Evolvent Technologies Presents:

Transforming Health Care

Better Data for Better Care
Transforming Health Care
Better Data for Better Care

Written and compiled by the staff at Evolvent Technologies, Incorporated, Falls Church, Virginia.

For more information about Evolvent capabilities and what Evolvent can do for you, contact us via e-mail at info@evolvent.com or by phone at 888-379-2146.

For updates, resources and our latest magazine, please visit us at our website www.evolvent.com
Dedication

The Evolvent Team is proud to dedicate *Transforming Health Care* to those we ultimately aim to serve:

Our wounded warriors who deserve the best, smartest care we can give – supported by the most efficient, effective and data-rich technologies we can offer; and,

Our veterans of all times and ages who have borne the battle and who also deserve the same attention and care; and,

Our ill and injured across this land who suffer, sometimes needlessly, and who so desperately need better data, richer information, and smarter care to return to health as fast as possible.

Note:
Any proceeds from this book will go to one of the following charity partners of Evolvent:
Fisher Foundation
OurMilitaryKids.org
NIH Children’s Inn
# Table of Contents

Foreword........................................................................................................................................ix

### Section 1

A Vision of the Future -
Transforming Health Care (Introduction to Section 1).................................1
A Tale of Two Futures...............................................................................................11

### Section 2

Key Enablers (Introduction to Section 2) ............................................................15
Security and Privacy as Enablers of Better Health Care.................................17
Sustainable Health Information Exchange........................................................59
Health Care Financial Reform:
The Small Picture of the Health Care Financial Landscape.........................73

### Section 3

Transformation of Health Care (Introduction to Section 3) .........................85
Consumer Empowerment...................................................................................87
Patient-Centered Medical Home........................................................................97
Telehealth...........................................................................................................105
Health 2.0 and the Future of PHR.................................................................115
Mobile Health Care .........................................................................................129
Accelerating Clinical Research......................................................................143
Clinical Decision Support .............................................................................149

Afterword ..........................................................................................................155
Author’s Biographies.......................................................................................159
Glossary of Acronyms.....................................................................................173
Acknowledgements

Each time we initiate a “book project,” it seems to draw out more talent across our organization. This project was no different. Many hands have contributed, and the ideas of all are brought together in the volume you see. Without all the efforts of our myriad contributors, this compendium of thought on how technology can help health care transform itself and deliver better care through the better delivery of information would not have been possible.

My thanks first to our core production team that kept this project on track. Mr. Greg Parish, Jr., again served as research manager, coordinator, analyst and writer, and did a magnificent job. Greg's intelligence, acumen and ability to synthesize ideas across the spectrum of all that is going on in health care today is remarkable and has made this book, I believe, an important work in our field. Closely aligned with our writing team have been three individuals who kept this project moving and managed production activity on a very tight schedule – Ms. Jenn Cupka, Ms. Brittany Palmer, and Ms. Kari Larsen. These three kept us on track and made our ideas come to life in this finished product! Thanks! Finally, joining our production team this year has been Ms. Stella Ramsarooop, who as production editor has really raised the bar in terms of the finished quality of our manuscript. Stella's professional capability as a journalist, her clear style and eye for quality communication have been of enormous help in improving our work. Thanks, Stella!

And now, for the writers. I can hardly believe the talent and intelligence that we have assembled at Evolvent. Each of our leaders has contributed to this work and the combined power of this collaboration is clearly evident. Our primary writing team included J.D. Whitlock, Steve Gantz, Bill Sorrells, Geoff Howard, Greg Parish, Jr, and Dave Parker. Contributing writers and reviewers included: Greg Parish, Jr., Monty Nanton, Kent Stevenson, Paul Ramsarooop, Joey Meneses, Dave Walton, Davis Foster, Anna Worrell and Anna Khizhnyak. My thanks to all of these talented professionals for their time and intellectual contributions. We are very proud to have all of them in the Evolvent corporate family.

My continued and heartfelt thanks also to our client community for the opportunities we share to do good work. It has been an honor and a pleasure to work with our colleagues across federal health care for the last ten years and while much has changed and will change – the force we can be together for transforming health care is powerful indeed.

There is also an unsung hero at Evolvent, who – like me – is deeply committed to our clients, employees and the future of health care – that is my
partner of the last ten years, Paul Ramsaroop. Paul and I are proud of our team, but most gratified by the difference we are all making.

Finally, I would like to acknowledge and thank my family who gives me so much motivation, encouragement and conviction on a daily basis – making it clear how vitally important it is that we deliver better data to enable better care.
Foreword

Why this book and why now?

Much has been said, written and continues to be written every day about the successes and more often – the failings of our health care system. For those of us who live in the world of health care and health IT every day, we are right at the focal point of a lot of national attention. And, rightly so. From a cost perspective, our health care system is fundamentally broken given its costs and our health care performance compared to many developed countries that spend significantly less.

This conclusion has often been stated, sometimes aggressively, and has been a catalyst for much of the recent attempts at reform – yet we have not focused the debate on the results we seek as a society, just merely on payment methodologies and a few band-aids or attempts at moving to nebulous concepts such as “evidence-based” or “accountable care.” The results I would suggest we seek are actually the improved delivery of care for all at a more reasonable share of national income.

How much good conversation is actually occurring? How many good questions are being asked? How would we know? I ask this because it seems that in spite of all the national attention and the hyper-attentiveness of our nation’s leaders to health care and in particular, electronic patient record adoption – are we making much forward progress?

In some cases, clearly the answers are a resounding “Yes!” Electronic record adoption is on the rise and certainly the incentives proposed by the Federal government over the last few years will probably only accelerate this trend.

In other cases, we still see health IT systems that are arcane and proprietary and most importantly are fragmented within and across institutions. Most health care delivery organizations have hundreds of separate and disconnected technologies that do not share data even internally – let alone a full-fledged health information exchange (HIE) capability at a local, state, or national level.

Why does this matter?

If we seek to improve care, extend access to all, and do both of these in a more cost-effective manner – transformative change is required. Much of this change may be systemic in nature and beyond the scope of fairly apolitical health IT experts such as the authors of the book you are reading. Yet, we posit clearly in this work the following principles:
• How we deliver care can be fundamentally changed, extended, supported, and enriched by a host of different operating concepts that are made possible by changes in technology.

• The cost of care can be radically changed through better use and exchange of information.

• The quality of care can be dramatically improved through better use and exchange of information.

• Transforming health care really is about how we design the delivery of care and how it is supported by better data for both consumers and providers.

This change will not be easy nor will it come without disruption. Most industries that have deployed new technologies to streamline processes, improve performance, and reduce costs – de facto, see major changes in industry structure. Consider the following contrast:

• If I have a problem with a prescription refill, then I need to speak with my HR benefits person, who coordinates with the insurance provider who must call the provider who must talk to the pharmacy benefits management company that queries the dosage and validity of the script and then we start the communication flywheel all over again – spending needless hours on the phone at arguably an un-documented cost to national productivity. In some cases, personal health records, e-prescribing, and secure messaging are transforming this issue – but in all too many cases, we are still in the dark ages of voicemails, lost faxes, and missed calls.

• If I have a problem with the funding for a check or an electronic transfer, I can log on to my online banking application, move funds, schedule payments, know my balance and communicate with my bank – all without the need for intermediaries and without respect to the time of day. Far fewer hands need touch this transaction, it occurs quickly – and at a much lower transaction cost.

It is not just my records or prescriptions that are at issue. What about the exponential increase in types and forms of data produced across the care continuum and how that data on my care can be used to greater effect? We are actively working some projects now where multiple imaging technologies, genomic data, metabolomic data and clinical notes all converge to provide an enormous pool of information which must be sifted for patterns and nuggets which might lead to new discoveries for the particular patient or for care more broadly. What about the amazing phenomenon of social networking for health reasons we have seen on the Internet? Can this be augmented and leverage for better care? As we see the continual increases in chronic disease
and complex conditions, all the data at our disposal will be required to deliver and improve care.

So these are some of the ideas and notions behind *Transforming Health Care – Better Data for Better Care*. Those are some insights into why this book and why now. We are at a very exciting time in health care and health IT and we look forward to sharing our insights and research with you. To collaborate with us and keep up to date, visit us at [www.evolvent.com](http://www.evolvent.com). Let us know what you think – nothing can change the world for good more quickly than the active transfer of good ideas into transformative practice.
A Vision of the Future

Our corporate legacy at Evolvent has always been closely linked to federal health care – in particular, military medicine and the Department of Veterans Affairs. Our colleagues across these two distinguished organizations, and throughout their long and varied histories, have seen many successes in the deployment of health IT. We are proud to continue to be colleagues to this day and to serve in many of the important efforts currently underway to continue the legacy of utilizing IT to transform care delivery for wounded warriors, veterans, and their families.

After long years of war, our systems continue to operate under enormous strain and the case for smarter use of technology is stronger than ever. This book is built on the shared experiences of our work across military and veterans’ health care as well as the entire federal health care community including the FDA, NIH, and Health and Human Services (HHS). It is also built on a large degree of primary research led by our Research and Development team (J.D. Whitlock, Bill Sorrells, Steve Gantz, and Greg Parish, Jr.) and informed by the lessons learned from current work. As in past writing, I can only note with amazement the great work we have seen and the progress we have noted – we continue to learn a lot along the journey!

So let us look at our principles again:

• How we deliver care can be fundamentally changed, extended, supported and enriched by a host of different operating concepts that are made possible by changes in technology.
• The cost of care can be radically changed through better use and exchange of information.
• The quality of care can be dramatically improved through better use and exchange of information.
• Transforming health care really is about how we design the delivery of care and how it is supported by better data for both consumers and providers.

Transforming Health Care – This is a Big Deal.

Nearly one-fifth of our national income is spent in this one industry alone. Much of this is spent by public funds redistributed for Medicare, Medicaid, drug benefits, and all forms of federally delivered care. It will also likely be highly disruptive. For one claims management company supporting military medicine, more than 1,000 low-wage jobs support a manual claims review
process which could be automated and made much more patient-friendly – yet that company would likely go out of business. As an economist by training, this makes a lot of sense in the medium term – but as a society in the middle of a recession and with political change seemingly always in vogue – how can we make transformative change?

This is why the principles are important – transformative change comes through focused efforts in small increments. While a “big-bang,” federally mandated restructuring of health care might work – it is far more likely in our society that “grass-roots,” “experientially proven” small increments will teach us all far more effectively and probably more quickly as well. So the tenets of our work are critically important to understanding what we argue for: different care delivery options need better and perhaps different information, costs can be positively impacted through intelligent use of data, quality of care can be improved through better use and sharing of data, and the foundational conclusion – design of care must be supported by better data for both patients and providers.

So in spite of the likely disruption of transforming health care, we pressed ahead. Happily, we found no shortage of great ideas and experiments on improving care while writing this book. Our writers meetings and research conversations have been enlightening and highly rewarding as we sought to synthesize much of the transformation work that is occurring right now. We hope to have captured much of this energy in these pages to share with you as you join the quest for better care.

How Is This Book Organized?

- In this first section, we are outlining the vision for transformation and some of its key elements. Additionally, we pose a stark contrast of the vision of health care just ten years into the future and how that could help or harm care in an acute scenario.
- In the next section, we look at key enablers for successful transformation. In particular, we focus on two of the most seemingly intractable problems at the forefront of the current debate – security/privacy, and sustainable health information exchange.
- In the third section, we share our thoughts and research on a wide range of topics from care design thinking such as patient-centered medical home and mobile health care to consumer empowerment and clinical decision support.

To prepare for the vision of the future ten years from now, and what we might experience in that health care industry as a patient, let us look at a few
more of the ideas which are important for our understanding and approach to transforming health care.

**Political and Financially Driven Reform – Where Are We?**

Much of the conversation in the political realm has been about the exponential rise in the cost of health care in the US – and as a result, much of the reform effort has focused on cost reduction and containment through better automation, sharing of information, and reduced duplication of effort (particularly in expensive tests such as CAT Scans, MRIs, etc). Some limited effort has been spent on “medical home” initiatives which seek to reduce costs through better care coordination.

But the bulk of the effort thus far has been focused on “meaningful use”, and grant funded pilots for health information exchange (HIE). As we discuss in the HIE chapter, this is a key enabler – yet it is likely impact on the cost and quality of care may be somewhat muted if a sustainability paradigm does not emerge or if the gaps in data standards and transactional models leave a highly disjointed and inefficient process for sharing data.

Much has been written and is clearly available for review on the construct of “meaningful use,” but it is clear that successful electronic medical record (EMR) adoption by health care delivery organizations is critical to the long-term transformation of health care. Much has also been written about what constitutes successful EMR adoption, yet the true picture of what IT can do for health care is somewhat confused by the presumption that just rolling out an EMR is sufficient for progress. **We would argue that a badly implemented EMR is both highly disruptive and expensive – so how the EMR is designed, maintained and most importantly – integrated – is critically important.**

Our work at Evolvent is primarily about the integration of systems to facilitate better information for the improved delivery of care. From image-enabling a global EMR to building specialty behavioral health tools, to unleashing clinical data repositories through HIE solutions and web services – we fundamentally understand the design, development and delivery of more cost-effectively integrated systems that deliver data across the health care continuum.

Improvements in quality and cost emerge at many points as a result of this more complete picture of what health IT can do to transform care. Enhanced value and opportunities for better care are only beginning to be understood – and this is really the exciting frontier of technology in the health field.
It Is All About The Patient ….and Their Care Eco-System

There are a lot of reasons why all of us came together to write this book, and why we believe strongly in what technology can do to help transform health care. But for me, it is important to remember that at the beginning of all efforts – there is a “why” that matters. For me that reason is personal.

As I have written before, I am richly blessed with a healthy family for the most part, but like most everyone else, we have sick family members of all ages and types of relations. Many of us have experienced sickness and disease in aging parents and grandparents and the care eco-system required is only growing. As the baby boom generation eases into retirement and assisted living, the needs will continue to present themselves for all our families.

In my family, it is my two youngest sons that are the source of my motivation. My wife, a true warrior mom and hero, has fought to build a team and a care eco-system for these kids that keep them moving forward and the rest of the family sane.

Our two boys are profoundly and severely autistic with mitochondrial disease and PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections). They need constant care and have a host of interventions – from diet to therapeutic, which require a lot of research, measurement, testing, and above all – the coordination of data. It is a Herculean task – and we have a lot of energy and resources behind us. Yet we still wonder what we have missed? What data was not or is not available? Did the provider get the test results? What do they mean? Were they the right tests? Were the results compromised by something we did or did not do?

The overwhelming need for information and the desire for improvement for my two little guys drive me to the conclusion that my daily work can and must do more for the delivery of care. The amount of data that is unutilized or unproven or seemingly incongruous – or just plainly does not make sense in the care of these kids is a daily exercise in frustration and a monumental task. What chronic disease does to the child, the mom, the dad, and yet is so often unsupported by a health care system focused on each test or another drug. Our systems, our providers all have so much knowledge – yet so little is brought to bear in the eight-minute visit. Surely the outcome of all our education and understanding could be more helpful?

So this is my perspective – as a part of the care eco-system. But I am only one actor in the system – my wife is a primary actor, the grandparents who sacrifice, the typical son – my eldest who is an amazing brother, a host of therapists, doctors, nurses, and educators as well as babysitters – all join forces
to weave together a system of care that works. What does IT do for the system – beyond email right now the answer is simple – not much. But it is coming.

Over the last few years, I have learned a great deal about health care from another distinctly different vantage point – the work we chose to pursue: how to help wounded warriors with traumatic brain injury. In many ways the issues are no different than my personal ones – there is more data than current systems can handle or provide and our design of care is inadequate for care coordination to the whole eco-system.

One of my colleagues, and a widely respected leader, stated recently at a conference we both attended that we have a moral obligation to those who serve us in harm’s way to return our citizen soldiers to their communities in good health or with the resources needed to sustain health. This sense of community duty and responsibility informs our daily work and is the spirit which underlies this book.

**Disruptive Technologies**

So what can technology really do? If it is more than an EMR implementation – then what is it? A recent presentation by Dr. Molly Coye of the Health Technology Center hits the highlights and identifies some key disruptive technologies that we’ll look at in more detail later in the book.

Dr. Coye's work identifies the “Core Challenges In Health Care” to be the following:

- **Deliver best knowledge wherever and whenever needed** - The best knowledge is essential for care –but the flow of useful information and decision support to providers and to consumers and patients is still an unrealized goal.

- **Manage chronic disease more effectively** - An aging population will generate a tidal wave of chronic conditions which cannot be managed with 15-minute office visits or revolving-door emergency department and hospital stays.

- **Increase the capacity and productivity of caregivers** - The demand for health care services is surging just as nurses retire, primary care residencies sit empty, and the supply and distribution of providers is rapidly deteriorating

- **Reduce the high human and economic cost of errors and quality defects** - Progress in safety and quality over the last half-decade has been encouraging –but only a fraction of the improvements that are possible by reducing medical errors and quality defects.
- **Promote functional independence** - Consumer preferences and economic realities make early diagnosis and care at home and in the community—with patients and caregivers mobilized for self-care and armed with new technologies.

- **Redesign health care facilities to support new models of care** - As care shifts into the home and the community, new and different types of facilities will be needed. Existing facilities will be reconfigured to optimize the use of resources and outcomes for patients.

All of this can begin today though with many of the first generation and in some cases more advanced tools identified by Dr. Coye's team as “high value technologies that enable transformative change”:

<table>
<thead>
<tr>
<th>Technology Platforms</th>
<th>High Value Technologies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Molecular Medicine</strong></td>
<td></td>
</tr>
<tr>
<td>Focus on predictive, targeted, and more individualized</td>
<td>Biomarkers</td>
</tr>
<tr>
<td>treatment strategies</td>
<td>Molecular Diagnostics</td>
</tr>
<tr>
<td></td>
<td>Targeted Therapies</td>
</tr>
<tr>
<td></td>
<td>Clinical Decision Support Tools</td>
</tr>
<tr>
<td><strong>Diagnostic Imaging Devices</strong></td>
<td></td>
</tr>
<tr>
<td>Focus on less invasive analytical techniques with</td>
<td>CT Angiography</td>
</tr>
<tr>
<td>combined diagnostic/treatment capabilities</td>
<td>Virtual Colonography</td>
</tr>
<tr>
<td></td>
<td>High Intensity Focused Ultrasound</td>
</tr>
<tr>
<td></td>
<td>Mobile Imaging</td>
</tr>
<tr>
<td><strong>Surgical and Interventional Services</strong></td>
<td><strong>NOTES</strong></td>
</tr>
<tr>
<td>Focus on minimally invasive techniques and interven-</td>
<td>Ultrafiltration</td>
</tr>
<tr>
<td>tional services, implantables and prosthetics</td>
<td>Endovascular Devices</td>
</tr>
<tr>
<td></td>
<td>“Smart” Implants</td>
</tr>
<tr>
<td><strong>Communications</strong></td>
<td></td>
</tr>
<tr>
<td>Focus on telemedicine, virtual consultations and staff</td>
<td>Telemmedicine</td>
</tr>
<tr>
<td>communications technologies</td>
<td>Instant Voice Communications</td>
</tr>
<tr>
<td></td>
<td>Integrated Whiteboards</td>
</tr>
<tr>
<td></td>
<td>Video Translation</td>
</tr>
<tr>
<td><strong>Sensors and Remote Monitoring</strong></td>
<td></td>
</tr>
<tr>
<td>Focus on physiological and environmental monitoring and</td>
<td>Remote Patient Management</td>
</tr>
<tr>
<td>feedback for care management and patient safety</td>
<td>Remote Environmental Monitoring</td>
</tr>
<tr>
<td></td>
<td>Real-Time Location Systems</td>
</tr>
<tr>
<td></td>
<td>Medication Adherence Technologies</td>
</tr>
</tbody>
</table>


Virtual Environments and Simulation
Focus on applications for self-care, social networking, training and clinical practice

Computer-based Self Treatment (CBT)
Social Networking
E-learning
Simulation-based Training

Note: Dr Coye references from The X3 Summit, June 15, 2009: Technology, Health Design and Innovation of Care—Why This Conversation? Molly Joel Coye, MD, MPH Founder and CEO, Health Technology Center

**Toward a Knowledge Driven System for Care Delivery**

But our teams and Dr. Coye are not alone! Recently the Institute of Medicine’s *Roundtable on Value & Science Driven health care* published “The Strategy Map”, a model of how a variety of critical initiatives and “collaborative” work together to pursue the construct of a “knowledge”-driven system that will result in achieving their target – by 2020, ninety percent of clinical decision will be supported by accurate, timely, and up-to-date clinical information, and will reflect the best available evidence ([www.iom.edu](http://www.iom.edu)).

As we will explore in later chapters, there are many related “drivers” or “enablers” that are required to realize this vision – yet it is heartening that across health care, a large number of parties are coming to the debate with the same hopes and aims.

**An Empowered Consumer in Health Care – “Wisdom of Crowds” and Social Networking Impact Meets Informatics**

What is often missed is the role of the consumer – not to be interpreted exclusively as the patient. The entire eco-system referred to earlier has a need to be empowered by better and more relevant information.

Many of the early “consumer” movements in health care focused on “authoritative” Internet resources where consumers could be properly educated. The nature of the medium – public Internet – has meant that controlled information, appropriately vetted by those who know is next to impossible to achieve.

So what do we do with an uncontrolled, unfiltered, unvetted, and seemingly endless supply of “information” publicly available over the Internet? Enter new ideas and theories on how to approach this as an “enabler” rather than a distracter.
Social networking for medical information is clearly an established phenomenon that is not going away soon. Many emerging groups can and do provide valuable information to the care eco-system that otherwise would be beyond the professional medical community’s time and resources to deliver. This comes with huge problems however. For example, one online community for sufferers of lyme disease may generate more than 400 emails a day – many with little or no data and relevance. Another community for a particular dietary intervention for irritable bowel syndrome (IBS) may generate recipes and rant in an equal measure and an equivalent volume of email.

What if ratings schemas, greater fidelity in disease state data and the power of informatics tools could harness social networking to improve the usefulness of the data? Would that help? New tools and applications are emerging which suggest that the “wisdom of crowds” can be harnessed in the brave new world of the Internet. Stay tuned.

**Emerging Career Fields in Health Data and Informatics**

As CEO at Evolvent, I am forever mindful that all of our work is dependent upon finding, engaging and growing talented professionals. There is a definite labor shortage in health care and it is not just doctors and nurses. We are short of all sorts of currently needed expertise – and we will have no choice but to invest in the growth of new professionals in the emerging fields of health data analysis, consumer empowerment applications, mobile health care and especially informatics.

The “HR” side of transforming health care is beyond the scope of this book – but rest assured that our industry will have to face the challenge of finding the new talent sooner rather than later. We are simply short-handed at a time when we are most in need of new brainpower.

**“Health” Driven Health Care Delivery Organizations and “Engaged” Consumers**

Recently, a national commentator and erstwhile political leader posited that we “have the best health care system” in the world (a true red herring tactic) but we have a “health” problem in this country. I guess the conclusion was that if all the sick folks would just get themselves well, our problem would go away. All too often this is where the debate gets stuck on spin cycle.

Yet from Dr. Coye’s work and that at the IOM, we can see that the driver for health care delivery organizations will indeed have to shift from an emphasis on seeking to deliver a diagnosis and a drug to an emphasis on keeping people healthy. This will require as an “enabler” for transformative change that a vast
majority of consumers become far more “engaged” in this type of conversation. That is societal change in scope and it is not only possible, it is critical. Consider the positive examples of how we have changed society’s perspective on littering, drunk driving and smoking – all negative behaviors that could serve as an example for how we can tackle obesity, diabetes and possibly some cancers.

**A Society that Embraces “Healthy” Choices in Nutrition, Lifestyles, “Green” Standards and Reduces Environmental Damage and Toxicity.**

In our research, there will clearly always be more that we do not know than what we can claim to know for certain. Yet the convergence of data clearly shows healthy choices across lifestyles, nutrition, “green” movements and environmentally responsible choices to be of benefit not just to sustainable life but to our individual health as well. For every toxin poisoning the planet, there is a human toxic impact which may or may not be well understood. As a society, we are beginning to pay attention and the results will speak for themselves.

Now, having considered these visions of what is possible and desirable in the aim of transforming health care for the better – let us examine a tale of two futures.
In 2011, we are at a critical juncture concerning the future of Health care Information Technology (HIT). Billions of dollars of grants and incentive payments are already, or will soon, significantly influence both the short-term and long-term future of HIT. Will all this investment and effort come together into a coherent framework that permits the secure, but seamless, exchange of your clinical data? Or will various technical, political, and economic factors result in a patchwork of clinical data stovepipes that do not effectively communicate?

Let us look at a hypothetical health care scenario ten years from now and describe two possible futures; one in which your clinical data is available at a critical time, and one in which it is not. In both scenarios, it is 2021 and you are traveling out-of-state on business. While driving you are hit head-on by another vehicle and sustain life-threatening injuries. You are unconscious.

Now our two scenarios diverge. Let us consider the “what-good-looks-like” future first.

In the ambulance on the way to the local trauma center, the paramedic opens your wallet / pocketbook and pulls out a card that uniquely identifies your clinical record. This might be part of the Voluntary Universal Healthcare Identification (VUHID) project, or perhaps it is simply a website that points to your clinical record on the Personal Healthcare Record (PHR) of your choosing. It is not a “Big Brother” assigned number, and it is not available to the public. It is a universal identification system in which you elected to participate, and your clinical data may only be accessed by appropriately credentialed clinicians.

The paramedic slides the card into a scanner that sends your universal identifier to staff at the ER. The ER staff immediately query the Nationwide Health Information Network, via a local EHR or HIE interface, which is able to pull your clinical record from the EHR or HIE attached to your Primary Care Medical Home (PCMH) and/or pull from your PHR. A C32 Summary of Care document lists your problem list, medications, allergies, insurance and other information.

In your case, the allergy list is particularly useful information because you are allergic to the contrast agent commonly used during CT scans in trauma situations to diagnose internal bleeding. This critical information enables your ER physician to order steroids as prophylaxis prior to the contrast agent, thereby minimizing your allergic reaction. The CT scan reveals internal bleeding, and you are rushed into surgery to open you up, stop the bleeding and save your life.
After a couple weeks in the hospital, you are discharged and return home to the care of your Primary Care Provider (PCP). During your slow and painful recovery, you use your tablet device or smart phone at home to keep in touch with your PCP, whose practice uses a Primary Care Medical Home (PCMH) model. This PCMH structure reimburses your PCP for providing patient-centered care in an environment that leverages all widely available health care information technology. Because of this, secure messaging with your provider (via your mobile device – and possibly also your PCP’s mobile device) is built seamlessly into your PCP’s workflow.

You have a follow up appointment with your PCP in a few days, but you are feeling fatigued and wonder if it is anything to worry about. You type out a message to your PCP while eating lunch that says, “Just wanted to let you know I have felt a little winded the last day or so. OK to wait for my appointment Friday to discuss this?”

Your PCP responds with a phone call. After answering some of her questions, she sends you directly to the ER, where you are diagnosed with pulmonary emboli (blood clots in the lungs) and given anticoagulants immediately. After careful management and follow up, these blood clots are dissolved and you are able to safely complete your recovery.

Now let us consider an alternate future. A future in which EHR meaningful use only gets halfway towards projected goals because HIE business models are not financially sustainable. A future in which state and “county option” legal barriers prevent widespread connection to the Nationwide Health Information Network. A future in which well-meaning, but shortsighted privacy advocates push the legislative landscape far enough towards “privacy” that efficient sharing of clinical data is crippled. A future in which Accountable Care Organization (ACO) and PCMH based funding reform proves to be a “bridge too far” away from the entrenched status quo.

In short, a future in which the technology was ready, but our health care system was not. In this future, after your accident in the ER, your allergy to the contrast is not known because there is no Nationwide Health Information Network connection between the ER in one state and your PCP in another state. Or maybe there is, but you have a common name, and because there is no voluntary universal health care identifier in common use, the matching algorithms used on the Nationwide Health Information Network returns multiple potential patient matches that is too difficult for the ER staff to sort through quickly.

Because of this, you are not administered prophylactic steroids prior to the contrast agent, and therefore go into anaphylactic shock while in the CT
scanner. The CT scan is not completed, and you are rushed back into the ER to deal with your allergic reaction. This delay means that your internal bleeding is not recognized until it is too late, and you die on the OR table.

Or, perhaps you survive your trauma despite these misadventures because of heroic efforts on the part of the ER and OR staffs. Now you are back home, feeling a little winded. You wonder if you need to call your PCP, or if it is safe to wait a few days until your next appointment. You decide you can wait a little longer, especially since you know your PCP is very busy and is not able to return phone calls right away. Later that night, you collapse on the floor, and your spouse dials 911. You have thrown a large clot, which has completely blocked a pulmonary artery. You are dead before the ambulance reaches your local ER.

In our hypothetical 2021 health care scenario, well-connected health care that permits efficient transfer of your clinical data enables your full recovery from life threatening injuries. Without this “Better Data for Better Care,” you are dead (twice over). Of course this is an extreme example created to illustrate a point, but it is an important one.

The rest of this book is an exploration of the enablers and the benefits of well-connected health care. Let us look at the enablers first.
Enablers: What is Needed for Success in Transforming Health Care?

The dictionary definition of “enable” of which “enabler” is the noun states:

- To supply with the means, knowledge, or opportunity; make able
- To make feasible or possible
- To give legal power, capacity, or sanction to
- To make operational; activate

Note: [www.thefreedictionary.com](http://www.thefreedictionary.com)

In short, an enabler is a prerequisite – a legal, structural, or resource capacity to allow change to occur. For the purposes of this book, we have limited our discussion here to the conundrums of security and privacy, financial reform and health data exchange. Much of the buzz in the health IT space has centered on security and data sharing, and we explore both these topics in detail. We also explore from our perspective, what financial reform has meant for the industry.

Each of these enabler chapters presents, by necessity, a highly complex discussion. As a company, we have had many years of experience in both security and data sharing and a few of us hale from the financial world. Our writers and research teams have blended both current thinking and market research with our practical real world experience across the broad range of thought-provoking issues underlying each enabler. We hope you will find this a stimulating and enlightening discussion and welcome your feedback.
Security and Privacy as Enablers of Better Health Care

The promise of more efficient and better quality health care through the widespread use of health information technology cannot be fully realized without effective security and privacy protections for health data and the systems, organizations and people that access, store, process and transmit that data. Security and privacy in health care is commonly viewed as both an imperative and an obligation, as most organizations participating in health operations are subject federal and state laws and regulations requiring various safeguards for health information.

Health care in the United States is becoming more patient-centric and with this shift in focus comes increasing levels of consumer empowerment as health information technology fosters greater individual involvement by patients in their own care. In this environment, providing effective security and privacy for health information becomes a potential source of competitive advantage, in the sense that individuals as health care customers will choose to do business with health care organizations that give them confidence that their personal health information will be protected.

For those who will be the primary users of health information technology solutions such as electronic health records (EHRs) and health information exchanges, adhering to appropriate security and privacy policies and compliance with applicable regulations are prerequisites to success - and in many cases are necessary just to participate in health IT initiatives. In this chapter, there are descriptions of both the obligations and the opportunities for health care organizations in respect to security and privacy and seeks to illustrate ways in which security and privacy measures can enable more efficient and effective health care.

It goes without saying that protecting the security and privacy of medical records and other personal information has long been a central focus for health care organizations, whether driven by legal and regulatory requirements or business objectives. In fact, since the passage of the Health Insurance Portability and Accountability Act (HIPAA) in 1996 and subsequent implementation of HIPAA’s Privacy Rule and Security Rule, health care entities in the United States have operated under a common national framework that establishes a minimum standard for the protection of health information. Moreover, in the last five years, the move by government and industry to embrace the use of health information technology has placed a renewed emphasis on security and privacy, heightened by distinct but parallel trends among public and private sector health care organizations.
On the public sector side, the U.S. government identified an important policy objective – first articulated in 2004 under the Bush administration and reiterated in 2009 by President Obama – to achieve widespread saturation of electronic health records and to establish personal health records for all citizens. In pursuit of this goal, major legislative provisions were established to encourage the adoption of health IT and were included in both the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009 and the Patient Protection and Affordable Care Act in 2010.

Both of these laws stipulate various health information security and privacy requirements, some of which revise or enhance regulatory provisions enacted under HIPAA and some of which introduce new requirements. These laws also assign responsibility for further policy development and rulemaking related to security and privacy to the Department of Health and Human Services (HHS), the National Institute for Standards and Technology (NIST) and other key federal agencies with significant health missions, particularly the Departments of Defense (DoD) and Veterans Affairs (VA).

Commercial and non-government health sectors turn to health information technology to contain growth in health care costs, improve quality of care and increase their operational efficiency and effectiveness. Industry trends such as market consolidation, outcome-based operations such as accountable care organizations and greater levels of integration among health care entities in integrated delivery networks are all enabled by health IT and all demand effective privacy and security protections for health data, systems and organizations.

Private sector health care organizations are subject to many of the same privacy and security provisions mandated for government agencies under HIPAA, HITECH and health care reform legislation, so private sector entities have a similar need to establish the sorts of effective security architectures, standards and practices that allow health data sharing to occur. Without the implementation and consistent use of such security and privacy measures, health data will not be made available for exchange and if data is not shared, it cannot be used to improve the quality of care or to achieve other beneficial health outcomes.

**Government Drivers for Security and Privacy**

HIPAA requirements are certainly not new – the Privacy Rule went into effect in 2003 and the Security Rule two years after that – so HIPAA and the regulations it produced (45 CFR 160, 162 and 164) provide a foundation for security and privacy among health care organizations, but do not encompass the entire legal and regulatory environment. Developing a better understanding of
the current drivers for more effective health data security and privacy requires a review of the legislative changes and administrative rulemaking undertaken by the federal government to encourage adoption of health IT, partly by increasing the level of confidence providers, payers, patients and other health care stakeholders have in security and privacy protections for health data. A full description of all the legal obligations applicable to health care organizations is beyond the scope of this discussion, but current government-sponsored efforts to enhance health information security and privacy are often driven by one or more of the following sources.

**The Health Insurance Portability and Accountability Act of 1996 (HIPAA)**

Among the many provisions included in HIPAA (P.L. 104-191) were requirements that the Department of Health and Human Services (HHS) develop standards related to security of health information and privacy of individually identifiable health information and requires that organizations subject to the law “shall maintain reasonable and appropriate administrative, technical and physical safeguards to ensure the integrity and confidentiality of the information; to protect against any reasonably anticipated threats or hazards to the security or integrity of the information and unauthorized uses or disclosures of the information; and otherwise to ensure compliance with this part by the officers and employees of such person” (Subtitle F, §1173(d)).

This statutory obligation resulted in the development of the HIPAA Security Rule (codified at 45 CFR §160 and §164), which established national minimum standards for security measures to be used by health care plans, health care clearinghouses and health care providers to protect electronic health information. Since the Security Rule went into effect in 2005, it has become the prevailing security standard applicable to non-governmental organizations like commercial health care providers. Government health organizations are also subject to HIPAA, in addition to a variety of other general and domain-specific security and privacy regulations.

Beginning in 2003, the HIPAA Privacy Rule (codified at 45 CFR §164 Subpart E) specified a variety of constraints on the way health care organizations use personal health information such as medical records and requires those organizations to make their patients aware of their rights under HIPAA. Perhaps most germane to health IT, the Privacy Rule prohibits the use or disclosure of personal health information by covered entities except for specifically enumerated permitted uses. The primary permitted uses for health information without consent are treatment, payment and health care operations, unless the health care operation in question is marketing, for
which explicit authorization (consent) is required (45 CFR §164.508(3)). The same regulations also address specific uses of personal information, which are permitted as long as the individual is given an opportunity in advance to opt-out and a list of uses and disclosures permitted without the need for consent, mostly related to public health, public safety and legal and administrative proceedings (45 CFR §164.512).

**The Federal Information Security Management Act (FISMA)**

Enacted as Title III of the E-Government Act of 2002 (P.L. 107-347), FISMA established a set of information security requirements for all federal executive agencies and directs those agencies to comply with security requirements and guidelines developed by the National Institute for Standards and Technology (NIST), notably including Federal Information Processing Standards and the 800 series of Special Publications addressing a wide variety of information security processes, procedures and technologies. Under FISMA, federal agencies are required to certify and accredit their IT systems following procedures specified by NIST and to report security and privacy information about those systems.

The law’s relevance to health IT security is that EHR systems and other health IT systems maintained by or on behalf of federal agencies must be formally authorized to operate following government security control standards, which are more detailed than the administrative, physical and technical safeguards required under HIPAA. Separate from FISMA, there are privacy provisions contained within Title II of the E-Government Act that require federal agencies to conduct privacy impact assessments for information systems containing personally identifiable information and within those privacy impact assessments to describe not only what information will be collected and for what purpose, but also the alternatives offered to individuals to give consent regarding what information is collected and how that information is used or disclosed to others (§208(b)(2)(B)(ii)).

**Health Information Technology for Economic and Clinical Health (HITECH) Act**

Enacted as Title XIII of the American Recovery and Reinvestment Act of 2009 (P.L. 111-5), the HITECH Act both added to the statutory security and privacy requirements under HIPAA and modified some existing regulations in ways intended to improve security and privacy protections, as well as encourage compliance through stronger enforcement mechanisms. HITECH raised the level of civil and criminal penalties that can be imposed on entities found to be in violation of HIPAA privacy or security provisions and shifts HIPAA
enforcement from a fully reactive model based on voluntary compliance to one in which the HHS Office for Civil Rights will proactively audit health care organizations for compliance. HITECH expanded HIPAA’s coverage to apply directly to business associates as well as covered entities (health care plans, health care clearinghouses and health care providers), replacing the previous approach in which covered entities were responsible for their business associates’ violations of privacy and security rules. HITECH also included provisions establishing a national standard for health data breach disclosure, requiring organizations to notify government authorities as well as individuals affected by data breaches.

Many of the HITECH provisions for security and privacy have yet to be implemented through formal rulemaking or other regulatory development processes, but collectively the Act represents a significant source of government intentions for approaching health IT security and privacy. As the HHS Office of the National Coordinator (ONC) develops the regulations and guidance needed to implement the provisions in HITECH, its efforts are supported by the work of two federal advisory committees established within the legislation, the Health IT Policy Committee and Health IT Standards Committee (§3002 and §3003, respectively). The committees are comprised of members from commercial, government, academic, legal and non-profit sectors and charged with making recommendations to the National Coordinator on appropriate policies and standards for health IT, including those related to security and privacy.

**Fair Information Principles and the Privacy Act**

The Privacy Act of 1974 (5 USC §522a) codified a set of fair information practices originally issued by the U.S. Department of Health, Education and Welfare in 1973. These practices provide the basis for a variety of privacy guidelines and regulatory schemes found in other laws, including the ability for individuals to prevent the use of their personal information for purposes other than for what it was originally collected. The Privacy Act applies to all federal agencies and covers personally identifiable information about U.S. citizens and resident aliens. The Privacy Act is voluntarily followed by some states and other non-federal government authorities, as are the Fair Information Practices that were incorporated into the Act and that provided the basis for other privacy frameworks used by other non-federal agencies and many public and private sector organizations within and outside the U.S., notably including the Organization for Economic Cooperation and Development (OECD) Guidelines on the Protection of Privacy and Transborder Flows of Personal Data. The Privacy Act is not health-specific, but federal agencies involved in health must adhere to regulations in the Privacy Act in addition to health-specific laws such as HIPAA and government-specific laws like FISMA.
Incentives for EHR Adoption and Meaningful Use

To encourage adoption of EHR technology, the HITECH Act allocates federal funds as incentives to health care providers and professionals financial to adopt EHR systems, if they can demonstrate “meaningful use” of electronic health records. While meaningful use measures cover a wide range of functional and technical capabilities, there is one measure explicitly about security: organizations implementing EHR technology must “conduct or review a security risk analysis…and implement security updates as necessary,” a requirement derived from an existing requirement in the HIPAA Security Rule.

In addition to this meaningful use measure, there is a set of standards, specifications and certification criteria that EHR technology vendors must satisfy in order to have their products certified – use of a certified product is required in order for a provider to receive the available funding. There are no specific privacy measures in the proposed rules on meaningful use, nor are there privacy certification criteria or standards required for EHR technology. Among the objectives and benefits many EHR system vendors and health information exchange initiatives now seek to achieve is helping health care organizations satisfy requirements under meaningful use.

Domain-specific Federal Regulations

While laws such as FISMA and the Privacy Act apply to many types of information and systems, there are numerous additional federal regulations that apply to specific health domains or to certain segments of the population. These additional regulations most often dictate privacy requirements, but also impact security measures implemented by organizations that must provide adequate protection of the sorts of information addressed by the regulations.

For instance, information in medical records relating to diagnosis of or treatment for substance abuse is subject to rules (42 CRF Part 2) that prohibit any disclosure without patient consent, except in cases of medical emergency, certain research programs and for the purpose of auditing compliance. Any consent granted applies only to disclosure to the specific individual or organization making the request for disclosure; subsequent intent to re-disclose or use of medical record data by the same entity for a different purpose requires a separate consent. Similar security and privacy regulations exist to protect the confidentiality of medical records and health care claims for current members of the armed forces and veterans (38 USC §5701 and §7332).
State Security and Privacy Laws

Laws like HIPAA and its Security Rule and Privacy Rule are explicitly intended to establish federal minimum standards, but many states opt to enact legislation that imposes stricter privacy and security requirements on organizations with operations in the state in question or that serve patients or other customers who are state residents.

Only four states do not have their own notification laws for breaches of personal information and in addition to data breach statutes, some states have also implemented regulations that establish minimum standards for safeguarding personal information, applicable to organizations holding any personal information about residents (see for example, Massachusetts’ 201 CMR 17). Health care organizations must therefore be cognizant not only of federal regulations, but also of the laws applicable to states where they do business and states to which they may transmit health information when participating in health information exchanges.

Security for Health Information Technology

The complexity of the regulatory environment for health IT presents a significant challenge for health care organizations seeking to establish and maintain compliance with all relevant state and federal laws. While health care organizations in both the public and private sector are subject to a full range of security requirements, the current government and industry emphasis on implementation of electronic health records and health information exchanges dictates the aspects of security on which health care entities need to focus.

With respect to EHR adoption, a great deal of attention for providers is centered on demonstrating compliance with meaningful use requirements, while EHR system vendors work not only to satisfy meaningful use certification criteria, but also to make credible assertions that health information security is stronger when EHRs are involved than the existing protections afforded for paper records. In contrast, discussions of security for health information exchanges are more focused on standards and technical security capabilities needed to enable data sharing among health care organizations without exposing personal health information to risks of loss, theft, corruption or unauthorized disclosure.

Several changes in policy and regulation brought about by the passage of the HITECH Act are leading health care organizations to revisit their security practices and review safeguards to determine if adequate protective measures are in place. The HITECH Act has refocused security priorities for health care organizations on compliance with security requirements under HIPAA,
particularly with the prospect of routine compliance audits and stiffer penalties for organizations found to be in violation of HIPAA rules. In addition, health care organizations intending to seek federal funding for health IT initiatives need to give special attention to adopting and implementing technologies that adhere to accepted health IT standards – especially for health information exchange – and that satisfy meaningful use requirements.

Planning for Stronger Enforcement

Prior to the passage of the HITECH Act, enforcement of HIPAA compliance was largely a reactive practice, with investigation of violations initiated only after complaints were submitted to the HHS Office for Civil Rights (for Privacy Rule violations) or the Centers for Medicare and Medicaid Services (for Security Rule violations). The processes followed by OCR and CMS did not provide for any proactive enforcement actions to be taken and the government relied on voluntary compliance by covered entities.

In July 2009, authority was delegated to OCR for enforcement of the Security Rule as well as the Privacy Rule and OCR has indicated that it intends to begin a stronger enforcement program in the form of HIPAA compliance audits. The specific audit criteria have yet to be finalized, but once initiated, the audits will focus on how covered entities are meeting specific HIPAA requirements such as implementation of appropriate safeguards, policies and practices and will seek evidence that risk analysis, contingency planning and other key activities are in fact being carried out as required under the law. In concert with stronger procedural methods for enforcement, the HITECH Act also increased the civil and criminal penalties for non-compliance, mandated formal investigations for any cases of HIPAA violations involving willful neglect and gave state attorneys general the right to sue covered entities for violations on behalf of state residents.

These changes in the legal enforcement framework for HIPAA are likely to result in more enforcement activity against alleged HIPAA violators, as they extend the reach of legal enforcement from the federal level out to the states. For example, using the authority granted under HITECH, in January 2010 Connecticut Attorney General Richard Blumenthal sued insurer Health Net following a breach involving records on nearly 450,000 patients, and in October 2010 the Indiana Attorney General’s Office sued insurer WellPoint, alleging the company failed to notify customers and authorities in a timely manner following a breach that affected as many as 32,000 Indiana residents.

The lawsuit against Health Net was settled in July 2010, with an agreement by Health Net to pay $250,000 in statutory damages and to pay for credit monitoring, identity theft insurance and the cost of security freezes for Connecticut enrollees affected by the breach.
By shifting to a more proactive stance and checking for compliance by covered entities and business associates, absent of any complaints, the government's new compliance process is accurately perceived as a significant strengthening of HIPAA enforcement, particularly for security. This comes as welcome news for those in the health care privacy and security arena who believe that reactive enforcement alone is tantamount to no enforcement at all – a belief supported by the relative scarcity of civil and, especially, criminal cases brought against HIPAA violators in the years since the Privacy and Security Rules went into effect and by recent surveys that suggest that a significant proportion of health care organizations have not implemented core Security Rule requirements such as conducting a risk analysis.2

Health care organizations may be less enthused about having to face government audits for HIPAA compliance, but that prospect should provide motivation for such organizations to assess their own levels of compliance and take necessary steps to satisfy HIPAA requirements. Given the need for health care organizations to demonstrate compliance not only with HIPAA regulations and rules promulgated under HITECH, but also with meaningful use measures and criteria, the federal government has also begun to revise and expand the set of guidelines, checklists and compliance tools available to covered entities and business associates. In addition to the HHS Office for Civil Rights, the National Institute for Standards and Technology (NIST) was delegated authority under HITECH (Subtitle B, §13201) for testing health IT standards and implementation specifications, including establishing the infrastructure to support testing and providing methodologies and guidance on interoperability testing, as well as testing for conformance with various health IT standards and with meaningful use requirements.3

One key activity for health care organizations is performing risk analyses, which are required in several contexts. Under the administrative safeguard provisions of the HIPAA Security Rule, covered entities are required to perform a risk analysis, specifically to “conduct an accurate and thorough assessment of the potential risks and vulnerabilities to the confidentiality, integrity and availability of electronic protected health information held by the covered entity” (45 CFR §164.308(a)(1)(ii)(A)).

---

2 According to survey results published in November 2010 by the Healthcare Information and Management Systems Society, 76 percent of health care organizations surveyed report that they conduct formal risk analyses as required under HIPAA; a proportion of respondents similar (74 percent) to results of the 2009 survey.

3 NIST has established a Health IT Standards and Testing website at http://healthcare.nist.gov/ where it provides information on its programs and activities in support of health IT initiatives and standards adoption.
While this has been a requirement for HIPAA-covered entities since the security rule went into effect in 2005, it has received renewed attention due to stronger enforcement provisions in the HITECH Act and its inclusion as the single security-related measure included in the meaningful use measures. Also, as part of the HHS rules under which health care organizations must provide notification following breaches of health information, organizations suffering a breach are required to conduct a risk assessment to determine if there is a significant risk of harm to the individuals whose data was disclosed.  


One limitation of the existing government guidance applicable to risk analysis is that substantially all of the guidance is written in a way that focuses on risk assessments of individual information systems, not the individuals executing processes that use those systems or on organizations overall. For meaningful use, the scope of the required risk analysis is limited to the EHR system or modules for which financial incentives are sought, but the risk analysis requirement under the HIPAA Security Rule is not limited to systems. Instead, covered entities and business associates must address risks to any protected health information held by the organization.

Also, as is likely not lost on private sector health care organizations, there are many sources of risk management and risk analysis guidance outside of materials produced by the U.S. federal government, including the ISO/IEC (International Organization for Standardization/International Electrochemical Commission) 27000 series of standards, which covers risk assessment and risk management for information systems in both ISO/IEC 27005 and the risk assessment section of ISO/IEC 27002. Organizations looking for

---


more enterprise-level perspectives on assessing and managing risk can find relevant guidance in ISO 31000, within major IT governance frameworks such as ISACA’s Risk IT Framework based on COBIT (Control Objectives for Information Technology and related Technology), or the Risk Management section of the Information Technology Infrastructure Library (ITIL).

### Security for Health Information Exchange

While there are several types of security capabilities that vendors of EHR systems and modules must include in their products in order to get them certified under meaningful use, the organizations acquiring and using these EHRs are not typically required to implement specific security features. This apparent disconnect is logically consistent with most of the security controls specified under HIPAA and FISMA regulations, but the result remains that the decision of what actual security and privacy controls an organization puts in place remains highly subjective and is therefore likely to vary among health care entities.

Where security and privacy laws are concerned, Congress rarely mandates specific security measures or technologies, often choosing to delegate technical specifications to NIST or other authorities. The net result is sets of “recommended” or “addressable” security safeguards that endorse a risk-based approach to implementing security that allows organizations to choose not to put some controls in place, as long as they provide justifications for such decisions. This approach embodies fundamental economic principles about security, particularly the idea that it does not make sense to allocate more resources to securing information and systems than what those assets are worth.

The problem lies in the reality that different health care organizations will value their information assets in different ways, will face different threats and corresponding risks to those assets and will have different tolerances for risk that determine what is “acceptable” and what is not. Security requirements in HIPAA regulations cover a wide variety of types of security measures, but generally offer very little in terms of explicit controls that must be implemented or technologies that satisfy technical requirements. In marked contrast, many security standards and mechanisms associated with health information exchanges require that health care organizations implement specific technologies in order to participate.

Whether using private network infrastructure or public networks like the Internet, parties involved in health information exchange universally agree that sensitive personal data like the contents of medical records should only
be transmitted using secure communication channels. For server-to-server or network-to-network exchanges, this typically means securing connections using accepted standard protocols such as Secure Sockets Layer (SSL) and Transport Layer Security (TLS), so that the communication path is protected, whether or not the messages or other content sent over that path is also encrypted.

Content (or payload) encryption is less pervasive in health information exchanges, although many policy makers advocate the use of content encryption in addition to transport encryption. One of the early themes that emerged from the initial work on health IT security standards by the Office of the National Coordinator is the need for stronger protection of the confidentiality and privacy of health data exchanged between entities – whether in a point-to-point exchange model or a multi-party exchange environment such as a health information exchange. Some members of ONC’s federal advisory panels suggest that the use of content encryption is the best way to afford that protection and that it does so in a manner consistent with public expectations about protections of personal health data.

Policy makers and privacy advocates are concerned that current legal requirements for the protection of health data may not apply to all the entities that participate in health information exchanges, particularly intermediaries such as health information service providers who may offer data exchange services to health care providers or organizations. One way to mitigate such concerns is to render the data unreadable to intermediaries, which in general means encrypting it. There is also some debate as to whether such content encryption should be a mandatory requirement, or should remain “addressable” as it is under the HIPAA Security Rule.

One argument in favor of mandating the use of encryption is the technical feasibility of such an approach. By applying Web Services Security standards such as SOAP (simple object access protocol) Message Security, solution developers and implementers have a lot of flexibility to separate message contents from message header or envelope, and to separately protect each part of the message if desired. The real challenge lies not in separating routine data

---

6 The term “health information service provider” or “HISP” refers in general to a non-health care entity that provides business and technical services to health care entities to facilitate participation in HIEs or to enable directed point-to-point exchanges of health data between entities. The term is often associated with the work of the federal Direct project, which acknowledges that many individual practitioners or small-office providers lack the technical capabilities to participate on their own in exchanges of health data.

7 Discussions about encrypting electronic messages send over networks often employ an analogy to postal mail delivery, where the destination and return address are visible to those responsible for delivery the mail, but the contents inside the sealed envelope are not.
from payloads, or from enabling content (or full-message) encryption, but instead in what encryption model should be used in order to make encryption possible without imposing barriers to interoperability.

There is no value in encrypting data before transmitting it if the recipient cannot decrypt the message, but ensuring that all senders and receivers are able to handle encrypted data requires a common infrastructure, such as the sort of public key infrastructure (PKI) used for the Nationwide Health Information Exchange. Where multiple federal, regional and state-level HIEs are in operation, even if all the exchanges use the same technical standard for encryption, additional efforts are needed to coordinate among the exchanges if they are to be interoperable.

There are ways to enable technical interoperability without full-scale PKI and the key distribution and management overhead that comes with such an infrastructure. That potential aside, no one should underestimate the significance of the tasks of establishing, managing and overseeing the certificates and supporting services necessary to facilitate end user encryption and decryption among health information exchange participants (to say nothing of integrating such capabilities into end user electronic health record systems, transaction gateways, web services, SMTP clients or other messaging tools). Multiple technical alternatives are incorporated within available open standards and many health IT product vendors support these standards, but there is a great deal of additional processing and management required to accommodate pervasive use of content encryption. The complexity of such a solution may explain why, to date, only the transport-level encryption is used for the Nationwide Health Information Network and the only content encryption used is the digital signing of SAML assertions included within the SOAP messages exchanged among Nationwide Health Information Network participants.

Most approaches to encryption in health information exchanges involve the use of digital certificates, whether or not the certificates are implemented and managed in a formal PKI architecture. The simplest level of data exchange envisioned in the health IT arena is a point-to-point transmission between two computers. Depending on the communication scenario, in such a model (sometimes called “directed exchange”) the sender and receiver may choose to establish a secure communication and send unencrypted data, encrypt the data and send it over an unsecured channel, encrypt both the data and the communication channel, or encrypt neither the data nor the channel.\(^8\) In all

\(^8\) The last of these alternatives is rarely mentioned in discussions of data exchange over networks, but represents the status quo in much of the industry, as health care organizations routinely send medical records to each other via facsimile over conventional telephone networks.
but the last of these cases, digital certificates provide the means not only for encryption, but also for enabling mutual authentication between sending and receiving systems and for providing limited non-repudiation of origin.

Technical health IT standards such as SSL and TLS that are specified for establishing secure communication links rely on digital certificates, as do email encryption technologies like S/MIME that are leveraged in secure messaging standards such as IHE’s (Integrating the Healthcare Enterprise) Cross-Enterprise Reliable Document Interchange (XDR). The challenges with digital certificates are at least as much about administration and governance as they are technical. As any HIE solution that relies on digital certificates has to put appropriate processes in place for issuing, managing, revoking and checking the validity of certificates used in exchanges. There are multiple approaches to handling certificate issuance and management, including centralized, federated and distributed models (the last of which includes scenarios where users or entities self-issue certificates), but the federal health IT standards and implementation specifications issued to date tend to favor either centrally-managed certificate infrastructures or federated approaches using Security Assertion Markup Language (SAML).

At the federal level, the Office of the National Coordinator chose to adopt a centralized model for the Nationwide Health Information Network. During the 2008 trial implementation phase and subsequent limited production operation of the Nationwide Health Information Network, participating organizations were issued X.509 certificates from a single, centralized certificate authority in a public key infrastructure supporting authentication, basic authorization and non-repudiation of origin. Data exchanges and other transactions using the Nationwide Health Information Network rely on authentication at the entity (that is, organization) level, rather than at the individual user level. All individual users within a given participating organization connected to the Nationwide Health Information Network effectively share the credential represented by the digital certificate issued to their organization.

As the usage models for health information exchanges evolves to include the participation of smaller health care organizations, individual practitioners and potentially individual patients, there is a gap in current health IT security standards in the sense that there is no consensus standard for individual user identification and authorization.

Federal health IT policy makers have focused first on solutions for consistent provider identification and authentication, intending in part to address a perceived gap in the HIPAA Security Rule, which requires that HIPAA-covered entities implement policies and procedures to authenticate
individual users or entities seeking access to protected health information (45 CFR §164.312(d)), but does not stipulate the means by which such authentication should occur. The Privacy and Security Tiger Team advising ONC has presented recommendations advocating mandatory use of digital certificates for entity authentication for all entities involved in health information exchange. Adopting such an approach would require not only the technical capability among entities participating in HIEs to implement and use digital certificates, but also the establishment of processes for validating would-be participants (to ensure they are legitimate organizations) and for issuing credentials to approved entities. The most recent recommendations from the Tiger Team suggest that instead of relying on a central certificate management authority, ONC should establish an accreditation program (perhaps similar to the one used for accrediting EHR testing and certifying bodies under the meaningful use program) to authorize multiple certificate issuers. While a federated or distributed model for credentialing would almost certainly be more scalable than a single-issuer model, there remain unaddressed aspects of governance and oversight related to how ONC can ensure that organizations seeking approval as certificate issuers conform to all relevant technical and governance criteria and are sufficiently trustworthy to handle entity identity proofing and issue authentication credentials.

Health information exchanges at federal, regional and state levels all share a similar need to validate the identity of individuals or organizations requesting credentials such as digital certificates that will enable them to participate in HIE transactions. Identity verification should be a part of any approved credentialing process, but it is equally important to establish governance processes and criteria to establish the trustworthiness of credential issuers, particularly in federated or distributed models where many issuers may be involved.

Without such governance, validating the identity and even asserting the role of an organization or individual requesting a credential is not an assertion of trustworthiness, only of accurate identification. Checking the validity of an issued credential (such as a certificate look-up) should result in some level of confidence that the presenter of the credential is whoever or whatever the presenter asserts, however, knowing whether that person or entity is trustworthy is a separate issue. In the Nationwide Health Information Network context there is a notional understanding that entities that apply to participate in the

---

Nationwide Health Information Network will not only be vetted for identity and type of organization, but also be evaluated in some manner to make sure the entities meet appropriate criteria (functional, technical, security-related, organizational, etc.).

Many state-level HIE initiatives follow similar processes to enroll new participants. The determination of eligibility or trustworthiness may be relatively straightforward for participants such as government agencies, hospitals, health care plans and other well-known health care organizations. When participation includes small practices, individual practitioners and technical service providers, more rigorous evaluations may be required before these entities are issued credentials. As a point of reference, the trust model for the Direct initiative – which emphasizes directed point-to-point health data exchanges between providers – explicitly assumes that determinations of how trustworthy a potential exchange partner is should be an “out of band” process, with trust negotiated between parties prior to engaging in data exchanges. This approach more realistically acknowledges the practical limits of on how much trust is really conveyed through security provisions like electronic means of identification and authentication.

Security Requirements for Meaningful Use

The final versions of the HHS rules on meaningful use and associated health IT standards and certification criteria for EHR technology were published in late July 2010. Compared to the draft versions initially released in December 2009, the language in the final regulations reflects a decision to ease the requirements by which eligible health care providers and professionals will be able to qualify for financial incentives to adopt EHR technology. With respect to security, there is one security-related measure contained in the final version of the rules, but changes in the language of this measure and additional changes in security-related certification criteria and associated standards should make it a relatively straightforward proposition for health care entities to comply with security requirements under meaningful use.

The basic security requirement under meaningful use is the same now as it was when the draft rules were issued: health care entities are required to conduct a risk analysis, following the same requirement that exists in the HIPAA Security Rule (codified at 45 CFR 164.308(a)(1)). During 2010, in anticipation of Stage 1 meaningful use rules going into effect for 2011 and in advance of more proactive HIPAA security audits planned by the HHS Office for Civil Rights, the government provided more detailed guidance on what expectations OCR will have for health care entities with respect to their risk analyses.
To satisfy the meaningful use requirement for entities to conduct or review a risk analysis, the risk analysis must address only the certified EHR technology used by the entity. This is a significant reduction in scope compared to the previous wording of the requirement, which essentially incorporated the HIPAA requirement by reference and therefore applied to all electronic personal health information held by the entity. The meaningful use language was further amended to clarify the meaning of “implement security updates as necessary,” so that the final requirement now reads, “Conduct or review a security risk analysis per 45 CFR 164.308(a)(1) of the certified EHR technology and implement security updates and correct identified security deficiencies as part of its risk management process.”

The change in language should greatly facilitate health care entities’ ability to comply with the requirement, regardless of their current level of proficiency (or HIPAA compliance) in performing risk analyses. The revision not only puts a clear boundary around the systems or technologies that must be addressed in such a risk analysis, but in doing so opens up an opportunity for EHR technology vendors to provide product-specific risk information to the entities that acquire their products. Every entity will still need to consider the use of EHR technology as implemented in its own environment (or as accessed, if it uses hosted EHR services), but many of the technology-related risks associated with a given EHR product should be able to be identified in advance.

In addition to the security measure in the meaningful use rules, there are several security-related certification criteria and associated functionality that must be considered by EHR vendors seeking certification of their products under meaningful use, as summarized in Table 1.

<table>
<thead>
<tr>
<th>Access control</th>
<th>Assign a unique name and/or number for identifying and tracking user identity and establish controls that permit only authorized users to access electronic health information.</th>
<th>No specific requirements for identification and authentication are associated with meaningful use, but many dependencies exist for requirements within these rules and are incorporated by reference from HIPAA or other legislation.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency access</td>
<td>Permit authorized users (who are authorized for emergency situations) to access electronic health information during an emergency.</td>
<td>This “break glass” provision is intended to give an exception to consent requirements, although support for consumer preferences’ tracking and adherence is not explicitly required for meaningful use.</td>
</tr>
</tbody>
</table>

### Section 2: Key Enablers

<table>
<thead>
<tr>
<th>Feature</th>
<th>Description</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Automatic log off</td>
<td>Terminate an electronic session after a predetermined time of inactivity.</td>
<td>Automatic log off is a HIPAA Security Rule technical safeguard specified as part of the access control standard.</td>
</tr>
<tr>
<td>Audit log</td>
<td>Record actions related to electronic health information in accordance with the standard specified and enable a user to generate an audit log for a specific time period and to sort entries in the audit log according to any of the elements specified in the standard.</td>
<td>The standard in question specifies the minimum information that must be logged, rather than any technical, format or process requirement.</td>
</tr>
<tr>
<td>Integrity</td>
<td>Create a message digest in accordance with the standard specified.</td>
<td>The referenced standard specifies the use of the SHA-1 or higher hash algorithm, corresponding to the five SHA hash variants specified in federal Secure Hash Standard (FIPS 180-3).</td>
</tr>
<tr>
<td>Authentication</td>
<td>Verify that the person or entity seeking access to electronic health information is the one claimed and is authorized to access such information.</td>
<td>No specific requirements for identification and authentication are associated with meaningful use and the referenced standard addresses the sufficiency of identity information in an electronic transmission subject to authentication and authorization, rather than any specific practice or protocol.</td>
</tr>
</tbody>
</table>
**Table 1: Meaningful use EHR certification criteria related to security**

The final privacy and security standards recommended for adoption under meaningful use include few specific requirements, as illustrated in Table 2. The only explicit standards mentioned are FIPS 140-2 for encryption and FIPS 180-3 for secure hashing algorithms, with SHA-1 cited as a minimum strength reference. In general, it seems health IT vendors and EHR implementers will be given a lot of flexibility in meeting technical standards for meaningful use, as seen in the revised standard for encryption and decryption of electronic health information for exchange: “Any encrypted and integrity protected link.”

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Encryption and decryption of electronic health information for exchange</td>
<td>Any encrypted and integrity-protected link.</td>
</tr>
<tr>
<td>Record Actions Related to Electronic Health Information (i.e., audit log)</td>
<td>The date, time, patient identification and user identification must be recorded when electronic health information is created, modified, accessed, or deleted; and an indication of which action(s) occurred and by whom must also be recorded.</td>
</tr>
</tbody>
</table>
Verification that electronic health information has not been altered in transit

| Verification that electronic health information has not been altered in transit | A hashing algorithm with a security strength equal to or greater than SHA-1 (Secure Hash Algorithm 1 as specified by NIST in FIPS Publication 180-3) must be used to verify that electronic health information has not been altered. |

Record treatment, payment and health care operations disclosures

| Record treatment, payment and health care operations disclosures | The date, time, patient identification, user identification and a description of the disclosure must be recorded for disclosures for treatment, payment and health care operations, as these terms are defined at 45 CFR §164.501. |

Table 2: Security and privacy standards adopted for meaningful use

Security and Trust in Health IT Systems

In the context of health information technology adoption, trust is seen as an essential element for widespread implementation and use of health IT to succeed. Focusing on trust in health IT and the role health IT security and privacy provisions can play in engendering that trust, illustrates the importance of being specific when talking about trust. In the health IT arena, there is not just a single discussion of trust, but instead the need for trust is reiterated at multiple levels.

Much of the current discussion of trust in health IT suggests a need for individuals to have confidence in the systems and technologies used to store, access and disclose their health records, but the trusting relationship more relevant to the discussion of health IT is that between individuals (patients) and their doctors or other health care providers. Providers and other professionals working for or representing health care organizations involved in exchanging health information also need to establish trusting relationships, so that all parties are assured that patient data is being used for legitimate, authorized purposes and to give some level of confidence that the data being shared is accurate and its integrity is intact, particularly where the data will be used in clinical decision making.

The emphasis on security and privacy in electronic health record (EHR) systems as a prerequisite for building consumer trust in these systems overstates the extent to which security controls can provide trust and understates the importance of the provider-to-patient relationship. It is unrealistic to think that typical consumers will be able to learn or understand enough technical information about the EHR systems that their providers or hospitals or insurance companies use to be able to make independent determination as to whether the security and privacy measures afforded by such a system are
sufficient. Instead, most people will rely on their doctors or other providers (the actual users of the EHR systems) and their relative comfort level with digitizing their health records will likely be strongly correlated to the level of trust they put in their providers.

The point is not to diminish the importance of having strong security and privacy protections for health data stored in EHR systems, but instead to reiterate that patient trust (or lack thereof) in health information technology cannot be provided through technical means alone. Few patients today have a detailed understanding of how their medical records are stored (paper files, computer or some combination) or for the physical, technical, or administrative measures in place to secure them.

With the prospect of easier and more frequent sharing of health data enabled by EHR systems, patients might be expected to be more interested to know how their records are being handled, but consumer acceptance of health IT should be influenced by the benefits – purported and, over time, actually realized – to themselves, their health care providers and the health care system. Health information is usually considered to be far more sensitive that other personal data, but as supermarket and other retailer loyalty programs have illustrated for years, many people are willing to disclose some personal information in return for perceived tangible benefits and this pattern should apply to health data as well.

To help individuals make informed decisions about EHRs and other health IT, there needs to be more education and outreach to consumers about EHRs, their intended and permitted uses and benefits and also the ways in which personal health data is protected against loss, theft, misuse and unauthorized disclosure. The best way to deliver these messages is to leverage the trusting relationship that already exists between patients and providers, since from the patient perspective, their doctors are much more likely to take on patient interests as their own than EHR software vendors, insurance companies or even government health agencies.

**Federal Government Approaches to Managing Trust in Health Information Exchanges**

The Nationwide Health Information Network, a government-sponsored initiative started in 2004 and re-emphasized in HITECH Act, is no longer envisioned as a “network” at all (in the infrastructure sense), but instead as a collection of standards, services and policies that collectively support the secure exchange of health information between participating entities. The original idea for the Nationwide Health Information Network was that public
and private sector organizations would benefit from adopting a common set of parameters governing their health data exchanges and that once a few early adopters went into production using the Nationwide Health Information Network, participation would grow rapidly.

Instead, due in part to disagreements among different types of potential participants about how Nationwide Health Information Network standards should be implemented, and also due to concerns about policy incompatibilities between federal and commercial sector entities, there are currently very few organizations in production. The group of state and federal government agencies and a small number of commercial health care entities currently operating health information exchanges using the Nationwide Health Information Network are collectively referred to as Nationwide Health Information Network Exchange, an initiative focused on the data exchange needs of federal agencies.

To date the Nationwide Health Information Network has largely enabled health information exchanges between large organizations, but addressing the data exchange needs of small providers has received greater attention due to the recent focus on meaningful use measures, which require that providers’ EHR technology must be implemented “in a manner that provides for the electronic exchange of health information to improve the quality of health care.”¹¹ In order to enable secure health information exchange among smaller providers, the Direct (formerly known as “Nationwide Health Information Network Direct”) project began in early 2010, specifically intended to try to use or expand upon Nationwide Health Information Network standards and services to allow providers and other participants to securely send health information to trusted recipients in support of Stage 1 meaningful use requirements.

Without delving into the details of all the standards and services and use cases that the Nationwide Health Information Network and Direct are seeking to support, one very noticeable difference between the two initiatives is in the area of trust. Participants working on both initiatives agree that trust is an essential aspect of any solution, because health care entities – large or small – are not expected to participate in any health information exchange unless they feel they can trust the other participants and any third parties involved in operating or managing or overseeing the exchange. While everyone working on the two federal initiatives seems to agree that such trust is important, the approach each initiative is taking with respect to trust is quite different. In particular, the basic trust model proposed for Direct is much more explicit than the trust framework being developed for the Nationwide Health Information Network in terms of what “trust” actually means in a health information exchange context.

and on the extent to which participants involved in a multi-party exchange can agree on policies, standards and controls intended to support trust.

Both programs tend to use the word trust to mean confidence in or reliability of exchange participants, but stop short of trying to establish the trustworthiness of a given entity that would help others decide to accept the risk of engaging in an exchange with the entity. This may be due to implicit assumptions about the interests of different would-be participants in health information exchanges, or because insufficient weight is given to the manner in which participants can establish their trustworthiness, or perhaps too little attention is focused on the very real distrust that exists between potential HIE participants.

To its credit, the Direct project candidly acknowledges that different policies and assumptions will apply to different participants in different contexts, so the Direct basic trust model limits the scope of what any assertion of trust actually covers and allows for the possibility (even the expectation) that a given organization may participate in multiple exchanges governed by different sets of policies or rules.

The Direct approach has no central authority to assert trustworthiness of participants and no trust-by-default among participants. Direct participants are expected to make their own determinations about the relative trustworthiness of others. The Direct Security and Trust Workgroup’s keys for consensus summary addresses “only the level of trust necessary to establish confidence that the transmitted message will faithfully be delivered to the recipient, not that the two parties trust or should trust each other; this definition of trust is to be defined by source and endpoint out of band and may be facilitated by entities external to the Nationwide Health Information Network Direct specifications.”

In contrast, the Nationwide Health Information Network Exchange in particular and the Nationwide Health Information Network trust framework in general relies on a central governing authority that makes determinations of trustworthiness for all potential participants and presumably only allows participation by trustworthy entities. There is no current standard set of criteria to serve as the basis for determining trustworthiness, but when and if such criteria exist, they are expected to address at least the minimum technical requirements a participant must satisfy, along with providing identity assurance and articulating the business, policy, legal and regulatory requirements that apply to participants. The health information exchange trust framework

---

Section 2: Key Enablers

recommended in April 2010\textsuperscript{13} by the Health IT Policy Committee’s Nationwide Health Information Network Workgroup comprised five key components:

1. Agreed Upon Business, Policy and Legal Requirements / Expectations
2. Transparent Oversight
3. Enforcement and Accountability
4. Identity Assurance
5. Minimum Technical Requirements

Nationwide Health Information Network participants sign a legal document called the Data Use and Reciprocal Support Agreement\textsuperscript{14} (DURSA) which is intended to serve as a master trust agreement applying the same permissions, obligations, expectations and constraints to all exchange participants in all of the information exchange contexts it covers (treatment, payment, health care operations, public health activities, reporting on clinical quality measures and other uses authorized by individuals to whom the data pertains).

By executing the DURSA, participants do not actually agree to trust each other, but they do agree to acknowledge and accept that different participants may have different policies, practices and security controls such as system access policies. This means that a participant must rely on the determination of the Nationwide Health Information Network governing authority (which approves applicants for participation) that the policies and controls used by an approved participant are sufficiently robust and gives participants no real ability to question the approach that another participant takes on matters like security and privacy safeguards.

The reliance on a legal contract (the DURSA) and a planned monitoring, oversight and enforcement function strongly suggests that what the Nationwide Health Information Network has produced is a distrust framework, rather than one based on trust. While that might not sound as nice, if the scope of participation for the Nationwide Health Information Network continues to

\textsuperscript{13} Health IT Policy Committee Nationwide Health Information Network Workgroup presentation by Dr. David Lansky and Dr. Farzad Mostashari, presented at the April 21, 2010 meeting of the Health IT Policy Committee. Available from the ONC website at http://healthit.hhs.gov/portal/server.pt/gateway/PTARGS_0_11673_911635_0_0_18/Lansky_NHINWG_Recs_HIE_Trust_Framework042110UPDATE.ppt
include many different types of participating entities, many of which may have conflicting organizational interests, a common level of trust may never be established, so an approach designed to achieve cooperation despite distrust may be precisely what is needed.

The intent to use a single overarching trust model for the Nationwide Health Information Network is based on assumptions of feasibility: if Nationwide Health Information Network participants someday number in the hundreds or even thousands, negotiating trust between pairs or among small sub-sets of all those participants simply is not practical. By positioning a common, trusted authority in the center, all that should be required to achieve trust throughout the Nationwide Health Information Network is for each participating entity to establish a trusting relationship with the Nationwide Health Information Network governing authority.

It is not entirely clear how such bilateral trust agreements can be made with the many different organizational interests represented by the different types of organizations (providers, insurers, researchers, agencies) that might seek to participate in the Nationwide Health Information Network, to say nothing of the interests of the patients whose data would be exchanged by those entities. It does seem logical that working through a central agent – either a vested organization like ONC or a neutral network facilitator – could produce better success in negotiating trust than if all the participants tried to reach consensus on a multilateral agreements.

However, given the significant time and energy that many people have put into thinking about and trying to resolve issues like harmonizing the security and privacy requirements that apply to federal and private sector entities, it is also understandable why the Direct Security and Trust Workgroup declared that “real world evidence suggests that achieving global trust is not practical.”

Health Information Privacy

In the health care context, the term privacy or an asserted right to privacy generally means the ability of an individual to control access to or use of personal information about that individual. Grounded in fair information principles and codified in many federal and state privacy laws, controlling access includes granting or limiting the disclosure of personal information to specific individuals or entities for specific purposes. When applied to health IT, discussions of privacy largely focus on three primary topics: accounting of disclosures, notification and disclosure rules for health data breaches and

the establishment and maintenance of consumer preferences about the use of personal health information, often simply referred to as consent management. The HITECH Act addressed all three of these issues, including provisions that direct HHS and other federal agencies to develop and implement rules that serve to revise and extend the requirements in the HIPAA Privacy Rule.

New rules have been proposed and put into effect for disclosure and notification of breaches of personal information by health care organizations and associated entities and significant work has been done on still-unresolved matters of consent management. New accounting of disclosure rules are still pending.

While U.S. health care organizations are subject to a robust legal privacy framework, including existing accounting of disclosure rules and detailed specifications of when consent is or is not required before disclosing personal health information, there is some debate as to how fully the existing regulations cover IT-enabled health care practices, including the use of electronic health records and personal health records, as well as greater levels of data sharing made possible through health information exchanges.

**Accounting of Disclosures for Health Information**

An accounting of disclosures is a record, required to be kept and produced upon request, of the instances in which information in health records maintained by a HIPAA-covered entity is disclosed to other parties. The accounting documents not just that health information was in fact disclosed, but when, to whom and for what purpose the disclosure took place and a description of what specific health information was disclosed. First required under the HIPAA Privacy Rule that went into effect in 2003, current accounting of disclosure regulations dictate that HIPAA-covered entities keep a record of disclosures covering a six year history, but provide exemptions for disclosures made for the purposes of treatment, payment, or health care operations (45 CFR §164.528).

A provision in the HITECH Act ((§13405(c)(1)) revises the requirements for accounting of disclosures to remove the exemption for treatment, payment and health care operations and shortens the coverage to a three-year period instead of six years. Following the language in the HITECH Act, the new requirements were intended to go into effect as soon as January 1, 2011 (for entities that newly acquire EHR technology) and no later than January 1, 2014, although the law allows the HHS Secretary to delay the effective dates by two years if such a delay is deemed necessary. Such a holdup seems increasingly likely, for two primary reasons: first, the language of the HITECH Act (§13405(c)
Section 2: Key Enablers

(2)) instructs HHS to first adopt standards for accounting for disclosure and then promulgate regulations about what information health care entities (and presumably business associates, since HITECH also made business associated directly responsible for complying with HIPAA requirements) must record about each disclosure.

No such standards have yet been proposed, much less adopted and HHS is still in the process of reviewing comments it received in response to a request for information it published in May 2010 seeking opinions on the administrative burden that complying with new accounting of disclosure rules might place on health care organizations. Second, the final version of the EHR certification criteria published in July 2010 in conjunction with the final rules on meaningful use made accounting of disclosure functionality optional\(^\text{16}\) for stage 1 – a change from the interim criteria that required accounting of disclosure capabilities and therefore could have represented a key driver influencing health IT vendors to make sure their EHR systems offered the functionality in their products.

Taken together, the absence of standards and regulations on accounting of disclosures and the fact that such functionality is not required in order to certify EHR systems under Stage 1 of meaningful use suggest that the ability for health care providers to actually offer the sort of accounting called for in the HITECH Act may not be pervasive until Stage 2 takes effect in 2013.

While the need to produce accountings of disclosures should be familiar ground to health care organizations, the exceptions to the rules for treatment, payment and health care operations purposes likely have resulted in many covered entities not having to attend to these requirements, so there is understandable concern about imposing new administrative burdens on health care providers. To some extent, the effort to comply with the accounting of disclosure rules could be shifted to EHR vendors, if the ability to store and report comprehensive accounting of disclosure statements is made a requirement for EHR certification under meaningful use rules.

Many such systems already have this capability, so the level of effort to comply hinges on the details of the information that needs to be collected and whether these systems can capture that information with little or no modification. It is logical to assume that some additional work effort will be placed on health care personnel to record disclosures, as the recipient information and purpose for the disclosure are attributes that might not be easily captured in an automated fashion from transactional logs. If HHS is

---

Section 2: Key Enablers

going to consider the individual interest in knowing when and why their data has been disclosed, it should also consider defining the disclosure rules to include “use” or “access” to health information as a type of disclosure. Some of the most publicized breaches of personal health data privacy are really abuse of privilege by authorized EHR users like hospital staff; nothing in the current HIPAA rules or in the regulatory language proposed to date would include this sort of access within the scope of accounting of disclosures.

With applicability to all HIPAA-covered entities and business associates, the scope of the accounting of disclosures requirements obviously extend well beyond the government, but in formulating rules and approaches the government might find instructive some of the approaches and technical mechanisms already used by government agencies. Under the Privacy Act, all federal agencies are required to maintain and make available to individuals accountings of disclosures of personal information held in any agency system of records. The Privacy Act makes an exception for access to records by government employees as part of performing their job duties, but in general require that agencies keep a record of when, what and why a disclosure of personal information is made and the name and address of the person or organization to whom the disclosure is made (5 USC §552a(c)).

If, as private sector health care entities are likely to argue, there is significant new effort required to comply with stricter accounting of disclosure rules, HHS might also want to consider what incentives might be provided to help mitigate the compliance burden. Meaningful use is one way to approach this, insofar as the ability to maintain and produce the accounting of disclosures the law requires could be made a required functional capability of certified EHR modules or systems.

There is another potential source of incentive, depending on how the business case develops for health information exchange using EHRs and other health IT. In a business model in which data holders were compensated for sharing their data, the transaction history that would provide the basis of billing records could also be used to satisfy accounting of disclosure requirements. Absent such a business model, there are policy oversight and legal enforcement interests in auditing data sharing transactions as well (to see if entities are living up to their legal or contractual obligations) and the information needed to satisfy such monitoring activities could also likely be leveraged for accounting of disclosures.
Health Data Breach Disclosure and Notification

The HITECH Act included provisions requiring HIPAA-covered entities, business associates and non-covered entities that provide personal health records (PHR) to disclose breaches of personal health information (§13407), essentially creating a new federal standard for health data breach notifications. There were two sets of breach disclosure rules put in place – one for HIPAA-covered entities and business associates under the authority of HHS and the other for data breaches from PHR vendors and other non-covered entities under the authority of the Federal Trade Commission (FTC). Both rules went into effect after they were published in draft form in September 2009.

Although the rules greatly expand the scope of organizations subject to breach disclosure requirements, HHS chose to include a provision in the rules that unauthorized disclosure is not considered a breach under the regulations unless it causes or has the potential to cause significant harm to individuals whose data is disclosed. The determination of harm is left to the organization that experiences the breach – an exception to notification requirements that is troubling to privacy and consumer advocates because it introduces a measure of subjectivity into what seemed to be an objective requirement (the harm provision was not part of the language in the HITECH Act) and it raises the possibility that organizations who suffer disclosures will understate the risk in order to avoid having to comply with the rules.

Concerns over the harm provision appear to be at least one of the reasons behind HHS’ decision to withdraw the final version of its rules on “Breach Notification for Unsecured Protected Health Information,” which it had submitted to the Office of Management and Budget for final review prior to publication. HHS gave no specific reason for wanting to reconsider the rule, other than to note the complexity of the issue, but shortly after the draft rules were published in 2009, objections to the harm provision were raised not only by patient privacy advocates but also by members of Congress.17

There is an active legal debate over unauthorized data disclosures and potential or actual harm to the victims of such breaches that extends beyond the health breach disclosure context. Lawsuits filed over breaches of personal information are routinely dismissed when the parties who bring the suits are unable to demonstrate actual harm or injury has occurred, rather than that the potential for harm exists. The legal issue in these cases has little to do with privacy or, generally, with violations of breach notification laws, but with

17 In a letter to HHS Secretary Kathleen Sebelius dated October 1, 2009, Congressmen Henry Waxman, Charles Rangel, John Dingell, Frank Pallone, Jr., Pete Stark and Joseph Barton objected to the inclusion of the harm exception and asserted that legislators explicitly rejected including such as provision when drafting the HITECH Act.
standards of civil procedure and tort liability requirements, which demand that plaintiffs be able to show actual harm in order to bring causes of action for negligence or poor security or data handling practices.

General or domain-specific breach notification laws such as those for personal health information should in theory help overcome the negligence right of action issue, but at least in the case of federal health data breaches, that will only be true if organizations responsible for data breaches cannot exempt themselves from notifications because they believe (or have no evidence) that the subjects of the breaches suffer actual harm.

Both the HHS and FTC breach disclosure rules apply only to unsecured data – in HITECH language that means data that is not rendered “unreadable, unusable or indecipherable” – organizations holding personal health information can in many circumstances avoid the requirement to disclose breaches if they implement encryption for the data under their control. This disclosure exemption has increased attention in the industry on mechanisms to encrypt data at rest, including while stored in operational databases and when stored on removable media such as backup tapes.

While encryption of data in transit is pervasive in health care environments – and such encryption is required for EHR technologies under meaningful use – encryption of health information remains an “addressable” technical safeguard under HIPAA (45 CFR §164.312(2)(iv)). It is possible that the desire to avoid the publicity associated with reporting a health data breach will provide sufficient motivation for health care organizations to implement additional security measures such as encryption of data at rest to better protect health data privacy.

Among the requirements in HHS’ health data breach notification rule is that breaches affecting more than 500 individuals must be reported to HHS and made public. Even a cursory review of the approximately 200 breaches listed by the HHS Office for Civil Rights reveals that the vast majority of breaches experiences by HIPAA-covered entities and business associates occurred due to loss or theft of records stored on portable media, computers or paper. This pattern suggests that the most pervasive vulnerabilities in health information security are not technical security measures provided by EHR systems or other types of health information technology, but instead are weaknesses in operational procedures, administrative practices and security awareness among health care organization employees.

18 A current listing of breaches affecting 500 or more individuals is available from the HHS website at http://www.hhs.gov/ocr/privacy/hipaa/administrative/breachnotificationrule/breach-tool.html.
Experience to date with health data breaches further suggests that any efforts or regulations proposed to improve health data security and privacy should include strengthening operational controls and training individuals in effective data protection practices. If human behavior with respect to health data remains a pervasive source of weakness (as seems likely), then regulators and health care organizations should emphasize the use of technical controls like data encryption that mitigate or eliminate the risk of harm due to breaches of personal health information.

**Consumer Preferences, Patient Privacy and Consent**

Patient privacy protections are more contentious than the security controls health care providers are obligated to use. While compliance with health information security requirements is far from universal, with respect to security objectives there tends to be agreement among all key health care stakeholders as to the importance of security and, essentially, that health information security is both needed and valuable. Where patient privacy rights are concerned, there is no such agreement, as the level of fine-grained control over information disclosure recommended by many privacy advocates would significantly diminish health data sharing and in turn could frustrate efforts to achieve desired health care outcomes for health information exchanges.

The HHS Office of the National Coordinator is squarely in the midst of this debate, as it places privacy protections (along with security) high on its list of priorities. ONC puts particular emphasis on adhering to the privacy principles enumerated in the *Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information*,19 which it released in December 2008 with the endorsement of then-HHS Secretary Michael Leavitt. In general, this Framework brought forward and augmented the Fair Information Practices originally articulated in 1973 by the Department of Health, Education and Welfare that formed the basis of the Privacy Act of 1974. The 2008 Framework has eight core principles: individual access, correction, openness and transparency, individual choice, collection, use and disclosure limitation, data quality and integrity, safeguards and accountability.

These principles do not carry the weight of law, but they are frequently used as a point of reference by government policy makers and advisors working to establish the rules under which health information sharing will take place. The challenge for federal policy makers is to balance the desire

---

Section 2: Key Enablers

to provide individuals with personal privacy protections with the desire to improve the delivery and quality of health care through greater access to health information. While protecting individual rights like patient privacy and honoring consumer preferences is seen as a prerequisite for gaining acceptance of the use of EHRs and data sharing through health information exchanges, when making tradeoffs between privacy and quality of care, some benefits of greater information sharing may be too compelling to be constrained by privacy rights.

Even if a point of consensus exists that a better foundation of trust is needed before the grand vision for health information technology can be achieved, the fact remains that it is exceedingly difficult to arrive at a common framework of trust when different stakeholders have different goals and priorities for adopting electronic health records and exchanging the data those records contain. Many of the anticipated benefits from the interoperable electronic health records rely on widespread adoption of health information technology and universal participation among individuals, stemming from President Obama's January 2009 call for every American to have an electronic health record by 2014.

For patients, the key challenge seems to be ensuring sufficient privacy and security protection to give individuals confidence in the EHR systems and the use of their data, to get them to want to have their health records in electronic form at all. Putting patients in control of their data and capturing and using patient consent and usage preferences seems to be the favored way to engender trust among individuals, but in doing so the value of health information exchange in improving quality of care may be negatively impacted. If consent is enabled at a level of granularity that allows individuals to keep certain portions of their health records hidden, the result for anyone requesting access to those records through health information exchanges may be incomplete data. Depending on the nature of the data omitted from an ostensibly comprehensive view of a patient, the risk of clinical mistakes due to incomplete records goes up, threatening the improvements in quality of care and reduction in medical errors that electronic health records are intended to produce.

The importance of complete information in clinical care settings is well established. It is not coincidental that data disclosure for the purpose of treatment is explicitly exempt from consent requirements that apply to some other uses of health data under the HIPAA Privacy Rule (45 CFR §164.506). Based on anecdotal evidence offered to the federal Health IT Policy Committee20 and

---

20 Office of the National Coordinator for Health Information Technology. (April 19, 2010). Health IT Policy Committee Meeting Transcript. Available from the ONC website at http://healthit.hhs.gov/portal/server.pt/gateway/PTARGS_0_11673_911979_0_0_18/2010-04-21_policy_final_transcript.pdf

48 Transforming Health Care
other policy makers, current medical practitioners are aware both of the potential for patient dissatisfaction with the level of privacy protection offered under current regulations and the risks that can result from giving patients the ability to withhold particular details in their health records.

 Particularly where information such as prescriptions is concerned, if one physician is unable to see medications prescribed for a condition that a patient has chose to withhold, the chance of misdiagnosis or drug interaction rises. Even if patients are made aware of the potential dangers of withholding medical information, many providers object to the idea of giving patients granular control over the data in their health records. The approach of requiring data disclosure for treatment (that is, of exchanging data without seeking consent) might satisfy clinicians, but when surveyed about health information technology, consumers often respond that absent some degree of control over health data disclosure, they might opt to withhold information from their doctors rather than have the information become part of their records.21

 From a practical perspective, both privacy advocates and full-disclosure proponents acknowledge that many clinical IT systems such as EHRs lack the technical capability to enable granular maintenance and enforcement of consent and other privacy preferences. Finding the right balancing point between patient privacy and consent and optimizing the utility of data shared through health information exchange remains as much a business and policy problem as it is a technical challenge.

Managing Consent to Disclose Personal Health Information

 As health care organizations move to make electronic health record (EHR) systems interoperable and exchange health record data among entities, they need to consider whether and to what extent, they will provide individuals the ability to exert control over the use of their health information. Sharing data contained in EHR systems through health information exchange (HIE) mechanisms promises a number of potential benefits, including improvements in quality of care; reduction in medical errors and the negative health consequences resulting from those errors; efficiency gains from cost savings and less time required to transmit health record data; and more effective health care at the time of treatment enabled by clinical decision support.

Many of these anticipated benefits presume widespread adoption of EHR technology by providers and medical professionals and also universal or near-universal participation in keeping health records electronically by members of the public in their role as patients. Pervasive use of EHR technology should maximize the proportion of health data that is stored electronically, while broad interoperability among EHR systems through health information exchanges should maximize the availability of that data for use in clinical care, public health, research and other important purposes.

From the perspective of health care providers and other organizations, increasing the availability of and access to health records stored electronically is a primary objective for health information exchange. From the consumer or patient perspective, however, protecting the privacy of personal health information is of equal or greater importance to improving health care delivery.

Implementing privacy protections for data stored in EHR systems is an important prerequisite both for health care entities to engage in health information exchanges and for encouraging individuals to be willing to participate in EHR-based health care. Many privacy rights associated with personal health information are enumerated in HIPAA, FISMA, the Privacy Act and under explicit federal regulations addressing particular types of treatment (e.g., mental health, substance abuse) or segments of the population (e.g., veterans, Medicare enrollees).

A key requirement in many privacy regulations is the need to obtain consent from individuals before disclosing their personal health information, subject to a variety of exceptions. Many state governments have enacted privacy laws that augment the provisions contained in federal laws; in at least ten states these laws reflect explicit rights to privacy included in state constitutions. The consent-before-disclosure requirements specified in state and federal law, health information exchange and data sharing contracts and relevant government and organizational policies collectively define the mandatory consent management practices for a given health care organization.

There are, however, additional patient-centered consent practices that organizations may choose to implement, perhaps to satisfy privacy preferences among the customers or constituents it serves or to help engender trust between those constituents and the organization, or even to position strong patient-centric privacy practices as a competitive differentiator. There is no single “right” answer when it comes to managing consent and consumer privacy preferences. While legal requirements and constraints on use and disclosure

---

22 An expressly stated right to privacy is contained in the state constitutions of Alaska, Arizona, California, Florida, Hawaii, Illinois, Lousiana, Montana, South Carolina and Washington.
exist in some specific contexts, the scope and extent of consent provisions provided by a given organization to its patients or constituents should reflect not only legal and regulatory compliance, but also the organization’s goals and priorities for using health IT.

Once electronic health record systems are in place and interoperable, health care providers and public health practitioners will have access, subject to proper authorization, to integrated health information made available through data sharing enabled by health information exchanges. Many public and private sector organizations are now in the process of implementing or enhancing their EHR systems and establishing the capabilities to share the data in those systems with other organizations, using standard data formats, technologies and service specifications.

Health care providers have additional incentives both to adopt EHR systems and to implement data exchange capabilities, in the form of federal funding available under meaningful use. To successfully realize the benefits enabled by widespread use of health IT, health care organizations need to assure their patients and the other organizations with which they intend to share data that appropriate policies, practices and safeguards are in place to protect the privacy, confidentiality and integrity of information stored in electronic health records.

To provide patients with the confidence that their personal health information is stored and managed securely and that it is not being accessed or used by anyone inappropriately or in any way contrary to their rights to privacy, health care organizations must consider ways to empower individuals to exert some degree of control over the use and disclosure of their personal health information. One way to approach legal, policy and business requirements for giving individuals control over their information is to focus on individual consent. Managing consent in a health information exchange context includes soliciting, capturing, maintaining and enforcing patient preferences regarding the use of their health information.

While no single approach to consent management will be appropriate for all health care organizations, the ongoing debate within the federal government about consent effectively illustrates the primary considerations and key tradeoffs that all organizations face when determining how to approach patient privacy. Acknowledging the strong regulatory guidance contained in the HIPAA Privacy Rule, the Office of the National Coordinator, working with its federal advisory committees on both policy and standards, focused its attention during 2010 on managing consent in the context of health information exchanges.
Many of the alternatives ONC has considered stem from a policy analysis commissioned by ONC and made public in March, 2010, entitled *Consumer Consent Options for Electronic Health Information Exchange: Policy Considerations and Analysis.*23 This report makes a distinction between “all or nothing” consent directives that might apply to the entire contents of a health record and models that sub-divide the contents of a health record and attach potentially different consent directives to different portions of a record.

When considering consent management alternatives, it simplifies the discussion somewhat to separate the approach used to solicit consent from the data categorization and granularity of health record data against which consent will be managed. There are three primary approaches to soliciting consent from individuals: opt-in, opt-out and no consent. The basic characteristics of each approach are summarized in Table 3.

<table>
<thead>
<tr>
<th>Consent Model</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Opt-in</strong></td>
<td>No data is shared or disclosed until the patient gives consent</td>
</tr>
<tr>
<td></td>
<td>• Maximizes individual control over data</td>
</tr>
<tr>
<td></td>
<td>• No data will be shared until patients can be convinced to give consent</td>
</tr>
<tr>
<td><strong>Opt-out</strong></td>
<td>Data is shared unless the patient explicitly requests that it not be shared</td>
</tr>
<tr>
<td></td>
<td>• Maximizes amount of data shared, at least initially</td>
</tr>
<tr>
<td></td>
<td>• May run counter to patient privacy desires</td>
</tr>
<tr>
<td></td>
<td>• Individuals may not be aware of their ability to opt-out without education</td>
</tr>
<tr>
<td></td>
<td>and outreach</td>
</tr>
<tr>
<td><strong>No consent</strong></td>
<td>Data is shared and patient consent is not sought or considered</td>
</tr>
<tr>
<td></td>
<td>• Simplest model to implement;</td>
</tr>
<tr>
<td></td>
<td>• Maximizes amount of data shared/made available</td>
</tr>
<tr>
<td></td>
<td>• Gives individuals no voice or control in sharing their information</td>
</tr>
<tr>
<td></td>
<td>• Legally, participation in exchanges for some purposes for use cannot be</td>
</tr>
<tr>
<td></td>
<td>supported</td>
</tr>
</tbody>
</table>

Table 3: Summary of key elements of the three primary consent models

The comparison provided in Table 3 is an over-simplification; additional considerations and potential impacts from adopting any of these approaches must be addressed in the specific organizational context to which they are applied. In general, the three consent models can be most directly compared in terms of the level of control they offer to individuals over data disclosure and in terms of the amount of data that is made available to share via health information exchange. The relative levels of control over disclosure and data available for sharing via health information exchange are shown in Figure 1.

---

When using any model other than the “no consent” option, a second determination needs to be made regarding the way in which consent will be associated with data in health records. There are at least six ways to approach granularity in electronic health records, summarized in Table 4, each of which may be used separately or in combination. In many ways, handling granularity within a consent management approach is much more complicated than the consent model used. Many of the ways to sub-divide an individual health record according to patient privacy or sensitivity concerns are not easy to implement within existing EHR systems and schemas and even if granular consent models are implemented in external policy engines, directories or databases, to be able to incorporate granular consent by data type, provider or encounter may require parsing and analyzing the entire electronic health record before any health information exchange request can be fulfilled.

Similarly, some of the standard schemas and message constructs recommended for use in health information exchange may by default contain more information than is needed to satisfy a given request, which can run afoul of federal regulations enacted under HITECH, particular the need to limit disclosure to the minimum necessary to satisfy the purpose in question (P.L. 111-5, §13405(b))

<table>
<thead>
<tr>
<th>Data Type</th>
<th>Consent is given based on the category of information or individual data elements in the record</th>
<th>• Maximizes control over sensitive information that may be contained in records</th>
<th>• Results in incomplete information being shared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider</td>
<td>Consent is given for data associated with particular providers</td>
<td>• Serves as a proxy for limiting disclosure by nature of treatment</td>
<td>• Results in incomplete information being shared</td>
</tr>
</tbody>
</table>

Figure 1: When implemented, the three basic consent models can result in significantly different levels of control over data disclosure and the amount of health record data available to share via HIE.
### Table 4: Summary of key aspects of alternative approaches to consent granularity

<table>
<thead>
<tr>
<th>Consent Type</th>
<th>Key Aspects</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Encounter</strong></td>
<td>- Allows disclosure control over multiple categories of data to avoid over-disclosure by inference</td>
</tr>
<tr>
<td></td>
<td>- Level of granularity not supported by many EHR systems</td>
</tr>
<tr>
<td></td>
<td>- Results in incomplete information being shared</td>
</tr>
<tr>
<td><strong>Purpose for Use</strong></td>
<td>- Aligns well with most legal requirements</td>
</tr>
<tr>
<td></td>
<td>- Facilitates limited or phased participation in HIE</td>
</tr>
<tr>
<td></td>
<td>- May not provide sufficient privacy protection unless combined with some data-level restriction</td>
</tr>
<tr>
<td><strong>Data Requester</strong></td>
<td>- Enables individuals to limit disclosure to known entities or others they trust</td>
</tr>
<tr>
<td></td>
<td>- For external requests, prior knowledge or requesting individuals is impractical</td>
</tr>
<tr>
<td></td>
<td>- May require manual consent process</td>
</tr>
<tr>
<td><strong>Timeframe</strong></td>
<td>- Reduces need to try to build historical record</td>
</tr>
<tr>
<td></td>
<td>- Practically reflects the fact that some patient data may remain in hard copy even when EHR is used</td>
</tr>
<tr>
<td></td>
<td>- Results in incomplete information being shared</td>
</tr>
</tbody>
</table>

Given the state of current EHR and HIE technological solutions, for many health care organizations managing consent on the basis of the purpose for which health data is requested might be a suitable starting point for finding a workable solution to this issue. Such an approach has the advantage of following the requirements of all the major federal privacy laws and being consistent with the Nationwide Privacy and Security Framework favored by federal government policy makers. To date, none of the federal health IT programs have specified privacy requirements more stringent than the federal regulations promulgated under the authority of the HIPAA Privacy Rule and in some cases strengthened through provisions in the HITECH Act.

What this means for health care organizations is that maintaining compliance with HIPAA requirements should be sufficient to satisfy legal obligations and audit criteria specified by the HHS Office for Civil Rights. With respect to meaningful use, the Stage 1 criteria in effect until 2013 do
not include any explicit privacy measures or requirements. The health care providers, professionals and organizations eligible to seek incentive funding and to which the meaningful use determination applies are, however, HIPAA-covered entities, so there is an assumption that these entities will demonstrate compliance with requirements in the HIPAA Privacy Rule.

Health care organizations that interpret the relatively lower level of emphasis on health data privacy (compared to security) as a reason to maintain the status quo on privacy may be missing an opportunity to facilitate adoption of health IT. Recent research comparing electronic health record adoption in the United States and European Union concludes that concerns over privacy of health record data remain the key obstacle to broader EHR use in the United States.

In their paper, Privacy and Security in the Implementation of Health Information Technology (Electronic Health Records): U.S. and EU Compared, they analyze the legal privacy protections in place for health information in both the U.S. and EU and attribute the much greater penetration of EHRs in many European countries (such as Holland, where nearly all residents have EHRs) to the existence of stronger privacy regulations. Specifically, the researchers point to a notable lack of public support for health IT such as EHRs in the United States and key differences in legal and policy approaches to data privacy in the U.S. and EU.

The recommendations in the report include suggestions that US health data privacy laws be strengthened (beyond the impact of HITECH on HIPAA) in areas such as giving a private right of action to individuals who suffer from violations of privacy laws, implying that affording redress rights to individuals would help overcome privacy-driven reluctance about using EHRs. It remains to be seen whether the Department of Health and Human Services’ Office for Civil Rights has the resources and resolution to follow through on its stated intentions to more vigorously and proactively enforce federal health data privacy and security regulations and if so, what impact stronger enforcement might have on public perceptions about data privacy in health care.

Section 2: Key Enablers

Other Privacy Considerations

In addition to rules and regulations on accounting of disclosures, health data breach notification and consent, the HITECH Act included a variety of other provisions intended to enhance privacy protections for personal health information. Rules still forthcoming from HHS will make explicit several of the changes in the privacy portion of the HITECH Act (Subtitle D, §§13400-13410). These changes include:

- The change in liability for business associates (§13401), which under HIPAA had no direct accountability for violations of the Privacy or Security rules (instead, the covered entity with which the business associate had a contractual agreement was liable for its business associates’ violations). Now business associates are directly accountable for violations, including being subject to the civil and criminal penalties for violations that were also strengthened as a result of HITECH.

- Restrictions on the sale of protected health information without explicit consent by the individual, subject to several exceptions (§13405(d)), notably including purposes of public health, research, treatment, health care operations, or situations such as providing an individual with a copy of his or her record or moving data between covered entities and business associates doing processing on behalf of the entity.

- The requirement that individuals be able to get a copy of whatever data a covered entity has stored electronically about them and to direct that information to a designated entity like a new doctor (§13405(e)). While many people believe that they own their own health record data, data ownership is just a privacy principle, not a legal right. This provision in HITECH does not resolve the data ownership question, but it does give individuals the right to request their data and obligates the entity to provide it; it also says any fee charged to the requesting individual cannot be more than the entity’s actual cost to provide the record.

- New rules limiting the amount of data disclosed about an individual (§13405(a)). This provision in the law has two key aspects: first, if a patient asks a covered entity (say, a doctor) not to disclose personal health information related to a specific service or encounter and the individual pays out of pocket for the services received from the entity, then the entity has to comply with a request not to disclose the data, unless the request to disclose is for treatment. Second, the law also obligates an entity that discloses protected health information to limit any disclosure to the minimum necessary for the purpose for which the data was requested. This means, for example, that someone should not disclose an entire medical record to someone asking for information
about payment for a specific service. The determination of “minimum necessary” for particular purposes is currently left to the discretion of the entity doing the disclosing and there are no standards or guidelines on what the minimum data is for any of the anticipated purposes for use in health information exchange.²⁵

Sustainable Health Information Exchange

To realize some of the many benefits anticipated from health information technology, such as electronic health records and health information exchanges, the use of such technology needs to be pervasive. Despite the promise of lower costs, better quality of care, reduced medical errors and other health IT outcomes, health IT adoption among health care providers and organizations is not yet widespread. It is inhibited by a variety of factors including the relative immaturity of local, state and federal health IT infrastructure to support health data sharing and the integration of health IT systems.

To try to overcome some of the barriers to health IT adoption, the federal government has made significant financial incentives available to state and regional health information exchanges, which along with state-level efforts to launch health information exchanges has resulted in over 230 such initiatives nationwide, according to the eHealth Initiative’s 2010 Annual National Survey on Health Information Exchange. Current major HIE initiatives exist at the local, state, regional and national level and in many cases there are multiple HIEs that may serve the same community of health organizations.

The majority of current HIE initiatives are still in the process of planning, development or implementation (fewer than a third of the HIE’s identified by the eHealth Initiative were operational in 2010) and in many cases the effort to launch HIEs is supported at least in part by federal or state government funding. A key consideration for any of these HIE initiatives – if they hope to survive and remain operational beyond the time period in which their funding is provided largely through federal grants or other one-time sources – is to develop and implement an operational model that allows a health information exchange to become self-supportive in a way that is sustainable into the future.

The term sustainable, when applied to an HIE, means the exchange is economically viable on an ongoing basis and, most importantly, that the HIE generates enough revenue to offset its operational costs and provide sufficient incentive for the owners or operators of the HIE to maintain it. This chapter describes some of the challenges associated with sustaining HIEs at all levels and highlights some of the approaches and business models adopted by HIE initiatives in an effort to ensure sustainability.

While many industry observers view independence from federal funding as a prerequisite for sustainability, that fact that an HIE initiative does not rely on federal funds does not make it sustainable unless it will be able to operate at least at a break-even level. According to the 2010 eHealth Initiative survey, of the HIEs surveyed that said they were not dependent on federal funds, fewer
than 17 percent (18 HIEs) reported sufficient operating income to break even. The fact that there are at least 18 HIE initiatives that appear to be sustainable suggests that sustainability can be achieved and the approaches adopted by current HIE initiatives should provide some insight to identifying operational models that work and those that do not.

The problem of sustainability is met by HIE initiatives at the federal level, as well as those at regional, state and local levels. The primary federal government health information exchange initiative is the Nationwide Health Information Network, managed by the U.S. Department of Health and Human Services (HHS) through the Office of the National Coordinator for Health Information Technology (ONC). The Nationwide Health Information Network provides no physical infrastructure for health information exchange, but does establish a set of data and technical standards, service specifications and policies that are intended to enable secure information exchange among public and private sector health care organizations.

Since its initiation in 2004, the Nationwide Health Information Network has evolved through architectural design, trial implementation and limited production phases to its current status in which health data is exchanged among a small group of federal agencies and non-federal organizations under grant or contract with federal entities. To continue to expand and achieve the vision for the Nationwide Health Information Network as a national mechanism integrating large numbers of participants, ONC must address many of the same sustainability issues faced by state and regional HIEs, including those related to managing governance, establishing legal standing, protecting security and privacy and defining an effective operational model.

**Seeking a Business Model for Health Information Exchange**

The Health Information Technology for Economic and Clinical Health (HITECH) Act contained within the American Recovery and Reinvestment Act included a variety of provisions offering financial incentives to health care providers to adopt and “meaningfully” use health information technology, such as electronic health record systems. It also directed ONC to perform a variety of activities “consistent with the development of a nationwide health information technology infrastructure that allows for the electronic use and exchange of information.” (P.L. 111-5, §3001(b)).

What is not explicit in the HITECH Act is what funding, if any, should be specifically allocated to establishing or operating such an infrastructure. While several programs established under HITECH provided grants or other federal funds to regional and state HIE initiatives, the emphasis at the federal
level has been on identifying and specifying sufficient health IT standards and interoperability mechanisms to try to ensure that the many disparate HIEs across the country will be able to share data across, as well as within, the boundaries of each HIE.

ONC awarded no fewer than a dozen contracts in 2010 to help further the development and recommended implementation of standards for health information exchange. As the work specified in these contracts is completed, participation in the Nationwide Health Information Network should become a viable option for a much larger set of entities, at which point ONC may be able to determine an operating model for the Nationwide Health Information Network that will allow the government to reduce or eliminate its role running and maintaining the Nationwide Health Information Network Exchange, although its oversight role is likely to remain.

ONC has long suggested that at some future point in time and maturity of the Nationwide Health Information Network, one or more private sector organizations will take over operation of the Nationwide Health Information Network and directly provide infrastructure services used for health information exchange or manage the information flow among health information exchange participants. To expect a commercial or non-profit entity to step in and provide HIE services for the Nationwide Health Information Network, even using the Internet for technical infrastructure, there needs to be a revenue source or other business opportunity to attract service providers.

The lack of incentives for non-government entities to provide infrastructure, security, monitoring and other necessary services for the Nationwide Health Information Network will likely require the federal government to continue to significantly support the Nationwide Health Information Network and avoid slowing health IT adoption. In the absence of federal-level coordination of infrastructure development efforts and corresponding funding dedicated to those efforts, health information exchange capabilities may be provided separately and incompatibly at regional or state levels, frustrating the widespread interoperability goals the Nationwide Health Information Network is intended to achieve.

One possible way to provide incentives for running regional or national exchanges such as the Nationwide Health Information Network would be to establish a service- or record-based transactional system in which health information exchange participants would be paid for providing the data requested by other exchange participants. If the widespread adoption of health IT actually results in producing the sort of cost savings so often projected, some portion of any savings to be realized could be allocated to paying the owners or
stewards of data made available for exchange in HIEs. In theory the amount of money involved could be quite small and still provide the necessary financial incentive to potential service providers. Such a system would be analogous to the per-transaction interchange fees (typically under 50¢) associated with the completion of automated teller transactions, where the fee is paid by the ATM card issuing bank and received by the acquiring institution and the interchange provider.

Having a financial incentive built into health information exchange could simultaneously foster greater adoption and help participating entities maintain compliance with various privacy and security requirements. If, for instance, the holder of a health record was entitled to a payment each time the record was accessed or information from it was sent to a requester, not only would record holders have an incentive to make the data available for exchange, but by logging each transaction in order to generate billing records, the record holder would also produce an accounting of disclosures as required under HIPAA.

Laws governing health information exchange, particularly including HITECH and HIPAA, impose constraints on covered entities and business associates in terms of how much they can charge for data in electronic health records when providing to others who request it for a variety of different purposes. The HITECH Act strengthened regulatory prohibitions on the sale of electronic personal health information, generally requiring that covered entities and business associates are not allowed to receive remuneration in exchange for protected health information about an individual unless they have been authorized by the individual to do so (P.L. 111-5, §13405(d)).

The law allows for several exceptions when remuneration is permitted, notably including when the purpose of the exchange is for public health activities, research, treatment or health care operations, but the language used in the law strongly implies that the amount of any remuneration should be limited to the costs associated with preparing and transmitting the data. The result is a regulatory scheme that allows little room to establish a market for individually identifiable health data, which may have the effect of limiting the potential return on investment for entities that might establish infrastructure or services to support health information exchange.

There are few legal restraints, however, on the ability of exchange providers to charge health care entities (such as providers, hospitals, insurance plans or integrated delivery networks) for access to an exchange and the services it provides, whether or not the exchange enters into a formal business associate arrangement with the health care entities. This presents an alternative business model for sustaining HIEs that may not be available for health IT initiatives of the health care organizations that participate in the exchanges. Transaction
or subscription fees charged to providers, payers and other HIE participants are sources of revenue employed by some of the largest and most financially stable operational exchanges, including the New England Healthcare Exchange Network (NEHEN), Indiana Health Information Exchange (IHIE) and HealthBridge.

These and some of the other most prominent operational exchanges often held up as examples of sustainability all operate as non-profit organizations and all were initiated well before the recent government emphasis on health IT. The vast majority of current HIE initiatives were driven at least in part by new legislation and associated federal funding opportunities. Through the provisions of the HITECH Act alone, billions of dollars in federal grants were awarded to state and regional initiatives, including 56 state-designated entities (SDEs) receiving grant awards through the State Health Information Exchange Cooperative Agreement Program; 62 Regional Extension Centers (RECs) funded through the Health Information Technology Extension Program; and 17 established HIEs receiving additional funding and recognition as model exchanges under the Beacon Communities Program.

The influx of federal dollars to these HIE initiatives is likely to enable the achievement of these programs’ primary objective, which is to establish health information exchange capabilities. To move beyond the establishment phase into long-term operations and maintenance, many health information exchanges will need to take proactive steps to put organizational structures and operating models in place that will sustain the momentum created through federal funding.

**Challenges to Making HIEs Sustainable**

Regardless of the business model or models adopted by health information exchanges, there are a number of obstacles currently faced by HIE initiatives that threaten their ability to achieve sustainability. These include practical challenges such as a lack of understanding of the potential value of health IT, a concern exacerbated by the relative immaturity of so many HIE initiatives and the need to achieve widespread use of health IT before evidence of significant cost savings or service improvements can be demonstrated. In this respect the expanded use of HIEs reflects a classic conundrum: HIEs need greater levels of participation in order to produce intended benefits, but potential participants want to see evidence of benefits before agreeing to participate. Health IT adoption, like any technology-enabled transformation, involves significant and potentially disruptive changes to current health care practices and in many cases requires new or unfamiliar skill sets among health care practitioners or the resources that support them.
Section 2: Key Enablers

Federal funding programs like the EHR incentives available to health care providers who demonstrate “meaningful use” of EHR technology are intended to mitigate some or all of the financial burden of adopting health IT, but many organizations still face significant cost and effort in order to assimilate and adapt to new technologies. For all of these reasons, HIE initiatives need to provide training and outreach to participants along with technical capabilities and services. These initiatives also need to ensure that the services they provide are easy enough to use and produce the expected results when used, to avoid discouraging new users.

While enormous efforts have been made to date to determine and develop appropriate standards to enable health IT and, especially, to make different entities’ health IT systems interoperable, some gaps in health IT standards remain. Where available or agreed upon standards are incomplete to support comprehensive solutions, different HIE initiatives are likely to fill gaps in different and potentially incompatible ways. Even where consensus exists on particular standards, there may be variations among entities in the way those standards are implemented that result in less interoperable solutions than intended.

For example, many HIEs have adopted the Health Information Technology Standards Panel (HITSP) C32 component standard for exchanging summary medical record information, which in turn relies on the HL7 continuity of care document standard. The C32 includes a wide variety of coded and free-text data fields, which can be populated and rendered in different ways depending on the specific implementation decisions made by an organization using the standard. This means that the interoperability anticipated through the adoption and use of the C32 standard may not be realized in practice, unless different participants involved in health data exchange using C32 also agree on the way data should be written to the C32 schema (for instance, when medical record data is extracted from an EHR system), they may process, display or transfer data from C32 messages in inconsistent ways.

Many would-be HIE participants also lack the technical capacity or staff knowledge to implement and manage some of the technologies needed for successful data exchange. For instance, both Nationwide Health Information Network Exchange and Direct, as well as many state HIE initiatives, rely on digital certificates within a public key infrastructure (PKI) model in order to provide security for data exchanges. While large health care organizations like hospitals and health insurance plans would likely be able to install, configure and use certificates to support data exchange, such abilities are less often found among the small providers that deliver roughly half of the health care services in the United States. To the extent that HIEs can offer participants enabling
services like data encryption, messaging and technical support for health IT systems, the HIEs may be able to facilitate participation and thereby augment the value of their exchanges and enhance prospects for sustainability.

A further challenge to interoperability – and by extension, utility and sustainability – among different HIEs is the tendency by many state and intra-state regional HIEs to focus on exchange capabilities and services only within the user community defined by the HIE and not on inter-state, regional or nationwide operations. There are reasons that help justify decisions to limit the scope of HIE initiatives to the state level, including the way federal grant funding has been allocated and the desire by some state-designated entities to provide capabilities to resident health care providers to help satisfy meaningful use requirements for data exchange.

Federal initiatives like the Nationwide Health Information Network offer a possible resolution to this problem, as state-level HIEs could potentially achieve integration with other HIEs simply by becoming participants in the Nationwide Health Information Network. In September 2010, Indiana became the first state participant in the Nationwide Health Information Network, with the Regenstrief Institute using the Nationwide Health Information Network to send public health information on behalf of the state to the Centers for Disease Control and Prevention (CDC). As the number of operational HIEs continues to grow, achieving inter-HIE integration via the Nationwide Health Information Network may become an increasingly attractive option for state and regional HIEs, especially compared to the effort required to establish multiple HIE-to-HIE connections.

The HITECH Act not only established a number of federal programs to fund HIE initiatives, it also directed HHS and other government agencies to develop policies, regulations and requirements for many aspects of health IT relevant to health information exchanges, including governance, standards compliance and direct accountability of business associates (as HIEs are often categorized) for complying with requirements in the HIPAA Security Rule and Privacy Rule. Even HIEs set up explicitly without government involvement are subject to compliance with these policies, standards and regulations, a situation made more complicated by the fact that some of the rules and regulations that HITECH mandated have not yet been produced.

**Current Approaches to Sustainability**

Regardless of the business model in place or availability of public funding support, the nature and amount of use of health information exchanges are contributing factors to sustainability. Active use of a HIE is important not
only to demonstrate viability of the operation, but also to provide a basis for
determining the appropriate mix of data, services and purposes for the HIE that
will produce value to participating organizations and, therefore, make the HIE
a useful resource. In this sense, the idea of sustainability is often characterized
in terms of establishing a “critical mass” of HIE usage, after which point the
continued realization of benefits serves to retain current users and attract new
ones.

Much of the federal grant funding awarded to state and regional HIE
initiatives is intended to provide sufficient financial support to enable the HIEs
to reach this point. In order to reach a level of use that will help sustain HIE
initiatives, those responsible for planning, implementing and operating HIE
need to look at ways to encourage active use of the services offered. When the
set of potential HIE users is defined to include all health care providers and
associated professionals, it should be clear that not all HIE participants will fill
roles as both information providers and information consumers - or will not
fill those roles equally.

It is also important to recognize that the incentives that drive participation
in terms of making data available to an HIE are often quite different than
the incentives that drive use. From a legislative perspective for instance, the
federal funding available to eligible health care providers and professionals
demonstrating “meaningful use” of health information technology requires
that EHR systems be able to exchange health information with other sources,
but does not require users of such technology participate in HIEs in order to
conduct data exchanges.

The level of participation is also an important factor in making an HIE
initiative sustainable, both in terms of securing participation of health care
entities in newly established HIEs and for maintaining active participation
among entities who may be served by an HIE over time. Exchange initiatives
sometimes focus too much on technical infrastructure and data exchange
mechanisms and standards without giving equal or greater emphasis to
ensuring that entities are willing and able to participate and that the HIE
provides sufficient data and services to deliver value to its users. Several early-
phase state initiatives have encountered the “empty HIE” problem, in which
HIE services are made available to participants, but only limited health data is
available for sharing through the HIE.

Providers and other potential HIE users who attempt to use HIEs and
do not find the information they need are unlikely to continue to try. The
willingness of health care entities to participate in HIEs is driven by a variety
of factors (some of which may not apply to some prospective participants)
including technical competency, organizational policies, legal and regulatory
requirements, initial and ongoing costs of participation, anticipated or realized value from participation, purposes for use supported by the HIE and provision by the HIE of adequate security and privacy protections, including support for managing consent to disclose data in medical records or other health information about individuals.

When it comes to funding operations, there are several different approaches HIE initiatives use to produce revenue, many of which are used together. The funding model used by a given HIE is driven by a number of factors, particularly including its organizational structure and characteristics such as whether HIE participants are members or partners in the HIE or non-member users of the services offered by the HIE.

Sources of funding in use today include:

- **User fees** paid by HIE participants such as hospitals, health care systems and integrated delivery networks, physicians, laboratories and public and private sector payers, including health insurance plans and accountable care organizations. These fees can take the form of ongoing subscription or membership dues, initial participation fees paid at the time an entity signs on to participate in the HIE or incremental charges associated with particular services offered by the HIE (for example, different fees for participating in public health reporting versus participating in health data sharing in support of treatment).

- **Transaction fees** charged to participants as they use the services provided by the HIE. Transaction-based funding requires a mechanism that allows the HIE to track actions performed by participants and in many cases to distinguish among requests or communications that do not incur charges (such as a participant lookup) and those that do (such as retrieval of health records by a requester from a respondent).

- **Fees assessed by the state** (or with the approval of the state) to support HIE services offered as a sort of public utility. This model considers health information exchange as a type of public good and funding for HIEs under this model may be provided through assessments paid by health care industry participants, business licensees or individual citizens and organizations through taxes collected by the state and allocated to fund HIE operations.

- **Fees charged for the sale of data**, including data used for research or public health activities and for advertising and marketing purposes (subject to regulatory limitations). Many states already generate revenue from the sale of data in records such as those maintained by motor vehicle departments and active markets exist for both personally identifiable and de-identified data contained in health records. Any decision to try to generate revenue
through the sale of personal health data must consider federal and state legal constraints and conditions placed on remunerated health information disclosures, including how much HIEs can charge, allowable purposes for which data can be sold and the need to obtain consent from individuals prior to sale.

- **Federal or state grants** available to HIEs to enhance or expand services. In contrast to federal funding initiatives that are intended to support the initial establishment of HIEs, such as the State Health Information Exchange Cooperative Agreement Program, opportunities exist for HIE initiatives to receive additional funding to augment health IT infrastructure and HIE capabilities. Several grant programs also exist to help HIEs provide technical and practical assistance to health care providers and other organizations to implement health IT and become active participants in health information exchanges. To date, high visibility initiatives like the Beacon Community Cooperative Agreement Program have rewarded HIE initiatives that have already established core infrastructure and services.

No single “best” operational model has emerged among current HIE initiatives and, as noted above, many HIEs use a combination of funding sources to generate operating income. While some of the more established HIEs are notable for their structure as non-profit organizations, other alternative structures also appear viable, including for-profit, public utility and public-private partnership models. The collective experience of many state and regional HIEs suggests that sustainability can be achieved using different approaches, as long as effective governance structures and a suitable business model are put in place.

### Sustainability for Federal Health Information Exchange Initiatives

Sustainability for current federal government-sponsored health information exchange initiatives such as Nationwide Health Information Network Exchange and the Direct program (formerly known as “Nationwide Health Information Network Direct”) can logically be measured only in terms of participation and adoption of the standards and services they specify, because users of these federal initiatives do not pay the government for their use. The emphasis of these federal programs is to facilitate the direct interaction of health care entities so that data exchange can take place, but data that is exchanged is not transmitted through infrastructure or services owned or managed by the government. The Direct program is intended to facilitate point-to-point data exchanges between health care providers or other entities that are known to each other and involves no common infrastructure or centrally provides services.
In contrast, Nationwide Health Information Network Exchange offers a centralized registry of participants and the services they offer. It also centrally manages the digital certificates participating entities use to authenticate themselves to each other, but actual data transmissions are conducted over point-to-point communication between two participants, as illustrated in Figure 1. Through 2010, participation in Nationwide Health Information Network Exchange has been limited to federal agencies and non-federal organizations operating under government contracts or grants, in part because the governance processes and legal framework that would allow independent participation by non-federal entities has not been put in place.

![Figure 2: Data exchange using the Nationwide Health Information Network occurs between gateways, on behalf of or triggered by requests from participants' internal systems.](image)

Where sustainability is tied to levels of participation, it is essential for federal health information exchange initiatives to provide security and privacy protection for accessed and transmitted using the exchanges and to deliver functionality desired by participants. One noticeable difference between Nationwide Health Information Network Exchange and Direct is in the area of trust – specifically the extent to which exchange participants are expected to trust each other. Supporters and detractors of federal health data sharing initiatives seem to agree that trust is a prerequisite to successful health information exchange and that the long-term viability of health IT in general depends on establishing and maintaining trust among the stakeholders involved.

The basic trust model proposed for Direct is much more explicit than the trust framework being developed for the Nationwide Health Information Network in terms of what “trust” actually means in a health information exchange context and on the extent to which participants involved in exchanges can agree on policies, standards and controls intended to support trust. To its credit, the Direct project candidly acknowledges that different policies and assumptions will apply to different participants in different contexts, so the Direct basic trust model limits the scope of what any assertion of trust
actually covers and allows for the possibility (even the expectation) that a given organization may participate in multiple exchanges governed by different sets of policies or rules.

The Direct approach has no central authority to assert trustworthiness of participants and no assumptions of trustworthiness among participants. Because Direct participants are expected to make their own determinations about the relative trustworthiness of others, Direct users can participate in limited or incremental ways if they choose and over time expand the set of other participants with which they agree to exchange data.

By contrast, Nationwide Health Information Network Exchange relies on a central (or root) authority that makes determinations of trustworthiness for all potential participants, with the presumption that only trustworthy entities will be allowed to participate. Nationwide Health Information Network Exchange participants sign a legal document called the Data Use and Reciprocal Support Agreement (DURSA), which is intended to serve as a master trust agreement applying the same permissions, obligations, expectations and constraints to all exchange participants in all of the information exchange contexts it covers (treatment, payment, health care operations, public health activities, reporting on clinical quality measures and other uses authorized by individuals to whom the data pertains).

By executing the DURSA and participating in the Nationwide Health Information Network, participants do not actually agree to trust each other directly, but they do agree to acknowledge and accept that different participants may have different policies, practices and security controls in place. This means that a participant must rely on the determination of the Nationwide Health Information Network governing authority (who approves applicants for participation) that the policies and controls used by an approved participant are sufficiently robust and gives participants no real ability to question the approach that another participant takes to areas like security. The intent to use a single overarching trust model for the Nationwide Health Information Network is based on assumptions of feasibility: if Nationwide Health Information Network participants someday number in the hundreds or even thousands, negotiating trust between pairs or among small sub-sets of all those participants simply is not practical.

By positioning a common, trusted authority in the middle, all that should be required to achieve trust throughout the Nationwide Health Information Network is for each participating entity to establish a trust relationship with the Nationwide Health Information Network governing authority. What this means for prospective participants is that a decision to participate in the
Nationwide Health Information Network is a decision to make and receive requests for data exchange from potentially all other participating entities. As the number of Nationwide Health Information Network participants grows, the prospect of exchanging data with many other entities may be both an incentive and an obstacle to organizations considering applying to join the Nationwide Health Information Network, depending on the level of confidence they have in Nationwide Health Information Network governance and their willingness to delegate decisions about the participation of other entities to the governing authorities.
Health Care Financial Reform
The Small Picture of the Health Care Financial Landscape

The current economic down-cycle, which began in 2007, has had two immediate impacts on health care providers. The first impact came from the rise in the cost of capital and the consequent lack of access to renewable credit for entities like hospitals. By 2008, this was not a unique circumstance as organizations everywhere in the economy experienced increases in interest payments on loans.

The American Hospital Association reported that interest payments for hospitals increased by fifteen percent in 2008.26 Increased interest payments for health care providers have resulted in a decline in investment gains and an acceleration of debt in an environment of higher collateral requirements. The impact to capital expenditure planning within organizations has been significant in the context of health care reform. It is difficult to discuss the nuances of improving health care delivery if balance sheet requirements are affecting investment in the information technology needed for support.

The second impact to health care providers was the exacerbation of uncompensated care. Unemployment in the United States rose from a rate of 4.4 percent in March 2007 to 10.2 percent in October 2009.28 The American Hospital Association reported an eight percent increase in uncompensated care from 2007 to 2008 and noted that the Centers for Medicare and Medicaid Services (CMS) attributed the enlargement principally to the rise in the unemployment rate.29

Similar to the increases in interest payments, the increases in uncompensated care have created negative externalities for providers. Increases in uncompensated care have meant decreases in private insurance enrollment and decreases in private insurance enrollment have meant an increase in the percentage of national health spending by the federal government. Because the existence of larger insurance payers like the federal government affects the ability of provider organizations to negotiate reimbursement for care, this swell of uncompensated care has proven to have a significant impact. To complement this point, the federal government is predicted to fund over fifty percent of all

---

27 Ibid
national health spending by 2016 when anticipated numbers of baby boomers who are eligible for Medicare are also included in the analysis.\textsuperscript{30}

The issues surrounding the increases in interest payments on loans and uncompensated care as a result of the current economic-down cycle produce the small picture of the health care financial landscape: financial growth constraints during a recessionary period have influenced providers to postpone, reduce or cancel the investments in technology solutions needed for improvements in health care delivery. A 2009 X3 Summit presentation outlines some of the most regularly discussed short-term proposals in the provider community.\textsuperscript{31}

- Preserving liquidity position (i.e. monetizing non-core businesses),
- Instituting operational savings plans,
- Re-adjusting capital spend rate,
- Reviewing strategic plan for prioritizing short-term capital,
- Preserving and strengthening credit,
- Large-scale health care system integration (i.e. consolidating operations to improve efficiency)

\textbf{The Big Picture of the Health Care Financial Landscape}

Health care reform proponents have been reminded recently not to take for granted investments in information technology. This wake-up call has resonated in the industry with renewed attention to the big picture in health care finance. In other words, everyone is asking, “How did it get so bad?”

\textsuperscript{31} Financing and Making the Business Case, X3 Summit; 2009.
National health spending is projected to reach more than 20 percent of the Gross Domestic Product (GDP) by 2018.\textsuperscript{32} And between 1999 and 2008, insurance premiums more than doubled.\textsuperscript{33} U.S. Senate Finance Committee Chairman Max Baucus published a report in November 2008 on the cost situation in health care. The report claims the reasons for the aforementioned statistics are, “an expansion in the use of medical technology, higher rates of obesity, the aging of the population and losses in health care delivery productivity.” \textsuperscript{34}

This list could easily be added to or elaborated: uncompensated care in general (lack of insurance coverage), medical malpractice insurance costs, lack of preventive care financial incentives and resources (insufficient chronic care initiatives) and cost shifting (large payers not paying the full cost of care). Figure 1 depicts some additional cost issues.

Another well-known and outspoken voice on cost issues is the leader of the Dartmouth Atlas Project, Dr. Elliott Fisher. For two decades, Dr. Fisher has studied regional variation in Medicare spending.\textsuperscript{35} What the previous list of cost issues leaves out is the fact that differences in health care spending rates are best explained by the volume of services received by similar patients.\textsuperscript{36} This is what research from Fisher and others at Dartmouth has shown. And a report by the U.S. Congressional Budget Office (CBO) has supported the findings as well.\textsuperscript{37}

\begin{itemize}
\item Call To Action: Health Reform 2009, Senate Finance Committee Chairman Max Baucus (D-Mont.); Nov. 2008.
\item Ibid
\item A Dartmouth Atlas Project Topic Brief, Dr. Elliott Fisher; Feb. 2009.
\item The Cost Conundrum: What a Texas town can teach us about health care, A. Gawande, The New Yorker Annuls of Medicine; June 2009.
\item Geographic Variation in Health Care Spending, Congress of the United States Congressional Budget Office; Feb. 2008.
\end{itemize}
The crucial fact of our financial circumstances is that there is a problem with excess utilization of health care resources and nowhere is there more demonstrable data than in Medicare. “Nearly thirty percent of Medicare’s costs could be saved... if spending in high- and medium-cost areas could be reduced to the level in low-cost areas,” (Peter Orszag, 37th Director of the Office of Management and Budget).38

The problem of excess resource utilization has revealed that health care financial reform directly concerns health care delivery reform and vice versa. It is not just a matter of investments in technology. To proceed with a comprehensive analysis of financial remedies, one must ask how quality of care delivery objectives are met and determine if there is common ground for moving forward. Many of those who have studied the recent literature on health care reform have probably encountered the idea that could bring about a solution - care coordination.

**Understanding Key Aspects of the Care Coordination Discussion**

The most common element of the care coordination discussion is the emphasis on the free flow of ideas: clinicians using electronic records management tools to capture and utilize data, as well as conducting peer-review committees (critical assessments) to go over patient cases and share lessons learned from experience, treatment information, training information, new tools, new resources, new processes and best practices. Electronic medical records initiatives are definitely important to the subject of care coordination. In 2006, four out of five of those surveyed ranked “coordination of care across care settings” as the number one benefit of an EMR.39 So along with the development of the EMR, patients desire critical assessments among physicians.

Widespread approval of the care coordination concept is also a by-product of successfully deployed regional information networks and local care transition projects in many parts of the country. These projects have focused teams of providers on targeted education and communication efforts using electronic predictive models to provide patients with coaches for medication, diet and symptom management.40 41 EMR initiatives, collective critical assessments and co-management of local care transition projects have given care coordination a good name among reform proponents in terms of quality improvement.

---

40 *Discussion Grows over Hospital Readmissions*, S. Harris, Association of American Medical Colleges; June 2009.
The small picture of health care finance has caused us to re-think the big picture. Industry experts have agreed that the root of the problem is excess utilization of care. With this issue in the forefront, quality improvements in health care delivery have become a financial priority. If technology innovation and provider collaboration continue to improve quality in a way that is acceptable to all stakeholders, then one can foresee care coordination as the key principle for health care delivery moving forward.

The concept of care coordination is evident outside of care delivery as well. In increased efforts with financial management staff, hospital administrators have become more involved in studying cost reduction and cost containment: “utilization statistics, seasonal trends, staffing models, productivity analysis, supply alternatives, inventory management, make/lease/buy options and the variety of ways of determining costs.” ⁴² Changes in security, privacy and accounting requirements have improved coordination between financial managers and information managers. The following is a list of many of those changes:

- Performing Federal Information Security Management Act (FISMA) equivalent security self-assessment[s] based on National Institute of Standards and Technology (NIST) standards.” ⁴⁴
- Overall privacy policies and security measures to protect patient health information under the Health Insurance Portability and Accountability Act (HIPAA) ’96.

⁴³ Security Challenges and Threats, G. Sherburne, Evolvent Magazine; 2009.
⁴⁴ An Information Protection Strategy: Beyond Perimeter Defenses, M. Nanton & G. Sherburne, Evolvent Magazine; 2009.
Section 2: Key Enablers

- Sarbanes-Oxley Act of ’02 for Public Entities: Maintaining an internal control structure and procedures for financial reporting, implementing a code of ethics for senior financial officers, disclosure of off-balance sheet transactions and records retention.

- Evolution of Generally Accepted Accounting Principles (GAAP)

**Discharge Follow-Up and Patient Outreach**

Care coordination has been understood primarily as a combination of EMRs and peer-review committees for the sake of quality improvement. Local care transition projects have increased popularity for the idea of care coordination because they have embodied these two important constituent elements successfully. With emphasis on quality, local care transition projects in terms of discharge follow-up and patient outreach have been proven to lower preventable hospital re-admission rates when adjusted for the severity of patient cases.\(^{45}\) Re-admission rates have been reduced in some communities by as much as 50 percent.\(^ {46}\) This brings the analysis of common ground for health care financial reform and health care delivery reform full-circle.

Discharge follow-up and patient outreach reveal the concept of care coordination as the key to quality and cost issues in health care delivery improvement. It begins with regional information networks and EMRs that connect to a central hospital that exists in a large network of community-oriented primary care clinics. Comprehensive data reporting makes it possible to create electronic predictive models that can then calculate the correlation between in-patient case factors and high re-admission rates. Thus, efficient directing of education and communication efforts is simplified and enhanced.\(^ {47}\)

Education and communication efforts culminate in a patient coach, usually a nurse who has worked with the patient in the hospital.\(^ {48}\) The work of the patient coach and the collaboration between the hospital and primary care clinics determine the success of care coordination. While nurses ensure both before and after discharge that high-risk patients and their families have a complete understanding of medication, diet and symptom management, hospitals make certain that discharge summaries arrive within one business day to a primary care physician.\(^ {49}\)

\(^ {46}\) *Discussion Grows over Hospital Readmissions*, S. Harris, Association of American Medical Colleges; June 2009.
\(^ {48}\) Ibid
\(^ {49}\) Ibid
**Chronic Care Telehealth**

It is reasonable to assume that hospital re-admission costs mainly apply to chronic care cases. It is equally reasonable to think that long-term institutional care costs, which fall further along the same continuum as hospital re-admission costs, almost exclusively apply to chronic care. An example of a current delivery modality, in which care coordination can account for both the quality and cost issues of chronic care (in the particular instance of long-term institutional care), is home telehealth.

A great case study for home telehealth is the Veterans Health Administration’s (VHA) Care Coordination/Home Telehealth (CCHT) program that was implemented between July 2003 and December 2007.\(^{50}\) Thirty-two percent of VHA treated veterans lived in rural areas prior to the program.\(^{51}\) The VHA was creative and prudent in its choice of a home telehealth delivery modality for two reasons. The decision accounted for needed technology innovations to address unique access and quality challenges and the decision accounted for long-term institutional care concerns and costs.

Care coordination in the CCHT program is managed by a coordinator, caregiver and physician. When a patient is enrolled into the program, a coordinator selects the proper home telehealth technology, provides the necessary technical instruction to the patient and caregiver and consults with the patient’s physician about the essential medical data to acquire for regular monitoring such as “appropriate vital signs” and “other objective parameters” like blood glucose.\(^{52}\)

Based on the case assessment with the physician, care coordinators are responsible for performing a daily “risk-stratification” according to the “preset thresholds” of the agreed upon medical data. If, for instance, a patient’s data displays that he or she has out of range blood pressure, then the care coordinator informs the caregiver who then assists the patient with self-management while medical assessments are performed with the use of home telehealth technology. The CCHT program is not intended to replace emergency services in life-threatening situations. The aim is to monitor essential vital signs and to help patients avoid preventable acute events through self-management.\(^{53}\)

---

50 Care Coordination/Home Telehealth: The Systematic Implementation of Health Informatics, Home Telehealth and Disease Management to Support the Care of Veteran Patients with Chronic Conditions, A. Darkins, Department of Veteran Affairs, Office of Care Coordination Services, Washington, D.C.; 2008.
51 Ibid
52 Ibid
53 Ibid
The success of the local care transition projects previously mentioned is also evident in the CCHT program. Every three months, patients and practitioners are surveyed. Outcomes analysis in 2008, one year after the program was fully implemented, showed high satisfaction (86 percent) among patients and that practitioner feedback was also favorable to the program. To once again prove the inevitable relationship between cost and quality in health care, the outcomes analysis of health care resource utilization of CCHT patients determined a 19.74 percent reduction in hospital re-admissions just six months after full initiation.54

**McAllen, Texas and the Mayo Clinic**

The question of, “How did it get so bad?” should be modified to, “How does one compare McAllen, Texas and the Mayo Clinic?” But first, recapturing the steps of the analysis would be useful:

1. Recent impacts to capital expenditures in investment technology have helped to reinvigorate the discussion about health care financial reform.
2. Industry experts agree that the volume of services received by similar patients best explains big differences in health care spending rates.
3. The problem of excess resource utilization has revealed that health care financial reform directly concerns health care delivery reform and vice versa. Hence, quality improvements in health care delivery have become a financial priority.
4. The idea of care coordination has continued to gain popularity among health care reform proponents because of improvements in electronic records technology and successful examples of provider collaboration (i.e. local care transition projects).
5. Current delivery modalities that use care coordination, including discharge follow-up/patient outreach and chronic care telehealth, bring the analysis of common ground for health care financial reform and health care delivery reform full-circle both in terms of stakeholder satisfaction with quality and reductions in costs like hospital re-admission rates.

---

54 *Ibid*
The next step is to prove that quality and cost are inversely related in health care. Improvement in care delivery (care coordination) reduces relative high spending (hospital re-admission rates). But this full-circle of analysis can also be traced in the opposite direction. McAllen, Texas is a good example.

In 2008, Medicare paid twice as much per person in McAllen than it did in cities with similar population characteristics. McAllen patients received more diagnostic testing, more hospital treatment, more surgery and more home care, yet there was no evidence of improved patient satisfaction with care access and quality. Instead, patient feedback in McAllen supported evidence from other parts of the country of a correlation between a decline in quality and relative high spending.

In 2008, Medicare paid the most per person in Louisiana, Texas, California and Florida and all four states were near the bottom of national rankings in quality of patient care. Patients in these states were “less likely to receive low-cost preventive services, such as flu and pneumonia vaccines, faced longer waits at doctor and emergency-room visits, [and were more likely to have] complications…from hospital stays, medications, procedures and tests.”

Lower quality of patient care in high spending areas, highlighted by McAllen, Texas, proves that quality and cost are inversely related in health care. Higher costs (over-utilization) are associated with lower quality (negative patient perceptions). This points again to the importance of how quality and cost are reconciled in health care reform: care coordination. If a comprehensive understanding of the mutual relationship and solution of quality and cost has been accomplished, then it is possible to deal with the big picture of health care financial reform and to ask the more targeted question of, “How does one compare McAllen, Texas and the Mayo Clinic?”

The Mayo Clinic has one policy that provider organizations in McAllen, Texas do not have. That policy is not less expensive care, but more coordinated care. The Mayo Clinic realized decades ago that to succeed at care coordination would require changing the financial incentives for providers, so they began paying everyone on salary instead of McAllen-style fee-for-service. Comparison on the basis of payment methods is valid because payment methods can influence quality improvements such as more care coordination and care coordination is the proven solution to the two most important issues to health care financial reform - quality and cost.

56 Ibid
It is not a coincidence that Medicare spending per patient at the Mayo Clinic is less than in other places in the country with similar patient demographics. Habitual occurrences of care coordination such as the following description are the reason: “In the transplant ward, ten physicians, nurses and other staff members gathered for an hour…to review patients. If [the] director of [the] transplant center had a concern about potential infections, he could turn to the infectious-disease specialist in the room.” Dr. Denis Cortese, former CEO of the Mayo Clinic, puts it best when he explains the simple reality of cost reduction and care coordination, “When doctors put their heads together in a room, when they share expertise, you get more thinking and less testing.”

The comparison between McAllen, Texas and the Mayo Clinic is about how payment methods can incentivize providers to coordinate care. The previous discussion of discharge follow-up/patient outreach and chronic care telehealth was about the existence of current delivery modalities that use care coordination. Combining payment methods that incentivize care coordination with consistent delivery modalities is to create what the U.S. Congress has called an Accountable Care Organization (ACO).

According to the House Tri-Committee Health Reform Bill (HR 3200), an ACO is a group of regional providers (primary care physicians, specialists, hospitals) that are capable of responsibility for quality improvements in care delivery because of small picture financial incentives to coordinate as a team across entities. The bill proposes that patient assignment to an ACO be based on claims data so that assignment changes can occur on the basis of obvious preference.

---

58 Ibid
61 House Tri-Committee Health Reform Bill (HR 3200); July 2009.
A Knowledge Junction-Style Challenge

Health care financial reform culminates in the single proposal of the ACO. This is in conjunction with the fact that current provider payment methods and delivery systems have voluminous variety. There is a need for high-level standardization (i.e. payment methods and delivery modalities) and there is a need for great flexibility in terms of means of adoption (i.e. appropriate and adequate financial incentives and contract agreements). The relationship between these two specific kinds of needs has also come up in the literature on knowledge management.

Knowledge Junction is a principle for developing knowledge management standards in a large organization. The idea is that standardization in a large organization has to combine all forms of knowledge that are “fundamental” to the organizational “intranet.” 62 To translate: successful standardization on a large-scale requires understanding the fundamental end goal.

Payment methods that incentivize care coordination and consistent delivery modalities are the basis of an ACO. The end goal of an ACO is to implement incentive structures that include penalties if providers fail to sustain improvements in care coordination. With this fundamental understanding of an ACO, industry supporters of the proposal can have greater flexibility in adopting appropriate and adequate financial incentives and contract agreements. If these efforts are successful, it may be possible to redesign the landscape of health care delivery with more quality and less cost.

Better Data for Better Care – The Art of the Possible

So far, we have considered a vision of the future, explored a scenario of two divergent future states and deeply examined three of the critical enablers for a transformational change in health care. In this section, our writers delve into operating concepts, key applications of technology and key technology tools for both accelerating and reinforcing transformation. Before we look at each of these component parts, I would like to reiterate our principles presented earlier:

- How we deliver care can be fundamentally changed, extended, supported, and enriched by a host of different operating concepts that are made possible by changes in technology.
- The cost of care can be radically changed through better use and exchange of information.
- The quality of care can be dramatically improved through better use and exchange of information.
- Transforming health care really is about how we design the delivery of care and how it is supported by better data for both consumers and providers.

Major Health Care Players are Already Transforming Care as We Know It…

When we speak of transformation and the necessity of it, and the enablers that are essential – it is often easy to assume that this is all futuristic and unreal. In the following essays, our writers will cite example after example of those who are transforming care now. This is not pie in the sky – this is really happening.

Our teams are using telehealth technologies to extend access to care for wounded warriors. Our clients are implementing patient-centered medical home programs on a global basis, literally across millions of patients. Health information exchange is working to reduce the cost of care – and social networking is harnessing the “wisdom of crowds” to make the patient smarter and more articulate as they engage providers.

The first set of essays is about operating concepts and trends that are impacting the transformation of the health care sector. In each of these writings, we have identified applications and technologies that are working and driving value.

Consumer Empowerment explores the concept that consumers should have more control in the use of their health care dollars. Information transparency, real cost information and comparative treatment op-
tions are really help return market power and decision-making capac-
ity to the consumer.

**Patient-Centered Medical Home** explores the approach to providing primary care and care coordination services which facilitates partnerships between individual patients, physicians, and, when appropriate, the patient’s family.

**Telehealth** speaks to the successes of the delivery of care through communications technologies and projects across the country. Moving beyond patient consults through video-teleconferencing to a full suite of telehealth applications including monitoring and training modalities, telehealth programs are increasingly measuring real ROI in improved access to care and reduced costs.

The next set of essays focuses on specific applications and functional areas for transforming care.

**Health 2.0 and the Future of the PHR** describes patient focused Internet tools such as personal health records including a discussion of the differences of the major products. Additionally, this essay looks at social networking applications, and other chronic disease management applications emerging on the Internet today.

**Mobile Health Care** explores the current and possible impact of mobile devices (smart phones, PDAs, tablet PCs and the emerging impact of iPads). New and emerging impacts of the whole field of mHealth from both the provider and patient perspective including possible improvements to clinical workflow, patient care, and customer service are identified as well as an overview of the wide range of “apps” that are growing exponentially for the patient and their family.

**Clinical Research** points to emerging models of conducting research that are enabled by new technologies and the possibilities of interoperable and accessible data stores. Correlation, pattern recognition, classical data mining and the movement toward real-time analytical capabilities all demonstrate that health care can begin to move into a less static and more time and care sensitive model for the patient and population specific research need.

**Finally, in the Afterword,** we turn to how these six essays and our future state can be successful given the involvement of different actors in the daily drama of health care. A set of ideas are proposed in line with our principles for what we can do to operationalize the concepts explored for a transformed future.
Over the past few decades, most industries have significantly increased quality, while decreasing costs in response to market pressures. The health care industry, however, has been impeded in its ability to achieve similar levels of efficiency due to numerous obstacles, including regulatory and attitudinal barriers to market forces. Consumer-directed health care may be one way to help decrease costs and improve the quality of health care in the United States.

The phrase “consumer-directed health care” or “CDHC” is often used in current health care literature with terms such as “consumer-empowered health care” or “consumer-centric health care.” Regardless of the terminology used, the concept is that consumers (patients) should have more control in the use of their health care dollars.

Health care is evolving to a demand-control model with economic forces similar to those that affect all other purchasing behaviors. Although health and health care are not quite the same as purchasing other goods and services, it is clear certain trends have been impacting our economy and service industries including health care.

These include but are not limited to:

1. Personal responsibility (taking charge of one’s personnel or family health)
2. Self-Reliance (self-care)
3. Individual ownership (“skin in the game”)
4. Portability (insurance benefits, electronic health records, etc.)
5. The right to know (privacy, consent, disclosure)
6. Empowerment (right to choose)

Health care consumerism is about transforming a health benefit plan into one that puts economic purchasing power and decision-making in the hands of the consumer. It is about supplying the information and decision support tools they need, along with financial incentives, rewards and other benefits that encourage personal involvement in altering health and health care purchasing behaviors. The key here is information.

---

63 “Health care Consumerism: The Future of Employment Based Health Insurance Post PPA-CA,” Ronald E. Bachman, Center for Health Transformation, Consumerism Corner - Vol. 1, No. 8
64 Bachman
“Returning market power and decision making authority back to the individual - consumer directed health care - is critical to the creation of a 21st century intelligent health and health care system that offers more choices and better quality at lower cost.” ~Former Speaker of the U.S. House of Representatives Newt Gingrich, Founder, Center for Health Transformation

Arguably until the mid 1990s, information was not really available to health care consumers except from their local health care network, employer or maybe word-of-mouth. With the tremendous growth of Internet content and the ubiquity of computing resources, all world economies continue to experience an information explosion that is near real time in countless cases, especially considering the incredible growth in social networking including Facebook, Twitter, MySpace, etc.

The information age is unavoidable and consumer thirst for more information-based services that are both portable and content rich is changing the landscape of health care. Consumers are demanding more timely information so they can take control of their health care choices.

**Figure 4: “Health care Unwired: New business models delivering health care anywhere,” Health Research Institute, Price Waterhouse, Sept 2010**

**“Health Care Unwired: New Business Models Delivering Health Care Anywhere,” Health Research Institute**

Implicit in this idea is that economic forces push patients to take more fiscal responsibility for their health care expenditures making them better-informed and more perceptive “buyers” of health care. As in other industries, when consumers become better educated about their choices of goods and services, they demand a higher level of quality and lower costs from suppliers. In competitive markets, health service providers must compete on the basis
of both price and quality to win the business of these consumers, although in some markets, where health care resources are scarce and competition is absent, this does not apply.

Still, health care consumers can often find the services they need, often at a lower cost and with better quality by researching the World Wide Web. Those health care organizations that create a competitive advantage by effectively leveraging information technology to market their health care offerings will position themselves better as health care consumers “shop” for services.

In 2010, the Department of Health and Human Services introduced a powerful new tool for health care consumers at www.HealthCare.gov. The new Website, called for in the Affordable Care Act, is designed to empower health care consumers with relevant information to take control of their health care and make choices that are right for them according to the Department of Health and Human Services (HHS).65 Better information equals better care.

One important tool allows consumers to see price estimates for private insurance policies. This feature allows consumers to easily compare health insurance plans, putting consumers - not their insurance companies - in charge by providing one-stop shopping and taking the guesswork and confusion out of buying insurance. To help consumers make more informed choices, the site includes new information including two notable metrics never before made public:

- Insurance providers are required to provide the percentage of people who applied for insurance and were denied coverage
- Insurance companies are required to provide the percentage of applicants who were charged higher premiums because of their health status.66

Other available information includes:

- Monthly premium estimates
- Cost-sharing information, including annual deductibles and out-of-pocket limits
- Major categories of services covered
- Consumer’s share of cost for these services

66 www.hhs.gov/news
Going back to the earlier theme, information is allowing consumers to make better decisions. Consider the five key building blocks of Healthcare Consumerism according to the Center for Healthcare Transformation:

- Personal Accounts
- Wellness/Prevention and Early Intervention Programs
- Disease Management and Case Management Programs
- Information and Decision Support Programs
- Incentive and Compliance Reward Programs

History shows that before the 1960s and the coming of federal health care programs such as Medicare and Medicaid, patients in the United States paid directly out of pocket for up to 49 percent of their health care costs. As employers began offering health insurance to attract employees during periods of high economic growth, however, the landscape began to change. At the same time, the introduction of the federal Medicare program established a second large payer.

With the rise in private insurance, health care consumers became more reliant on third parties to pay their health care bills. By the 1980s, rising health care costs, rampant new diagnostics procedures and drugs continued to outpace overall economic growth and became a serious business problem for employers, insurers and health care organizations themselves. Caught in the middle, unfortunately, were the patients themselves. So plan designers and innovators created preferred provider organizations (PPOs). And these kinds of flexible programs with in and out of network options started to give the power of choice and a share of the cost back to the consumer.

Yet increasing reliance on third parties had already caused a steep decline in patient out-of-pocket costs. By 2002, patients paid only 14 percent of their medical expenses out-of-pocket; designated third parties paid the remaining 86 percent of expenses.

The major problems with the current system of private insurers, is the use of adverse selection, higher administrative costs and incentives to limit expenses at the risk of providing poor medical care. CDHC implies that patients who have greater control over their health care expenditures and greater responsibility

---

67 “Ahead of the Curve: Issues facing America: Consumer-directed health care,” Sharat Kusuma, MD; Ryan M. Nunley, MD; Aaron Covey, MD; James Genuario, MD; Samir Mehta, MD; and the Washington Health Policy Fellows, American Academy of Orthopedic Surgeons Newsletter, April 2008.
68 Kusuma
69 Kusuma
for their health care choices will, through wiser consumer demand, more efficiently allocate resources.

The initial implementation of CDHC plans on health care utilization and overall spending by patients is encouraging. Initial data from several organizations, including Aetna, Kaiser and McKinsey and Company, show that CDHC plans reduce health insurance costs for employers and significantly slow the rate of cost increases for such plans.70 71


71 Rand
For example, data from Humana and Aetna revealed that costs for employees in CDHC plans increased an average of 3.6 percent to 6 percent annually (2003-2004). During the same time period, employers with traditional indemnity plans experienced rate increases of 10 percent to 20 percent.72

Data on utilization of health care resources are also encouraging. One study has shown that individuals with high-deductible plans did indeed cut back on utilization with no adverse effects on their health status. This is significant. CDHC patients were also more likely to use cost-effective preventive care measures and were much more apt to comply with treatment regimens for chronic conditions such as diabetes and hypertension.

Considering the US economy cannot sustain the current trend toward increased health care spending, which is predicted, under some scenarios, to consume a staggering two-thirds of the U.S. gross domestic product by the year 2050, informed consumers will hopefully drive down health care costs while also forcing higher quality to slow down this crippling negative economic indicator.73 74 75

---

72 Rand  
73 Kusuma  
From Harvard University’s Regina Herzlinger, to business guru Michael Porter, policy experts are emphasizing the importance of reintroducing the consumer as a market force back into the health care sector as a way to manage business costs and improve overall quality...in comes consumer-directed health care plans.

Studies have shown that when patients are exposed to the cost of health care treatment and procedures, they tend to select the best and most cost effective options and not the cheapest or most expensive. They tend to gravitate towards the ones that are most rational.76 This trend of trying to engage the consumer as an active participant in that decision is very much part of the vision of health care in the future. IBM’s health care 2015 Care Delivery document describes the future world of activating health consumers. Moving them from a “fix me” mentality to that of comprehensive agents with their own personal health management.

Across the board, health care consumers are being armed with transparent information about the real cost of treatment. They can see the cost to them and to the health plan online or in documents that are sent to them from their insurer. Historically, insurers have long shielded members from seeing the contracted costs that are paid to network providers, offering no way for patients to easily compare the real cost of care and what the cost of the options are in front of them. Over the past four years, health plans have begun to publish the payment rates to providers on their Websites, much to the chagrin of the providers themselves. Treatment cost estimators allow patients to compare typical costs for alternative treatment plans allowing them to weigh the financial costs of the medical decisions.

Couple that transparent information about the real cost of treatment to comparative information about provider quality and outcomes. Health care consumers are now demanding more specific and detailed data about the number of procedures performed and the success rate of those procedures. They want to know how well the hospital follows key clinical practice guidelines such as follow up after a shoulder surgery or childbirth.

Now we have two important components: the cost of care and the quality of care. The quotient of cost and quality is value. That is what making these two factors invisible to consumers is all about. Trying to put choice on the overall information to make good decisions into consumer's hands should improve the overall health care experience for consumers. Better data for better care.

76 Snyder
Getting consumers engaged in this assessment and perception of value and thus seeing different value in various alternative provider options is a key component of the transformation of health care over the next decade. Although there may be debate about the merits of this approach like other approaches to health care reform, it will evolve over time. What is clear is that the health care delivery market is already responding to these challenges to compete in the marketplace and having to compete for patient loyalty.

An Arizona hospital has taken an approach more common in the travel industry and put it to use in its emergency department. The health system has begun to post emergency department wait times on the front page of its Website and defines these wait times as the time it will take a patient to get from the emergency department’s front desk to the examining room. The system posts wait times for each of the three facilities and wait times are updated every ten minutes.

The Georgia Department of Community Health is building a site that puts quality metrics front and center. The consumer considering elective surgery for example will be able to find information about the condition as well as treatment options from medical experts. The Website will permit the comparison of hospitals in terms of cost, quality and customer service for some of their patients and other related metrics.

Eleven percent of the more than 5,000 online consumers surveyed in Forrester’s 2008 health care survey indicated that they had received health services at a walk in health clinic at a retail location. Most national health insurance carriers now cover these services where these retail clinics are staffed with nurse practitioners and are intended to address common and routine conditions - conditions that often overflow emergency departments when primary care is scarce.77

American Well recently launched their Website that allows consumers to speak with a specialist on demand. Physicians can make themselves available to the system and consumers can draw immediately from this pool of readily available physicians and schedule an instant phone or video consult - telehealth.

Health care has indeed taken flight to the Internet. The Internet has long been a powerful source of health information for consumers and Websites like Web M.D. or the popular Up-to-Date get tremendous use. UpToDate is often used by providers - a different type of health information consumer.

Microsoft Health Vault and Google Health are both intended to go beyond general health information and to help individuals manage their care.

77 Snyder
by building personal health records that can be viewable to their respective provider teams, other family members and now link consumer medical devices that transmit health data to case managers to “stay ahead” of the patient. These medical devices create positive behaviors, reduce emergency department visits and lower morbidity for diabetes, heart disease and the like.

Aggregating patient information from insurers and the patients themselves and someday directly from care providers gives the consumer more specific insight into their history and their alternatives going forward. An electronic health record will not only link all of the over 400 Wal-Mart in-store clinics that have been proposed, but also it will serve as the main source of data for the Dossia personal health record for Wal-Mart’s two million US employees. 

This supports a wellness program for the example of the Wal-Mart customers and employees along with care decision tools for the newly diagnosed and management tools for the chronically ill. It also creates a new focal point for consumers shopping for a provider. This means not just comparative metrics, but also consumer opinions from other people online who also have had encounters with a particular provider. This social network, what Forrester calls the “groundswell,” is shaping the market dynamics in virtually every industry and health care is no exception.

People often talk about people they know as the most common source of recommendations when looking for their care provider. Online, the social networks are bringing together people through blogs, wiki’s, messaging and more to share opinions and advice. All of this combined with the pervasiveness of IT and the Internet is causing consumers to demand more accessible, efficient and affordable health information that is rich in content.

How will health care organizations brand themselves in this world of health care consumerism? What is the role of security and risk management in defense of that brand? No doubt, people are very concerned about their health care privacy. Trust is an asset that is difficult to restore once lost. If an institution is seen as being unable to safeguard patient privacy, then it gives consumers a good reason to look elsewhere. Yet this remains a tough problem where everyone in the continuum of care has to be ever diligent.

The stories of lost laptops and unauthorized access are easy to find and make headlines routinely. No one can lapse. However, health care organizations, including the payers and providers, can turn security into a brand asset. Deploying technologies to encrypt data or even erase that data remotely is now

79 Snyder
common. Strong authentication and smart rules engines for content access are also good strategies that can make their own headlines. This is often in partnership with a health care IT security integrator to help the provider’s efforts to be a good and constantly vigilant custodian of the patient’s data.

So the consumer movement is really engaging the patient to be an active force in the marketplace, to shop on a variety of components: price, quality and, in some cases, the consumer’s perception of a trusted brand. Even more so, consumer’s huge demand for social networking tools and health related information is forcing all parties in the continuum of care to respond with rich information that is mobile, current and secure.

As health care models are matured and information technology is leveraged beyond what anyone would have imagined only a decade ago, now a significant part of the foundation of the delivery of care, there must continue to be quantum leaps in bringing health care where resources are scarce while also giving consumers a choice in those services they receive.
What if health care consumers can go to a place where their doctor does not keep them waiting, actively keeps them healthy and works with a whole team of other health care professionals. And, also imagine that place makes the doctor’s life easier and health care cheaper. Could this be health care nirvana?

In a nutshell, this is the idea behind what is called the “patient-centered medical home.” It is an idea that is spreading across the country. The Patient-Centered Medical Home (PCMH) is an approach to providing comprehensive primary care for children, youth and adults. The PCMH is a health care setting that facilitates partnerships between individual patients, their personal physicians and, when appropriate, the patient’s family.

The American Academy of Pediatrics (AAP) introduced the medical home concept in 1967, initially referring to a central location for archiving a child's medical record. In its 2002 policy statement, they expanded the medical home concept to include these operational characteristics: accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective care.80

The American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) have since developed their own models for improving patient care called the “medical home” (AAFP, 2004) or “advanced medical home” (ACP, 2006).81

In January 2008, the National Committee for Quality Assurance (NCQA) released standards for Physician Practice Connections/Patient-Centered Medical Home. PCMH is a model for health care providers who seek to replace episodic care based on patient complaints and illnesses, with coordinated care and a long-term healing relationship between the patient and their primary care team.

---

The ACP, AAFP, AAP and American Osteopathic Association, representing approximately 333,000 physicians, have developed the following joint principles to describe the characteristics of the PCMH:

- **Patient Personal physician** - each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous and comprehensive care.

- **Physician directed medical practice** – the personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients.

- **Whole person orientation** – the personal physician is responsible for providing for all the patient’s health care needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life, acute care, chronic care, preventive services and end of life care.

- **Care is coordinated and/or integrated** across subspecialty care, hospitals, home health agencies, nursing homes and the patient’s community including family, public and private community-based services. Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.

One important feature of the medical home is that doctors are also supposed to be able to hand-off some of the less specialized, and often time-consuming, tasks to others. The idea of having all care team members practicing at the “top of their license,” or doing what they are most trained to do, should best serve the patients and the health professionals.

While doctors and patients may be happier and healthier in the PCMH model, what will really determine the success or failure in the long run is whether it actually saves money. That is a big concern and unless it can demonstrate this not only improves quality and patient experience, but also controls costs, early successes will diminish. One key silver lining is the hope of actually reducing the overall cost to deliver health care. One key element of success is the effective use and leveraging of information technology (IT).

Let us walk this IT-based PCMH with a recipe to consider:

1. Build content-rich, easy to use EMR/EHR/PHRs that both create high levels of consumer satisfaction from both the provider and patient perspective. Give them information they want in a form they want to see and give
them tools to use that information to make better decisions. Information to deliver better health care and information to help shape behaviors for sustaining better health.

2. Offer information services to which both the providers and patients want to return. There is no doubt there has been an explosion in social networking in the last two years because of social networking services such as MySpace, Facebook, Twitter, etc. So much so that thousands of businesses and both federal and state government organizations have a social networking presence - even the Pentagon!

Even more so is the power and ubiquity of mobile devices that serve as both a cell phone and computer allowing people to connect in many ways and receive very content rich information services all at their fingertips. The consumer demand for mobile-form information services is enormous and health care related tools are no exception. From fitness planners to nutritional guides for patients and from pharmacy drug interaction guides to a mobile version of UpToDate for providers, including everything else in between, information resources must be leveraged.

3. Secure everything where necessary. Once privacy and trust is lost, it is lost permanently.


5. Stay ahead of the “frequent flyers.” Often the patients with more complex conditions tap the health care resources the most. Home telemonitoring solutions have proven very helpful to the Veteran Affairs patients and other large health care organizations where case or nurse managers and often providers actively “coach” their patients when their health care metrics are not improving or go “out of bounds” and “cheerlead” them when they improve or sustain good health.

6. Participate and advocate to other local communities and state officials to get on the health information exchange (HIE) bandwagon. There is no doubt that patients will get health care from other service providers. Having as much complete visibility to shared health data gives the primary care providers and other health care participants more/timely information when rendering future care. Better data for better care.
7. Build quality throughout the health care chain. Measure, measure, mea-
sure - continuous improvement. Leveraging IT will greatly help via near
real-time electronic dashboards, decision support tools, etc.

8. Share your best practices and worst practices with everyone.

9. Create streamlined channels of communication where there is no fear of
new ideas.

10. Use proven, systematic and repeatable processes to improve: Six Sigma,
COBIT, TQM, etc. There are plenty to choose from and each has its best
use, learn organizationally how to use them. Otherwise, it is just another
buzzword from 30,000 feet.

11. Let your patients be a part of the all the above. Active participation can lead
to better buy-in.

12. Learn from others. It does not make much sense to re-invent the medical
home “wheel.”

13. Re-shape the culture. Change is tough for many and leaders need to be out
front, otherwise it will be viewed as another “drive-by” program. A clear
vision is essential and probably the most important criteria for success.

14. Stay the course and look for quick wins to gain enthusiasm, but keep
preaching the long-term goals.

Although the above is not a complete list, it does highlight some of the
major points.

Some peer-reviewed literature that examined the prevalence and
effectiveness of medical homes include:

- In 2007, researchers from the Centers for Disease Control and
Prevention published a study involving interviews with 5,400 parents;
the authors concluded that continuous primary care in a medical home
was associated with higher rates of vaccinations for the respondents’
children.82

- Schoen and colleagues (2007) surveyed adults in seven countries, using
the answers to four questions to categorize the respondents as having
a medical home or not. Having a medical home was associated with

82 Allred NJ, Wooten KG, Kong Y (February 2007). “The association of health insurance and
continuous primary care in the medical home on vaccination coverage for 19- to 35-month-old
Section 3: Transformation of Health Care

less difficulty accessing care after hours, improved flow of information across providers, a positive opinion about health care, fewer duplicate tests and lower rates of medical errors.83

- A review of 33 articles by Homer, et al., on medical homes for children with special health care needs published in 2008 “provided moderate support for the hypothesis that medical homes provide improved health-related outcomes." 84

- A 2008 review by Rosenthal determined that peer-reviewed studies show “improved quality, reduced errors and increased satisfaction when patients identify with a primary care medical home.” 85

- In a survey of parents or legal guardians of children with special health care needs published in 2009, 47.1 percent of the children had a medical home and the children with a medical home had “less delayed or forgone care and significantly fewer unmet needs for health care and family support services” than the children without a medical home.86

- Reid, et al., (2010) showed within the Group Health system in Seattle that a medical home demonstration was associated with 29 percent fewer emergency visits, 6 percent fewer hospitalizations and total savings of $10.30 per patient per month over a twenty-one month period.87

<table>
<thead>
<tr>
<th>PC-MH Pilot</th>
<th>Hospitalization reduction %</th>
<th>ER visit reduction %</th>
<th>Total savings/patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colorado Medical Homes for Children</td>
<td>18%</td>
<td>N/A</td>
<td>$169-530</td>
</tr>
<tr>
<td>Community Care of North Carolina</td>
<td>40%</td>
<td>16%</td>
<td>$516</td>
</tr>
<tr>
<td>Geisinger</td>
<td>15%</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Group Health Cooperative</td>
<td>11%</td>
<td>29%</td>
<td>$71</td>
</tr>
<tr>
<td>Intermountain Health Care</td>
<td>4.8-19.2%</td>
<td>0-7.3%</td>
<td>$640</td>
</tr>
<tr>
<td>MeritCare Health System and BCBS of North Dakota</td>
<td>6%</td>
<td>24%</td>
<td>$530</td>
</tr>
<tr>
<td>Vermont BluePrint for Health</td>
<td>11%</td>
<td>12%</td>
<td>$215</td>
</tr>
</tbody>
</table>

And in a 2010 study of seven PCMH pilot programs, there were numerous positive results when examining hospitalization frequency, emergency department visits and savings to patients:


Considering the costs associated with emergency department visits alone, the reduction in emergency department visits for the seven PCMH health care organizations is astonishing. While the level IT maturity was not the same for each organization examined, certainly those that had EMRs were in better position for early PCMH successes. The key ingredient for success in implementing new IT solutions to help PCMH projects is making sure the workflow and change management is well defined, agreed and codified as a major part of the implementation.

How important is IT? The US Air Force is rolling out their version of the PCMH and calling it the Family Health Initiative. In early 2009, the idea to have military and retiree beneficiaries see their primary care provider most of the time was a crucial success factor as was appropriate staffing. One key foundation cornerstone for the Air Force medical home is leveraging and making effective use of IT.

---

To date, the performance metrics for the Air Force medical home are positive –especially provider continuity and all 75 Air Force military treatment facilities will be under the PCMH by the end of 2011. Looking at the above model, you can easily see the key ingredients for success including the use of IT.

Although leveraging IT to support PCMH implementations like the US Air Force has can lead to successful outcomes, it is not a “magic box.” Oftentimes, health care organizations field some of the newest and best IT available to stay on the cutting edge, but, unfortunately, they fail in the change management aspect that often leads to poor satisfaction, ineffective workarounds and, in some cases, significant patient safety issues. Those organizations that do not have the organic change management expertise can easily get help.

Organizations that do not have necessary organic resources for effective change management and try to grow it on the fly often struggle and eventually seek outside assistance anyway. Shifting from a physician-centered model to a PCMH patient-centered model is no doubt tough. This requires careful thinking, research and exploitation of best practices along with a strong commitment from executive leadership with a clear vision on the way forward. Of all things that are important, leadership is above all.

The patient-centered medical home only works if patients take active roles in their care, however. Health care teams see patients for just a few minutes at a time. The rest of the time it is up to patients to self-manage their health. Empowering patients with education and online self-management tools is critical to their success and their families. The medical home structure calls for each individual patient to be treated by a team of medical professionals under the direction of a primary care physician.

This is the ultimate collaborative approach, which, in order to reach optimum effectiveness, will require each care team member to have access to complete and up-to-date patient data. The PCP will need to know when the cardiologist has discontinued a beta-blocker. The pulmonologist will need to know when the PCP orders a chest x-ray. All of the patient's physicians will need to know when the patient has visited, been hospitalized or visited an emergency department and so on.

This all creates a tremendous opportunity for the health IT industry. Reporting and tracking outcomes for quality performance measures is essential for the medical home to succeed. Often these tasks are performed manually with paper-based medical records that are labor-intensive, time consuming and terribly costly. Information technology can expedite these processes by giving each care team member consistent, real-time access to clinical data. Of course, this will require open, standards-based systems that can transmit
and receive data across networks and delivery mechanisms, essentially giving health care teams access to information where and when they want it and in the form they need it.
Telehealth

The way we communicate today has certainly come a long way, even in recent years. Many people really do not know how far we have come or know the amazing capability that exists. To illustrate this let me share a story. Recently I was on my way back home to Alaska from a business trip. There I was at 37,000 feet taking advantage of the Wi-Fi access on the plane. The quality of service was better than I previously thought. I was invited to Skype with a good friend taking care of her sick mother in Greece and then started instant messaging with a friend on his cell phone in Alaska…while I was somewhere over West Arkansas. And by the way, I was also watching live the Arkansas vs. Georgia football game on the plane’s Direct TV.

With all this capability, one has to wonder how information technology can equally be leveraged for health care. The good news is that it is. It may not be as widely used or adopted as it should be, but there is hope that information technology is bringing patients and medical personnel together in new ways regardless of distance, time and terrain. There is no doubt, telemedicine today is greatly expanding the reach and range capability of health care professionals and positively impacting lives.

New telehealth initiatives across the country are starting to address critical shortages of medical specialists and primary care, helping provide care to patients who previously did not have access. Widespread adoption of electronic health records is expected to boost telehealth adoption even further.

This is because in addition to videoconferencing capabilities that allow clinicians to remotely communicate with each other and patients, digitized health records will provide remote specialists with more complete information about those patients. Much of this is done with growing participation of HIEs and the maturing of the Nationwide Health Information Network. Meanwhile, the use of digital medical images from picture-archiving systems and digital cameras are making a wide range of information available to doctors about patients regardless of distance, time or terrain.

Health care organizations are deploying telehealth to patients where there are shortages of specialists such as dermatologists, neurologists, radiologists, critical care doctors and mental health specialists. Telehealth is also helping to close the care gap for patients who live in rural areas, as well as patients with debilitating illnesses for whom travel is difficult or impossible. In some instances, telehealth is helping to link patients with medical expertise even while the patient is in transit.
A great example is how the Alaska’s wide and rough terrain prompted the creation of a statewide health care network. Many Alaskan communities are located hundreds of miles from large regional medical centers and are designated as “medically underserved.” Physicians and mid-level providers are scarce in Alaska’s rural and remote locations. By far, most of the providers are located in the Anchorage area, and to a lesser degree, Fairbanks and Juneau.

Fortunately information technology improvements surged in the mid-90s allowing a telehealth strategy to be envisioned. The Alaska Federal Health Care Partnership formed the Alaska Federal Health care Access Network (AFHCAN) to address the health care needs of the 315,000 federal beneficiaries in a statewide telehealth project. As specialties were added beyond primary care, including dermatology, otolaryngology and cardiology.

Between 2001-2007 there were over 50,000 telehealth patient encounters with over 1,300 different providers participating. Most of the cases involved primary care, (38,000) which the telehealth system prevented unnecessary patient travel in one of five cases. Of the remaining, 11,000 cases were referred to participating specialty providers where three of four cases resulted in travel savings. Over $14 million was saved in unnecessary travel alone and today, the state saves $3.5 million each year.

The Alaska telehealth project also illustrates the reliance on partnerships from caregivers in the field, participating provider consultants, health care IT vendors and leadership from stakeholder organizations. Without a clear vision, effective partnerships and appropriately leveraging IT, Alaska could not have realized the positive outcomes for the health care beneficiaries they serve.

The state of California has launched the California Telehealth Network (CTN) to connect patients and physicians using broadband technology. By 2011, CTN is expected to link almost 900 health care facilities across the state. Currently, it is set up across 50 sites where UC-Davis Medical Center serves as the network’s control center. CTN visually links small hospitals and health clinics with a system of physicians, surgeons and specialists as far as hundreds of miles away.

The connection will allow health care professionals to:

- Check on patients in real-time using home telemonitoring solutions
- Review X-rays and diagnostic tests
- Advise on procedures, prescription drugs and emergency treatment

---

90 California Telehealth Network (CTN), http://www.caltelehealth.org/
The primary goal for using broadband as a telehealth means is it is hoped to reduce medical costs and improve clinical outcomes overall.

Another great example is Cincinnati Children's Hospital Medical Center, which is linking patients in ambulances with remote medical specialists. “This is telemedicine on the go,” said Dr. Hamilton Schwartz, who came up with an idea for using high-resolution video and other telemedicine gear, such as digital stethoscopes for pediatric patients - including sick premature infants - while these children are in transit to Cincinnati Children's Hospital Medical Center from other hospitals.91

In pediatrics, care often needs to be delivered while the patient is being moved from one facility to another. But emergency or intensive care specialists at the destination hospital can get a head start in delivering care if they can remotely examine and observe patients before and during transit.

Schwartz and his clinical team worked with telehealth products vendor GlobalMedia to design the TransportAV mobile telemedicine device. It mounts on a stretcher and supports 3G, 4G and 802.11 networks. It includes a high-resolution camera, which can be used for video or freeze-frame pictures if there is not enough network bandwidth in the area for clear images in motion. TotalExam, a “Star Trek-ish” looking device, is the size of a dry-erase marker and can be used for examination of patients’ throats, eyes and skin from an Internet-connected remote PC or videoconferencing system.

For adult diabetes management, the problem presents a different approach, specifically one to help foster healthier nutrition management alternatives. Type 2 diabetes requires significant amounts of dietary planning and continued consumption of healthy foods. However, due to the struggling economy, low wages and high unemployment, many individuals with the condition are finding it difficult to maintain a healthy diet and to stay in touch with their physicians.

A study published in the Journal of Nutrition Education and Behavior has found that telemedicine, which allows patients to communicate with their doctors electronically, may help solve some of these problems.92 Researchers from the State University of New York in Syracuse said that as much as 10 percent of adults with diabetes consider money to be a problem when it comes to sticking to a nutritious diet. However, after a round of counseling...

via telemedicine that covered less expensive ways they can stick to dietary recommendations, researchers found that a majority of participants improved their diets.

At Massachusetts General Hospital in Boston, doctors and IT staff have created a telemedicine program also aimed at helping critically ill children. The Connected Pediatric Critical Care program lets on-call attending physicians examine patients from their homes and communicate with on-site pediatric ICU staff using real-time videoconferencing and robotic gear.93

The program involves six pediatric critical-care attending physicians equipped with videoconferencing units in their homes, letting them connect to a portable robotic telemedicine station, nicknamed “PICU Bot,” or “Bot,” for short. Bot units can be rolled to the patient’s bedside. The physician can remotely control digital cameras and medical scopes attached to the unit to examine the patient. Videoconferencing capabilities let the doctor talk with on-site hospital clinicians, respiratory therapists and other specialists, as well the patient and the child’s parents.

The use of PICU Bot is being studied to see how improved communication between attending physicians and ICU staff impacts critical care. The study will help Partners Health care decide whether to roll out Bots and videoconferencing capabilities in its other hospital ICUs for adult patients. The Bot is used during nights and weekends when on-call attending ICU pediatricians are at home. Videoconferencing gear from Polycom and other vendors allow remote doctors to control examination cameras and medical gear to observe patients miles and hours away, helping to save lives in emergency situations.

Another leading telehealth application is called telestroke. When a patient suffers a stroke, there is a critical three-hour window for appropriate intervention to be provided to prevent serious complications, such as permanent brain damage and paralysis. However, there are two general kinds of strokes - blood clots, which make up the majority of strokes and prevent blood flow in the brain and hemorrhagic strokes, which are caused by bleeding in the brain. At University of Pittsburgh Medical Center, stroke specialists provide immediate guidance to ER doctors at 15 hospitals in Pennsylvania, including several non-UPMC hospitals that do not have in-house stroke specialists or neurologists available on a constant basis.94

---


Using telemedicine solutions, which includes videoconferencing capabilities, remote UPMC stroke specialists can observe, talk to and examine suspected stroke patients in the other hospitals’ ERs quickly, as well as view the patients’ CAT scans and electronically pull up other test data. This helps stroke patients to receive the appropriate treatment faster, saving lives and reducing permanent disability and rehab.

One big hurdle for telemedicine is that its capabilities for improving care are advancing faster than many health insurers’ willingness to cover these services. While government programs like Medicare cover some telehealth services, coverage is usually tied to services provided to patients living in regions where there are shortages of primary care doctors, not specialists like stroke experts, who are even scarcer. Perhaps coverage of telemedicine services by health insurers and other payers will expand in the years to come as more is learned about how telehealth can not only improve patients’ care and save lives, but also help to cut costs.

Such research is under way at Mayo Clinic, which, along with Intel and GE Health care, launched a program to study how home telemonitoring can help sick, elderly patients avoid hospitalization. During a yearlong study, 200 Mayo Clinic high-risk patients over the age of 60 who suffer chronic conditions including heart failure, diabetes and lung disease, will use telemonitoring devices to take their vital signs, such as blood pressure, peak air flow and weight or blood sugar readings every day.

The medical devices transmit the readings to a remote patient-monitoring system located in the patient’s home. Depending on the medical device, data is transmitted to the system by wired or wireless connections, such as Bluetooth. From there, data is transmitted to a Mayo Clinic health information system and accessed by clinicians who watch an application dashboard for early signs of patients who could be developing a medical problem such as weight or blood pressure out of normal range.

Using the videoconferencing capabilities, clinicians can observe and “cheerlead” with the patient and offer up intervention that prevents a condition from worsening to the point where the individual needs hospitalization. Considering the high costs of ER visit, this strategy bodes well for reducing medical insurance costs and relieves some pressure and wait times in participating ERs.

In rural Louisiana, telemedicine is helping to diagnose breast cancer in patients who might otherwise not get screened. A mobile van equipped with digital mammography allows rural women to quickly have their mammograms performed and read by remote radiologists. Mobile digital mammography is one of the telemedicine services offered via the Louisiana Rural Health Information Exchange, which was launched in 2007 to serve Central, Northern Louisiana.

A highlight of the exchange is its support of telemedicine services that help link rural patients with medical experts at LSU Medical Center in Shreveport. Without those telemedicine services, patients often would need to wait three months or more for an in-person appointment with specialists like cardiologists and pulmonologists, not to mention a long road to the facility. Compounding the problem is many of those low-income patients do not have personal transportation and cannot afford the price of a cab or other transportation to get to the medical center.

A key service of the exchange is mobile digital mammography, where women in rural Louisiana communities can get the screening, whether or not they have insurance coverage. Remote radiologists can often detect a possibly cancerous or suspicious spot immediately after the patient has her digitized mammogram. Considering the impacts of early detection of improved morbidity and quality of life, the long-term costs to deliver health care can be reduced significantly is this and/or other similar care models are exploited for other communities and not necessarily rural. Economically challenged urban communities suffer similar constraints in term of access to affordable health care.

Some U.S. employers are offering health services on-site to workers at company facilities and Cisco is tapping its technology expertise to help make that happen in its workplaces. Cisco’s use of telepresence technologies allows remote clinicians to examine and communicate with Cisco workers while at company facilities.

Cisco has 67,000 employees globally, with 20,000 in San Jose, California, where its HealthPresence Center is located. Cisco also recently added the ability to provide remote diagnosis to its Research Triangle Park, N.C., facility. Add family members and it services almost 45,000 people. Employees can make appointments online and just hop over to Building Q, where they wait in a lobby for no longer than three minutes before being escorted to one of 15 private care suites.

Advances in sensor technology, wireless networks, mobile monitoring devices and telecommunications have all made it possible to address the increasingly dire shortage of health care professionals in rural areas. There are approximately 60 million Americans living in rural or frontier areas and the average age of physicians practicing in these areas is over 55 years. In fact, in over one-quarter of the counties in the United States, there are no practicing physicians.  

The recently passed American Recovery and Reinvestment Act provides funding to support a telemedicine infrastructure for rural areas. It also provides funding to support wellness initiatives, which are important ways to reduce the demand for emergency medical treatment. This writing offers a three-part approach that can leverage these Recovery Act initiatives to respond to the health care crisis in rural and frontier areas.

This approach includes:

- Expanding the use of telemedicine
- Better managing care for chronic disease patients via the use of the medical home concept
- Investing in Ka band satellites to ensure affordable, pervasive and dependable network connectivity for both telemedicine devices and a medical home network

In spite of the fact that the United States is spending more on health care than any other country in the world, the nation ranks poorly on many health indictors when compared to those of other advanced countries. There are actions that need to be taken to correct these problems. Rural and frontier America face the most growing disparities in the provision of health care. There is a big push, however, governmentally and health insurance industry-wide, to reduce the cost of delivering health care, while expanding the level of service.

Technology companies like Intel and General Electric have been actively pursuing the creation of home health care monitoring systems that would have the ability to transmit data from devices like blood-pressure cuffs, electronic scales and glucose meters directly over the Internet and even now using Bluetooth to create an effective wireless solution for the patients. Google, IBM and many others, too, are developing telemedicine solutions in home systems.

---


that will have Internet data transmission capabilities. The overall aim of this new partnership between the technology companies and the health insurance industry is to create technology that will guarantee and provide a real life interaction between patients and doctors over the Internet - real time data leading to better care.

The health insurance industry is finally ready to accept a nontraditional delivery system and help invest to get telemedicine initiatives matured along with the government and both believe that telemonitoring technology is an excellent solution to increase the degree of medical services, while at the same time decreasing the cost. Newer systems will use high-definition cameras and monitors in a telepresence format that will create an experience between the doctor and patient that will be much like that of a visual conference call. A trained medical professional, along with an IT technician, will be the onsite presence at the patient’s residence along with the monitoring and telecommunications equipment that will be set up to connect with the same type of equipment back at the doctor’s office.

There is also another telemedicine solution that is a small telepresence room or pod that can be driven to any location and have patients be seen on the mobile unit or a pod that can be moved, inside a medical facility, from room to room. Once all is connected, there will be an online link between the physician and the patient and it is hoped the experience will be very intimate to the degree that the patient will feel like he or she is in the same room with their physician.

There are various telemedicine systems being used in test modes throughout the country, by various health insurance groups and technology companies, with the ongoing monitoring of the new technologies efficiency, cost effectiveness and how the test group of patients perceives this new method of delivering health care. The majority of the testing is being done in areas where there is limited access to adequate health care or rural areas where the travel distance in receiving health-care services can be problematic. However, telehealth initiatives can, and are, also being used in other opportunities where it makes sense. The telehealth space is marginally being exploited however.

One of the most valuable direct benefits of IT’s emergence on a global scale is the impact it is having on health care. As medical technologies and use cases emerge in conjunction with computer networks, medical information systems and decision-support services, ITers and clinicians in close harmony will provide, support and extend health care delivery in ways that brings the provider and patient together virtually.
Not so many years ago, ubiquitous health care would have been unthinkable. But improvements in IT have allowed health care to take a great leap forward, providing a bright outlook for the future. When an IT-driven culture shift, health-related information and services can be readily available anytime and anywhere. Medical researchers will be better equipped to synthesize data into meaningful e-Discoveries while collaborating across cultural and organizational lines, which will lead to beneficial treatments.
Health 2.0 and the Future of the PHR

Health 2.0 is participatory healthcare. Enabled by information, software and community that we collect or create, we the patients can be effective partners in our own healthcare and we the people can participate in reshaping the health system itself. ~Dr. Ted Eytan

Patient focused Internet tools have matured significantly in the last couple years, mirroring and building on the recent explosion in the adoption of social networking tools and on the slow growth of Healthcare Delivery Organizations (HDOs) that are using EMRs. It is now possible to envision how these tools might come together to offer patients a comprehensive suite of functionality within a tightly integrated, portal-like user interface, even if major pieces of this functionality were delivered by multiple third parties and even if the patient changes their health plan. A toolset that could, within one user login and user interface:

- Uniquely identify the patient across different HDOs and even across different HIEs, via a Voluntary Universal Healthcare Identifier (VUHID)
- Deliver benefits and eligibility functionality – even if the patient changes their insurer, because their VUHID could be used to match the current (or even multiple) insurer/s
- Deliver access to clinical and medication data from different HDOs, as long as each HDO had an EMR that could export clinical data in a standards based format like CCR or CCD via the Nationwide Health Information Network
- To include test results, immunizations, past office visits, prescriptions, allergies and health conditions
- Eventually, to include the level of detail found in text from outpatient clinical notes, operative reports, discharge summaries, etc.
- Deliver secure patient-provider communications, tightly integrated with appointing and prescription refill functionality, to streamline the most common processes for both patient and provider
- Deliver trusted health education resources, with subscription to new content, tailored to specific diseases or any other topic of interest to the patient

Deliver social networking functionality, to enhance communications with providers, family members or patients with similar diagnoses

Deliver information on cost and quality measures for different HDOs and providers, to help patients find the best source of additional care when required

Deliver the functionality of specialized third party applications that integrate with the patient portal and leverage its authentication service and clinical data

Although some of these tools fall outside the scope of what most people think of as a Personal Health Record (PHR) today, the idealized PHR as envisioned by the National Alliance for Health Information Technology includes most of these features. They describe a PHR as “an individual’s electronic record of health related information that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared and controlled by the individual.” In addition, they envision that clinical, financial and other information should seamlessly be integrated in a PHR for maximum benefit.

The key phrase in the definition above is “multiple sources,” or more plainly, clinical data from multiple HDOs. This is the hard part; requiring multiple HDOs, each with their own EMR, to have the capacity to exchange clinical data via a common standard that every EMR is capable of using. Given the slow progress of EMR implementation among HDOs, combined with the slow progress of interoperability standards, it is clear that this vision is not going to become reality overnight. However, this slow progress is coalescing towards the idealized PHR becoming reality. We will first look at the current state of affairs and then look forward to the likely future of the PHR and Health 2.0.

Three general categories of PHRs exist today, each with their own pros and cons. Let us briefly examine each:

1) **Insurer Sponsored PHRs**

Insurer sponsored PHRs are currently the most widely used. They generally do a good job of aggregating all types of claims data from across different HDO organizations in order to present a comprehensive scope of care delivered to the patient. Some are maturing and adding features like lab results and the export of data to EMRs to encourage use by providers.

---

However, because these PHRs are not generally tied to an EMR and the data is most frequently only claims data, the usefulness of this data is very limited. Additionally, because these PHRs are not generally tied to individual HDOs, they do not provide appointing functionality or communication with a patient’s provider. These features are precisely the kind of conveniences that most patients expect to get before they will bother using a PHR. Lastly, there is generally no interoperability with other insurers’ data, so, when a patient changes insurers (as most patients do), there is little continuity of data for the patient.  

2) Microsoft HealthVault / Google Health

For simplicity (and not to choose favorites), let us call this the Healthvault model. These PHRs attract users by the growing wealth of functionality found in third party applications with pre-built plug-ins. For example, home health monitoring devices with an interface into Healthvault make it very easy for a patient to track their progress (or a bad trend) and share this data with their provider. Some analysts point out that the Healthvault model does not even require patients to use the core functionality of the PHR.

If a plug-in application exists for Healthvault that adds value to patient care and, if in order to use that application they must use Healthvault, then the patient will likely provide consent for Healthvault to store their data even if they have no intent of ever using Healthvault itself. One value added application leads to many for this particular patient and before long they are “data invested” in Healthvault. Additionally, given the resources of Microsoft and Google, this model has staying power. For example, Microsoft recently introduced a new front end to Healthvault called MyHealthInfo, which permits a very rich user interface along the lines of a personalized health dashboard.

The biggest potential strength of the Healthvault model is that it is not tied to any one insurer or HDO and therefore can more legitimately represent itself as a true longitudinal, cradle-to-grave PHR. To emphasize this point, Peter Neupert, Corporate Vice President of the Health Solutions Group at Microsoft, uses the term “Personal Health Management System” instead of PHR when describing the capabilities of Healthvault. In a 2009 edition of Health Affairs he writes:

What differentiates personal health management systems from EMRs or PHRs is that they (1) contain data from many different sources, including EMRs and PHRs; (2) give people total control over their data and enable them to add their own information, such as progress on a fitness plan or self-management of chronic conditions; (3) seamlessly connect to the workflows of multiple provider and payer systems; (4) offer secure, programmatic access to these data and processes, to enable the development of new kinds of tools and services; (5) cater to the needs of the “family health manager” – the person most often responsible for a family’s care; and (6) make it possible for people to search for (and share) relevant health information, knowing that this information is credible and actionable.105

Leaving aside the semantics of PHR vs. “Personal Health Management System,” this sounds like PHR nirvana. However, the potential strength of the Healthvault model “open” architecture is also its Achilles heel. Because Healthvault has no direct tie to any EMR or other source of clinical data, it is entirely dependent on the progress of interoperability standards, the progress of EMR adoption and the willingness for HDOs to permit access to “their” (the patient’s) data, in order to become any more than a third party application hub. Today, only a handful of HDOs offer the ability to transfer a patient’s data to Healthvault. If patients rise up en masse and demand that their HDOs enable the transfer of their clinical data to Healthvault, then this model may work sooner rather than later. However, the odds of this happening in the near future are relatively low.

Barring a short term revolution in data liquidity, it is difficult to see how the Healthvault model will be able to “seamlessly connect to the workflows of multiple provider and payer systems” in the near future – even if its architecture seems like the most logical long term model.

3) “Tethered-to-an-EMR,” HDO Sponsored PHRs

When large HDOs have an EMR and offer a “tethered” PHR, then they are able to deliver their patients a PHR with a built-in interface to clinical data. Additionally, when this kind of HDO is integrated with a payer (as in a staff model HMO), a world of possibilities is opened involving the integration of clinical and business process automation from a patient’s perspective. Perhaps not surprisingly, the best commercial example of this PHR model is Kaiser Permanente’s My Health Manager, used by about one third of Kaiser’s 8.4 million members.106

---

105 Personal Health Management Systems: Applying the Full Power of Software to Improve the Quality and Efficiency of Care, Health Affairs 28, no. 2 (2009): 390-392
Fully deployed in 2007, My Health Manager offers all of the following functionality, which is an excellent start towards the PHR “wish list” at the beginning of this chapter. Using My Health Manager, a Kaiser member can:

- View lab results, immunizations, past office visits, prescriptions, allergies and health conditions
- View, schedule or cancel appointments
- Refill prescriptions
- Act on behalf of another family member (with proxy permissions)
- Communicate securely with their providers and pharmacists
- View trusted health and medication information and utilize behavioral change programs for smoking cessation, weight management, nutrition, insomnia, pain, depression and stress reduction
- Manage their health benefits, including estimating the cost of treatments and viewing medication formularies.107

Use of My Health Manager continues to grow, driven by the top three most frequently used features: viewing test results, scheduling appointments and prescription refills. Based on user surveys conducted by Kaiser, they have determined that “members find greatest use in a web Website that facilitates e-connectivity with their health care team, allows them to view key components of their medical records and conduct clinical transactions online and provides them with information so that they can make knowledgeable decisions about their health.”108 Kaiser recommends that other PHRs focus on these same priorities to maximize their chance of success. Of course, as we have already discussed, Kaiser’s integrated payer-provider model allows them to “start on second base” compared to the insurer model, the Healthvault model or most other HDOs.

On the downside: Just like with the insurer model, if a patient leaves Kaiser, they leave behind all the functionality of My Health Manager. They do not necessarily lose their clinical data, however, because Kaiser is working on an interface to port clinical data in My Health Manager to HealthVault.

107 If You Build It, Will They Come? The Kaiser Permanente Model of Online Health Care, Health Affairs 28, no. 2 (2009): 334-344
108 If You Build It, Will They Come? The Kaiser Permanente Model of Online Health Care, Health Affairs 28, no. 2 (2009): 334-344
The Future of the PHR

How do we get from the status quo PHR to the idealized PHR? How do we best combine public policy, technology, incentives and education to maximize the chance that our health care system can deliver a PHR that is not tied to any one HDO, but nonetheless offers ubiquitous access to all of a patient’s clinical data wherever it resides? To paraphrase the title of this book, how do we leverage better patient data for a better patient experience? Let us look at each one of the idealized PHR elements in a little more detail, with examples where they exist.

Voluntary Universal Healthcare Identifier (VUHID)

In order to efficiently and safely collect a patient’s clinical data from different HDOs and different EMRs into one PHR, it is necessary to uniquely identify a patient across different HDOs. The best way to do this is to implement a universal health care identifier. Demographic matching algorithms that are used now for this purpose are prone to error, with potentially catastrophic results for patient safety. For political reasons, it is unlikely that the government will attempt to establish a mandatory universal identifier. This leaves a voluntary universal identifier as the best near term solution.

Global Patient Identifiers Inc. (GPII) has a proposed mechanism in place to implement a VUHID. It is not in our scope here to discuss the mechanics of how VUHID would work, However, these details are presented at http://gpii.info/.

What we are concerned about are the benefits of a VUHID to individual patients and what kind of public policy might be needed to jump-start VUHID into mainstream use. Again from the gpii.info Website, the benefits of VUHID for a patient are:

- **Convenience** — Once a VUHID identifier is issued, patients should no longer have to repeatedly supply identifying information, even when seeing a new physician for the first time
- **No patient identification errors** — VUHID reduces Enterprise Master Patient Index (EMPI) demographic matching errors, estimated to occur 8% of the time
- **Reduced risk of identity theft** — Participating in the VUHID system means that each patient’s medical information will be linked using his or her unique identifier — not names, addresses, birth dates, social security number, telephone number, etc. This eliminates the potential breaches of confidentiality associated with demographics-based exchange of such vital data
Better control of medical privacy — A key benefit of the VUHID system is the ability to provide private identifiers (PVIDs) to an individual. Private identifiers are anonymous. They work by enabling electronic linkage of various types of clinical information without revealing the patient's identity. For example, suppose a physician orders an AIDS test but does not want anyone to know who that test is for. A PVID can be attached to the sample and the laboratory would return that result to the physician using only that PVID for identification.

Better medical care - In support of the vision of a nationwide health information network - the beginnings of which are seen in the good work of RHIOs and HIEs around the country - the VUHID system makes it feasible for physicians to have complete and accurate medical information available at the point of care. It has repeatedly been shown that a physician equipped with complete medical information is able to provide more efficient and less error-prone care for their patients. The VUHID system plays a key role in making that optimum care feasible by ensuring that there is never any confusion concerning a patient's identity.109

There are a lot of tough policy issues surrounding health care, but VUHID is not one of them. It can be argued that VUHID (or something very similar) is a prerequisite both to the future of the PHR and also to safe transmission of patient data between HDOs / RHIOs via the Nationwide Health Information Network. In our view, The Department of Health and Human Services (HHS) should actively encourage the adoption of VUHID by including VUHID interoperability into EMR accreditation requirements.

Access to Clinical Data from Multiple HDOs:

The long term answer here is ubiquitous EMRs, all of which can securely port patient data into a PHR at the request of the patient, via the Nationwide Health Information Network that will become the arbiter of data standards and formats. In the meantime, there is technology available today that enables transfer of clinical data from multiple HDOs into a PHR and accommodates varying states of HDO EMR maturity. Health Postbox Express (HePoEx) is a plug-in to HealthVault that allows HDOs to send clinical data to a patient’s HealthVault account securely. HePoEx supports delivery of records in Continuity of Care Record (CCR) format, for any HDO that can support CCR. However, it also allows clinical data to be sent in almost any other electronic format as well. If the provider does not have an EMR, the system can handle scanned copies.

109 http://gpii.info/benefits
To receive their health records, a patient provides their HePoEx ID to their provider, along with their authorization form for Release of Information (ROI). The provider or HDO staff then logs on to www.hepoex.com with their provider account, enters the HePoEx ID provided by the patient, uploads the clinical data / documents and submits the form. The uploaded data / documents are converted into a single encrypted package and uploaded to HealthVault.

The patient then receives an email with a 16-digit pass code and detailed instructions to retrieve the clinical data. A link embedded in the email takes the patient to HealthVault, where they may enter this pass code. After the pass code is verified, the patient is additionally required to provide the answer to the secret question they had previously registered with HePoEx. After providing the correct answer (two-factor authentication), the patient is able to import the clinical data into their HealthVault record.

This model is attractive to HDOs because no Information Technology (IT) infrastructure setup or advanced training is required. Any provider / HDO staff can request a provider account, open a browser and start sending health records securely in minutes. This decreases turnaround time for requests for ROIs, resulting in increased patient satisfaction. For the majority of providers that do not yet have EMRs, it is cost effective when compared to the time and money spent making paper copies. Automatic audit reports for completed ROIs assists HDOs with HIPAA compliance.110

Often when a patient requests a ROI from a provider, it is specific to a referral. A limitation of the HePoEx model is that it only works if the referral provider agrees to look at the patient’s PHR. If the referral provider insists on paper copies due to the fact that looking at clinical documentation in a PHR is too much of a disruption to their HDO’s workflow, then this model does not work. To turn the tables, if patients start taking their business to specialty providers that incorporate this type of business process and away from those that do not, then HDOs would quickly adjust.

**Secure Patient-Provider Communication**

According to an August 2009 survey by Lightspeed Research, 1 in 2 Americans would like to be able to email their provider to ask questions and request prescription refills. Women are more likely than men to desire this online communication. In addition to the obvious convenience of saving time, 49 percent of patients desire written vs. verbal instructions from their provider in order to make it easier to comply with treatment recommendations. Forty-nine percent of patients are also unwilling to pay for an email consult, which

110 http://hepoex.com
of course explains why integrated payer-provider HDOs like Kaiser are so far ahead of most other HDOs with third party payers in this regard.\textsuperscript{111}

Although many providers are at first resistant to the idea of opening up their practice to email, after they try it, most find that responding to an email is easier than responding to a phone consult because it is easier to budget their time. For example, if a provider has five minutes available before a scheduled office visit, they may well be able to respond to an email consult, but they would not pick up the phone and respond to a phone consult because they have no idea how long that phone call would last.

In order to comply with HIPAA requirements, it is much easier to enable email / online patient-provider communication in the context of a patient portal specifically designed to accommodate HIPAA. Providers that permit online communication with their patients armed only with an email account are opening themselves up to significant legal liability, because HIPAA requires that the clinical information used for diagnosis in emails be treated as any other clinical data. In the absence of a PHR tethered to an EMR that can handle HIPAA requirements, vendors such as Medfusion and RelayHealth offer secure patient-provider communication solutions, to include e-prescribing and other features. For practices without EMRs, they market themselves as a logical step toward an EMR.

Hopefully, the medical home initiative and reform towards paying providers to manage conditions instead of visits will incentivize better and more widespread patient-provider communication in the not too distant future. The technology is ready as soon as the business model is ready.

**Deliver Trusted Health Education Resources**

Patients want information on their (and their loved ones’) health concerns. They want to stay up-to-date as medical science evolves and new treatments or medications are released related to their health concerns. Providers want their patients to get trusted health information, so they do not have to waste valuable time in the exam room debunking fad treatments.

Additionally, whether or not patients understand anything about RSS (Really Simple Syndication), thanks to Facebook and Linked In, most are familiar with the concept of “subscribing” to topics / groups / organizations of interest to them and receiving updates in one centralized location. So it is not surprising that PHRs and third party Websites are copying this model. To cite one example of many, MyDailyApple.com is a Google Health integrated service that delivers news and search results tailored to specific health concerns.

\textsuperscript{111} http://www.healthpopuli.com/2009/11/americans-want-to-use-email-for-all.html
In the idealized PHR, a patient subscribes to health topics / disease conditions of interest to them and he or she is delivered updated content in one centralized location (and/or via email). If they have a question, e.g. “is this new medication for my chronic disease appropriate in my case,” with one mouse click they initiate an email to their provider that references the content they just read. This streamlines the business process not only for the patient, but also for the provider because the provider can swiftly understand the clinical context of the request (as opposed to a query based on, “my brother told me he heard about some new drug on CNN”).

**Deliver Social Networking Functionality**

“Our profession, at its core, is fundamentally flawed relative to how today’s world communicates and functions. The infrastructure of health care needs a total repair from the ground up. It needs to be Facebook-ed and Wiki-ed” ~Dr. Jay Parkinson, Hello Health

This subject ties directly to and builds on the previous two topic areas. There is enormous potential in bringing social networking capabilities into the communication equation between patients and their providers, between patients and their family members and between patients with similar health concerns.

Social networks offer HDOs a new tool to connect with health care consumers. As consumerism continues to take hold and consumer-directed health plans become more commonplace, HDOs need to remain in constant communication with patients they serve to keep those individuals loyal to their facility or practice. Social networks allow for multifaceted, regular communication with patients that assist in building and maintaining this necessary loyalty. As consumer control over the spending of their health care dollars increases, their behaviors will more closely mimic their behavior in purchasing other products and services.112

Hello Health is a new model of health care delivery that has been described as “part EMR, part practice-management system and part social-networking Website, complete with profiles and photos of doctors and patients, all in a secure environment that complies with federal privacy standards.” Patients pick a provider via their Facebook-like profile and pay a monthly enrollment fee (usually on the order of $30-$35) that covers quick questions via email or IM, prescription refills and viewing their medical records online. Some practices include simple lab tests and generic medications for acute conditions

---

in the enrollment fee. Office visits are guaranteed within 24 hours if necessary and patients can schedule an appointment themselves online by viewing open slots on their provider’s calendar.

Five different modalities of outpatient visit are offered (with different prices set by each practice): house calls, office visit, video visit, phone visit and IM visit. The Hello Health model does not include accepting insurance, but patients can, of course, submit office visit invoices for reimbursement if they have out-of-network coverage. Hello Health’s parent company, Myca, sells the Hello Health software platform for use at other practices that want to adopt its model.113

Another way of describing Hello Health is concierge health care meets social networking. A video on the Hello Health Website states “The Internet has made your life simple and convenient in every other area, so why not your health?” Whether or not Hello Health’s business model succeeds, they have certainly blazed new ground in the integration of social networking and health care delivery.

Another innovative example of health care social networking is Emota.net. A startup funded by the National Science Foundation, Emota is working on an “emotional networking” solution to help busy families and care professionals stay aware, in touch and supportive of the elderly. The interface for the elderly is a touch screen, always on a dedicated hardware device connected to the Internet. The presentation is like a “two-way interactive picture frame” that allow the elderly to communicate through touch-based video, voice and text tools (without any technical skills). The interface for family members and friends is an iPhone app or a web widget that helps them stay aware of the elderly and provide timely emotional and physical support when required. The interface for caregivers is a dashboard that lets them monitor multiple patients and provide support as needed. The Emota technical architecture is built to allow rapid integration with PHRs, remote patient monitoring and telehealth applications.114

An example of social networking among patients is patientslikeme.com. Their goal is to “enable people to share information that can improve the lives of patients diagnosed with life-changing diseases.” Patients with one of 19 (as of November 2009) serious conditions can create a profile, track their symptoms, find patients like themselves and communicate via forum discussions or private messages. Profile charts let patients see how their treatment is affecting their health over time and anonymous patient outcome data is used by providers, pharmaceutical companies and research organizations to drive treatment research and improve medical care.

113 http://www.myca.com/applications/hello-health
114 http://www.emota.net
Deliver information on Cost and Quality Measures

An important part of the equation for consumer-driven health care is the availability of cost and quality measures for providers and HDOs. The potentially life-altering (and certainly bank account altering) decision about whether to see the in-network surgeon recommended by your health plan or an out-of-network surgeon recommended by a friend is the kind of decision almost all patients face and all patients wish they had better data to support their health care decisions. Is there outcomes-based data to support paying more for the out-of-network surgeon? How much more will the out-of-network surgeon cost? How do other patients rate both surgeons?

Angie’s List is a well known consumer Website with over a million paying members that rate all kinds of service providers, from painters to plumbers to heart surgeons. Ratings for doctors, dentists, hospitals and health plans are an increasingly popular part of the Website. Just like non-health care service providers, health care providers are given the opportunity to respond to negative reviews, but Angie’s List had to incorporate the complexity of a HIPAA waiver into the dispute resolution process. Categories of ratings for physicians include availability, office environment, punctuality, staff friendliness, bedside manner, communication, effectiveness of treatment and billing and administration. Given the track record of Angie’s List, it is likely that health care ratings on Angie’s List will become an increasingly influential part of patients’ decision-making process when choosing providers and HDOs.

The problem with Angie’s List is that it includes no quality of care data. There have been many attempts by health plans to rate their physicians on quality of care using claims data, but this is very controversial because it is so difficult to do in a statistically creditable way. It may be that valid physician quality ratings will have to wait until wider adoption of EMRs and payment reform makes the right kind and amount of clinical data available on all physicians.

The Informed Patient Institute, http://www.informedpatientinstitute.org, advocates for making more - and more useful - health care quality information available to patients. It does not rate providers and HDOs, instead it “rates the rater” to inform patients which rating organization and mechanism is the best state-by-state. One of their favorites is the National Committee for Quality Assurance (NCQA), which rates health plans at http://www.ncqa.org in a very consumer friendly format. NCQA takes a process and technology based approach to evaluating physicians. For example, evaluating a provider’s ability to know and use patient histories, follow up with patients and other providers, manage patient populations, use evidence-based care and employ electronic tools to prevent medical errors.
An idealized PHR could combine information on cost, clinical quality, subjective patient ratings and process ratings from different sources into an aggregated and statistically valid report card. This vision is likely several years off.

**Deliver the Functionality of Specialized Third Party Applications**

All kinds of “Health 2.0” web and mobile applications are being developed today to help patients manage chronic diseases, assist the healing/recovery process, manage fitness, diet, etc. Here is a small sampling:

- **ScanAvert.com** delivers instant personalized decision support in the supermarket. Patients register and establish a profile at the ScanAvert Website, identifying any allergies, dietary preferences/avoidances, illnesses/conditions, prescriptions, etc. Then they use the camera on their mobile phone to scan bar codes on food items they are considering for purchase. The item's ingredients are compared to the consumer's profile. If a product's composition is incompatible with a customer's profile, an alert is generated identifying the substance(s), accompanied by proposed compatible substitutes. (This intriguing application would be even better if it were available as a PHR plug-in so that the patient's diagnosis, allergy and (changing) medication profile could be seamlessly imported into ScanAvert.)

- **AccessDNA.com** generates a personalized genetics report based on a survey taken by the patient. This report identifies which genetic tests might be worth while, lets patients compare thoughts on a discussion board and allows patients to ask questions of a board certified genetic counselor.

- **TrialX.com** matches patients to relevant clinical trials based on their health conditions. It is available as a plug-in to both HealthVault and Google Health.

- **411fit.com** allows users to set weight loss and exercise goals, enter diet and exercise data and receive daily feedback on their progress. What makes 411fit unique from other diet Websites is a very rich user interface and social networking features, which allows friends (or personal trainers) to monitor and encourage progress.

**Summary**

David Kibbe, MD, senior adviser to the American Academy of Family Physicians, believes that it will be PHRs that ultimately drive the sharing of data between RHIOs:
“We can’t expect government to build a network. Government didn’t build the Internet. Government didn’t build PCs … its you and me.”

Summary points: First, there is a great deal of innovation going on right now that is dramatically increasing the ability of patients to manage their own care and better communicate with their providers. Second, the synergy between this innovation and the economic trends towards patient empowerment will ultimately become an unstoppable force driving towards the idealized PHR. Third, the idealized PHR (or something close) will deliver enough benefits to enough patients that it truly could become the “data broker” between RHIOs in the event the Nationwide Health Information Network is unsuccessful.

Mobile Health Care

In today’s demanding and dynamic medical environment, clinicians cannot always have easy access to a desktop computer, paper charts or hard copy reference material. This lack of informational resources creates delays and inefficiency and limits the timely delivery of optimal health care. Worse yet, lack of automation and information at the customer point of contact can lead to lost patient information and increased medical errors. To combat this problem, today’s provider can choose from a tremendous array of handheld computing devices that can be adapted to the continuum of health care.

At the same time, it is important the right tools are fully exploited within a health care setting. But which tools are the right tools? Tablet PCs, personal digital assistants (PDAs) and smart phones have created a new platform for health care in the wired and wireless environment.

**Smart Phones**

PDAs and cellular-based devices have become useful tools in the life of a busy clinician. With a plethora of mobile medical applications, powerful e-mail capabilities and wireless computing gaining ground in the health care setting, the provider’s reach and range have rapidly expanded at the point and time of health care delivery.

Pagers are quickly being replaced by PDAs with cellular capabilities or “smart” phones. A study published in the open-access journal BMC Medical Informatics and Decision Making revealed surgeons at a London hospital whose pagers were replaced with PDAs combined with mobile phones responded to calls more quickly, improving communication between clinicians.116

The use of combined smart phone devices in the study suggested this technology could reduce the time clinicians take to respond to a call. This is attributed primarily to the fact the smart phone acts as a bidirectional device and enables faster communication between the caller and the physician or clinician.

It should be no surprise about the natural convergence that has occurred between mobile hardware and software with the increasing number and variety of relatively inexpensive “smart” phones such as the Blackberry, Palm and the now iPhones becoming a strong market leader. The convergence can

better facilitate the delivery of health care for underserved rural and urban populations, as well as a typical busy health care setting.

In a market research study by Spyglass Consulting Group, they found nearly every physician in the country is using a smart phone. Its survey of more than 100 physicians, taken in February 2010, found that 94 percent use smart phones for personal and professional use, including at the point of care.117

Another major advantage of smart phones is the allowance of easy retrieval of information on a broad range of subjects, limited only by software and memory resources. For example, drug guides that list drug types, interactions, doses and prescribing information have become popular. Medical dictionaries and applications customized for different specialties, along with access to the Internet for use with medical information portals, are giving the health care provider and patients an incredible array of medical information resources that in the past were only available in hard copy.

**Tablet PCs**

Where smart phones fall short, tablet PCs provide a significant computing resource in the wireless health care setting. This form factor offers a more mobile way to interact with a computer. Tablet PCs often appear where normal notebooks are impractical or unwieldy or do not provide the needed functionality. Tablet PCs have revolutionized health care data capture, accessibility and mobile usage. Even if the provider has been taught to write down everything, this device can easily capture written data electronically and stores it as a permanent part of an electronic medical record.

The tablet PC combines the features of paper, PDAs and notebook PCs, while providing mobile computing capability in a form closely associated with a chart. Today’s tablet PC is lightweight and equipped with substantial processing power that can handle most client-based electronic medical applications. Considering the huge success of the Apple iPad that was released this year, other vendors are scrambling to get similar devices fielded because all health care information consumers are demanding it.

From the registration process to the bedside and all places between, tablets can be used to get patients in the system, document their care while in the system and process them out of the system for any patient encounter.

117 “Point of Care Communications for Physicians,” Spyglass Consulting Group, July 2010
**Key Applications for Tablet PCs**

Tablet PCs improve inpatient care by using electronic chart collection at the bedside and accessing medical records and reference information from applications and the Internet. And now, with medicine reconciliation being measured by the Joint Commission as one of the National Patient Safety Goals, tablet PCs make the process easier at the patient point of contact. In addition, electronic forms reduce paperwork, make documentation readily available to all caregivers and reduce medical errors and duration of stay.

Tablet PCs also have made their way into emergency response settings. These PCs use global positioning system technology to determine best routes to accidents and hospitals. On the scene, emergency response crews capture patient information and transmit it to hospital computing systems using cellular accessories. The improved communication helps on-scene coordinators and trauma centers plan patient care based on events and information in real time, when timing can mean the difference between life and death. This allows faster patient handoff and minimizes the administrative burden for both the emergency response teams and the hospital.

In home health care - which spans several disciplines, including mobile nursing services, physical and occupational therapy, medical social work, nutritionist services and companion/aide services - the tablet PC fits perfectly. Combined with a tablet PC, home health applications integrate clinical data collection with billing functions and enable paperless data entry.

At the same time, the tablet PC is well suited for use with electronic forms, while its unobtrusive mobile design eliminates barriers between the patient and caregiver during data collection and review. Key performance indicators for tablet PCs in home health delivery can include the number of patients seen per day, reduced medical errors, reduced administrative work and timeliness of work.

**Going Wireless**

As self-management of chronic diseases becomes more prevalent and frequent, regular monitoring is growing more important. Wireless and mobile technologies are right at the center of the action, suggests a new report from the California Health care Foundation.

Health economist Jane Sarasohn-Kahn, notes that the Pew Internet & American Life Project found that people with mobile broadband Internet access are far more likely than those with only wired connections to seek health information online. The report, “Participatory Health: Online and Mobile Tools Help Chronically Ill Manage Their Care,” says that cell phones can help
people get in the game. Sarasohn-Kahn cites research showing that medicine and health is the third-fastest-growing category of iPhone apps, trailing only games and travel.¹¹⁸

Consider the following from a recent report from the Health Research Institute report on mobile health care: ¹²⁰

- Mobile health can improve the use and the value of physicians’ time. One-third of physicians surveyed by HRI said they make decisions based on incomplete information. They believe the greatest benefit of mobile devices will be to help them make decisions faster as they access more accurate data in real-time.

- Forty percent of physicians surveyed said they could eliminate 11 to 30 percent of office visits through the use of mobile health technologies like remote monitoring, email or text messaging with patients. Such shifts could rewrite physician supply and shortage forecasts for the next decade and beyond.

- Physicians are interested in different types of applications. Primary care physicians (PCPs) are most interested in prescribing medication wirelessly and specialists, in accessing electronic medical records (EMRs) wirelessly.

¹¹⁸ “Participatory Health: Online and Mobile Tools Help Chronically Ill Manage Their Care,” Jane Sarasohn-Kahn, Sept 2009, page 8-10

¹¹⁹ Figure 1: “Participatory Health: Online and Mobile Tools Help Chronically Ill Manage Their Care,” Jane Sarasohn-Kahn, Sept 2009, page 8

In-person consultations are still the main method of reimbursement, but physicians are getting limited reimbursement for phone consultations, email consults, telehealth and text. Payment models that address how mobile health reduces costs are more effective, but require changes in delivery-care processes.

Providers in search of additional funding should consider marketing mobile health solutions. According to the survey, consumers said hospitals are the preferred place to buy mobile health products and doctors are overwhelmingly the most trusted in terms of getting health information.

Although the implementation of mobile computing in the health care setting can potentially provide significant gains, its full value cannot be recognized without proper planning on the wireless enterprise design. The goal is to be better able to define, implement, deploy and evolve wireless solutions that meet the needs of the evolving health care environment.

Consider the following steps prior to deploying wide-scale wireless solutions:

- Understand clearly the organization’s objectives and processes;
- Get executive leadership involved from the start;
- Establish an enterprise wireless working group to develop a long-range strategy;
- Conduct an enterprise technology assessment;
- Identify the type of data to be transmitted;
- Conduct detailed on-site analyses of critical physical and clinical problems in all health care settings to determine if wireless computing offers the right solutions;
- Ensure the design of wireless infrastructure products and components comply with your enterprise information technology architecture and standards;
- Choose the right partner/vendor;
- Lay the groundwork for cultural change before wireless solutions take hold;
- Secure data everywhere;
Develop a device management strategy and approach to control hardware and software purchases, inventory management, training and internal information technology support;

Consider deploying an enterprise-wide mobile infrastructure solution;

Determine how to quickly and cost-effectively integrate wireless technology into your health care setting and achieve the most positive impact for your organization;

Include clinical champions early and continually; after all, they will be using the technology.

Mobile computing technology has shown benefits to clinicians, including ease of work, improved communication, fewer errors and better patient care. However, many attempts to introduce information technologies into a clinical environment failed to win the widespread support of clinicians when the motivation was to bring the application of technology for its own sake rather than the solution of clinical problems. The fact clinicians are using handheld devices and tablet PCs - and using them to solve clinical problems - bodes well for the future of health care.

But now, mobile health care is actively in demand by the patients, too. There is strong growing demand by health care consumers to take a more active role in their health and for their families.

The Health research Institute survey goes on to say, 40 percent of U.S. consumers would be interested in purchasing or leasing a device to monitor various bits of health information like blood pressure or heart rate then automatically send data to their doctors. A similar number - 41 percent - said the same about mobile phone applications that would allow them to track health information or remind them to take some action such as taking a medication or refilling a prescription.  

---

121 Health Research Institute
122 Figure 2: “Health care Unwired: New business models delivering health care anywhere,” Health Research Institute, Price Waterhouse, Sept 2010
Of the 2,000 adults surveyed, 56 percent said they like the idea of remote health care services and 41 percent indicated a willingness to have more care delivered by mobile device.\textsuperscript{123}

\textbf{Mobile Health Care Going Global}

The United Nations Foundation and several partners are committing $400 million toward making childbirth safer, vaccinating children, reducing infant mortality and combating malaria - and mobile technologies are a big part of the strategy.\textsuperscript{125}

Called the Maternal and Newborn mHealth Initiative, this coalition of not-for-profits will develop and widely deploy mobile health technologies to address problems related to maternal health in developing countries. The organization will work with the Health Metrics Network, the World Health Organization, the U.S President’s Emergency Plan for AIDS Relief (PEPFAR), the Rockefeller Foundation and others to build a web-based “global information and experience sharing system” for mobile and e-health.\textsuperscript{126} The programs will address child health and maternal health - two of the Millennium Development Goals that the UN identified in 2000 to help improve standards of living around the world.

\textsuperscript{123} Health Research Institute
\textsuperscript{124} “Health care Unwired: New business models delivering health care anywhere,” Health Research Institute, Price Waterhouse, Sept 2010
\textsuperscript{125} mHealth Alliance, United Nations Foundation, http://www.unfoundation.org/global-issues/technology/mobile-health-for-development.html
\textsuperscript{126} United Nations Foundation
According to UN Foundation CEO, Kathy Calvin, data collection around health issues will improve significantly. “When health workers were going out on vaccination campaigns or were tracking outbreaks of diseases or tracking stock-outs of commodities, such as condoms, they would typically write it down on a piece of paper and send it someplace. And maybe three months later, it would be noted.”

Calvin added they are now using handheld devices, in some cases, cellular phones. Even in the poorest of regions, mobile phones are ubiquitous. This created a tremendous leap for health workers and creates huge potentials when considering the use of better mobile devices.

**In Comes Apple’s iPad**

The greatest promise of the iPad and the coming generation of health care tablets is putting the electronic health record – patient records, decision support tools, safety stops, billing, etc – in the hands of health care providers at all times. As health care evolves to respond to our current challenges, the flexibility to put tools into the hands of clinicians will be crucial.

However, electronic health record platforms out there are still maturing and building the capabilities that would allow them to take advantage of truly mobile health care. Some of the more rigid, cumbersome systems will take some time. More flexible systems with a “plug-in” based infrastructure may be ready sooner. The fact is that current EHR's are designed for hospitals and clinics with workstations, but they are certainly on their way to embracing mobile health care.

Fortunately for the iPad in health care, the application design solution for the very successful iPhone provides for the same easy design capability. The ability for developers and clinicians to fill niche requirements quickly with a targeted app has turned the iPhone and now the iPad into the “peripheral brain” of many clinicians, putting incredible amounts of information at their fingertips. And many developers are embracing the mission of evidence-based health care, trying to put decision-support tools and practice guidelines into the hands of clinicians such as CORE – Clinical ORthopedic Exam – from Clinically Relevant Technologies.

This app provides instruction on common physical exam techniques, including sensitivity/specificity and follow-up testing information. Although only one example, the iPad apps targeted for health care are growing at an outstanding rate - and they are inexpensive, too.

---

127 United Nations Foundation
Whether you are looking for diagrams of the human body or looking for a handy reference, these apps available for iPad can help you find that for which you may be searching. Some examples include: 128

- **Human Body 3D Anatomy**: This app is available for $2.99 and can be used to refresh yourself on all of the systems in the human body. It includes complete information on different systems and uses 3D animations to make anatomy come alive.

- **iAnatomy**: View cross sections of the body with actual CT scans of different areas. Includes cadaveric images, as well as helpful labels. Perfect if you are looking to refer to different scans and images. Cost is $0.99.

- **Skyscape’s Medical Bag**: Features helpful reference information that you can take with you wherever you go, for $1.99. Includes a number of clinical tools, lab tests and medical calculators that can help you find the information you need.

- **Medscape**: This remains the essential free reference app for health care professionals. Medscape offers clinical relevance, accuracy and more. It is still a trusted name in medical apps and bringing it on rounds is a great way to have instant access to the information you need, including breaking medical news and the latest procedures.

- **Eponyms**: If you are looking up different medical terms, this free app is invaluable. While this version is meant for student, veteran health care professionals can use it as a refresher.

- **Taber’s Medical Dictionary**: Take medical reference to the next level with this app. Includes photos, care statements and more than 60,000 terms. You do have to buy a $49.95 subscription, but for those who are looking for a reliable reference to take with them, this is a great choice.

- **3D Teeth**: If you are a dentist or if you are trying to determine whether a patient needs to see a specialist, you can use this app, available for $1.99, to view reference information about the mouth and teeth, see 3D images of teeth and get information on different diseases.

If you are looking for helpful iPad apps for use with drugs and dosing, these can be of great help.

- **Epocrates**: Find drug references, interactions and more. A helpful drug reference resource from one of the most trusted names in medicine. Cost: Free.

---

128 Apple App Store
• Monthly Prescribing Reference: A free and helpful drug resource for doctors and other health care professionals. Includes information on interactions for prescription and over the counter drugs.

• Skyscape RxDrugs Dosing Companion: This free resource can help you figure out dosing for thousands of generic and brand name medications. Carry with you as part of your regular rounds.

• Davis's Drug Guide: You can get this comprehensive guide for a $49.95 yearly subscription. Regularly updated so that the latest information is at your fingertips.

• iMeds XL: This iPad app costs $3.99 and provides prescribing information. You can search by drug name or drug class. Helpful information on interactions, side effects and dosing.

• Psych Drugs: This free app focuses on drugs commonly used to treat psychological illnesses. A helpful app that can help you learn about anti-anxiety medications, antipsychotics, mood stabilizers and more.

• MedCalc: Use this handy and free iPad app to figure dosing and get access to a number of formulas. No more looking up formulas and then plugging them in to a calculator. This app will do the work for you - quickly and conveniently.

Get help diagnosing a condition right on your iPad. No need to leave and look for information; everything you need, can be seen right in your hands.

• Diagnosaurus DDx: For $0.99, you can have access to this powerful diagnosis tool. Perform diagnosis at the point of care, using the easy reference system that offers information on a number of diseases and conditions.

• Pedi STAT: Use this app, available for $2.99, to check symptoms, normal growth and other essential information related to pediatrics and caring for children.

• iRadiology: Review radiology concepts and images with this free app before or during rounds. A great resource for interns and residents - and even as a review for veterans.

• NeuroMind: Look into the mind with this helpful and interesting free app that offers images, information and more that can provide you with insight into the mind.

• Medical Lab Tests: Use this iPad app, available for $5.99, to review normal lab values, including more than 100 blood tests. Quick way to evaluate lab results.
• ECG Guide: Use this handy iPad app to look at regular and abnormal ECGs, helping you get a handle on the situation and diagnose different possibilities. Available for $0.99.

• Mental Illness: Use this app, available for free, to help diagnose mental illness. Get a solid understand of mental illness and offer better patient care as a result.

• Patient Care: Enhance the way you care for patients with the help of these iPad apps. Portable medicine and increased technology mean that you can help patients understand their care better than ever better.

• Blausen Human Atlas: This app, available for $19.99, is meant to help doctors and other health care professionals communicate with their patients. The idea is to help them share core concepts and more with patients, enhancing understanding.

• MedSpeak: Communicate with Mandarin or Cantonese speakers with this application. Each version is available for $14.99 apiece. Learn how to properly communicate with patients who do not speak English.

• Medical Spanish (with audio): You can learn basic Spanish phrases. For $6.99 you can get the phrases you need to better communicate with your patients. Audio helps you work on proper pronunciation.

• AirStrip OB: This free app is meant to help doctors and other health care professionals monitor a baby’s symptoms remotely. It is used in tandem with the patient and can reduce trips to the hospital. AirStrip also has apps for Cardiology, Imaging, Critical Care and more.

Applications like the above for the iPad and now often developed by doctors and hospitals, are pushing the iPad well into the medical realm. The ways that Apple’s iPad is changing health care is remarkably touching the entire continuum of care. Below are some other examples how the iPad is used for learning and for many clinician-patient interactions, as well as by individuals who work in health administration. 129

Dr. Edward Bender, a computer programmer and cardiothoracic surgeon at Saint Francis Medical Center in Cape Girardeau, has brought research for heart surgery to the Apple iPhone and iPad through apps that doctors and patients can use to predict the risks of heart surgery and to help students and residents prep for procedures. Bender developed the apps on his own and worked with ARMUS Corp., a Silicon Valley IT company on design and functionality. Prices for the apps at the iTunes App Store range from free to $3.99 each.

At Kalkaringi, Australia, the home of the Land Rights movement, Aboriginal Health Workers such as Dee Hampton are using the iPad, connected by Next G to Katherine West’s database located in a secure datacenter in Sydney, in her daily rounds of her elderly or “health clinic shy” clients at their home or at the shop. By connecting to the KWHB health clinics database via the iPad, health workers have a reasonably unobtrusive information package equivalent to the old days of taking the patients paper files with them, but with far more accessible portability.

In Japan, doctors use the iPad to assist them with explanations during patient consultations. Prof. Hiroshi Mizushima, a medical informatics expert at Tokyo Medical and Dental University, said, “Surprisingly, compared with other professionals, medical practitioners lag in their use of IT tools. Having said that, we can now use these tools in various situations, such as having patients use a touch screen device to answer questions about their health during consultations and using moving images to explain illnesses to patients.”

Cherokee Regional Medical Center in Iowa uses the latest technology. Inspired by the seemingly endless possibilities available at her fingertips, Jessica Mattioda, a nurse supervisor at CRMC, recently spearheaded a project to implement multifunctional Apple iPads and medical apps into the facility’s day-to-day nursing practices. Application updates have the potential to save CRMC money by having the ability to download updates when available in lieu of purchasing books, which can be quite expensive and outdate quickly.

Dr. Jon Mendelsohn, medical director of Advanced Cosmetic Surgery & Laser Center, is using several iPads as a way to take his office paperless. Patient charts will be securely loaded onto his iPad, so that they are accessible anytime he visits with a patient, including nights and weekends. Patients will use iPads to fill out paperwork and staff will use them as teaching tools with patients to go over procedures and pre- and post-operative instructions. Mendelsohn said he loaded his library of publications onto the iPads as well, so that patients can learn more about facial surgeries while in the waiting room.

Fine motor skills are really not required for the iPad, making this device a natural for anyone with diminished fine motor skills and other disabilities. Dr. Weber writes about one man with Parkinson's Disease who used his iPad with ease, compared to a regular computer with a keyboard and mouse. Previously critical of iPad, Dr. Weber has “softened up a bit” after watching his friend go through the motions and is now starting to think of other areas and other applications for the iPad that would be helpful for people who find it difficult to work with a traditional keyboard and mouse.
Samaritan Hospital and Albany Memorial Hospital, members of the Troy-based health care organization Northeast Health, are now offering iTriage to consumers who use smart phones or smartphone devices such as the iPhone, iPod Touch, iPad android devices and Palm and will soon be offering it to Blackberry users. The application can be downloaded for free and provides access to information about Northeast Health hospitals, including specialty services offered, location maps and community services.

With its ten-hour battery life, Kaweah Delta hospital’s director of technical services, Nick Volosin thinks the iPad will replace the laptop for everyday office applications such as email and also for checking X-ray images, EKG results and patient monitoring programs. The hospital has been using the Citrix software on the iPhone for a while now, so integrating the iPad into the system is not expected to be a problem. And, despite the $500 per unit price on the device, the iPad is still affordable when compared to some specialized touch screen tablets used by hospitals, which could cost as much as $3,000 each.

The newly expanded Walt Disney Pavilion at Florida Hospital for Children in Orlando and St. Luke’s Health System in Boise, Idaho, began testing a customized version of an app called Medical Video JLog from Eagle, Idaho-based Unity Medical. Florida Hospital for Children will employ iPads as a way of explaining tests such as CT scans and MRIs to children with videos and interactive question-and-answer features. St. Luke’s has loaded its iPads with about 20 educational videos on topics such as heart and vascular procedures and physical therapy.

**What Now?**

Everyone in the health care organization has a stake in striving to have the best and most accurate information available at the patient point of contact. The time is now to move beyond pagers and paper to put the information mobile clinicians really need in their hands or on a belt clip. Health care consumers are not waiting and least of all the health care deliverers themselves need it more than ever.

Considering the estimates by the Association of American Medical Colleges that the US will be short over 90,000 primary care providers, specialists and surgeons by 2020, it only makes sense that information technology, including mobile computing in health care, is better leveraged to expand the reach and range capability for health care needs.
Accelerating Clinical Research

The traditional model of clinical research involves a clinician, armed with a research hypothesis, writing up a proposal and submitting it to an Institutional Review Board (IRB). After approval and funding, an often very laborious process is involved in identifying research subjects. Then depending on the study, a very laborious (and therefore costly) process is involved in acquiring data, often including an extensive manual review of paper medical records.

Months or even years can be eaten up by writing a research proposal, getting it approved and funded and searching for research subjects, only to find out that not enough research subjects can be found that meet the research criteria. The worst part is the research that is not completed and the medical breakthroughs that are not discovered and the lives that are not saved, because this process is so difficult and so expensive that many good research hypotheses never get off the ground.

There is a better way. Now that large health care organizations like DoD, the VA, Kaiser and many Academic Medical Centers (AMCs) have had EMRs in place for a few years, there exists a steadily growing mountain of clinical data on tens of millions of patients. There are many holes in the data and depending on the research need, some required data is still on paper or stove-piped away in difficult to access specialty systems.

Also, the EMR data must be exported to a data warehouse to permit mining the data without shutting down the EMR and data warehouse projects are expensive. Nevertheless, these clinical data warehouses now exist or are soon coming online at large innovative health care organizations and the answer to thousands of unasked research questions are now orders of magnitude easier to discover.

Gartner Research health care analyst Vi Shaffer has coined the term Advanced Clinical Research Information System (ACRIS) to describe the kind of system that will be required to manage clinical research in this new world order. An ACRIS is:

- a complex constellation of capabilities that can rapidly assemble data assets for research questions and provide data mining and research processes support to meet the needs of clinical and translational research and related biostatistics and bio computation. The Enterprise Data Warehouse may be shared between the ACRIS and an enterprise business intelligence system that assembles data from some of the same
sources, but for the purposes of performance management. However, the requirements for clinical research are very different from - and even more complex than - the requirements for business intelligence.

An ACRIS includes tools that enable:

- Mining of patient data, including that contained in transcribed and other unstructured reports
- Automatic correlation of data with medical knowledge in published research, providing more effective/efficient secondary research
- Use of external data and open-source tools, including assistance in translating between ACRIS data models and vocabularies and those of other institutions, for collaborative research
- Cohort identification
- Creation of research study data marts from enterprise and other clinical trial data
- Facilitation of researcher workflows, including support of the scientific method, grant preparation, internal/external collaboration and documentation.¹³⁰

Shaffer points out that the need for ACRIS capabilities are being accelerated by the rapidly advancing interest in genomics and translational research, as well as the fact that the funders of research are coming to expect the research process velocity and discipline that an ACRIS can deliver.

This all closely mirrors the goal of the National Institutes of Health (NIH) in funding the Clinical and Translational Science Awards (CTSA) program. This consortium includes 55 medical research institutions located across the nation. When fully implemented in 2012, 60 institutions will be linked together with the goal of collaborating on and energizing the discipline of clinical and translational science. Drawing from the NIH Roadmap for Medical Research and extensive community input, the CTSA program creates an academic home for clinical and translational research. The CTSA program vision statement is to: “Improve human health by transforming the research and training environment to enhance the efficiency and quality of clinical and translational research.”¹³¹

Let us briefly examine the experience of one of the CTSA facilities, The Ohio State University Center for Clinical and Translational Science. Vi Shaffer at Gartner feels that OSU is a leader in understanding the critical link between

¹³⁰ Gartner Research Report, Hype Cycle for Health care Provider Applications and Systems, 2010
¹³¹ CTSA web site: http://www.ctsaweb.org
operational medicine and clinical research. They ensure epidemiology expertise is imbedded throughout the entire clinical research process. They are focused on developing translational research information architects, to ensure that the data collected during research can be efficiently and effectively “translated” into operational medicine as soon as it is clinically responsible to do so.

OSU had an early start with clinical data warehousing and the lessons they have learned in the last ten years from the blood, sweat and tears associated with pioneering this work are now baked into their clinical data warehouse data model. The data model and associated business logic surrounding the clinical research process is a goldmine for other health care organizations wanting to copy their success. And copying their success is critical if we want to expand translational research and empower thousands of researchers with all the clinical data that EMRs will produce in the next 5-10 years.

Vi Shaffer feels it is important to replicate the success of larger Academic Medical Centers (AMCs) like OSU at second tier AMCs. She states that to do this the market desperately needs accelerators and the acceleration required is part technical, part change management and part research operations.132

Another pioneering CTSA facility is the Harvard Clinical and Translational Science Center. Among their many accomplishments is the development of a scalable informatics framework that is enabling clinical researchers to use existing clinical data for discovery research and, when combined with IRB-approved genomic data, facilitate the design of targeted therapies for individual patients with diseases having genetic origins.

Dubbed i2b2 (Informatics for Integrating Biology and the Bedside), this platform enjoys wide adoption by the CTSA consortium and is now used by over 40 health care organizations worldwide. A cousin to i2b2, also being developed at Harvard, is SHRINE (Shared Health Research Information Network). SHRINE helps clinical researchers overcome one of their greatest problems – compiling large groups of patients across different health care organizations that meet criteria for a clinical trial.

Qualified investigators may use the SHRINE web-based query tool to determine the aggregate total number of patients at participating hospitals who meet a given set of inclusion and exclusion criteria (currently demographics, diagnoses, medications and selected laboratory values). Because counts are aggregate, patient privacy is protected. SHRINE is still in beta testing at Harvard, but could soon enable a significant leap forward in the federated discovery of patients for clinical trials.

132 Interview with Vi Shaffer, 22 Oct 2009
Another aspect of the future of clinical research is the ability to conduct computer simulations of health care interventions. The Archimedes Model is a full-scale simulation model of human physiology, diseases, behaviors, interventions and health care systems. By using advanced methods of mathematics, computing and data systems, the Model enables managers, administrators and policymakers to be better informed and to make smarter decisions than has previously been possible.

The core of the Model is hundreds of equations that represent human physiology and the effects of diseases. Attached to these are hundreds more equations and algorithms that realistically simulate the health care system including processes such as tests, treatments, admissions and physician behaviors. Together with population data, the equations are integrated into a single, large-scale simulation model that accurately represents what happens to real people in real health care systems.133

The Archimedes model has been able to recreate studies done with “real humans” with remarkable accuracy. Critics are concerned that the model is trying to use algorithms to define connections that even medical science does not understand. Archimedes failed to predict that raising “good cholesterol” would actually lead to an increase in heart disease (as did the rest of medical science – any model can only be as good as the science used to build it). Critics are concerned that Archimedes’ creator, Dr. David Eddy, is keeping the model shrouded in secrecy and not providing the kind of access that other clinical researchers need in order to validate the methodology and understand how all 10,000 of the variables and equations interact.

Dr. Eddy states, “Clinicians tend not to trust models, which is understandable, since many models are junk and it can be difficult to tell which is which.” He goes on to point out that when the model fails, like in the cholesterol study, this is a good thing, because it can help pinpoint holes in medical science that need to be filled in. When they are filled in, this new information becomes another variable or equation in the model and the predictive power of the model becomes that much stronger.

Proponents of Archimedes point out that the model would never be used independently to recommend a new intervention. If the model pointed to a particular treatment or intervention as more efficacious than the status quo, then clinical trials would always be performed to confirm the treatment worked on carbon based human beings instead of software model based human beings. The key point is that Archimedes could be used as an accelerator to pinpoint treatment modalities that could then be confirmed with clinical trials – as opposed to “fishing” with clinical trials that can drag on for years and decades.

133  http://archimedesmodel.com/
Unlike clinical trials, Archimedes can easily run a wide variety of modifications to the experimental hypothesis. Unlike clinical trials, Archimedes can conduct experiments that could not be done on humans for ethical reasons. It can model factors like arterial plaque that cannot easily be measured with diagnostic devices. Because it can run 16,500 person-years of simulation per minute, it can conduct large-scale studies with so many required variables that it would be astronomically expensive (and take decades) to complete them with clinical trials.

Last but not least, Dr. Eddy’s team is currently working on ARCHeS, an online interface that will allow physicians and researchers to access Archimedes and design their own trials.¹³⁴

Hopefully the future of clinical research looks something like this: Physicians, epidemiologists and other researchers at AMCs across the country are able to access mature ACRIS-type systems to mine mountains of clinical data, discover new relationships among the data and propose new hypotheses on better treatments and interventions. They log on to ARCHeS and run these studies on a massive Archimedes platform built to support a large volume of analysis.

If confirmed on Archimedes, they use i2b2, SHRINE or similar platforms to streamline the process of identifying patients that qualify for a clinical trial. Additionally, patients can use tools like TrialX.com and researchmatch.org to discover and volunteer themselves for clinical trials they are eligible for, even if their clinical data is not accessible to the AMC conducting the study. Clinical trials are conducted and repeated to the extent required to satisfy the medical community that the proposed new treatment or intervention is in fact an improvement. An improved clinical research process along these lines would greatly accelerate the advancement of medical science.

Clinical Decision Support

As we have just seen, hopefully the intelligent application of information technology in clinical research will be able to significantly expand the volume and quality of new medical science produced. That is the good news. The challenge now becomes - how are we going to effectively convey this new knowledge to clinicians in ways they can most effectively use it?

The answer is evidence-based Clinical Decision Support (CDS) that is baked into the EMR clinical workflow process, always available but minimally obtrusive to the provider. Ideally, like the Archimedes model just discussed, it is informed by data specific to the patient being treated, so that treatment recommendations may be tailored to the patient to the extent possible. CDS encompasses a variety of tools and interventions, such as computerized alerts and reminders, clinical guidelines, order sets, patient data reports and dashboards, documentation templates, diagnostic support and clinical workflow tools.

Because CDS is optimized in the context of EMR workflows, it cannot progress any faster than EMR adoption. Some HDOs are beginning to have some success with CDS, but many others have had limited success or have not even begun in earnest. Success is difficult to replicate because of the complexity of clinical decision-making, the technical complexity of effectively delivering CDS and social aspects of incorporating changes into clinical practice that are very different at different HDOs. 135

A 2008 Journal of Biomedical Informatics article entitled, “Grand Challenges in Clinical Decision Support,” authored by a “who’s-who” of CDS experts, is an excellent roadmap for the technical and process interventions that are required in order to refine and accelerate CDS efforts. Using an iterative, consensus-building process, they have identified a top ten list of challenges facing CDS. A summarization of this list will make an excellent cornerstone for our CDS discussion:

- Improve the human-computer interface: CDS should unobtrusively, but effectively, remind clinicians of things they have truly overlooked and support corrections, or better yet, put key pieces of data and knowledge seamlessly into the context of the workflow or clinical decision-making process.

• Summarize patient-level information: The challenge is to intelligently and automatically summarize all of a patient's electronically available clinical data, both free-text and coded, and to create one or more brief (1-2 page) synopses of the patient's pertinent clinical data.

• Prioritize and filter recommendations to the user: The challenge is to rank in priority order and reduce the number of computer-generated recommendations that a clinician has to deal with to a manageable number, thus reducing the “alert-fatigue” that is a frequent cause of user dissatisfaction.

• Combine recommendations for patients with co-morbidities: The majority of elderly patients have multiple co-morbidities and medications that must be addressed, but the majority of clinical guidelines today do not adequately address these co-morbidity and polypharmacy issues.

• Use free-text information to drive CDS: At least 50 percent of the clinical information describing a patient's current condition and stage of therapy resides in the free-text portion of the EMR. We need methods of extracting the clinical information contained in this free-text into a form that would allow CDS systems to utilize it.

• Prioritize CDS content development and implementation: CDS development should be prioritized according to value to patients, cost to the health care system, availability of reliable data, difficulty of implementation and acceptability to clinicians

• Mine large clinical databases to create new CDS: We need to develop and test new techniques to allow researchers to mine large clinical data repositories in order to expand the global fund of clinical knowledge. We must address the social and political challenges facing researchers as they struggle to create or gain access to these large clinical databases.

• Disseminate best practices in CDS design, development and implementation: The CDS implementation process needs to be expressed and catalogued in a way that allows information from successful sites to be easily found by others.
• **Create an architecture for sharing executable CDS modules and services:** The goal is to create a set of standards-based interfaces to externally maintained CDS services that any EMR could “subscribe to,” in such a way that HDOs can implement new state of the art CDS interventions with little or no extra effort on their part.

• **Create internet-accessible CDS repositories:** The challenge is to build one or more internet-accessible repositories of high quality, evidence-based, tested, CDS knowledge modules. These interventions and services could be easily downloaded, maintained, locally modified, installed and used on any EMR.  

Approximately half of these recommendations simply need a combination of technical innovation and market forces to mature into fruition. The other half will require a coordinated centralized effort to be successful, it is therefore important that the federal government play some role in the solution. Just like the Certification Commission for Health Care Information Technology (CCHIT) approach to certifying EMRs, it is important to strike the right balance between the government and private sector role.

The government ultimately needs to referee the definition of standards and help establish centralized architectures, but only with strong and continuous private sector input to ensure quality feedback and innovation. It appears there has been a lot of discussion, but little action towards a coherent centralized CDS architecture. We hope this will change so that HDOs can implement state of the art CDS with little effort (at least compared to the effort required to implement the EMRs that the CDS will ride on). No one would argue with the statement that medical science is a public good. Logically, the infrastructure required to most effectively translate this science into clinical practice should also be a public good.

Government established EMR “meaningful use” criteria include CDS requirements, which means that HDOs will have to demonstrate at least some level of CDS integrated with their EMR in order to receive ARRA incentive payments. Hopefully this economic incentive will drive progress with CDS in the short term.

Also in the short term, there is plenty of relatively simple CDS that can be implemented without significant EMR integration expenses. Vendors like UpToDate and MDConsult, providers of evidence-based medicine resources

---

via the Web, are enabling very lightweight EMR integration models by accepting search queries and patient demographics via URL. For example, if a clinician has made a new diagnosis and wants help with treatment recommendations, one click from within the EMR results in a URL request to UpToDate.

Imbedded in the URL is the diagnosis the clinician just input into the EMR, so that UpToDate can return search results on the diagnosis without the provider having to open a new browser window and typing in the diagnosis on the UpToDate welcome screen. It may only save a few seconds, but those few seconds are critical in the exam room. It may very well mean the difference between the clinician consulting an evidence-based resource – or not bothering to. Because the programming effort on the EMR end is minimal, this is the kind of CDS that can be quickly implemented.

Another tool available in the short term to improve CDS is Adjusted Clinical Groups (ACGs), developed by a team at Johns-Hopkins over the last ten years. ACGs take clinical history and medication data from the patient file and categorize patients into risk adjusted acuity groups. This allows, for example, prediction of which patients are on their way to becoming “train wrecks” in the future and would therefore be good candidates for case management. In addition, ACGs can be used to refine CDS recommendations. For example, when a patient is given a new diagnosis, the diagnosis plus their ACG profile can be combined to more accurately describe the typical disease progression and how the patient should be treated differently given their ACG profile. 

Using ACGs to boost the power of CDS is the “middle ground” between, on the one hand, CDS that is uninformed of patient-specific data and, on the other hand, CDS that has complete awareness of everything about the patient, to include genomics data. The former is widely available now, the latter is in its infancy and is incredibly complex to implement. Using ACGs is the best option we have that could be made widely available today.

Speaking of genomics data, experts predict that, in the not too distant future, advances in nanotechnology and molecular biology will allow us to screen a single drop of blood for thousands of genetic markers, giving us the ability to predict the likelihood of illness over a patient’s lifetime. Significant work is already underway to figure out the best way to model this genomic data and include it into CDS. As medical science continues to discover how gene expression relates to specific morbidities and treatments, this capability will become increasingly powerful in its ability to tailor CDS recommendations to specific patients.

137 Interview with Gary Nissen, CEO of Health Plus Technologies, 30 October 2009
Last but not least, physicians need to be very involved with CDS implementations. Dr. Terry Steinberg, CMIO of Christiana Care Health System in Delaware, puts it this way:

‘Hit enter to confirm that the computer is smarter than I am,’ is the way clinicians see CDS – they have a real love-hate relationship with it. They like knowing they have a safety net, but they don’t like it when the computer tells them something they knew already. 138

CDS experts agree that CDS is something that has to be “done with physicians, not to them.” HDOs must incorporate the voice and unique culture of their physicians into any CDS implementation and, at the same time, ensure that CDS is effective in bringing practice patterns closer in line with evidence-based recommendations.

138 Lawrence, Daphne, Making the Right Decision, Healthcare Informatics, vol 26, no 10, October 2009, pp. 14-18
Afterword

In the complex writing process we have completed for this volume, two facts stand out:

- Health care is in deep need of transformation and the creativity and innovation, which new and different uses of technology can encourage.
- A tremendous amount of unfocused thinking and energy is being applied to aid the transformation process in health care.

Clearly, our vision, research, and daily activity as a group of health IT professionals is grounded in pragmatic reality. Many of the ideas and notions explored in this volume would have been presumed by the medical profession to be mere fantasy just a few short years ago. We are seeing positive, constructive applications of even the most “out there” technologies and areas of research. And, our colleagues in military medicine and the VA continue to blaze trails that will inure to the benefit of all health care.

Can we see progress with the enablers? We would suggest a highly tentative “yes”. Adoption and exploration of technology is on the rise, yet far from widespread.

Successful health information exchange is still a lofty goal, yet several successful models are emerging – a claim which could not have been made just a few years ago. Security and privacy concerns are gaining both improved technical solutions and greater clarity as to what the concern actually is. Finally, financial reform is seeing movement away from the classic “fee for service” model to “case management” reimbursement and pools for chronic disease sufferers. While the jury is still out on how health care reform will change and shift with power shifts in Washington, it is clear that the way we pay for care will be an agenda item in our national debate for some time to come.

Do we see forward progress in each transformative element discussed? From consumer empowerment to patient portals and primary care medical home, it is clear that more transformative projects are moving forward now than at any time in recent memory – far more than can be written about in one volume. This will continue to generate a wealth of information on how health care can structure itself to lead to improved outcomes and how technology can truly assist in this process.

Individual technology applications and functional solutions also continue to emerge at exponential rates – driving an enormous volume of effort both to analyze the impacts but also to integrate solutions so that data is captured and informs the entire continuum of care. We are clearly moving to what Gartner
calls the “real-time health system” and “high velocity medicine” – an amazing thought and one that is extremely heartening to all of us.

Where do we go from here? First, let us look at how our essays and research has supported and extended our core principles identified at the beginning in our vision:

- How we deliver care can be fundamentally changed, extended, supported, and enriched by a host of different operating concepts that are made possible by changes in technology. – *We have shown across all the essays in this volume a number of different concepts from wholesale reorientation efforts like patient-centered medical home, to simple workflow driven changes made possible by the advent of mobile technologies such as the iPad.*

- The cost of care can be radically changed through better use and exchange of information. – *We have shown through all of the essays in this volume that cost can be managed and clearly can be reduced through the utilization of a wide variety of information technology. We have also examined operating constructs that in conjunction with technology converge to transform the health care paradigm.*

- The quality of care can be dramatically improved through better use and exchange of information. – *We have identified throughout this volume the potential benefits of bringing a greater and more relevant amount of data to the clinical encounter, empowering patients and enabling providers to really deliver “evidence” based care.*

- Transforming health care really is about how we design the delivery of care and how it is supported by better data for both consumers and providers. – *In each of the essays, it is clear that a presumption in favor of considering how the delivery of care is designed is critical to the success of the technology intervention.*

Finally, what can we do? We would suggest for each of the following actors an idea to explore.

- **Consumers** – constantly explore the data for your own knowledge and be inquisitive about the meaning of information. Medical science depends on a lot of trial and error and this requires an engaged if not empowered consumer.

- **Providers** – continually demand from your technology partners a thoughtful examination of how solutions can help the delivery of care improve and how they can help plot a path forward for a more information-rich health care industry, rather than our mostly ill-informed, data-logged present.
• **Technologists** – be prepared to learn and care about the environment and context of the solutions you envision. It is not about the cool technology or the gadgets or even the progress of information science and analytics – *it is about making a difference for health care, enabling better care through the better understanding and application of data and information.*
Bill Oldham, Chief Executive Officer

Introduction

Over the last two decades, Mr. Bill Oldham, Evolvent Chief Executive Officer, has led many cutting edge and dynamic technology programs in the health care sector. From bringing telemedicine to the remotest regions of the Middle East to bringing data integration to our nation's military to supporting project management automation for the UN’s World Food Program– Bill has led teams and projects bringing innovation and technical excellence to the health care industry. Bill’s vision for the Evolvent team, a company supporting more than 200 health care technology customers, is to drive excellence in helping health care organizations utilize technology to improve care outcomes and performance.

Record of Innovation for Health Care

In a variety of roles, Bill has led projects and organizations to deliver value to the health care provider community through smarter, more cost-effective use of technology. As Chairman & CEO at Evolvent, the company has led innovation across many projects including:

- Reduce the cost of care delivery through process analysis, automation, and integrating systems with improved work processes
  - Leading Air Force Medicine’s implementation of Lean Six Sigma to define, analyze, and reengineer processes to improve care and reduce costs
  - Leading work process automation analysis and implementation efforts supporting medical evaluations, wounded warrior initiatives, and PTSD/TBI programs
  - Supporting DoD/VA information sharing initiatives and leading architectural efforts to change the technology base for both organizations to a lower cost model
  - Leading Army telemedicine initiatives in support of Wounded Warrior programs to bring psychological health support to our veterans more quickly and to improve access to care
  - Reduce the sustaining cost of technology through modernizing architecture, consolidation strategies, virtualization, and systems migration
• Built VA’s first Incident Response Center consolidating network and incident monitoring and action response teams.

• Created the Air Force Medical Service Knowledge Exchange – a health care knowledge management program currently serving more than 45,000 global users, ran the Knowledge Architecture team to build global solution for the Air Force to consolidate and leverage knowledge resources for humanitarian and medical support operations around the world.

Prior to Evolvent, Bill led development of wireless home health care monitoring and data collection service to automate “business” and documentation needs of home health workers, building a solution to reduce the time required to complete Medicare documentation and improve care plan data capture across the continuum of care. At the same time, this team led development of model utilizing telemedicine tools in support of Indian Health Service tele-psychology programs, building a web-based solution to extend care capabilities to remote patients in disadvantaged communities.

While working in the Middle East in the 1990s, Bill was Project Manager for MeduNet, a non-profit health information exchange/network in Saudi Arabia linking all Kingdom hospitals. This network developed early standards for analyzing the requirements for electronic patient records in Persian Gulf countries, and constructed a dedicated national network for telemedicine and information sharing which supported telemedicine, distance learning, networked clinical information systems, internet access, and video-conferencing – providing a humanitarian, dedicated network to provide health care resources to the remotest regions of the Middle East. At the same time the telemedicine services developed allowed for International provider continuing education or workforce development programs. The network provided the technical platform and supported course design and international educational partnerships for first Saudi school of nursing for women.

Throughout his career, Bill has sought ways to leverage technology to improve the performance of health care globally – better serving patients and providers at the lowest possible cost.

**Community supporter**

Bill also demonstrates a belief in the value of family and community through his efforts supporting a variety of causes and local programs, outlined below. A member of local IT support organizations and chapters of national organizations, local advocacy groups for health care IT, and a number of initiatives within the community including:
Better Data for Better Care

- American Telemedicine Association
- Healthcare Information Management Systems Society (HIMSS) National Platinum Member and Local Chapter Member in Northern Virginia and Texas.
- Northern Virginia Technology Council

As a part of efforts to promote better wounded warrior care, Bill is a founding executive of the Traumatic Brain Injury Consortium – a group of multi-national companies, universities, laboratories, and leading individuals committed to improving health care outcomes for veterans with TBI leveraging new technologies in sensors, screening, therapeutics, and informatics.

Bill believes that philanthropy is part of good citizenship. Personally, Bill has a history of giving back to the community with donations of money, talent and time. Organizations helped in the recent past include:

- Central Union Mission, Social Services for the Homeless, Washington, DC
- Episcopal Relief Fund, Diocese of Louisiana, New Orleans, LA
- John L. Young Center, Homeless Shelter, Washington DC
- Loudoun Interfaith Relief, Loudoun County, VA
- M.D. Andersen Cancer Center, Children's Art Project, Houston, TX
- Wagner Scholarship Fund, Scholarship Grants to Children of United States Air Force Medical Service Corps Officers, San Antonio, TX
- Whitman-Walker Clinic, non-profit, community-based HIV/AIDS Clinic, Washington, DC.

*International profile and beliefs*

Bill's career in health care started after spending a few years on Wall Street working in the financial information services industry. Leading North and South American operations for a small technology company based in the UK, Bill was able to use technology to transform sales and service delivery, expand partnerships and networks and better support customers. Following this experience, Bill left the financial industry for health care and work in the Middle East. That experience, coupled with graduate education in the UK and Holland, has led to a belief system grounded in the humanitarian imperatives of expanding global resources and access to care while ensuring that best practices are followed and costs are contained and/or reduced.
Paul A. Ramsaroop, President and Chief Operating Officer

Over the last twenty-five years, Mr. Paul Ramsaroop, Evolvent President and Chief Operating Officer, has been a leading technologist for start-ups and large corporations – leading teams and developing technical solutions in a wide range of industries. For the last fifteen years, Paul has been a leading technical visionary in health care applications, particularly focused on federal agencies. Since joining the founding team of Evolvent, Paul has served in positions of increasing responsibility within Evolvent finally taking over the operations group in 2004. Prior to Evolvent, Paul had worked with many start-ups across the country as well as more than fifteen years in the IT field with several well-known companies, including McDonnell-Douglas, Boeing, Intellidyne, and Maryville Technologies. He also served as CTO of a dotcom startup, HealthCPR, which championed a personal health bank a few years before its time.

Paul’s career began with acquiring an intimate hands-on knowledge of application development, programming in various languages from Assembler to Visual Basic, and advancing from developer to a founding Executive of Evolvent. Within Evolvent, Paul is currently responsible for daily operations and program delivery, along with employee and client relations. Paul’s well-known and reliable service attitude and determination to do what it takes to accomplish a task, makes him the man to turn to when seeking the tools and guidance to be successful.

Paul is highly skillful at managing programs and the people who run them. His role at Evolvent currently oversees the company’s growth and development plans for process improvement initiatives, work team management and functional expert development, as well as the oversight of the company’s efforts to secure a personal career plan for each associate. His insights and his dedication to the growth of the entire Evolvent team is a big part of what makes the company a highly sought after organization to work for.

A few of Paul’s accomplishments prior to his executive duties within Evolvent are:

- Leading a non-profit humanitarian effort in Panama partnering with the US Military
• Lead Technologist for US Department of Agriculture web consolidation effort
• Lead Technologist for US Navy facility web consolidation program
• Lead Technologist for large non-profit, NGO focused on humanitarian missions to rebuild their global project management system
• Senior Executive in charge of virtual data network initiatives
• Senior Web Operations Manager for DoD TRICARE enterprise Website
• Technical lead within the McDonnell-Douglas’ CADD system development team
• Technical Program lead launching the AFMS Knowledge Exchange (Kx 1.0) (https://kx.afms.mil/)

Like Bill, Paul also demonstrates a belief in the value of family and community through his efforts supporting a variety of causes and local programs, outlined below. A member of local IT support organizations and chapters of national organizations, local advocacy groups for health care IT, and a number of initiatives within the community including:

• American Telemedicine Association
• Healthcare Information Management Systems Society (HIMSS) National Platinum Member and Local Chapter Member in Northern Virginia and Texas.
• Northern Virginia Technology Council
• San Antonio Chamber of Commerce

Paul also believes that philanthropy is part of good citizenship. Personally, Paul has a history of giving back to the community with donations of money, talent and time. Organizations helped in the past include:

• Fisher Foundation in the National Capital Region and San Antonio
• Operation Homefront
• Ourmilitarykids.org
• NIH Children's INN
• John L. Young Center, Homeless Shelter, Washington DC
• Whitman-Walker Clinic, non-profit, community based HIV/AIDS Clinic, Washington DC
• Service International, a St. Louis based non-profit disaster relief organization
• Youth With A Mission
J. D. Whitlock, Vice President, Research and Development

Mr. J.D. Whitlock, Evolvent Vice President, Research and Development, has 15 years experience in health care administration, including assignments in group practice management and patient administration prior to specializing in health care information technology (HIT). A retired Air Force Lieutenant Colonel, J.D. spent the last five years of his Medical Service Corps career managing a portfolio of HIT projects at the Air Force Medical Service Office of the CIO.

These projects integrated Information Management and Knowledge Management disciplines to improve operational efficiency, promote transparency, and enable decision support for expeditionary, clinical, and business operations throughout the Air Force Medical Service.

In 2007, J.D. deployed to Craig Joint Theater Hospital, Bagram Airfield, Afghanistan, as Chief, Patient Administration and Aeromedical Evacuation. This combination of operational experience with in-depth HIT knowledge permits him to quickly understand the needs of his customers and deliver results that meet mission requirements.

J.D. began his military career in the U.S. Navy as a Surface Warfare Officer. He holds a Master of Public Health from UCLA, and an MBA in Management of Information Systems from the University of Georgia. He is certified as a Project Management Professional (PMP) and Certified Professional in Health care Information and Management Systems (CPHIMS).
Stephen Gantz, Chief Security Officer

Mr. Stephen Gantz, CISSP-ISSAP, CEH, CGEIT, CRISC, CIPP/G, Evolvent Chief Security Officer, has more than 20 years experience in information security, professional services, IT strategy, project management, software development, enterprise integration, and solution architecture development. He is deeply involved in health IT and health information exchange policy, standards, and solution development, and is recognized as a subject-matter expert on security and privacy in health information exchange.

Steve has supported federal government health IT programs at several agencies within the Department of Health and Human Services, including CDC, CMS, FDA, and IHS, and has worked with the Federal Health Architecture program and Office of the National Coordinator since their formation in 2004.

As Evolvent’s Chief Security Officer, Steve is responsible for the development and implementation of security-related services and solutions provided to defense and civilian agencies. He also oversees the compliance of Evolvent’s customer-facing and internal programs with relevant security and privacy laws and regulations, particularly including FISMA, HIPAA, HITECH, and the Privacy Act, leveraging federal and international standards and guidelines such as the NIST 800 Series of Special Publications and the ISO/IEC 27000 series standards.

Steve received a Masters Degree in technology policy from the Harvard's Kennedy School, and also earned his BA from Harvard. He is also pursing a doctorate in management at University of Maryland University College, where his dissertation research focuses on the role of trust and distrust in achieving cooperation among organizations.
William Sorrells, Executive Director

Mr. William Sorrells, Executive Director of the Alaska eHealth Network, is responsible for building Alaska's statewide health information exchange (HIE). Bill has 11 years experience in health care administration specializing in health care information technology (HIT), where he also served as the Pacific Air Forces Group Practice Management Consultant. A retired Air Force Major, Bill spent his Medical Service Corps career as a two-time military treatment facility (MTF) CIO and managed a portfolio of HIT projects at the Air Force Medical Service Office of the CIO. These projects included leading an Air Force solution for creating an enterprise model for personal health records (PHR) and secure messaging between patients and providers; developing a “roaming” solution for DoD's electronic medical record (AHLTA) for Pacific Air Force MTFs; and helping develop a statewide telemedicine case management/messaging portal for the state of Alaska and the Alaska Federal Healthcare Partnership.

Bill began his military career as a missile systems analyst/technician and then a logistician before being commissioned in 2000. He holds a M.S. in Operation Management from the University of Arkansas, and an MBA and MSIS from Mississippi State University. He is certified as a Project Management Professional (PMP), Certified Professional in Health Care Information and Management Systems (CPHIMS), Certified Healthcare CIO (CHCIO) through the College of Health Information Management Executives and a board certified Fellow through the American College of Healthcare Executives.
Mr. Gregory Parish Jr. is a new business analyst with Evolvent, which has informed the start of his career at the company. Greg’s writing and research this year have contributed to his ongoing professional and intellectual interest in health care information management.

Greg is a recent graduate of Harvard University, where he obtained a Bachelor of Arts in Government. He has a background in health care information management research, serving as an intern at the Healthcare Information and Management Systems Society (HIMSS). Greg also served as an intern at Evolvent, prior to becoming a full-time employee.
Stella Ramsaroop, Editor

Ms. Stella Ramsaroop, Editor, is a columnist for Kaieteur News, one of the four national newspapers in Guyana, South America. While focusing her column on the social and political issues that affect Guyana, Stella has most significantly championed women's issues – and in particular, addressing domestic violence. In 2010, she co-hosted the “Break the Silence, Stop the Violence” rally, spoke at domestic violence workshops and participated in multiple television discussion panels to bring awareness to the issue of domestic violence in Guyana and to encourage victims to speak up and get help.

In college, Stella took first place in News Writing and Editorials, as well as placing in several other areas, on a regional level. Her work also garnered a national award for layout and design and the prestigious appointment as a Leader of the Student Press of North America by the Associated Collegiate Press.

Stella has been writing and editing for ten years on projects that include the many issues of the Evolvent Magazine and editing the book, The Road to El Dorado - The People's Revolution – as well as many years as a columnist. In 2008, she opened a quaint used bookstore that specialized in used, rare and collectible books. In 2010, she added a café on to the bookstore. However, Stella's primary focus is now her column and the work she does as a women's advocate in Guyana.
Mr. Geoff Howard, Evolvent Chief Technology Officer, is a proven technology leader with a diverse background covering technology, management, and science over the past 20 years.

Geoff’s technical experience covers all aspects of software architecture and development with a focus on Internet technologies and Service Oriented Architectures, as well as security, hardware, and networking. Within the medical space, Geoff’s experience covers Electronic Health Records, Health Information Exchange, and Healthcare Imaging.

He has significant involvement in both the legacy and future of the Military Health Service Electronic Health Record, and with the Health Information Exchange between the DoD and the Veterans Administration. His experience on varied complex projects has led to an ability to apply technology and best practices effectively to accomplish business and mission objectives.

Since joining Evolvent in 2003, Geoff has led or directed engagements for the MHS, Veteran’s Administration, Air Force, Navy, Department of Energy, Department of Agriculture, Department of Homeland Security, and Department of State and brings insight in to architecture and best practices from these engagements across the federal space. Geoff holds a BA degree in Physics from Cornell University.
Monty Nanton, Executive Vice President

Monty Nanton, Evolvent Executive Vice President, brings more than 24 years experience delivering health care and health information technology project management to Team Evolvent. Monty is a proven leader in military medicine with extensive experience in coordinating human, financial, and materiel resources.

Monty’s military experience encompassed responsibilities from five commands in both tactical and TDA environments to executive staff positions in managing medical information technology for the peninsula of South Korea, Medical Center CIO roles including a tour at BAMC, and joint initiatives in medical surveillance throughout CONUS and deployed operations.

As a Senior Aviator, Monty’s exposure to the full spectrum of military health care from evacuation at point of injury to level 3 care, Mr. Nanton is well respected and a known SME in military medicine. He has a proven track record of technology management and implementing solutions that support organizational goals.

Monty is an Army Senior Service College graduate. He received National Training Standards for Information Systems 4011 & 4012 from the National Defense University, Washington D.C. He has completed the Army Medical Department Executive Skills Course, and is an Acquisition Certified Acquisition Professional (Defense Acquisition University, San Antonio, TX). Monty has also received certification from the National Defense University as Chief Information Security Officer.
Dr. David Parker, M.D., Chief Medical Officer

Dr. David Parker, M.D., Evolvent Chief Medical Officer, is a board-certified Family Physician who has taken that knowledge, 8 years of practice in the Military Health System and put it to work over the past 17 years in the clinical information technology arena. He has a demonstrated ability to bridge these three domains (clinical, military, and IT) to form innovative designs and solutions.

Dave currently serves as the Chief Medical Officer for Evolvent. He is widely known and respected in the health IT arena in the Department of Defense’s Health Affairs organization, and is constantly consulted as the person “who really knows what is what” with regard to the DoD’s electronic health record and associated systems. He now is taking the lead in bringing this experience to the broader set of Health IT Programs.

Dave has been at the forefront of the electronic health record (EHR) industry and a leader in the development of DoD health IT systems since the beginning of his career. He was the chief functional proponent and SME for the Clinical Integrated Workstation (CIW) project—the DoD’s first EHR effort/prototype. He led the functional design and requirements effort for DesertCare, the DoD’s first web-based EHR and one of the earliest to be utilized in “theater”. This application, discussed in Bill Gate’s book, Business @ The Speed of Thought, was deployed personally by Dave to a remote base in Saudi Arabia, where he installed the server and software, as well as trained the providers and technicians. This has enabled him to be productively conversant in web, virtualization, database, SOA and other technologies and architectures.

Dave is a graduate of The University of Texas at Austin and The University of Texas Medical Branch, Galveston, and completed a Family Practice Residency program at Scott AFB, IL.
# Glossary

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAFP</td>
<td>American Academy of Family Physicians</td>
</tr>
<tr>
<td>ACGs</td>
<td>Adjusted Clinical Groups</td>
</tr>
<tr>
<td>ACO</td>
<td>Accountable Care Organization</td>
</tr>
<tr>
<td>ACP</td>
<td>American Academy of Pediatrics</td>
</tr>
<tr>
<td>ACP</td>
<td>American College of Physicians</td>
</tr>
<tr>
<td>ACRIS</td>
<td>Advanced Clinical Research Information System</td>
</tr>
<tr>
<td>AFH-CAN</td>
<td>Alaska Federal Healthcare Access Network</td>
</tr>
<tr>
<td>AMCs</td>
<td>Academic Medical Centers</td>
</tr>
<tr>
<td>ARRA</td>
<td>American Recovery and Reinvestment Act</td>
</tr>
<tr>
<td>ASAP</td>
<td>Advanced Screening for Active Protocols</td>
</tr>
<tr>
<td>C32</td>
<td>Component 32</td>
</tr>
<tr>
<td>CBO</td>
<td>Congressional Budget Office</td>
</tr>
<tr>
<td>CCD</td>
<td>Continuity of Care Document</td>
</tr>
<tr>
<td>CCHIT</td>
<td>Certification Commission for Healthcare Information Technology</td>
</tr>
<tr>
<td>CCHT</td>
<td>Care Coordination/Home Telehealth</td>
</tr>
<tr>
<td>CCR</td>
<td>Continuity of Care Record</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CDHC</td>
<td>Consumer-Directed Health Care</td>
</tr>
<tr>
<td>CDS</td>
<td>Clinical Decision Support</td>
</tr>
<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
</tr>
<tr>
<td>COBIT</td>
<td>Control Objectives for Information and related Technology</td>
</tr>
<tr>
<td>CORE</td>
<td>Clinical Orthopedic Exam</td>
</tr>
<tr>
<td>CRMC</td>
<td>Cherokee Regional Medical Center</td>
</tr>
<tr>
<td>CTN</td>
<td>California Telehealth Network</td>
</tr>
<tr>
<td>CTSA</td>
<td>Clinical and Translational Science Awards</td>
</tr>
<tr>
<td>DoD</td>
<td>Department of Defense</td>
</tr>
<tr>
<td>DURSA</td>
<td>Data Use and Reciprocal Support Agreement</td>
</tr>
<tr>
<td>EHR</td>
<td>Electronic Health Record</td>
</tr>
<tr>
<td>EMRs</td>
<td>Electronic Medical Records</td>
</tr>
</tbody>
</table>
Glossary of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ER</td>
<td>Emergency Room</td>
</tr>
<tr>
<td>FISMA</td>
<td>Federal Information Security Management Act</td>
</tr>
<tr>
<td>FTC</td>
<td>Federal Trade Commission</td>
</tr>
<tr>
<td>GAAP</td>
<td>Generally Accepted Accounting Principles</td>
</tr>
<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
</tr>
<tr>
<td>HDOs</td>
<td>Healthcare Delivery Organizations</td>
</tr>
<tr>
<td>HePoEx</td>
<td>Health Postbox Express</td>
</tr>
<tr>
<td>HHS</td>
<td>Department of Health and Human Services</td>
</tr>
<tr>
<td>HIE</td>
<td>Health Information Exchange</td>
</tr>
<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
</tr>
<tr>
<td>HISP</td>
<td>Health Information Service Provider</td>
</tr>
<tr>
<td>HIT</td>
<td>Health Information Technology</td>
</tr>
<tr>
<td>HITECH</td>
<td>Health Information Technology for Economic and Clinical Health</td>
</tr>
<tr>
<td>HITSP</td>
<td>Health Information Technology Standards Panel</td>
</tr>
<tr>
<td>HL7</td>
<td>Health Level 7</td>
</tr>
<tr>
<td>HMO</td>
<td>Health Maintenance Organization</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>IEC</td>
<td>International Electrochemical Commission</td>
</tr>
<tr>
<td>IHE</td>
<td>Integrating the Healthcare Enterprise</td>
</tr>
<tr>
<td>IHIE</td>
<td>Indiana Health Information Exchange</td>
</tr>
<tr>
<td>IM</td>
<td>Instant Message</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>ISACA</td>
<td>Information Systems Audit and Control Association</td>
</tr>
<tr>
<td>ISO</td>
<td>International Organization for Standardization</td>
</tr>
<tr>
<td>IT</td>
<td>Information Technology</td>
</tr>
<tr>
<td>ITIL</td>
<td>Information Technology Infrastructure Library</td>
</tr>
<tr>
<td>NCQA</td>
<td>National Committee for Quality Assurance</td>
</tr>
<tr>
<td>NEHEN</td>
<td>New England Healthcare Exchange Network</td>
</tr>
<tr>
<td>NHIN</td>
<td>Nationwide Health Information Network</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institutes of Health</td>
</tr>
<tr>
<td>NIST</td>
<td>National Institute for Standards and Technology</td>
</tr>
<tr>
<td>OCR</td>
<td>Office for Civil Rights</td>
</tr>
<tr>
<td>OECD</td>
<td>Organization for Economic Cooperation and Development</td>
</tr>
<tr>
<td>ONC</td>
<td>Office of the National Coordinator</td>
</tr>
<tr>
<td>Acronym</td>
<td>Definition</td>
</tr>
<tr>
<td>----------</td>
<td>-----------------------------------------------------------</td>
</tr>
<tr>
<td>OR</td>
<td>Operating Room</td>
</tr>
<tr>
<td>PC-MH</td>
<td>Patient-Centered Medical Home</td>
</tr>
<tr>
<td>PCMH</td>
<td>Primary Care Medical Home</td>
</tr>
<tr>
<td>PCP</td>
<td>Primary Care Provider</td>
</tr>
<tr>
<td>PDAs</td>
<td>Personal Digital Assistants</td>
</tr>
<tr>
<td>PEPFAR</td>
<td>President's Emergency Plan for AIDS Relief</td>
</tr>
<tr>
<td>PHR</td>
<td>Personal Healthcare Record</td>
</tr>
<tr>
<td>PICU Bot</td>
<td>A Portable Robotic Telemedicine Station</td>
</tr>
<tr>
<td>PKI</td>
<td>Public Key Infrastructure</td>
</tr>
<tr>
<td>PPOs</td>
<td>Preferred Provider Organizations</td>
</tr>
<tr>
<td>PVIDs</td>
<td>Provide Private Identifiers</td>
</tr>
<tr>
<td>RECs</td>
<td>Regional Extension Centers</td>
</tr>
<tr>
<td>ROI</td>
<td>Release of Information</td>
</tr>
<tr>
<td>SAML</td>
<td>Security Assertion Markup Language</td>
</tr>
<tr>
<td>SDEs</td>
<td>State-Designated Entities</td>
</tr>
<tr>
<td>SOAP</td>
<td>Simple Object Access Protocol</td>
</tr>
<tr>
<td>SSL</td>
<td>Secure Sockets Layer</td>
</tr>
<tr>
<td>TLS</td>
<td>Transport Layer Security</td>
</tr>
<tr>
<td>UMPC</td>
<td>University of Pittsburgh Medical Center</td>
</tr>
<tr>
<td>VA</td>
<td>Department of Veterans Affairs</td>
</tr>
<tr>
<td>VHA</td>
<td>Veterans Health Administration</td>
</tr>
<tr>
<td>VUHID</td>
<td>Voluntary Universal Healthcare Identification</td>
</tr>
<tr>
<td>XDR</td>
<td>Cross-Enterprise Reliable Document Interchange</td>
</tr>
</tbody>
</table>
“It is not just my records or prescriptions that are at issue. What about the exponential increase in types and forms of data produced across the care continuum and how that data on my care can be used to greater effect? We are actively working some projects now where multiple imaging technologies, genomic data, metabolomic data and clinical notes all converge to provide an enormous pool of information, which must be sifted for patterns and nuggets, which might lead to new discoveries for the particular patient or for care more broadly. What about the amazing phenomenon of social networking for health reasons we have seen on the Internet? Can this be augmented and leveraged for better care? As we see the continual increases in chronic disease and complex conditions, all the data at our disposal will be required to deliver and improve care.”