DUKE
THE FUQUA SCHOOL OF BUSINESS

HSAC
Health Sector Advisory Council

CHAPI
Collaborative on Healthcare for Aging Populations and Advanced Illness

Program Overview

By 2016, Cisco estimates a demand for 10.8 exabytes (1 exabyte = 1 billion gigabytes) of mobile voice/data per month. An aging US population needing more health services and a tech savvy younger generation will use smart phones, tablets, and new remote sensor devices to monitor and manage health. Sermo, Web 2.0, MedWatcher, Text4Baby, Stage 2 Meaningful Use, PatientsLikeMe, and MeYouHealth are new markers at the virtual crossroads of a digital health care frontier.

First used in 2004 (Webster), "social media" is a term that continues to evolve as platforms and technologies continue to change and expand. Here we define social media broadly as a group of Internet based platforms and applications that allow ***all*** users to ***interact*** with and ***share*** information. Unlike traditional media (print, broadcast) and websites where users are limited to information that was created for them, social media facilitates participatory information sharing, user-centered design, interoperability, and collaboration. It enables speed and breadth of information dissemination in real time; provides for one-to-one, one-to-many, and many-to-many communications; and involves engagement by participants who can create, comment, add to, and share thoughts, ideas, and information 24/7. As Clay Shirky famously wrote, "Here Comes Everybody."

Social media and health care trends

Three trends involving social media, automation and payment reform are converging to change how providers, patients and payers interact.

- Empowered, sensored and "connected" patients
- Networked, smart phoned, data and tech savvy doctors
- Bundled payments, HITECH and Stage 2 meaningful use

The convergence of these 3 brings disruptive, fast- paced change in an industry segment - health care - that has lagged behind the digital revolution leadership of financial services or telecommunications. It raises considerable challenges and opportunities for patients who want greater access, transparency, and quality; physicians seeking new modalities to diagnose, treat, and interact; and payers who want lower cost, higher quality and value-based products and services.

Empowered, sensored and connected patients

Private and public providers have long been feeding enormous amounts of information to patients through the internet at their websites: mayoclinic.org, WedMD, health.nih.gov. These are only three standouts in a universe of health-related information meeting the demand of 8 out of 10 Americans reporting they have used the Web to search for health information.

New on the landscape, though, are patient pioneers, armed with sophisticated technological tools, who are leading a growing movement that moves beyond passive information gathering. "E-mpowered, E-ngaged, E-quipped, and E-nabled," e-patients advocate for full and open access to their own health data, so that they can learn more about their bodies, their health conditions, and become full partners with physicians in their care.

Consider Hugh Campos, for example - a "self-quantifier" currently engaged in a campaign to gain open access to the raw data stored on the medical device – a defibrillator - implanted in his chest. (http://www.thedoctorweighsin.com/hugo-campos-fights-to-get-his-defibrillator-data/)

And then there's Larry Smarr:
(http://www.technologyreview.com/biomedicine/39636/#.T0zYiK8-gSx.twitter).

Larry has amassed significant personal information through self-monitoring, gene sequencing, web searching and copious interaction with specialists. He self-diagnosed and confirmed with his doctor ulcerative colitis. His gastroenterologist describes Larry as:

> "the paradigm for what will happen in the future… consumers are going to be the driving force—it isn't going to be physicians. They're going to demand to quantize themselves about their own wellness and what can be done."

As Dave deBronkert (aka e-patient Dave), a leader of the patient engagement movement, states: "Everyone in healthcare seems to feel powerless to improve things. Well, I don't. . . Let patients help!"

Hugh, Larry, and Dave are outliers, disruptive innovators at the edge. They are harbingers of the empowered, sensored and connected patient moving forward in ways that may well flip the "doc in charge" model on its head.

Hoping to harness the power of patient engagement via social media tools, payers and pharma are also working to strengthen connections and relationships with members and consumers. Aetna, WellPoint, and UnitedHealth Group all offer mobile apps to directly engage members in the management of their own healthcare. And, although still somewhat digitally cautious while waiting on clear FDA guidelines on social media use, pharma firms are also moving deeper into the social media domain. "Syrum" – a social game platform for Facebook developed by Boehringer Ingelheim is set to go live in March. As well as developing new drugs to attack deadly diseases, players will also take part in clinical trials and learn about the processes involved in patent applications. (http://blogs.bmj.com/bmj/2012/02/17/david-kerr-saving-the-world%E2%80%93pharma-dips-a-toe-into-social-media-gaming-for-health/)

Networked, smart phoned, data and tech savvy doctors

Dr. Jay Parkinson is the founder of Hello Health and, more recently, Sherpaa – both web-based healthcare delivery systems. In his company's digital universe you can know your physician's favorite hobbies, interact by instant message, email, video chat, whatever medium works best for you and the physician. You can have "cyber visits" or be seen in person within 24 hrs. Hello Health and Sherpaa are manifestations of the new physician who guides care in partnership with patients using new media and resources.

In his recently published book, *The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care*, Dr. Eric Topol describes a brave new world of healthcare. He envisions a convergence of new technologies in genomics, information technology and mobile medicine that might completely upend the way we treat and prevent illness, and dramatically improve patient outcomes. He underscores the disappointing results so far with genome-based "personalized medicine" and celebrates pharmacogenomic breakthroughs which have resulted from genome-wide association studies (GWAS). He argues "with remote sensing and the ready accessibility of video chat, virtual office visits could soon replace the routine physical ones." Dr. Topol even suggests that Facebook, which is feared or inscrutable to most physicians, may be very useful to the new digitally connected physician if s/he follows Mostaghimi and Crotty's suggestion

(*Annals of Internal Medicine*) to have dual online citizenship with separate professional and personal social networking profiles.

It's a long way from traditional medical school training to a Facebook practice page, a YouTube library for patient education, or Twitter for connecting with colleagues, but the pioneers are here now. Hello Health, virtual office visits, and truly individualized medicine using a sequenced microbiome are on the edge of disruptive innovation. These small market share innovations herald a changing physician who will interact differently with patients, with peers and with payers.

OTC, bundled payments, HITECH and stage 2 meaningful use

Over-the-counter (OTC) medicine purchases have increased significantly in the last decade just as social media use has appeared and proliferated. With the conversions of allergy and ulcer medicines from Rx to OTC, consumers are increasingly looking to OTC meds for their health needs. Insurers, patients and even the FDA (see February 23, 2012 Federal Registry comments) want to improve compliance and increase OTC options for patients. On the other hand, patients now bear the full costs when flexible spending account funds could no longer be used for OTC purchases beginning in 2011. In a direct to consumer, OTC market, there are many opportunities for social media to increase patient awareness; for consumers to crowdsource and share directly their experience with these remedies. Ideally these new channels, devices and information can improve compliance and health outcomes; lower overall expenditures with a more personally empowered patient. And the new landscape creates broadened opportunities for misinformation and perverse incentives to "contaminate" content for consumers, manufacturers, providers and for regulators.

A long-held consensus finds the US fee-for-service (FFS) payment system increasing costs and creating barriers to care coordination and improving quality. The past 30 years of broad experiments with "managed care" left consumers and physicians frustrated that there were few rewards for not being hospitalized or re-hospitalized and hard-to-track "avoided costs" did not reward patients or their doctors who effectively monitored and controlled chronic conditions. The managed care lessons of the 1980's, both good and bad, and a continuing search for improved outcomes, lowered costs and higher quality has led to new payment models including bundled payment "episodes of care" and "accountable care organizations."

A bundled payment is based on the total care a patient receives during an episode of illness or a defined period. These fees for "care episodes," adjusted for case-mix complexity, will reward providers who have lower costs by avoiding re-hospitalizations, higher quality and better coordinated patient care. Already a standard in hospice, the bundled payment has come under controversial scrutiny by a recent MedPac recommendation of a U-shaped reimbursement providing higher payments on the first and last day of care. Would such a plan incentivize shorter hospice stays? If bundled payments for pre-hospice/ advanced illness populations were to be created, would this force lower reimbursement and utilization of needed hospice services?

“Accountable care organizations” hold the promise for patients to receive accessible, continuous, and coordinated care from a linked group of physicians, in-patient and out-patient treatment and diagnostic organizations. CMS has developed guidelines for the payment models, information coordination and a legal safe harbor to allow these fiscal and informational collaborations. As patient care is financed, paid and organized in cycles that extend weeks and months beyond a single physical encounter or procedure, and involve multiple services across the care spectrum, they create opportunities in which to use social media. These new channels, devices and content create substitutes or enhancements to face to face encounters which may be more cost efficient, more satisfying for patients and providers and incite greater patient compliance and involvement.

The Health Information Technology for Economic and Clinical Health (HITECH) Act was signed into law in February, 2009 as part of the American Recovery and Reinvestment Act (ARRA) of 2009. The Stage 1 Meaningful Use incentives and the recent Stage 2 incentives accelerate opportunities for digital and social media. ePatients have their own perspectives on the Stage 2 incentives (http://e-patients.net/archives/2012/02/an-e-patient-perspective-on-stage-2-of-meaningful-use-adrian-gropper.htmland). Adrian Gropper opines:

> “Stage 2 is a huge leap toward coordinated, patient-centered care and makes unprecedented efforts toward patient engagement…..mandating comprehensive structured summaries be available to patients for download as well as on-line viewing, Stage 2 enables patient-directed health information exchange as an alternative to hidden provider-provider transactions that characterized earlier HIE efforts…..these **privacy, transparency and accessibility** enhancements come none-too-soon as ACO payment reforms implicitly drive providers to keep patients in their particular network.”

May 7-9, 2012
Health Care Gets Social: patients and providers in a 24/7 network

Duke University has created two innovative forums to explore the opportunities and challenges when “health care gets social.” One group is a decade old, the Health Sector Advisory Council (HSAC), while the other, the Collaborative on Health Care for Aging Populations and Advanced Illnesses (CHAPI), is quite new. On Monday night, May 7, 2012 and Tuesday May 8, 2012, CHAPI will explore the convergence of these trends as “health care gets social” for aging populations and people with advanced illnesses. Beginning Tuesday night, May 8 the CHAPI participants will join the HSAC members to broaden these considerations of digital and social media to all patient populations regardless of age or illness.

An agenda for both meetings is being developed in collaboration with our thoughtful and experienced speakers, faculty, and CHAPI/HSAC members. Speakers include the following:

Lee Aase
Manager, Social Media, Mayo Clinic

Lee is an American pioneer in using social media tools in the hospital environment, and is an advocate for social media adoption in health care.

Aase received his Bachelor's Degree in Political Science from Minnesota State University, Mankato. From 1986 through 2000, he was employed in U.S. politics and government at the local, state and federal level, concluding as press secretary for former U.S. congressman Gil Gutknecht. His earliest political forays ranged from field work to campaign management for a variety of Republican Party entities.

In 2000, Aase began work at Mayo Clinic as a member of its media relations team, becoming the team's manager in 2004. Following a steady production of television news feeds and radio programs, he launched Mayo Clinic's first podcast in 2005. Aase subsequently led Mayo in developing an extensive library of podcasts, blogs, a YouTube channel, a Facebook page and a Twitter profile. In 2008, he became Mayo Clinic's manager for syndication and social media. In 2010, he became the Director of the Mayo Clinic Center for Social Media, a first-of-its-kind social media center focused on health care, built on the Mayo Clinic's leadership among health providers in adopting social media tools. This new Social Media Center was established with the collaborative assistance of Victor Montori, M.D., Mayo Clinic's Medical Director. To date, the Mayo Clinic touts the most popular medical provider channel on YouTube.

Bill Gradison
Scholar in Residence
Duke University Fuqua School of Business

Bill Gradison was appointed by the Securities and Exchange Commission as a founding member of the Public Company Accounting Oversight Board, which was created by the Sarbanes-Oxley Act of 2002. He was unanimously reappointed to a full five-year term in August 2004, and served as Acting Chairman from December 2005 to July 2006.

Before joining the PCAOB, Mr. Gradison was senior public policy counselor with the Washington, D.C., law firm of Patton Boggs from 1999 to 2002. He previously served as president of the Health Insurance Association of America for six years.

Mr. Gradison held elective office for more than 30 years. Before being elected to the U.S. Congress from his hometown of Cincinnati, Ohio, he was a member of the Cincinnati City Council for 13 years, serving as Vice Mayor and Mayor.

During his 18 years in Congress, from 1975 to 1993, Mr. Gradison was the ranking member of the House Budget Committee and the Health Subcommittee of the Committee on Ways and Means.

Following a brief stint on the finance faculty of the Harvard Business School, Mr. Gradison began his career in public service in 1953, as Assistant to the Under Secretary of the Treasury in Washington, D.C. He subsequently was Assistant to the Secretary of Health, Education and Welfare before returning to Cincinnati as a general partner of a New York Stock Exchange listed firm. He also served as Chairman of the Board of the Federal Home Loan Bank of Cincinnati.

Mr. Gradison received a B.A. from Yale University and an M.B.A. and a doctorate from the Harvard Business School.

Regina Holliday
Blogger and Activist
Medical Advocacy Mural Project

Regina Holliday is a patient rights' advocate and medical muralist in Washington, DC. She is using social media and public walls to inform citizens of the need for real time access to patient data, transparency in terminology and interoperability of systems.

After treatment at five different facilities in a less than three month period, Regina's husband Fred Holliday died of kidney cancer in June, 2009. As a caregiver on-site for her husband, she witnessed first- hand how the current system is failing caregivers and patients. She saw the situation as a call to action and began a series of murals chronicling the problems accessing data in the current medical system. National and international media have covered the progress of her mural "73 Cents." This mural depicts her husband dying in darkness surrounded by inaccessible tools of technology in a closed data loop. The title "73 Cents" refers to the cost per page for your medical record in the state of Maryland.

Regina Holliday can be found on Twitter as ReginaHolliday and on Facebook as Regina Holliday, Wash DC. She will visit CHAPI/HSAC via Skype at the May 7 - 9, 2012 sessions at Duke University.

Amy O'Connor

Amy leads the Digital Government Affairs team at Eli Lilly. She is a graduate of the University of Notre Dame and the Georgetown Public Policy Institute. Through the course of her career, Amy has spent some time in London working for the British Parliament, a few years assessing international operations for Lilly and the last six in Government Affairs focusing on strategy and business alignment. Most recently, Amy launched Lilly's digital public policy effort with LillyPad (@LillyPad) and the Campaign for Modern Medicines (@ModernMeds). Her goal is to develop Lilly's engagement on public policy issues to better promote innovative public policy solutions. In her spare time, Amy can be found exploring Washington, D.C. out with her dog, playing competitive sports or cheering on her favorite team and traveling to a new country. She is also a bit of a "foodie" and enjoys trying new restaurants and bringing friends together at her favorite places. With her finger on the pulse of policy, political and advocacy worlds, Amy will share her experiences and blog about these issues on LillyPad.

Jay Parkinson, MD, MPH
Founder, Hello Health & Sherpaa

After completing a residency in pediatrics and one in preventive medicine at Johns Hopkins, Dr. Parkinson started a practice for his neighborhood of Williamsburg, Brooklyn in September 2007.

- Patients visit his website
- See his Google calendar
- Choose a time and input their symptoms
- His iPhone alerts him
- He makes house calls
- Patients pay via PayPal
- Jay follows up by email, IM, videochat, or in person

This concept became Hello Health so other doctors could practice this way. Hello Health is a mixture of secure social network and electronic medical record that enables doctors and patients to connect both in their office and online via email, IM, and video chat.

Fast Company called Jay the Doctor of the Future and one of the top 10 most creative people in health care. He has a design firm called The Future Well which dreams up, designs, and builds products and services that inspire health and happiness. Sherpaa, a health service, was launched in NYC in February 2012. Sherpaa connects employees to groups of doctors via email and phone 24/7 to solve health problems. Jay is very active on his blog.

Nadine P. Peters
Partner, HoganLovells, Washington, D.C.

Nadine Peters' practice focuses on healthcare issues with an emphasis on health information privacy, including compliance with the Health Insurance Portability and Accountability Act (HIPAA) and federal and state privacy laws.

Nadine has extensive experience counseling clients on an array of healthcare regulatory matters including regulatory requirements of the Medicare and Medicaid programs. She primarily advises healthcare providers, pharmaceutical and medical device companies, health plans, e-health organizations, healthcare trade associations, and research institutions on matters related to electronic data sharing, use of health information in marketing and other initiatives, privacy and information security practices, and data breaches.

Nadine is also actively involved in the firm's Community Services Department, where, among other projects, she is working on improving the District of Columbia's response to HIV/AIDS.

Prior to joining Hogan & Hartson, Nadine worked at another leading law firm where she focused on health regulatory compliance and healthcare transactions. She also spent a year as an attorney at the U.S. Department of Health and Human Services (HHS), Office of the General Counsel, where she provided legal guidance to program officials at the Centers for Medicare & Medicaid Services.

While in law school, Nadine was an intern at Partners Healthcare System, Inc., Office of the General Counsel, and also a legal intern to a Massachusetts state representative, during which time she drafted legislation designed to improve Medicaid-enrolled children's access to dental care.

Barak D. Richman
Professor of Law
Duke University

Barak's research interests include the economics of contracting, new institutional economics, antitrust, and healthcare policy. He teaches contracts, antitrust, and health law, and he has guest taught classes at The Fuqua School of Business and the Sanford School of Public Policy. He was invited to the Yale/Stanford Junior Faculty Forum in 2004, received Duke Law School's Blueprint Award in 2005, and was a recipient of the Provost's Common Fund award in 2006.

Professor Richman received an A.B., magna cum laude, from Brown University; an M.A. in Economics from the University of California at Berkeley; a J.D., magna cum laude, from Harvard Law School; and a Ph.D. in Business Administration from the Haas School of Business at the University of California at Berkeley. Professor Richman also spent one year at the Pardes Institute in Jerusalem, Israel, studying biblical and Talmudic texts.

His recent work has been published in the *Columbia Law Review*, the *University of Pennsylvania Law Review*, *Law and Social Inquiry*, and *Health Affairs*, and he recently co-edited with Clark Havighurst a symposium volume of *Law and Contemporary Problems* entitled "Who Pays? Who Benefits? Distributional Issues in Health Care." Some of his papers are available at http://ssrn.com/author=334149.

Christian Sinclair, MD

Dr. Sinclair is a National Hospice Medical Director for Gentiva Health Services and the editor of Pallimed: A hospice and palliative care blog. His medical training started at the University California, San Diego, which he completed in 2000. From there he and his wife, Kelly, went to North Carolina for 3 years for an Internal Medicine residency at Wake Forest. In 2003-4, he completed a palliative medicine fellowship at the Hospice and Palliative Care Center in Winston-Salem, NC. In Kansas City he served for 8 years as an Associate Hospice Medical Director overseeing a 32 bed inpatient unit, leading the palliative medicine fellowship program in conjunction with the University of Kansas, and while continuing to see palliative care consults in the hospital and on home visits. Dr. Sinclair was the first chair and co-founder the American Academy of Hospice & Palliative Medicine (AAHPM) professionals-in-training special interest group (PIT-SIG). He was elected to the AAHPM Board of Directors in 2009 and recently elected to a second term. Dr. Sinclair is passionate about health care professionals engaging the public through social media. You can follow him on Twitter @ctsinclair or @pallimed.

Scott Stropkay, BFA

Scott Stropkay is a founding partner of the research, strategy and development consulting firm Essential.
Scott advises businesses and institutions on cross-functional innovation; helping leaders create innovative products and services in the consumer, healthcare, education, and commercial markets.

Scott views design as a business-to-end-user interpretation tool. He believes design thinking is about interpreting technologies to simplify features and interfaces for end-users, interpreting service offerings to make them appeal to specific market segments, and interpreting form and function possibilities as experience opportunities to build brands and fortify a client's business position.

Prior to Essential, Scott led an integrated design, human factors, and interaction design team at IDEO; served as Director of Design at Gillette; and was a Director of Design at Fitch, having started his career at RichardsonSmith. He has a Bachelor's of Fine Art in Industrial Design from The Cleveland Institute of Art and is a member of DMI, IDSA, APDF, MassMedic, and MDG.

James Tulsky, MD

Dr. Tulsky is Director of the Center for Palliative Care and Professor of Medicine and Nursing at Duke University. He serves on the National Institute of Nursing Research's (NINR) National Advisory Council for Nursing Research (NACNR)—the Institute's principal advisory board – and is a past recipient of both a VA HSR&D Career Development Award and the Presidential Early Career Award for Scientists and Engineers.

Dr. Tulsky has a longstanding interest in doctor-patient communication and quality of life at the end of life, and has published widely in these areas.

His current research focuses on the evaluation and enhancement of communication between oncologists and patients with advanced cancer, identification of clinical, psychosocial and spiritual trajectories of patients at the end of life, and development of self-management interventions for patients with life-limiting illness.