxoSmithKline (GSK) Pharmaceuticals, and Epidemico, an innovative informatics company, we are exploring the use of social listening data for pharmacovigilance and other R&D concerns. A core question is, "What valuable insights can we glean from social listening to help improve patients' lives—whether through improved safety, more relevant clinical trials, or research and development of new treatment options?"

Through social listening, publicly available social media data can be analyzed for a variety of insights into patients' perspectives, including study endpoints of concern to patients, greater understanding of patients' unmet needs in a therapeutic area, and areas of misinformation or lack of information about appropriate product use.

The integration of mainstream social media data (such as Twitter) and other data sources with deep and rich patient voice, and sentiment data, creates a unique addition/enhancement to the "everyone included" approach to healthcare. With over 800,000 members across 3,000 health conditions, Inspire has one of the largest patient cohorts, which has generated over a billion count of multi-dimensional unstructured data.

Presenting the combined experience as well as research findings will help conference attendees understand how healthcare social media can be harnessed to the good of many stakeholders. This collaboration is a step

forward in the "everyone included" approach. Our goal is for patients to better understand how they can participate in the discussion through social media and help shape the future of their care. We hope for healthcare providers and other interested parties to gain insights in to how this technology can be used to improve their care of patients.

How patient engagement and gamification correlate with hypertension control

Ryan Wynia, Geri Baumblatt, Maulik Majmudar, Khan Siddiqui

Background
Ambulatory blood pressure (ABP) is known to provide prognostic information about cardiovascular disease better than office BP. In-pharmacy automated ABP kiosks have also been shown to have similar accuracy as manual BP measurements done by healthcare providers. ABP kiosks in retail locations provide an accessible, affordable, convenient and accurate means for patients who cannot afford home BP devices to monitor their BP. Other studies have shown mixed results regarding effect of self monitoring of BP and long term BP control. Not much is known about the correlation of ABP control and self monitoring of BP with patient engagement and gamification.

Objective
To examine the relationship between ABP and patient engagement with a nationwide ABP kiosk platform.

Methods
De-identified historic data from a nation wide ABP kiosk network (www.higi.com) was analyzed from September 2012 to April 2015. Approximately 9,700 ABP kiosks were deployed within the network during the time period of the study. Approximately 1,928,900 patients created accounts on the engagement platform. Only patients with initial BP measurement in the hypertensive range and those who opted-in to share data for research purposes were included in the study. A total of 158,800 patients met all inclusion criteria for the study. Mean age of the study population was 49 years, with 58% male and 42% female. Almost half the patients were obese (49%). Level of engagement was defined as the number of average monthly logins on the gamificati on platform (i.e. kiosk, web portal, and mobile app). BP changes were defined as the difference between a patient's first and last reading on the kiosk network. Patient demographics, level of engagement with the gamification platform and their ABP trends were analyzed.

Limitations
Due to lack of control group in this study, the statistical significance observed in this study may not represent causation. We may have measured results of self-motivated patients who on their own or with the help of their provider

have achieved better control of the BP. Throughout the course of the study new kiosks were being deployed resulting in some locations where there was not enough time available to measure outcomes for that population; this may have resulted in underestimation of the results. Further studies are needed with control groups to measure the direct effect of gamification on hypertension control.

Conclusion
The results show a statistically significant relationship between frequency of engagement as measured by level of monthly logins on the gamification platform and lowering of systolic BP.

CLINICAL RESEARCH/DRUG DISCOVERY INNOVATION

ResearchMatch: an online platform to connect volunteers and clinical researchers

Loretta Byrne

Purpose
Members of minority groups, women, rural populations, and the elderly are often underrepresented in clinical research due to a number of barriers. ResearchMatch (researchmatch.org) is a CTSA developed tool that aims to remove these barriers through partnerships with researchers and advocacy groups to increase patient engagement and access to information. ResearchMatch is a disease-neutral, institution-neutral, online volunteer recruitment and engagement platform, available at no cost that matches individuals interested in research participation with researchers looking for volunteers.

Results
The system currently supports >90,000 volunteers, >3,500 researchers, and 117 institutions all working together to streamline the recruitment process and speed the process of discovery for translational research. Approximately 11% of the volunteers are African American, 4.4% are multi-racial and 7% are of Hispanic or Latino ethnicity. 99% of the volunteers have been contacted with a study opportunity; of those 60% say they are interested in learning more. To date ResearchMatch has proven an effective tool for study enrollment across a diverse field of populations and therapeutic areas.

Conclusion
ResearchMatch fulfills unmet needs of multiple stakeholders, namely underserved and minority populations. ResearchMatch can be leveraged to provide services beyond study recruitment. This will help multiple diverse populations obtain access to researchers and clinical trials with the overall goal of increased education, awareness and access to biomedical research

initiatives.

Quality of Life as the new metric for evaluating clinical trials

Sam Volchenboum

Big pharma has a problem. They have no way to reliably track their patients on clinical trials. They receive most of their data long after it has been collected and often too late to make intelligent business decisions. As a result, one in eight drugs never makes it to market despite the billions poured into clinical trials.

Interestingly, quality of life is becoming an increasingly important metric by which clinical trials are evaluated. In recent years, the FDA has placed more weight on QoL considerations when deciding whether or not to approve or reject a drug. In fact, they are now requiring QoL as a key endpoint for many drug trials. It is evident that the FDA is taking the view that the treatments we develop should help us live longer and better.

Despite the increased focus on how a drug impacts the way a patient continues to live their life, there are no objective ways to measure QoL. Most QoL data are patient-reported, and it's nearly always collected late in the trial process, at which point the costs of the trial make it literally "too expensive to fail."

The potential of being able to measure and score quality-of-life variables like lifestyle, activity, diet, and environment is tremendous, especially if we can do it early on in a clinical trial's lifecycle. For pharma, it means the ability to be more agile in the way they do business. It means the difference between failing fast vs. pouring millions more into a drug that is defined to fail. There is also an impact on the end users of these drugs. Being able to move more quickly in the trials phase results in the development costs of these drugs decreasing and can result in higher-quality treatment and meaningfully improved outcomes.

In this talk, Dr. Sam Volchenboum with discuss how researchers can employ a continuous multi-stream flow of remote patient data to help steward new insights about whether a given trial is promising (or not) as a business by focusing on QoL endpoints in the early phases of the trial. The result, he will argue, is better business decisions in pharma, which the industry desperately needs, as well as more affordable and more impactful drugs that make patients truly better.

LARRY CHU, MD, MS (EPI), MS (BCHM)
Executive Director

FDA advancing precision medicine with precisionFDA: a collaborative informatics community to explore regulatory science

Elaine Johanson

In 2010, for the first time ever, the human genome was used to diagnose and treat (1) the life threatening disease of a young boy that had baffled scientists for years. In a desperate attempt to figure out what plagued Nicholas Volker's intestinal inflammation doctors sequenced his DNA. What they found was a mutation that dictated a bone marrow transplant. Nicholas is now 11 and leading a healthy, happy life.

There are many more success stories similar to Nicholas', which have popped up over the years, where lives have been saved thanks to next-generation sequencing technology. Imagine a world where doctors have at their fingertips the information that allows them to individualize a diagnosis, treatment, or even a cure for a patient based on their genes. This is the President Obama's vision for the Precision Medicine Initiative (2) .

Even though more than 80 million genetic variants (3) have been found in the human genome, we still don't fully understand the role that most of these variants play in health or disease. Furthermore, the analytical validity of NGS technology for the diagnosis and treatment of disease is a nontrivial topic, and has peaked the interest of the FDA, which is working to assure the safety, efficacy and performance of genomic technology in a way that does not inhibit innovation. In order to help achieve the President's vision, the FDA launched precisionFDA (4), a community platform for NGS assay evaluation and regulatory science exploration.

PrecisionFDA represents a novel and forward-thinking approach to regulatory science. Rather than government regulators defining upfront and then imposing a specific set of performance standards, precisionFDA instead sees the government as providing a research sandbox where the genomics community can experiment, share data and tools, collaborate, and suggest their own standards for evaluating analytical pipelines – organically and transparently.

The ultimate success of precisionFDA will of course depend upon the support and engagement from its community members. This new level of collaboration around the evaluation and performance of NGS pipelines will help to overcome the challenges of precision medicine in the 21st century.

LARRY CHU, MD, MS (EPI), MS (BCHM)
Executive Director

GenomeConnect – making connections and engaging patients in genomic discovery

Juliann Koenig

Technological advances in genetic testing have allowed for an increasing number of genomic variants to be discovered in the human genome. Although awareness of the relationship between genetics and health has advanced in recent years, the impact of many variants on health and disease remains unclear. Consequently, many patients and families are the first to be identified with a given genetic change and experience an "N of 1" result – the situation where causality of a genetic variant cannot be determined if it has only been seen in a single person. They are turning to social media and other web resources to try to find others with the same genetic diagnosis or researchers studying their particular genetic change. GenomeConnect, an online patient registry developed as part of the NIH-funded Clinical Genome Resource (ClinGen) project, serves as a secure way for individuals and families to connect with one another and partner with researchers.

GenomeConnect is open to anyone who has had any genetic testing, regardless of test results or diagnosis. Participation is completely online, so individuals can join from anywhere in the world. As of January 2016, the growing community currently includes 431 participants from 48 states and 21 countries. After consenting online, participants complete a health survey that collects detailed information about their health history. Participants have indicated a history of a variety of conditions including chromosome abnormalities, childhood and adult onset single gene disorders, mitochondrial conditions, and even those without a known diagnosis explaining their health history or healthy individuals who have undergone predictive, direct-to-consumer, or carrier testing. Finally, participants are asked to upload a copy of their genetic testing report and the GenomeConnect staff collects important information about any genetic variants in a standardized manner. In addition to variants in known disease causing genes, some participants have had genetic variants found in candidate genes, or genes that have not been associated with a known condition.

By enrolling in GenomeConnect, participants have the ability to connect with other individuals, clinicians, and researchers. Using the secure online portal, participants can search for others based on diagnosis, age, and other demographics. Participants also can elect to receive information about clinicians, laboratories, or researchers trying to connect with them. Individuals with variants in candidate genes also can connect through GenomeConnect's involvement in Matchmaker Exchange, a tool for patients, clinicians, and researchers to search for genetic and phenotypic matches in an effort to determine if a genetic variant in a candidate gene is the explanation for a particular condition.

GenomeConnect also provides a means for patients to actively contribute to genomic discovery, fostering a better understanding of the relationship between genetics and disease. Collaborative efforts to encourage the sharing and public availability of genomic information have resulted in a number of clinical and research laboratories contributing genetic data to publicly available databases. Often times, however, these laboratories do not have access to critical phenotype information that could aid in interpreting these variants. After participants complete their health survey and upload their genetic testing report, their genetic and health information are prepared for de-identified data sharing with approved, public databases to facilitate interpretation of genetic variants. Overall, GenomeConnect provides a means for participants to connect with others while providing clinicians, laboratories, and researchers with genetic and health information that will allow for advances in genomic medicine. This presentation will focus on the importance of data sharing, how patients can play an integral role in data sharing efforts, and how registries such as GenomeConnect enable patients to become active partners in data sharing and genomic discovery.

Genomics research meets patients in the era of social media

Corrie Painter

As a biomedical scientist preparing to defend my PhD in biochemistry, the last place that I thought to look for information after being diagnosed with an exceedingly rare and aggressive cancer was social media. But after being told that there was no data to guide my clinical decisions and no scientific knowledge about my disease, I turned to any resource that I could find on the internet. I typed the words angiosarcoma cancer into my browser, and the series of events that followed reset the entire trajectory of my career and life's mission to accelerate the pace of discovery in cancer research. All of which was set in motion when I stumbled upon 8 people in an online support group. Beyond the statistics which suggested that I wouldn't live for one year were a handful of people determined to live.

Those first 8 people quickly turned into 2000, and the knowledge that we brought to our support group far outpaced the data being published in the literature. We funded research, we shared our genomic panel results and generated a conduit for people to be seen by doctors who we taught to become experts in angiosarcoma. It became clear that if I was going to make a deep impact for my very rare cancer it wasn't going to be behind the bench. So when the time came to choose between a traditional academic tenure track position or a path less defined in the world of advocacy, I chose the latter, and joined the Broad Institute of MIT and Harvard in order to tap into the potential of social media for a direct-to-patients nationwide genomics project.

They believed that engaging patients in research would greatly accelerate the pace of discoveries. Working iteratively from conception through implementation with patients and advocates we built the Metastatic Breast Cancer Project, a nationwide genomics studies that empowers patients to contribute their tumor samples and clinical information to research. In the 3 months since launch, we have enrolled 1200 patients who have provided responses that have generated new research questions that were unanticipated. For example, we have rapidly identified large numbers of patients with rare phenotypes, which has been historically challenging using traditional research methods. We will generate a clinically annotated genomic data set and share it widely in order to contribute to our collective understanding of this disease.

As a result of our early successes, we are now building the Angiosarcoma project (ASproject). Using social media, we will engage a living cohort of patients that will far exceed those seen at any one institution in order to generate the genomic landscape of a disease that would be intractable to study through traditional methods. Ultimately, we seek to establish a broad patient-researcher partnership to accelerate genomic discoveries across multiple cancers that may serve as a means to build a new clinical and translational research infrastructure for patients with cancer.

The proper role of the FDA For the 21st century

Dr. Joseph V. Gulfo

The current medical marketplace is vastly different from the marketplace that existed in the 1970s and ’80s when the Food, Drug and Cosmetic Act codified the Food and Drug Administration’s mission. Despite rapidly advancing technology and patients’ increasing desire to try new drugs and devices, the FDA has strayed significantly from the statutorily defined safety and effectiveness standards for drug approvals. The FDA now very often demands proof of clinical utility, including survival and disease outcomes, as a requirement for premarket approval. But hard proof of clinical utility is elusive, even for drugs that are clearly shown to be safe and effective as labeled. Rather than blocking safe and effective drugs on such grounds, we should allow physicians and patients to make outcome-oriented decisions, and rely on the medical marketplace to drive physician adoption of safe and effective drugs that prove to have great clinical utility in real-world settings.

A new study for the Mercatus Center at George Mason University evaluates current FDA policy toward new medical products and concludes that the FDA must return to its role as gatekeeper of safe and effective drugs and devices. The FDA has made significant incursions into private health decisions by exercising its public health mandate in a manner that was not intended by Congress. Rather than allowing doctors and their patients to determine how best to use a drug and ensuring that drugs placed in the market are safe and effective, the FDA has increasingly become concerned with controlling the

outcomes of future judgments by physicians and patients regarding benefits and risks. The new medical marketplace should refocus the FDA on safety and effectiveness, leaving patients and doctors to evaluate and determine benefits and risks based on their experiences with the drugs.

To read the study and learn more about its authors, Joseph V. Gulfo, MD, economist Jason Briggeman, and graduate student Ethan C. Roberts, see "The Proper Role of the FDA for the 21st Century."

Embracing diversity through precision, race-specific modeling of propofol-induced loss of consciousness

Samsun Lampotang

Background & Objectives

Propofol is routinely used worldwide and in the US on patients of different races. During propofol sedation, inadvertent general anesthesia due to overdosing or patient sensitivity can be life-threatening if untrained personnel cannot rescue the airway and re-establish oxygenation. Our aim is to reduce overdosing and potential associated complications during sedation of patients from races sensitive to propofol.

Material & Methods

We compared in 4 races the EC05 (Effective Concentration for 5% of a population), EC50 (median) and EC95 propofol concentration at the effect site compartment (ESC) at loss of consciousness (LOC), abbreviated as ESC ECXX @ LOC. Below, we use EC50 as an example of how we obtained ESC ECXX values where they were missing.

A literature search yielded varied administration protocols and results in different formats and drug compartments. We used the Marsh Diprifusor TCI model in Tivatrainer© (v8, build 5), a commercial program, to re-run protocols, where needed, to obtain data in a standard format: ESC ECXX @ LOC.

Milne et al1 administered propofol to 40 (19M, 21F) ASA I, II Caucasians via Target Controlled Infusion (TCI; Diprifusor, sw v2) that predicted ESC propofol concentrations. The ESC EC50 @ LOC (95% C.I.) was 2.8 (2.7-2.9) µg/ml.

Xu et al2 administered propofol via TCI (Diprifusor, sw v2) to 405 (97M, 308F) ASA I, II Chinese. The ESC EC50 @ LOC (95% C.I.) was 2.2 (2.2-2.3) µg/ml.

Natarajan et al3 (2011) used a non-TCI pump to administer a constant propofol infusion of 40 mg/kg/hr. The mean (±sd) dose of propofol at loss of verbal response was lower ($p < 0.001$) in Blacks (n=50) at 1.17 (0.25)

mg/kg compared to Caucasians (n=50) at 1.41 (0.4) mg/kg. When simulating Natarajan's protocol on Tivatrainer, the mean ESC propofol concentrations for loss of verbal response in Blacks and Caucasians were 0.85 and 1.18 µg/ml respectively. To derive a median EC50 ESC @ LOC for Blacks, we used the ratio of Black to Caucasian mean ESC @ LOC from Natarajan to arrive at a scaling factor: 0.85/1.18 = 0.72. We then multiply the ESC EC50 @ LOC for Caucasians from Milne et al (2.8) by that scaling factor (0.72) to obtain a derived ESC EC50 @ LOC for Blacks of (0.72 * 2.8) = 2.02 µg/ml.

Puri et al4 used a TCI pump displaying only blood concentration with 18 ASA I/II Indians. Blood EC50 (95% C.I.) at LOC was 2.31 (2.16–2.45) µg/ml. Repeating Puri's protocol with Tivatrainer, at a blood concentration of 2.31 µg/ml, ESC EC50 was 1.88 µg/ml.

Results
Figure. Propofol Effect Site Compartment EC05, EC50 and EC95 concentrations @ LOC predicted by the Marsh model for 4 races

Conclusions
Our data suggest reduced initial doses for Indians, Blacks and Chinese during propofol sedation, if using dosing guidelines or PK models based on Caucasian populations.

HEALTH CARE PROVIDER EDUCATION AND OUTREACH

Changing health professions education one game at a time

Ruth Nemire

Professions Quest is a wholly owned company of the American Association of Colleges of Pharmacy. In 2015 the game Mimycx was launched by Professions Quest for health professions education. The massive multiplayer online game is designed for five players (from any health or allied health profession) to interact and solve problems as a team. The core competencies of communication, ethics, team and team role developed by the Interprofessional Education Collaborative (IPEC) are used as outcomes for defining the activities and assessment of the player. Players must act independently and together to solve problems set in the future. The purpose of the game and the future setting is to help students (and practitioners) learn to work together on teams and to respect and communicate with each other. In addition since the current health care system is in need of change the designers of Mimycx want the students to have every opportunity to think differently about health care and their interactions. It is hoped that students exposed to learning together, outside of the current health system, will be able to envision and make changes for better health and wellness of

individuals and populations. The game can be played online 24/7.

This provides the opportunity for students to learn from, with and about each other in places all over the world. The game also includes the opportunity to chat and network when not solving problems. Faculty members have a designated portal and can log in to determine the type of quests available and the competencies that students are expected to achieve. Faculty have the option of opening up the game to world wide play or to only allow play within a college or university setting. Faculty have access to the information from the players interaction with others, their behaviors, and their scores. As players level up they have more responsibility for communication and teaching others.

There are small mini games incorporated throughout each episode or quest that enable players to gain skills and to think differently as they are solving problems. This game when implemented within or outside of classroom activities provides students the platform needed for learning together. There is no other game that provides this type of 5 member team play with assessment occurring in the background providing instant feedback to students. The future of education and health care will change, and Mimycx is a catalyst for that change.

Mobile and digital technology platform for patient care transition and the nexus for patient care, communication and medical education in the clinical learning environment

Anoop Agrawal

The Accreditation Council Graduate Medical Education (ACGME) has instituted new accreditation guidelines with primary focus on quality patient care and patient safety during transitions of care. Numerous studies cite patient care handoffs as a key cause of medical errors and the need to focus on process improvement. Baylor College of Medicine (BCM) GME has focused on making patient care transition the foundation for improving patient care, as well as, medical education.

BCM , in a collaborative venture with ConsultLink Inc (founded by a BCM faculty member), has developed the CLE (Clinical Learning Environment) 360 initiative to leverage mobile and digital technology in improving transitions of care, communication and education. CLE 360 was designed by college faculty and residents using the ConsultLink Care Collaboration PlatformTM. It is first deploying and managing the patient care transitions at BCM’s multiple affiliate hospital sites. The next phase creates the nexus for patient care, communication and education functionality based on data analysis from the initial deployment.

All stakeholders benefit from the nucleus created:

- GME – oversight and execution of education in the clinical environment, data capture for overall activity and results analysis feeding curriculum adjustments. (i.e., the ability to view analytics of procedure logs in real-time by supervisors to direct and optimize the learner's clinical training).
- Medical Education – facilitating competency-based learning via data capture of diseases managed by all levels of learners and each individual. The data entered as part of the handoff workflow can subsequently drive learner-directed and curricular needs.
- Physicians and trainees – providing task management functionality to improve rounding efficiency. Handoff details can be accessed and created from any device throughout the day such as when patient care plans are being formed at the bedside.
- Clinical site – ability to receive granular feedback on near misses or adverse events by incorporating hard stops for reporting as part of daily handoff workflow within the app.
- Faculty – participate in real-time remote supervision of residents such as during patient handoffs with the ability to provide immediate feedback at a preview stage

Reimagining the future of health care: innovation at the University of Pittsburgh School of Pharmacy

Ravi Patel

Pharmacy has been and will be the frontline of healthcare. The average American lives within five miles or less of a pharmacy and makes, on average, 35 visits to a pharmacy each year. The current changes in healthcare significantly affect patients and providers. Automation, consumerism, digital health, and shifting reimbursement models are causing continual, dynamic shifts in pharmacy and healthcare. To ensure that the frontline of healthcare proactively leads the change, the University of Pittsburgh School of Pharmacy has developed the PittPharmacy Innovation Program.

Since 2012, this Program has incorporated innovation, creativity, and entrepreneurship into the curriculum. Development of the Program stemmed from other successful models of education in engineering, design, and business. The School of Pharmacy has changed its didactic and experiential education to reflect the shifting healthcare landscape. Didactic learning throughout the curriculum include design-thinking, return-on-investment, and creative problem solving. Clinical curriculum changes include moving away from lecture-based, static curriculum. For example, the School's Drug Development course, teaching how new drug compounds traverse FDA regulation to become approved medications, was redeveloped as an

alternate-reality game. In this semester-long game, student groups are treated as biotechnology companies responsible for the scientifically accurate, fiscally sustainable, and timely development of clinical trials. High-fidelity human simulations, "jigsaw" teaching, and narrative framing supplement the experience. Course instructors also serve as game master and facilitate the course via an online platform jointly developed by students and faculty from the School of Information Science in its "Serious Games" course.

Partnerships, internal and external to the University, have offered unique experiential learning opportunity for students and faculty in the PittPharmacy Innovation Program. Clinical partners offer students the opportunity to reimagine operational challenges through augmented reality technology, such as Google Glass. Technology companies allow students and faculty to reimagine education by considering the role of wearables in clinical practice and as a part of education. University partners leverage students and faculty to reimagine the possibilities of collaboration between disciplines, such as the creation of hardware-based solutions to facilitate refilling medications.

The PittPharmacy Innovation Program is empowering students and faculty to reimagine the future of healthcare with its partners by leveraging innovation, creativity, and entrepreneurship among students and faculty.

HEALTH CARE SYSTEM IMPROVEMENT

Fighting addiction with data: How focusing on physician quality and practice patterns can impact America's opioid epidemic

Jayodita Sanghvi

Opioid use disorder (OUD — the medical term for addiction to opioid substances such as prescription painkillers or heroin) is an increasingly alarming epidemic. Overdoses involving opioids killed 28,647 Americans in 2014, and the rate of opioid overdose has tripled since 2000. Recent studies estimate that 2.4 million Americans meet criteria for OUD and many more use opioids recreationally, putting themselves at significant risk for addiction, overdose, and related morbidities. In addition to its devastating consequences to individuals, OUD is estimated to have a societal cost of $55.7 billion annually.

Although the root causes of America's opioid epidemic are multifaceted, physician behavior and practice patterns play a significant role. Consider that Americans consume 80% of the global supply of all opioids despite comprising less than 5% of the global population, and the vast majority of these opioids are prescribed.

Once a problem concentrated in America's urban-poor population, OUD has spread to all corners of American society and currently exerts a significant toll on the middle class and the actively employed population. The demographic shift poses a significant threat to the productivity of the American economy: Opioid usage (by prescription or otherwise) is associated with decreased employment, increased healthcare utilization, poor workers' compensation claim outcomes, increased rates of disability, decreased rates of return-to-work following injury, and decreased self-reported ratings of quality of life and overall health.

Findings:

American employers, insurers, and payers have an opportunity to address the opioid epidemic by influencing patient and physician behaviors. Specifically, by encouraging and rewarding patient visits to high quality physicians who demonstrate responsible opioid prescription patterns. By identifying, rewarding, and spreading the best-practices of high-quality physicians, Grand Rounds promotes primary prevention of the OUD epidemic within the covered populations of our customers and partners. We agree with experts in the field that prioritizing a primary prevention strategy is key to combating the opioid epidemic, especially given the unique features of OUD that make secondary prevention strategies particularly difficult and resource intensive.

Through our unique approach to data analytics and physician quality, Grand Rounds has identified significant regional variation in opioid prescription patterns within specialties. Furthermore, this variation can be predicted by our assessments of physician quality. Focusing specifically on the specialties of pain management, orthopedics, and primary care (the three highest opioid prescribing specialties) we find significant variation in the use of evidence-based, multidisciplinary treatments for chronic pain, which can be predicted by our assessments of physician quality.

End of life, not end of story: learning from patients to transform a health system's approach to advance care planning

Eliza Shulman

Care for patients at the end of life requires that patient and clinician have a common understanding of disease status and goals of care in order to ensure that dignity and autonomy are maintained. Having difficult conversations with patients is a critical skill that can be taught but is often left out of medical school curriculum. All too often, doctors neglect end of life decisions with patients and critical patient preferences are not documented in the medical record.

Physicians cite myriad reasons why these conversations do not take place, including discomfort with the topic, fear of taking away hope, time pressures, and a core lack of understanding of the process. During this talk, I will share my personal journey to understanding the role and importance of advance care planning, which began in an exam room sitting with a patient and listening, rather than completing the intended task of a post-discharge checklist. As I learned to listen more than speak, bring up difficult topics, and tease out what was really important, I realized that this was information that needed to be shared and standardized across the organization.

After endorsement from leadership, a team was formed to lead the design of new curricula and new modules for the EHR which has resulted in success for the organization as well as better care for our patients. The resulting program, implemented at Atrius Health, included a multi-disciplinary, multi-year strategy to engage the full health team in both personal (sharing experience) and structural (modifying the EHR to encourage and support end of life discussions) ways.

At the end of the three year pilot, we improved documented advance care planning by more than 270%, with over 80% of primary care teams trained in documentation, goal planning, and difficult conversations. This success has transformed this effort from a pilot to the current standard of care. We continue to seek new avenues to further this important conversation. Our goal, which is very much attainable, is that all of our patients have the opportunity to share preferences regarding treatment at the end of life and that these choices are honored. Death is inevitable; death with dignity and according to one's personal wishes should be as well.

ORGANIZATIONAL INNOVATION IN HEALTH CARE

DIY Disruption: Innovating from Within

Mandira Singh, Nicole Bell, Sanjay Shah

Anyone paying attention to the way healthcare operates knows it's bad. The industry is starved for innovation. Starting with a conversation around the need for novel approaches to solve health care's pain points, leaders from the innovation arms of Boston Children's Hospital, Cambia Health and athenahealth will discuss how they are creating new pipelines to creative solutions by actively wooing, nurturing, and colliding with the next generation of innovators and startups.

Representing the health system, software vendor, and payer worlds, the companies will discuss:

- The catalyst for launching their internal business development

platforms and/or accelerators
- Successful development business models aimed at lowering the high barriers of entry into health care for developers, entrepreneurs, providers, and even patients with great ideas
- The blueprint for fostering innovation from seed idea to implementation
- What it takes to build and run a successful "disruptive" community and innovation pipeline
- What they look for in startups, and how they are currently serving up new Marketplace innovations, apps or value-add services that increase profitability, drive operational efficiencies, and improve quality of care
- What the most-future proof tech infrastructure (e.g., developer portals on API-friendly, open platforms) to support and scale innovation looks like
- Secrets to making the most of DIY Disruption, whether you're running the largest innovation arm or the smallest startup

This conversation will spark dialogue about how entrepreneurs, students, patients or anyone with a novel approach to fixing what's broken in health care can partner with large stakeholders for success.

Border defying medical collaboration

Georgios Vrakas

Doctor- patient relationship is the foundation of a successful surgical journey. It is built on confidence, mutual understanding and of course, communication. It is about building a relationship that is truly a partnership.

We have looked at existing and secure technologies that patients use in their everyday lives to make this collaboration work for everyone. We have been utilizing networking platforms in an attempt to monitor our intestine transplant patients from a distance. We can 'keep an eye' on them using encrypted teleconference settings which can often be tools such as Skype, saving time and money for both sides by avoiding unnecessary commuting and utilization of office space. At the same time we achieve instant communication and therefore make a diagnosis on the spot, without wasting precious, detrimental time. In our specialist area we rely on instant, honest and open communication. That can be the difference between life and death. Data exchange is kept to the minimum required, but patient safety remains at the maximum.

At Oxford, which is one of the world's leading intestinal transplant centres we have even changed our technique and protocol in order to enhance and support distant, patient led monitoring: New surgical techniques have been developed to greater empower the patients. We are using transplanted skin, a visible organ, embedded in a composite graft, as a dynamic canvas that can foretell a rejection in our bowel transplant patients. Now the patients

look at the skin on their arm to start predicting what is happening. They then take the initiative to send us a photo in case the transplanted skin doesn't look optimal, and get instant medical review. Patients take their care in their hands by utilizing the skin flap- an educational tool that enables self-management.

On the other hand, there are still unexplored areas in medicine and this is evident by the diverse, sometimes contradictory management seen in different departments. Surgeons thrive on evidence. In our specialist area there is an absence of unequivocal evidence mandates. Always having patient care in mind, we developed close, international, collaborations between experts in an attempt to decipher medical enigmas. Sometimes it is harder to develop an inclusive collaborative approach with doctors as it is with doctors and patients.

We, my mentoring teacher and myself, started working at the same department a few years ago, but now that we work in different countries, different continents, yet we still collaborate closely on challenging patients. Through the development of our own unique doctor and patient inclusive process we are able to take advantage of exchanging data and photos of the affected area, which means we can establish a diagnosis and define a therapeutic concept almost instantaneously. Always with the patients' consent and always with the patients' direct involvement in their treatment. We have built a model of care from the ground up that is based on that absolute premise of trust, relationships and a desire for everyone to share information without barriers or boundaries. Despite working thousands of miles away, we decide on the best possible treatment, which is the key to avoid a life-threatening situation. And Everyone is Included.

Our network keeps expanding. From an isolated mentor mentee relationship, we are now consulting other centres in other parts of the world as well in an attempt to give answers to daily challenges that defy borders.

From innovation to realization: What it really takes to achieve transformational outcomes.

Shannon Adkins

Change is all around us. Indeed, it is the only constant! In a continuously evolving health care industry, we have all experienced change in our organizations. Internal forces from new leadership, new technologies, cost pressures and growth, as well as external pressure from competition and regulatory bodies, continually spark massive initiatives for organizational change. Our companies are investing millions in driving transformational outcomes, yet there is often a disconnection among initiatives and a growing fatigue from duplicative efforts. Ultimately, 60 percent of change initiatives fail.

Using case studies of operational transformation across global organizations as well as examples from participants, our workshop observes common pitfalls and challenges and examines our best recipe for manifesting true success: An interdisciplinary approach, where process excellence, change adoption, innovation, portfolio management and organizational effectiveness are integrated together in a holistic way, keeping people at the center of focus.

People's concerns must be addressed. Over the years, we've observed these common needs:

- Clarity, vision and benefits – "Why should I bother?"
- Information, tools and support – "How can I do this?"
- Action taken in response to their feedback – "Did you hear me?"
- Impact, consistency and sanity – "Don't waste my time!"

Using a hands-on approach, our workshop delves into the nuts and bolts of implementing operational transformation, giving participants people-centered tools to ensure greater outcomes with change. Far beyond project management, we will investigate process excellence, adoption, and leveraging an interdisciplinary team to arrive at a roadmap for success.

How to rock the boat and stay in it: The School for Health and Care Radicals

Helen Bevan

My name is Helen Bevan. I've been a healthcare rebel inside the English National Health Service for 25 years. I'd like to talk at MedX about building a movement of healthcare rebels.

The first principle of MedX is "lead as healthcare rebels". Anyone who challenges the status quo in healthcare doesn't choose an easy life. It's tough being a change agent particularly when you feel like you haven't got the authority or other people don't always want to change. Yet big change happens in healthcare only because of passionate people who are willing to take responsibility for change.

That's where the School for Health and Care Radicals (SHCR) comes in. It's an online school, free of charge, backed by the world's largest health organisation: the English NHS. It's a platform for healthcare rebels to learn together, using powerful, guided learning which also qualifies as continuing professional development. It's more than a school — it's a community of like-minded people across the world. By April 2016, 10,000 people from 44 countries will have taken part in the school; patients, families, students and clinical trainees, nurses, doctors, allied health professionals, support workers, researchers, teachers and managers. There are people from local

government and a surprising number of police rebels in the school. Here's a blog from citizen activist/rebel, Jon, who shows that "there is no such thing as an outsider at SHCR" http://bit.ly/1QUMQA2 and from Elissa, who describes the school as "one of the most inspiring educational experiences in my 10 years as a doctor" http://bit.ly/1P1cNeD

The school's built on the belief that:

- bottom up, grassroots engagement in change is as important as top down leadership of change
- if we are to significantly improve our healthcare systems we must value diversity and divergence as highly as conformance and cohesion
- We must invest resources in developing "leaders everywhere" as well as leaders of organisations and professions

Right from the start of the school, the level of engagement, enthusiasm and feedback spoke for itself. We won the global "Leaders Everywhere" challenge sponsored by Harvard Business Review and McKinsey and the school was named in "Britain's 50 New Radicals" list by the Observer (Guardian) newspaper.

However, our views were validated through the report of the external evaluation of the SHCR from the Chartered Institute of Personnel and Development (UK). This showed a statistically significant effect on every measure of impact measured at both individual and organisational level:

- Knowledge of change and improvement
- Sense of purpose and motivation to improve practice
- Ability to challenge the status quo
- Rocking the boat AND staying in it
- Connecting with others to build support for change

The CIPD evaluators said they had never before evaluated a learning intervention where there was an impact on EVERY measure.

The SHCR is a blueprint for healthcare rebels across the globe