THE POWER OF NARRATIVE: Contextualizing a Culture of Health through Story

Attendee Biographies for the Participatory Design Studio
February 5th & 6th, 2015
In this era of high-tech medicine and instantaneously-available information, Robert Wood Johnson Foundation (RWJF) believes that stronger use of the narrative has the potential to build bridges between patients and practitioners, data and knowledge, and “hearing” and “understanding.” Yet, current efforts to incorporate narrative-based methods into healthcare (such as narrative medicine, expressive writing, and theatre/medical arts) are disparate and fragmented. We see an opportunity to bring together a wide range of thought leaders and subject matter experts to explore the use of narrative in supporting care, healing and overall wellness – for both patients and practitioners – and codify best practices, methods, and tools to encourage wider implementation.

With support from RWJF, the Business Innovation Factory is hosting a Participatory Design Studio at their office in Providence, RI on February 5th and 6th, 2015, to share best practices, define the value of these methods, and co-create the content and format for a healthcare narrative “playbook”. This playbook will serve as a national resource for both patients and practitioners to learn, champion and implement.

We are bringing together a diverse group of passionate, seasoned and nationally-recognized professionals, whom are featured on the following pages.

We look forward to an exciting, inspiring, and productive few days with each and every one of you!
The Business Innovation Factory works with individuals, organizations, and communities who believe that business model innovation is on the critical path to transforming our most important social systems. We help leaders design and test new business models in the real world.

**Who We Are**

**Systems Thinking**
We must work across systems, avoiding the tendency to introduce point solutions. Systems are networks of business models that have evolved into cooperation. This is how we align incentives to drive behavioral change.

**Gold in the Grey Space**
We need to think and act horizontally. The tall walls between institutions and people limit possibilities. We can design powerful models by accessing existing capabilities across silos and disciplines, combining them in new and different ways.

**Co-Creation**
We want to engage people in the co-creation of new models, systems, and solutions. We don’t just design for users, we design with them. From patient engagement to student-centered learning, we believe co-creation generates more relevant and engaging models.

**Storytelling**
We use stories to pull people into transformation, asking them to co-create the narrative as it unfolds. Through stories, we help leaders see the world differently and create the will to invest in new opportunities.

**Human-Centered**
We need to shift our lenses and develop a rich understanding of the people we serve. By understanding their experience, behaviors, and motivations, we can identify the jobs they need done and imagine wholly new opportunities to serve them.

**Experimentation**
We must move faster from the whiteboard to the real world, creating tangible versions of our hypotheses that people can experience. Through a portfolio of rapid experiments that test multiple paths simultaneously, we can accelerate learning and development.
You can’t separate parts of a patient’s experience as our healthcare system does. It’s all part of their story; we, as health professionals, are simply characters that enter into their story at certain moments.

Theresa Brown, RN, lives and works as a clinical nurse in Pennsylvania and is an opinion columnist for the New York Times. Theresa’s second book, The Shift: One Nurse’s Twelve Hours on the Hospital’s Front Lines, will be released September, 2015 (Algonquin Press). Theresa obtained her ABSN from the University of Pittsburgh, and in what she calls her past life, a PhD in English from the University of Chicago.

She also writes for CNN.com, The American Journal of Nursing, Journal of the American Medical Association, the Pittsburgh Post Gazette, and was previously a regular contributor to the New York Times blog “Well.” Critical Care: A New Nurse Faces Death, Life, and Everything in Between is her first book and chronicles her transition from English Professor to bedside nurse.

Theresa is involved in the Robert Wood Johnson Foundation’s “Flip the Clinic” initiative, a Board Member of the Center for Health Media and Policy at the Bellevue School of Nursing at Hunter College, and a steering committee member for the ANA “RN Scope of Practice” focus group. She has received awards from The American Federation of Teachers, Yale University, and the UCLA School of Nursing, among others, and lectures nationally on nursing, health care, and end of life. Her clinical focus recently switched from inpatient medical oncology to home hospice.
Teaching medical residents reflective writing not only helps translate information, facts, and data into meaningful knowledge more easily remembered, but also upholds empathy -- a skill that tends to drop by the third year of residency.

Margaret (Maggi) Cary, MD, has been telling stories since she could talk. Just ask her mother. Years ago, her professional interest in storytelling was stimulated by teaching physicians to improve their communication with patients and colleagues by listening to their stories. She now teaches personal essay and narrative medicine at Georgetown University School of Medicine.

Her skills include executive and leadership coaching for physicians, keynote and Grand Rounds presentations, retreat and strategic planning facilitation and physician leadership development workshop creation and training. She developed and leads the Veterans Health Administration’s Physician Leadership Development program. Maggi has been a senior executive in public and private healthcare organizations and had a private medical practice. She coauthored a seminal book on healthcare technology, Telemedicine and Telehealth: Principles, Policies, Performance and Pitfalls.

She is a regular essayist on TheDoctorWeighsIn.com, has been published in many publications, wrote a seminal text on telemedicine and telehealth and speaks on and teaches coaching, storytelling and leadership.
I would love to see more patients and providers trained to tell their story using the three aspects of effective messages: Logos (structure and facts), Ethos (accountability and credibility), and Pathos (human affect).

Donna R. Cryer, JD, has channeled her personal experience as an IBD and liver transplant patient into professional advocacy as president and chief executive officer of the Global Liver Institute, the innovation and collaboration platform for the liver community.

Her e-health experience includes serving on the Office of the National Coordinator for Health Information Technology Policy Committee’s Privacy and Security Workgroup and on the Board of the Society for Participatory Medicine. She is a frequent speaker at top health and HIT conferences, including Health 2.0 and the mHealth summit. Her blog, DCpatient – An Impatient Patient’s Perspective from Washington, DC, and twitter feed @DCpatient are listed as top resources for insights into emerging e-patients and patient advocates.

Ms. Cryer is a patient representative to the U.S. Food and Drug Administration, a merit reviewer for the Patient Centered Outcomes Research Institute (PCORI), and a member of Stakeholder Advisory Group to the NIH Learning Health System Research Collaboratory. Additionally, Ms. Cryer serves on the Gastroenterology Board of the American Board of Internal Medicine and the Board of the Personalized Medicine Coalition. Ms. Cryer received an undergraduate degree from Harvard/Radcliffe Colleges and received a Juris Doctorate from the Georgetown University Law Center.
The arts are as necessary to wellness as empathy is to medicine. Theater provides a laboratory for training physicians and a safe space for community catharsis and healing. The integration of the arts in medicine results in health care that is more humane.

Valerie Rae Flower, Ph.D. is Executive Director of The Humane Theater Company. She received her BA in Theatre and Education from Taylor University, her M.A. in Theater from Miami University (Oxford Ohio), and her Ph.D. in Theater from Tufts University. As a graduate student, she taught acting at Tufts University and Boston College, and served as Artistic Director for Circles of Girls, a performing arts program that challenged pre-teen girls to speak into their communities through theater and storytelling. Valerie was Professor of Theater at Messiah College for fourteen years where she served as chairperson and taught a special topics course in medical theater arts. Directing credits include Wit at Penn State School of Medicine, and over forty undergraduate productions focused on systemic oppression and social justice.

Valerie created a one-woman-show, Between 2 Chairs, at Touchstone Theatre. The play addresses memory development and dementia, and toured to several theaters and community centers with local support form the Alzheimer's Association. In 2014, she initiated the Theater Artist in Residence program at the Doctors Kienle Center for Humanistic Medicine to explore the use of theater in physician training and the potential for community catharsis in hospital culture. She then created The Humane Theater Company based on a core belief that theater and medicine are poised to reunite. The relationship between storytelling and its medicinal effects was once widely understood as essential to the health and well being of individuals and communities. The Humane Theater Company illuminates this symbiotic relationship between theater and medicine by providing live theater experiences that humanize hospital culture.
Associate Dean at University of Wisconsin Law School & Director of Center for Patient Partnerships

The commercial arrangement [between patients and doctors] is an upgrade over a time when patients were often passive recipients of care delivered without their input or consultation by physicians who were taught to value their own knowledge of the human body over any knowledge a patient might offer about her own body.

Martha “Meg” Gaines, founder and director of the Center for Patient Partnerships, was called to advocacy work after her own experience with illness. In 1994, Meg was diagnosed with ovarian cancer which ultimately spread to her liver. In early 1995, a doctor told her to “go home and think about the quality, not the quantity” of her remaining days. Her children were toddlers at the time. But Meg did not go home and die. She went on an odyssey around the United States and found the surgeon who would save her life.

Once she was in remission, Meg returned to her job at the University of Wisconsin Law School and, in 1998, was named Assistant Dean for Student and Academic Affairs. But Meg soon felt called to a new career. Mindful of the role her education and resources played in her survival, Meg decided to commit her professional energies to helping other patients facing life threatening and serious chronic illnesses get the care they need. In September 2000, she and several colleagues founded the Center.

Meg received her undergraduate degree in religion from Vassar College in 1977 and graduated cum laude from the University of Wisconsin Law School in 1983. She earned her post-graduate Master of Laws degree in 1993 from the University of Wisconsin.
Using the moving body as a tool for patients to physically "work things out" gives them an opportunity to step outside themselves, try on different perspectives, and extend their experience beyond their own internal world.

For two years Fiona Geilinger has been working in the area of narrative medicine. She has worked on the ‘Finding Your Compass’ project, in creative partnership with dancer, choreographer, university lecturer and project manager, Rosaria Gracia. Their project has been noted for it’s innovation and it’s success. She has also made a film ‘Dogvane’, performed by Rosaria, about bipolar disorder.

Fiona has in depth experience and qualifications in contemporary dance (BA), film, fine art and design (MA, distinction). Other credits include: deputy picture editor and presentation director at Channel 4. Freelance, Fiona makes documentary title sequences for the BBC. She has been selected for; the British Animation Awards, the British Film Institute London Film Festival, the British Film Council and many other international film festivals for her live action dance and animation short films. Fiona makes films for site-specific gallery and architectural projections and she gives university and sixth form college guest lectures and workshops.

Fiona has first hand experience of the recovery model, having experienced depression, post-natal depression and clinical mania in response to antidepressants. She has developed effective self-management skills and inspires people to empower themselves and improve their mental health. She is committed to ‘giving something back’ to other people who are struggling to manage their condition and to address the stigma attached to mental illness.
Healthcare Journalist, Editor and Patient Safety Advocate; Advocate for Use of Theatrical Techniques in Transforming Healthcare Culture

Reenacting one's work experience through play can be both funny and moving. As team members begin to understand the physical and emotional challenges experienced in their colleagues' work, problem-solving ideas bubble up.

Suzanne Gordon is an award-winning journalist and author. She has written for the New York Times, the Los Angeles Times, the Washington Post, the Atlantic Monthly, the American Prospect, the Globe and Mail, the Toronto Star, JAMA, The Annals of Internal Medicine, and others. She is the co-editor of the Culture and Politics of Healthcare Work series at Cornell University Press.

Suzanne is the author or co-author of 18 books including Beyond the Checklist: What Else Healthcare Can Learn from Aviation Teamwork and Safety and Collaborative Caring: Stories and Reflections on Teamwork in Healthcare.

In the course of her work, she developed the concept of Team Intelligence. She is co-author of the play about team relationships in healthcare entitled Bedside Manners. The play has been performed at numerous venues included the Institute for Healthcare Improvement, and The Hospital of the University of Pennsylvania, Cedars Sinai Medical Center, and is being used in Interprofessional Education programs. She is also co-founder of HIIP – Healthcare Innovation in Practice, a project devoted to using innovative media to overcome resistance to culture change in healthcare.
Digital has transformed the way we engage and the culture. The speed and reach of information has led to depth. Self-disclosure is part of the process that transforms a group into a community.

Meredith is a sociologist, 9x's author, and longtime marketing communications professional. An early adopter of social media, she's nationally known as a fierce advocate for using digital networking tools to build community, enhance health literacy, empower patients, and support spiritual growth.

A Platinum Fellow of the Mayo Clinic Center for Social Media (MCCSM), Meredith currently serves as community manager for its Social Media Health Network. She played a key role in developing and editing, Bringing the Social Media Revolution to Health Care (Mayo Foundation).

Meredith is also founder and lead moderator of the weekly Twitter-based #ChSocM (church social media) chat. She created the hashtag universally used across denominations to tag content and conversation about social media and church (#chsocm). Her book, The Social Media Gospel: Sharing the Good News in New Ways (Liturgical Press), is considered the go-to guide for church communicators. Personal adventures include careers as a graphic artist, college professor, government bureaucrat, and senior management in an advertising agency. Feel free ask about her many close encounters with healthcare providers before, during, and after the ashram years.
With a blog, you are creating a micro-community around yourself and your illness. But very few health bloggers share their blogs with their health care provider.

Dr. Lisa Gualtieri’s research is at the intersection of technology and consumer-facing healthcare, focusing on (1) patient activism and advocacy, (2) the use of social media for patient recruitment in clinical trials, (3) giving a second life to abandoned wearables, and (4) identifying and removing barriers to utilization of preventive care.

As faculty at Tufts University School of Medicine, Dr. Gualtieri teaches Social Media and Health, Digital Strategies for Health Communication, Mobile Health Design, and Online Consumer Health. She also serves as consumer advocate on an FDA advisory committee. In addition to her professional activities, she is a runner and a swing dancer.
Counsel for Robert Wood Johnson Foundation

Gurdin serves as counsel at the Robert Wood Johnson Foundation, where she advises on matters of advocacy and other issues related to the Foundation’s tax-exempt status. She has also been closely involved with the Foundation’s internal learning initiatives to inform its own strategic planning. Prior to joining RWJF, Gurdin served as an attorney representing colleges, universities, private foundations, hospitals and other tax-exempt organizations in Pittsburgh, the Pacific Northwest and Washington, DC.

She holds a JD from Temple University, a MLitt in Theatre-in-Education from Trinity College Dublin, an AB in Theatre, Speech and Dance from Brown University, and was a Fulbright Scholar to the Republic of Ireland.

Prior to attending law school, Gurdin documented 25 years of theatre-in-education in Ireland by TEAM Educational Theatre (an offshoot of the Abbey, the National Theatre of Ireland), studied the work of Augusto Boal and other participatory theater methods, and helped to design theater outreach projects that addressed HIV/AIDS prevention and other issues for Ireland’s most disadvantaged and vulnerable youth.
Wellness can imply a passive state, while wellbeing implies active participation, which is an important distinction. This is a key part of the transformation into wellbeing that is necessary to change the direction and velocity of our health practices.

Bill Hill is a creative director, designer, entrepreneur, and educator helping global companies, non-profit organizations, and educational institutions evolve using his skills in business strategy, experience design, and branding. After an 11-year career at IDEO Product Development, Bill founded the San Francisco office of MetaDesign in 1992 with a mission to create value for clients through the integration of design and business. He helped build MetaDesign into an international consulting firm that solved branding, information design, and strategic service problems through branded identities, customer-centered interfaces, and environmental graphics.

Bill has continued to provide industry leadership through his teaching and speaking engagements at Harvard University's Graduate School of Design, the Institute of Design at Illinois Institute of Technology, the American University of Beirut, and Design Management Institute and as a consultant and advisor to REBRAND. He is a member of the Board of Advisors at ID and taught a course entitled “Designing Wellbeing” that explored the creation of new products, services, and businesses to support wellbeing.

From 2012-2014, Bill was Director of Creative Services at Silicon Valley Bank in Santa Clara, CA. He returned to consulting compliment his other full time job as the dad of a 12-year old daughter and overseer of a growing collection of chickens and rabbits in their garden in Marin county California. He is currently developing an app to help men with prostate cancer that choose an approach that focuses on balancing diet, stress management, exercise and a supportive community.
Art is a very powerful tool. After my husband’s death, I asked myself, “What can I do to rapidly change healthcare so no one else will ever go through what I just experienced?” By using powerful visuals and a strong story, I’ve been able to advocate for legislative changes to healthcare.

Regina Holliday is a patient rights activist and artist. After spending 16 years working in retail management and six years teaching art, Regina began painting a series of murals depicting the need for clarity and transparency in medical records. This advocacy mission was inspired by her husband Frederick Allen Holliday II and his struggle to get appropriate care during eleven weeks of continuous hospitalization at five facilities. After his death resulting from complications of kidney cancer on June 17, 2009, she began painting a large mural entitled “73 cents.” This piece can be viewed at 5001 Connecticut Ave. Washington, DC 20008 and depicts the Holliday family’s journey through the medical system during Fred's cancer care and their desperate attempt to access Fred's medical record.

Regina also speaks at medical conferences providing the patient view in HIT and paints on canvas at medical conferences. She paints the concepts discussed and presents them through a patient's view. She also began an advocacy movement called “The Walking Gallery.” The Walking Gallery consists of artists, medical providers, technicians, governmental employees and advocates who wear patient-entered care paintings on the backs of their business suits. These jacket paintings combined with the tools of social media have spread the word about the importance of the patient's voice in healthcare discussions.
There are things we never say to our doctors, and there are things doctors never say. These unsaid things form a delicate intersection and dangerous distance in the examining and counseling room. Narrative medicine seeks to close this space by increasing the attention we pay one another and ourselves.

Laura Hope-Gill directs the Thomas Wolfe Center for Narrative at Lenoir-Rhyne Center for Graduate Studies. She engineers the program to address the world’s need for narrative, for storytellers and story-listeners in every field. Most recently, she launched Narrative Medicine in Western North Carolina, bringing the systematized practice of narrative training from Dr. Rita Charon and the team at Columbia University to physicians and healers in Asheville, North Carolina, and beyond with a synchronous in-person and online program. With her students in the graduate writing program at Lenoir-Rhyne in Asheville, she is constantly exploring the singularity, the versatility, the profound inter-relativity of story and storytelling.

She says, “The act of telling a story invites our fullest attention to our humanity. There are no hiding places in such tellings, as the stories demand a wholeness, something we might have lost along the way and are now invited to retrieve so that we may begin to tell the truth of something, even of something that has not happened directly to us.” In 2008 she founded the multicultural poetry and storytelling festival Asheville Wordfest, which she continues to direct. She is the poet laureate of the Blue Ridge Parkway and an NC Arts Fellow for her writings on late-deafness what deafness teaches her about listening. Through the Thomas Wolfe Center for Narrative she seeks to build narrative quality across the disciplines from climate to medicine. She is currently in a draft of a narrative about being the grand-daughter of P.O.W.’s in an undocumented-until-recently Japanese internment camp. It has taken her twenty-five year to find the shape of this story.
Bill Kelly

Co-founder & CEO of ReelDx

*By enabling patients to articulate and produce their own story through video, we are giving them the power of owning their own narratives.*

ReelDx provides a secure cloud-based platform for the creation, storage, and sharing of clinical video. The platform has been used to create a variety of applications: educational content featuring exam-room videos of actual, unscripted interactions between patients and their diagnosing physicians; observational assessment tools to provide feedback to students and professionals; patient video journaling and monitoring tools for population management and clinical trial support.

Co-founder and CEO, Bill Kelly, has already accomplished much in the education and health/tech space. Bill previously founded Sapient Health Network (now part of WebMD) and Learning.com—but he’s not just an inveterate entrepreneur. At his core, he’s a passionate advocate for the power of online health communities, for layperson and clinician alike.

Bill’s current focus on enabling real patient videos for use in education and research will sound revolutionary to a lot of people, because it is. But it’s nothing new to Bill’s ReelDx cofounder, Dr. David Spiro, who pioneered the use of video diagnosis as a teaching aid over the past decade. David has worked with people like you around the world—med students, nurses, doctors, and other clinical practitioners—to continuously improve the process of creating these videos. Together, Bill and David are discovering numerous innovative applications of video in the delivery of health care.
Bruce Kelly, MD

Primary Care Physician at Charles George VA Medical Center

There's the notion that medicine and health care have lost their soul, and as a consequence the patient's soul... who they “are” has been lost as well. But there's an opportunity to inspire provider and patient to consistently look deep enough to see and know the person “before” their symptoms.

I'm grateful for the values learned growing up in the rural Midwest. I've come to appreciate how they inform who I am. Summers pouring molten aluminium and reading Hesse, undergraduate years of new ideas and waking to social consciousness, and two as an orderly in an inner city (Cleveland) emergency room opened my eyes to a wider world.

In medical school I found the beauty and mystery of human biology, and the contradictions of knowledge and uncertainty. I was exposed to the tenets of William Osler, humanistic, and holistic medicine. They have guided me since. I learned the immutable value of relationship/s, and timely playfulness in patient care. Moving to western North Carolina in 1980 for my (FP) residency brought me to the community of mentors, peers, and opportunities that have nurtured my interests and talents here since.

The majority of my career has been in private practice, with a concurrent decade as our hospice medical director. I've helped lead the creation of programs in health promotion (UNC-Asheville), bioethics and palliative care (Mission Hospital), curriculum development (youth and adult developmental disabilities), and now the medical humanities and arts at our VA where I provide primary care for 1200 veterans.

Thanks for this inquiry into how the stories of our lives matter in relation to our health, illness, and medical care.
Sarah Kucharski

ePatient Program Coordinator for Medicine X at Stanford University

*Sharing our stories - both patient and provider - fosters human connection. As patients, we don’t always have empathy for providers. But we must realize they are people too. To this end, patients can ask their provider, “How can I help you help me?”*

Sarah E. Kucharski is a consultant, public speaker and advocate fostering the patient voice in medicine through design thinking for innovation and social media. As a professional journalist, she has spent more than 15 years in public relations, news, contract and specialty publications, magazine editing and blogging.

Her special interests include patient engagement, the patient experience, the doctor-patient relationship, the patient-caregiver relationship, chronic illness, clinical trials and health literacy. She has a B.A. in journalism, a M.A. in liberal studies and a certificate from Columbia University’s Narrative Medicine program.

She also is CEO/Chairman and Founder of FMD Chat, a nonprofit medical organization, and Coordinator of ePatient Programs for Medicine X at Stanford University. As FMD Chat’s leader, she oversees the organization’s mission and financial objectives; fundraising; publicity and media relations; domestic and international partnerships; volunteer recruitment and development. For Medicine X, she manages the health care and emerging technology conference’s ePatient scholarship program and has served on the ePatient Advisory Board since 2012. Sarah is also on the Rare Disease Advisory Board for Collaborations Pharmaceuticals, which works with rare disease foundations, academic scientists and other companies to develop clinical candidates for rare diseases.
Patients and doctors often see the same thing—the problem with which the patient is afflicted—from two very different perspectives. For doctors, it is a disease, a physiological disturbance that can be understood and treated through biomedical theories and their applications. For the patient, it is an illness, the subjective experience of being sick.

Dr. Arno Kumagai is professor of internal medicine and medical education at the University of Michigan Medical School. He is an adult endocrinologist, and his clinical interests are in the intensive treatment of type 1 diabetes.

Dr. Kumagai received his BA in comparative literature from U.C. Berkeley and his MD from UCLA. He completed his residency in internal medicine at Harbor-UCLA Medical Center, and a fellowship in endocrinology at UCLA. Dr. Kumagai joined the faculty of the University of Michigan Medical School in 1996.

Dr. Kumagai’s current focus is in undergraduate medical education. He serves as director of the Family Centered Experience Program and Longitudinal Case Studies, two small group-based courses in the first two years of medical school. He also directs the second-year endocrinology sequence and is active in curriculum design and administration. His research interests include use of narratives in medical education, active and transformative learning, faculty development, critical pedagogy, and multicultural education. Dr. Kumagai is the recipient of numerous teaching awards, including the AAMC/Pfizer Award for Humanism in Medical Education (1999), the Health Care Foundation of New Jersey Award for Humanism in Medicine (1999), Kaiser Permanente Award for Excellence in Basic Science Teaching (2002), the Provost Innovative Teaching Prize from University of Michigan (2009), the Leonard Tow Humanism in Medicine Award from the Arnold P. Gold Foundation (2013) and the Distinguished Leaders in Diversity Award from the University of Michigan (2013).
Helping women develop the skills and confidence to tell their stories publicly reduces their isolation and is the first step towards their becoming genuinely healthy. By integrating an effective expressive therapy intervention into the primary care of women living with HIV, we can take the first step towards transforming primary care from treatment to actual healing.

Edward Machtinger, MD is a Professor of Medicine and Director of the Women’s HIV Program at the University of California, San Francisco (UCSF). His primary academic interests are the relationship between HIV and violence against women and developing a scalable model of trauma-informed primary care for any population that experiences high rates of trauma and its myriad of health and emotional consequences. His recent publications include a meta-analysis describing high rates of trauma and PTSD among US HIV-positive woman and a study demonstrating a significant association of recent trauma and HIV medication failure. Dr. Machtinger is also interested in the healing power of disclosure. He recently published the results of an intervention to help women safely and publicly disclose their HIV status and histories of abuse through story-telling and theatrical performance.

In November 2012, Dr. Machtinger presented his research at the White House to the Presidential Working Group on the Intersection of HIV/AIDS, Violence Against Women, and Gender-related Health Disparities and was a keynote speaker at the release of its report. In August 2013, he co-convened a meeting Washington DC of 27 key national leaders from the government, military, academia, community organizations and stakeholder groups to clarify the elements of a new model of trauma-informed primary care to improve the experience and efficacy of healthcare for both patients and providers.
Principal Medical Practitioner at
Brighton Health and Wellbeing Center

Through the use of the seven basic plot structures, patients can be assigned a perspective different than their own in order to experiment with a new lens with which to view their situation. It brings about deeper reflection about the human condition.

Dr. Laura Marshall-Andrews has been a General Practitioner (Family Doctor) in Brighton for 15yrs. She has a special interest in Narrative Medicine and the psychology of the consultation. She trained at Southampton University and then at Charing Cross Hospital London before moving to Brighton to become a GP.

In July 2013 she set up Brighton Health and Wellbeing Centre with her Managing Partner Gary Toyne and Acupuncturist Chris Dance. BHWC is the UK’s first Integrated NHS Primary Care Health Centre. The clinicians work closely with complimentary therapists to deliver holistic, personalised care which combines both traditional western medicine and complimentary therapies. The practice has a charity which works alongside it to fund non NHS therapies for people on low income. She has set up the countries first Healing Arts Centre in Primary Care. The Centre runs programmes in the Literary, Visual and Performing Arts. We are looking at creating a Narrative database at the Practice. The practice has been a huge success and the list has grown from 6,500 to 8,500 patients in just over a year.

Laura is committed to recognising the importance of subjective personal experience and expression when considering optimal healthcare. She has attended Narrative Medicine workshops at the University of Columbia and has founded the UK’s first Narrative Medicine and Medical Humanities Working Group in Brighton.
We want to ensure that each patient - who chooses to - has a voice, and that these collective experiences will be harnessed effectively to drive patient-centered change. We make patients count.

Pat Mastors, a nationally recognized leader in patient engagement at both the policy and grass-roots level, is President and Co-Founder of the Patient Voice Institute. PVI supports the work and shared wisdom of patients to catalyze “the democratization of health care”.

Pat is Patient Co-chair of the National Quality Forum’s Patient and Family Engagement Action Team, advisor to the Partnership for Patients (PfP), and author of the critically acclaimed book Design to Survive: 9 Ways an IKEA Approach Can Fix Health Care & Save Lives, which looks at how simplicity, efficiencies, and partnership with customers can drive a better health care system. She also created and patented a patient empowerment and engagement device called the Patient Pod, designed to empower patients at the bedside with tools of engagement and partnership.

A career news and medical reporter at several New England television stations, Pat’s focus turned to patient engagement following the death of her father after a long hospitalization. She worked successfully to help pass two patient safety laws in Rhode Island. But it was during her daughter’s critical illness in 2013 that Pat would experience the full benefits of being an informed, engaged patient advocate. Her desire that all might share similar advantages and opportunities propelled her to co-found the Patient Voice Institute.
When Fran Melmed founded context, she wanted to create not only a communication consulting firm that’s in it for the long haul with clients, but one that’s smart, innovative, pragmatic, unbound from bureaucracy and human. She also wanted a firm that focuses on one thing: wellness.

Fran works with clients who are keen to disrupt their current state and deliver, not demand better health. The companies that work with context include Comcast, Cigna, IKEA, and ADP, as well as leading wellness platform providers, Shape Up and Virgin Pulse. Fran cohosts CoHealth Checkup, an internet radio program that digs into workplace wellness trends with guests ranging from Yale’s David Katz to Stanford’s BJ Fogg. As a speaker, Fran has been invited to South by Southwest, Health 2.0 SF, Games for Health, mHealth Summit, HxRefactored. And as part of a select group, Fran presented to the CDC her workplace wellness tool, Hotseat, a tool that uses nudges, games, and social accountability to inject microfitness breaks into the workday.

Fran’s interest in this workshop comes from her belief that stories are one of our strongest, most-underused tools for delivering an a-ha! moment and building empathy and understanding.
Currently, healthcare is not a cohesive, comprehensive experience. It is a brief moment in people’s larger life story. There’s a huge opportunity for healthcare to use transmedia narratives in order to create a more immersive experience.

Dr. Kirsten Ostherr is a media scholar & design thinker who specializes in health and medical visualizations: historical, present and future. She is a Professor of English at Rice University and, with the support of the Andrew W. Mellon Foundation, she has recently completed a Master of Public Health degree at the University of Texas School of Public Health.

She is also the Director and co-founder of the Medical Futures Lab, a collaborative center dedicated to reimagining medicine at the intersection of humanity and technology. They are busy inventing digital medical humanities, experimenting with collaborative participatory design projects, and training the next generation of digital doctors there.

Her most recent book, Medical Visions: Producing the Patient Through Film, Television, and Imaging Technologies, was published by Oxford University Press in March 2013. Medical Visions explores how audiovisual media - from x-rays to 16mm film to television and the Internet - have trained both physicians and patients to see and understand health and disease. The book covers the entire 20th century, and peeks into the 21st – it is historical and theoretical, and it is meant to provide a useful framework for current medical professionals, educators, communicators, start-ups, and students to learn from the past to make the future better.
The patient’s story is so de-emphasized today; I think we have to bring back a balance--and reintroduce this notion of bearing witness. Focusing on the patient’s story not only helps patients and improves patient satisfaction, but also has the potential to re-engage physicians in why they went into medicine in the first place.

After medical school at the University of Tennessee in Memphis, Dr. Pearson completed eight years of surgical training in Texas: general surgery at Parkland Hospital in Dallas and surgical oncology fellowship at M. D. Anderson Cancer Center in Houston.

For the past fifteen years, Dr. Pearson has been a member of the surgical faculty at Vanderbilt University, where he has combined cancer research and teaching with the clinical practice of surgery. Following a rich literary tradition at Vanderbilt, he developed an interest in the value of patient narratives in medicine and was accepted for faculty fellowship at Vanderbilt’s Robert Penn Warren Center for the Humanities. Over the past decade, he has taught an undergraduate seminar on the importance of the patient’s narrative.

Pearson is the author of the novels, RUPTURE, and the sequel, PUBLIC ANATOMY, which won Best Mystery from the Independent Book Publishers Association in 2011.
Pam Ressler

Founder & President of Stress Resources, Adjunct Faculty at Tufts University School of Medicine (Pain Research, Education & Policy Program)

For many patients, the process of blogging shifts their relationship with their illness, decreases their sense of isolation, brings meaning to their lives, and links them back to the outside world. Telling the patient’s story and allowing them to have a voice is essential to the treatment of pain.

Pam founded Stress Resources in 2001, after more than two decades in the healthcare field to meet the needs of individuals and organizations. A recognized thought leader and sought after speaker to local, national and international audiences on strategies of resilience, Pam received her undergraduate degree in nursing (with honors) from the University of Michigan and her graduate degree in Pain Research, Education and Policy from Tufts University School of Medicine. She received further training in mind/body medicine and mindfulness at Harvard University School of Medicine and The Center for Mindfulness in Medicine, Health Care and Society at the University of Massachusetts Medical School. Additionally, she has studied in the Program in Narrative Medicine at Columbia University.

Pam has taught in the nursing program at the University of Massachusetts College of Nursing and Health Sciences in Boston and currently is a faculty member at Tufts University School of Medicine’s Pain Research, Education and Policy Program where her academic research explores the intersection of health and social media in patients with chronic illness.

Her areas of interest include: communicating the experience of pain and chronic illness, mindfulness and its use in leadership, education and healthcare, cultivating resilience, narrative medicine, and online patient communities.
Meaningful arts experiences tend to share certain characteristics. These characteristics include being person-centered, focusing on healing rather than curing, enabling a change in perception achieved by learning something new, encouraging meaningful engagement, and promoting a sense of being heard and valued.

Judy Rollins, PhD, RN, brings over 30 years of arts and healthcare experience in research, consulting, program development, and education. She is a registered nurse with a BFA in the visual arts, an MS in child development and family studies, a PhD in health and community studies, and holds a Certificate in Evaluation Practice from George Washington University, Washington, DC. She has developed programming for adults, children, families, and healthcare staff in hospitals, hospice care, and the community. Among the local arts programs she has developed are Allies in the Arts for Wounded Warriors at Walter Reed National Military Medical Center (WRNMMC), You Are a Work of Art for nurses at WRNMMC, ART is the heART for children and families in hospice care, and Studio G, an artists-in-residence program in pediatrics at Georgetown University Hospital. She is adjunct assistant professor in the Department of Family Medicine with a secondary appointment in the Department Pediatrics at Georgetown University School of Medicine, Washington, DC.

Author of over 100 publications, Dr. Rollins is editor for Pediatric Nursing and North America regional editor for Arts & Health: An International Journal for Research, Policy and Practice. A long time officer and board member of the Society for the Arts in Healthcare, she was among the first group of recipients of the Society’s Distinguished Fellow awards.
Jeff Rubin, who joined Accolade at its founding in 2007, was instrumental in developing our model for working with people. The go-to person for anything related to Behavioral Health Operations, Jeff guides us in how best to engage and influence clients. His basic philosophy—that health stems from mental and physical well-being supported by social factors—is core to our holistic approach to healthcare.

Jeff’s role includes the ongoing “care and feeding” of our engagement model, as he oversees the development and continuous improvement of processes and capabilities related to behavioral health. Providing tools and training to our Health Assistants and Stewards is also part of his job.

Prior to joining Accolade, Jeff was VP, Clinical Operations, for CIGNA Behavioral Health for 15 years and, earlier, he was chief psychologist at Manhattan Psychiatric Center. Jeff also has maintained a private practice in psychotherapy since 1983.

Jeff holds a doctorate in education, as well as a master of arts and master of science, all from Columbia University. He completed post-doctoral training in Organizational Development and Consultation through a joint program of William Alanson White Institute and Wharton.
One of the 8 emotional intelligence competencies in our Six Seconds model is increase empathy. I think there is no more powerful way to do that than to share stories, to give and receive the narratives that open us up to other people.

Paul has over 30 years of experience as a healthcare executive and consultant. He has held leadership positions in rural, suburban, and inner city hospitals, with responsibilities ranging from strategic planning to marketing to divisional operations. Paul was a Vice President at the largest Catholic hospital in New England, overseeing a campus that included a 60-bed acute rehabilitation hospital and the system’s inpatient and outpatient behavioral health services. In addition, he had responsibility for system-wide, university-affiliated ambulatory care programs.

Paul was also a consultant with Planetree, a pioneer in patient-centered care. At Planetree, Paul conducted leadership retreats and facilitated focus groups, with the goal of fostering cultural transformation around an ethic of patient centeredness in a healing environment. He worked with network hospitals throughout the United States, including many VA facilities, as well as healthcare organizations in Canada, Brazil, and Japan.

Paul is currently Senior Consultant at Six Seconds, the global emotional intelligence network. He certifies and supports coaches and consultants in Vital Signs, Six Seconds’ suite of organization assessment tools. Paul has a doctorate in human and organizational systems and a research interest in sustainability as organizational culture. He is a Life Fellow in the American College of Healthcare Executives.
**Victoria Sweet**

Associate Professor of Medicine and History at the University of California, San Francisco

*Medicine works best -- that is, arrives at the right diagnosis and the right treatment for the least amount of money -- when it is personal and face-to-face; when the doctor has enough time to do a good job, and pays attention not only to the patient but to what’s around the patient.*

Dr. Sweet is an Associate Clinical Professor of Medicine at the University of California, San Francisco, and a prize-winning historian with a Ph.D. in history. She practiced medicine for twenty years at Laguna Honda Hospital in San Francisco, where she began writing, and is a Guggenheim Fellow for 2014-2015.

In her book, *God’s Hotel: A Doctor, a Hospital, and a Pilgrimage to the Heart of Medicine* (Riverhead, 2012), she laid out her evidence—in stories of her patients and her hospital—for some radically new ideas about medicine and healthcare in this country.

In trying to control healthcare costs by privileging “efficiency,” she suggests, we’ve headed down the wrong path. Medicine works best—that is, arrives at the right diagnosis and the right treatment for the least amount of money—when it is personal and face-to-face; when the doctor has enough time to do a good job, and pays attention not only to the patient but to what’s around the patient. Dr. Sweet calls this approach Slow Medicine, and she believes that, put into wider practice, it would be not only more satisfying and beneficial for patient and doctor, but also less expensive for everyone.
When you engage with a patient simply as one person who is concerned about another, you much more naturally find out what you could do that might help them.

Dr. Weiner, an internist and paediatrician, has a primary research interest in identifying ways to improve how physicians individualize treatment decisions. He has developed the concept of “contextual errors” to describe medical errors that result from failures to take into account factors in patients’ lives and circumstances that are relevant to their care. He has worked with actors who present in physician practices as incognito standardized patients as well as real patients who audio record their encounters to collect data on physician decision making. He has developed and evaluated interventions both to assess and train health care providers to integrate patient context with research evidence when planning patient care. His work has been funded by the Robert Wood Johnson Foundation, the Department of Veterans Affairs, the National Board of Medical Examiners, NIH and NSF. In 2013 he was UIC’s Distinguished Researcher of the Year in the Clinical Sciences.

Dr. Weiner has served in various academic posts including as a residency program director (medicine and pediatrics), division head of (general pediatrics), senior associate dean (educational affairs), and vice provost (planning and programs) all at UIC. He is also co-founder of the Institute for Practice & Provider Performance Improvement (I3Pl) that offers consulting services to health care organizations seeking to improve performance-in-practice based on data collected from directly observed care.
After 35 years working in proximity to the best and brightest minds in health policy, at heart I’m still a patient. Everyone pays lip service to the voice of the patient, but it’s almost impossible to hear that voice over the clamor of innovation, money, politics, and ego that is American healthcare. I’ve got my fingers crossed for the power of narrative to change that.

Anne F. Weiss leads the Foundation’s efforts to achieve the highest possible value from our nation’s investments in health and health care.

Weiss joined the Foundation in 1999, after a distinguished career in health care policy at both the federal and state level. She served as senior assistant commissioner of the New Jersey Department of Health, where she directed the state’s oversight of the quality of care delivered by health care providers and health plans, and worked with physicians and hospitals throughout the state to issue New Jersey’s first report card on health care quality. She also oversaw New Jersey’s hospital rate-setting program, and served as executive director of the state’s blue-ribbon health reform panel. Previously, Weiss spent ten years in Washington, DC, serving as professional staff to the United States Senate Committee on Finance and at the Office of Management and Budget.

Weiss received her MPP from the Kennedy School of Government, Harvard University, and a BA in history and political science from Wellesley College.
Marete Wester

Senior Director of Arts Policy at Americans for the Arts

We’ve seen first-hand how the arts help people to express themselves and share their experiences. When effectively employed in communities, the arts offer lifelong opportunities for service members, veterans, and their families not only to address, but to transcend, their challenges.

Marete joined the staff of Americans for the Arts, the nation’s leading nonprofit organization advancing the arts in America, as Director of Arts Policy in April of 2006. In her current role she is responsible for the development of cross-sector policy issues and related strategic alliances nationally and internationally.

Among her focus areas include arts and the military, economic statecraft through creativity and entrepreneurship, as well as health, education and the environment. In 2006 and 2007 respectively, she launched and implemented over the past six years, Americans for the Arts’ signature policy forums, the National Arts Policy Roundtable in partnership with the Sundance Institute, and the annual Aspen Seminar for Leadership in the Arts. An experienced administrator of cross-sector collaborations and initiative development, she co-chairs the Steering Committee for the National Initiative for Arts and Health in the Military—an effort that brings branches of the military in collaboration with civilian agencies to advance the policy, practice, and quality use of arts and creativity as tools for health in the military and increase access to the arts as tools for health available to all active duty military, staff, family members, and veterans.

She holds a bachelor’s of music performance degree from Wilkes University, PA and a master’s degree in Arts Administration from Drexel University in Philadelphia.