FEATURING ORIGINAL RESEARCH

ePATIENT 2015

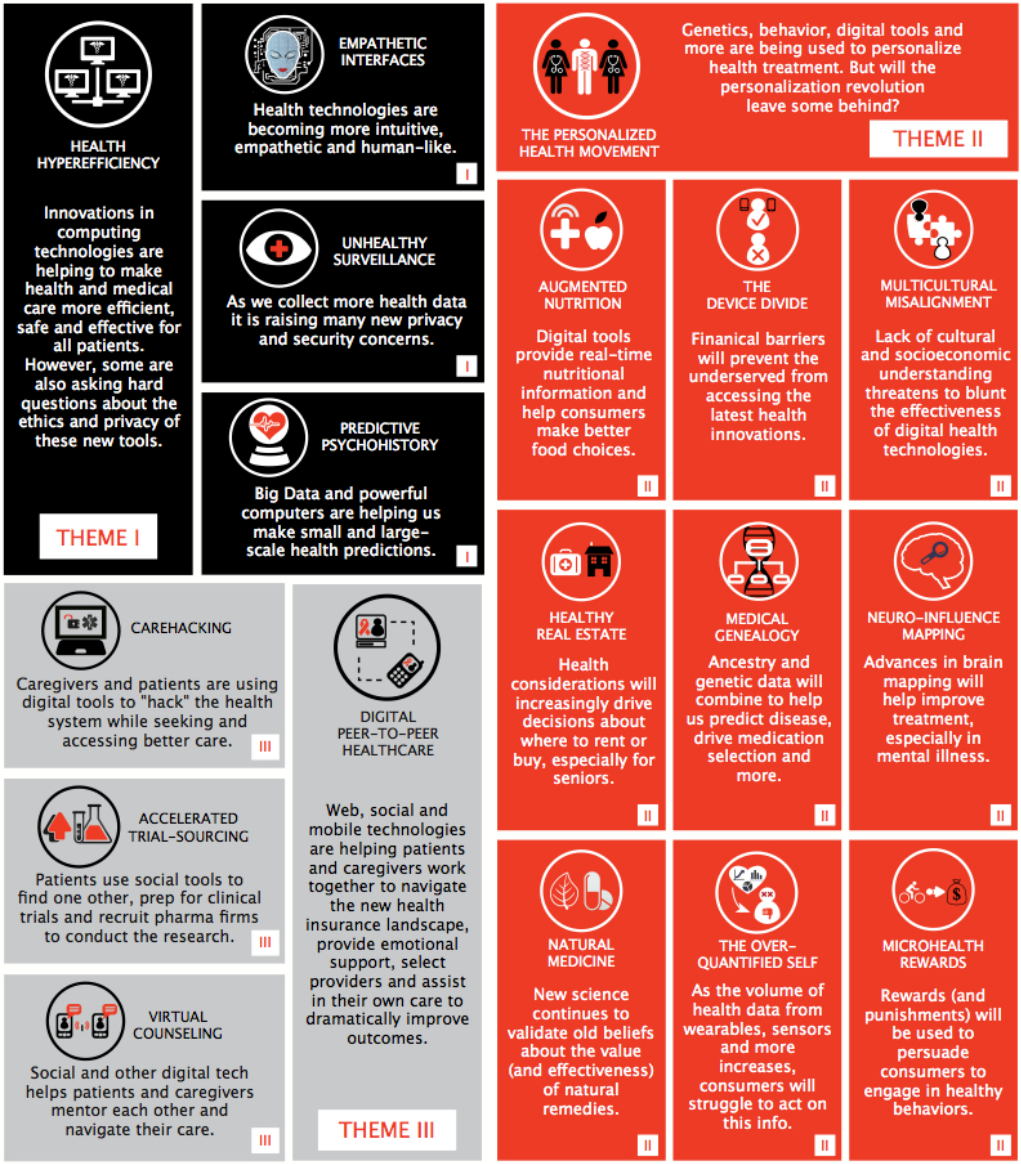
15 Surprising Trends Changing Health Care

"A fascinating and groundbreaking look at how technology and empowered patients are fundamentally changing health care."

ROHIT BHARGAVA
Best Selling Author of Likeonomics

FARD JOHNMAR
Founder of Enspektos

ePatient 2015
Trend Overview Infographic



ePatient 2015

15 Surprising Trends Changing Health Care

Rohit Bhargava
Founder, Non-Obvious Company

Fard Johnmar
Founder, Enspektos, LLC
Digital Health Futurist and Researcher

PUBLISHED BY IDEAPRESS PUBLISHING

IDEAPRESS PUBLISHING is a trademark of Influential Marketing Group, Inc. ENSPEKTOS, ENMOEBIUS AND DIGIHEALTH PULSE are registered trademarks of Enspektos, LLC

Copyright 2013/2014 by Rohit Bhargava and Fard Johnmar

Cataloging-in-Publication Data is on file with the Library of Congress

ISBN: 9781940858005

Book Cover and Interior Design by Robert Kalnitz

All Rights Reserved

PRINTED IN THE UNITED STATES OF AMERICA

First Edition: December 2013
All trademarks are the property of their respective companies.

CUSTOM PRINTING + BULK SALES
This publication is available at special discounts for bulk purchases or custom printing. For more information, please visit www.epatient2015.com.

No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording, or otherwise without the prior written permission of the publisher.

All URLs included in this book were current as of the printing of this publication.

Advance Praise for ePatient 2015

"Changes in our healthcare system are being driven by rapid advances in mobile platforms, health information technology, and social media. Fard Johnmar and Rohit Bhargava have monitored these trends from the start, and their book, ePatient 2015 - 15 Surprising Trends Changing Health Care, is a prescient roadmap that guides both patients and doctors as their relationships evolve."

—Kevin Pho, Founder and Editor, KevinMD.com

"The clairvoyance displayed by the authors is not only spot on, but is a welcome and disruptive shift from the current aseptic and vacuous thinking that has withheld true innovation and progress in the digital health sector. Free your mind, eliminate barriers to your success, and read this book."

—Matthew Zachary, Patient Advocate, Founder and CEO, Stupid Cancer

"ePatient 2015 is a valuable resource for digital health amateurs and experts alike. Fard and Rohit's focus on the patient as the center of the dynamic digital health world grounds their analysis of the space in a way that is both logical and incredibly relevant. The book highlights 15 trends that ultimately reflect the authors' deep understanding of the space, and serve as a shrewd guide to how technology and the social consumer are changing the face of modern health care.

— Kim Krueger, Research Analyst Health 2.0 and
Prerna Anand, Data Analyst, Health 2.0

"Fard and Rohit provide readers with a sense of what health care will be like in the near future, most notably how patients will receive much more actionable information that can help them make smart decisions about their own care, which is fundamentally different from just a few generations ago. For those in business who wonder where technology in health care will take their products, the 15 trends identified in this book can help them strategically plan for the future. Most importantly, it highlights what we believe about health care overall, that through collaboration and peer support, patients and their caregivers will receive a personalized and highly relevant care experience."

—Robert Nauman, Digital Strategist, Founder BioPharma Advisors

"The real danger is not that computers will begin to think like men,
but that men will begin to think like computers."

—Sydney J. Harris

Contents

Prelude: Why This Book is Like a Good Sneeze 1

Introduction: Little Sally's Fever and Henry's Doctor Delivers Some Very Bad News 3

The Background: How This Book Was Curated, and Why ePatients Matter 17

The Big Picture: How Three Big Themes Describe All of the Trends in This Book 27

Interlude: How the Trends Are Organized and Described 43

Part 1 - Health HyperEfficiency: From Human-Like Computer Interfaces to Data-Powered Oracles 47

Trend #1 - Empathetic Interfaces 49

Trend #2 - Unhealthy Surveillance 59

Trend #3 - Predictive Psychohistory 69

Part 2 - The Personalized Health Movement: Using Technology, Data, Genetics, and More to Escape Generic Medicine 75

Trend #4 - Augmented Nutrition 77

Trend #5 - Medical Genealogy.....85

Trend #6 - The Over-Quantified Self.....99

Trend #7 - The Device Divide 109

Trend #8 - Multicultural Misalignment.....119

Trend #9 - Healthy Real Estate 129

Trend #10 - Neuro-Influence Mapping 137

Trend #11 - Natural Medicine.....143

Trend #12 - MicroHealth Rewards.....153

Part 3 - Digital Peer-to-Peer Health Care: Harnessing the Social Web for Support, Knowledge, and Research.....163

Trend #13 - Virtual Counseling 165

Trend #14 - CareHacking.....171

Trend #15 - Accelerated Trial-Sourcing 181

Conclusion: How to Prepare for the Future of Health Care 189

A Final Request.....193

Appendix I - About the digihealth pulse Research Methodology 195

Appendix II - Resources and Further Reading 199

References.....201

Acknowledgements.....219

Prelude:
Why This Book is Like a Good Sneeze

Empowerment. Technology. Innovation. ePatients.

These are just some of the buzzwords that are frequently used in global discussions about health care. Every day there are new media reports about the failures and successes of those leading and shaping the healthcare industry while people battling illness—far removed from the public eye—are experiencing a breadth of emotions, ranging from fear to worry, confusion, and hope.

Health care is a real-time topic for all of us. As a result, many within it—doctors, patients, caregivers, and others—do not have the luxury of taking the long view or looking at events from a broader perspective. Our aim is to offer a big picture, people-oriented overview of what's next in health care.

We journey from the emerging realm of neuro-influence to the popular topic of wearable devices. We interview digital health futurists and ePatients who have launched emotion-driven global movements. And through it all, we have broadened our lens to capture a bigger view of the future. In this book, you'll learn about 15 trends that are fundamentally changing the way all of us experience health care. Pioneering technologies drive some of them. Ordinary people have sparked others when they have been inspired—or forced—to lead their peers.

By bringing these trends together, our goal was to curate and share a quantifiable

and well-researched vision of the future of health care. From the beginning, we resisted the impulse to approach our work with preconceived notions; instead, we decided to fearlessly follow the stories, trends, data, and technologies we uncovered—all the while unsure of what our effort would ultimately reveal about tomorrow.

As you'll see from the original data, dozens of stories, and many interviews we include in this book, the future of health care is an exciting one. And though the portrait we paint is not entirely rosy—several of our trends focus on the negatives of innovation—our vision for the future is an optimistic and human-focused one.

As American author Robert Benchley once wrote, "A good rousing sneeze, one that tears open your collar and throws your hair into your eyes, is really one of life's sensational pleasures."

The process of writing this book was a bit like that sneeze . . . and we hope your experience reading it will be as well.

Introduction

Little Sally's Fever and Henry's Doctor Delivers Some Very Bad News

The easy place to start a book about the future of health care is with a discussion of technologies or innovations, but we'd like to take a different approach. At its core, this book is about how digital health tools will benefit, harm, enlighten, confuse, empower, disempower, and influence people today, by 2015, and beyond.

Because of this, we think you will gain a deeper appreciation for the profound technology-driven changes to come if we began by telling two fictional, but plausible stories. The first is about a little girl named Sally, whose mother is very worried about her. The second focuses on Henry, who is about to receive some very bad news from his doctor. You'll read two versions of these tales: one set in 2013 (at the time of writing this book) and the other in 2015.

2013: Sally Has a Fever and Mom Can't Sleep

The room is dark except for the red light coming from the black digital clock sitting on Martha's nightstand. It is 2:23 a.m. and Martha can't sleep. Earlier that day she had rushed home from work to pick up her three-year-old, Sally, from day care early. One of the caretakers, Heidi, had been worried because Sally was not eating well and complaining that her head hurt.

When they got home, Martha took Sally's temperature using an ear ther-

mometer she'd purchased from the local drug store. Unfortunately, she wasn't sure what to think because when she measured Sally's right ear, the temperature read 98.9 degrees Fahrenheit. When she inserted the thermometer into her left ear, she got a reading of 102.1. And it was almost impossible to get Sally to sit still for the temperature reading anyway.

Martha had read online somewhere that a low dose of Tylenol combined with some "fluids" could help bring down Sally's fever. She decided to err on the side of caution and gave some to Sally. On the bottle, the suggested dosage said 5 ml for children 2 to 3 years old—but Sally was 3 and 10 months and a little big for her age according to those strange height and weight percentile charts she'd seen at the pediatrician's office. She wasn't sure if the 2 - 3 year old dose would be enough, but it was close to 10 p.m. and she didn't want to leave a message on her pediatrician's after-hours answering service only to wait for a callback. So she gave Sally 5 ml, fed her some soup, and put her to bed.

At midnight, Martha checked Sally's temperature. The ear thermometer didn't seem to be working very well. Each time, the right and left ears gave her different readings, sometimes as high as 103.5. Was Sally's fever getting worse? Did she have enough medicine?

Searching Google for answers was little help. Martha had read dozens of articles about fevers in children, but each provided her with conflicting advice. Some people recommended doing nothing while others said she should call her doctor.

It was now past two a.m. and Martha was frustrated and tired. "I need some answers," she thought, reaching for her cell phone. "I'm calling Dr. Mason." Getting through to the answering service, she left a voicemail and waits for a callback from Dr. Mason, or one of the other doctors in his practice who happens to be on call.

A stressful 26 minutes later, she received a callback from another doctor in Dr. Mason's practice so she explains Sally's symptoms. "When is the last

time she came in?" the new doctor asks. "Last month," Martha responded, wondering why the doctor didn't already know that from her file.

The doctor tells her it's probably a cold and to watch Sally's fever to make sure it doesn't go above 104. "This is going to be a long night," Martha told herself, staring blankly at the blinking digital display on her thermometer and reaching for her TV's remote control.

2015: Sally Has a Fever and Mom's Fast Asleep

The room is completely dark except for a soft blue light coming from the Well Home mobile application sitting on Martha's nightstand. It is 2:23 a.m. and Martha is sound asleep. Earlier that day she'd rushed home from work to pick up her three-year-old Sally from day care early. One of the caregivers, Heidi, had been worried because Sally was not eating well and complaining that her head hurt. Yet, Martha wasn't lying awake tossing and turning. Why? A medical device she'd purchased a few months earlier helped her understand what was happening with her daughter and how best to manage Sally's fever.

The device she had picked up from a local store was a new medical sensing technology that could interface with her Well Home smartphone app and monitor things like blood pressure, body temperature, and more. When she arrived home from day care, she attached the sensor to Sally's forehead so that it could continuously measure her daughter's temperature, heart rate, mood, and other vital signs. The device passively took temperature readings every hour throughout the evening. Sally's temperature hovered between 100.6 and 100.9 degrees Fahrenheit.

After each reading, the device automatically connected to Martha's online family medical record to track the temperature against previous norms for Sally and other children in their local area. Just before Martha put Sally to bed, she received a text message on her mobile phone featuring a link to an article with suggestions on how to manage minor fevers like Sally's. (She'd given the sensor manufacturer permission to send her

text messages containing useful health information based on data she collected with the device.) The doctor who wrote the article suggested that low-grade fevers like Sally's shouldn't be treated.

Just for final confirmation, Martha initiated a conversation with one of her pre-selected doctors who was immediately available for a face-to-face video chat via the telepresence module located on her Well Home mobile application. Martha turned the phone towards Sally so the doctor could have a look. "She looks fine, just let her get some rest," the doctor advised. "If her temperature goes above 101, you can give her a small dose of medicine. Based on her height, weight, and physical characteristics, my medical decision support tool suggests a dose of 7 ml should be about right."

Later that night, Martha's health monitor watch woke her gently with an alert that Sally's fever had increased to 101, so Martha administered the medicine, and Sally went immediately back to sleep.

After 15 minutes, Martha did too, confident that Sally would feel better in the morning.

2013: Henry Receives Some Very Bad News

Every time Henry shifted position, his chair made an annoying squeaking sound. Squeak, squeak, squeak. "Can't the hospital afford to have someone fix this chair?" he thought. Henry's physician, Dr. Thompson, was speaking but Henry wasn't listening. His mind went blank when she said, "The biopsy confirmed that you have non-small cell lung cancer." "This is not happening," thought Henry.

Dr. Thompson stopped speaking and looked at Henry for a moment. "We have a lot to discuss," she said, "but I can tell you need some time." "Here's some information about the type of cancer you have," she continued while handing over a few pamphlets and pieces of paper. "Please see the receptionist to schedule another appointment and we'll discuss

your treatment options."

Henry walked out of the hospital in a daze and drove from the parking lot. "How did this happen?" he wondered. He wasn't a heavy smoker. He was pretty sure he didn't have a family history of cancer, but it was hard to be sure because he didn't really keep in touch with many of his relatives on his father's side. When he got home, his first thought was to go online to learn more. He typed the words "non-small cell lung cancer" into Google. The results were scary. The photos of other patients with similar conditions looked gruesome. And the search page featured dozens of sites and all kinds of advice on some very involved ways he could "fight back," from getting better air filters for his home to changing his diet completely. And most medical journals Henry read were incomprehensible. Even worse, lots of sites promising some type of "all-natural" cancer cure were abundant.

The "support" forums were even tougher to navigate. There seemed to be lots of conversations, but he wasn't really confident he could jump into them when no one knew him. It felt intimidating, and he was sure he didn't have hours to devote to joining some online conversation group anyway.

After a few hours, he stopped reading, put his head in his hands, and thought: "What am I going to do?"

2015: Henry Receives Some Bad (and Good) News

Every time Henry shifted position, his chair made an annoying squeaking sound. Squeak, squeak, squeak. "Couldn't the hospital afford to have someone fix this chair?" he thought. Henry's physician, Dr. Thompson was speaking, but Henry wasn't listening. His mind went blank when she said, "the biopsy confirmed that you have non-small cell lung cancer." "This is not happening," thought Henry.

Dr. Thompson stopped speaking and looked at Henry for a moment. "I

know this is hard for you," she said, "but there's some information I think you should know." "Today, it's common to test cancer cells for certain genetic and molecular characteristics," she said. "We do this because we're now able to treat the disease with a scalpel rather than a hammer," she continued. "We think your cancer is the type we've found responds very well to a particular type of medication that has fewer side effects and is much more effective than standard chemotherapy."

"This won't be an easy journey," Dr. Thompson cautioned, "but cancer treatment has changed dramatically over the past few years. And, all the lifestyle and health data that you have been capturing through that device you've been wearing will help us find the course of treatment that will best fit with your level of activity and overall health."

"How did this happen—is there anything I could have done differently?" Henry wondered out loud. "A year ago, you and other members of your family gave us permission to access, share, and analyze your high-level electronic medical records and health history," Dr. Thompson said. "It looks like your cousin on your father's side also had the same condition—and the good news is that he's doing well," shared Dr. Thompson. "That's interesting," Henry said. "I heard about a cousin who had cancer, but I didn't pay more attention because we're not that close and haven't seen each other since we were kids."

"Well it looks like you may learn a lot more about him," Dr. Thompson said. "We have data on how his medicine has been performing for him, and we can send a private request to see if he would be willing to share this information with you."

"So what should I do now?" asked Henry. "Well, doctors aren't just prescribing medications these days," replied Dr. Thompson. "I'm going to write you a prescription for a free application you can download to your smartphone. It's been tested and we know it has high quality information. You can also use it to connect with others who have non-small cell lung cancer. I'd also like you to use the app to track how you're feeling, how your

medications are performing, and other important details. The good news is, it will sync with the wristband I see you're already wearing—and use all your past data to help us track your progress. The information you provide using the app will be automatically and securely sent to me, as well as added to your medical record. It will also help make your visits with me more productive. Here's information on where you can go to download the app. Please see the receptionist to schedule another appointment."

Henry left the hospital and drove out of the parking lot feeling worried but hopeful, too. After arriving home, he immediately downloaded the mobile application his doctor prescribed. The app provided him with a list of recommended online resources about non-small cell lung cancer.

He turned on the computer and went online to start reading more about his condition. Thirty minutes later, he received a text alert from the app. It was another patient, Pablo, who had been automatically paired with him as a "mentor" to help him through the first days of the disease. Pablo offered to give him a call that evening. Henry immediately accepted Pablo's invitation. An hour later, he received a secure message from his cousin accepting the request to share medical data and offering to speak by phone that weekend.

"This won't be easy," he thought, getting ready to respond to his cousin, "but I think I'm going to beat this."

What These Stories Teach Us About the Transformative Role of Information and Technology in Health

What do these fictional stories illustrate? At their heart, they both have a message of hope for the future of health care that is fueled by a combination of technology advancements and empowered patients. Today, stories of empowerment are more than just fiction—thanks to trailblazers who have jumpstarted and given a face to the ePatient movement. One of the most visible is cancer survivor, Dave deBronkart, who is known to most people (and the global healthcare industry) as ePatient Dave.

ePatient Dave is considered by many to be the quintessential example of the knowledgeable and empowered patient. He believes that technology has the potential to unleash a wave of innovation in health, but only if the information we gather, analyze, and share is accurate, comprehensible, and actionable. During an interview conducted for this book, ePatient Dave asserted, "No one can perform at their best potential if they don't have the right information." It is a mantra he shares often. His latest book is called *Let Patients Help* and also focuses on how patients can—and must—be a central part of the treatment process.

For a long time, it has been up to people like ePatient Dave to fight this battle. They navigate complex systems, demand access to their own data, and break new ground in patient empowerment. But, the odds have been stacked against them. Technology is not integrated. Medical collaboration is oftentimes minimal and inefficient. And perhaps most importantly, the ability to personalize care is too costly and complex.

Today, all of this is changing dramatically.

The fictional tales we used to begin the story of this book are meant to help you understand some of the ways mobile technology, genomics, sensors, and other new health tools are poised to benefit patients, caregivers, and physicians. In each story, we illustrated how technology-delivered health information can help people make more informed decisions, receive better quality care (and outcomes), and face the future with confidence rather than fear.

In Martha's case, you saw how the information she gathered via the diagnostic and knowledge tools available to her today left her worried and uncertain about her daughter's condition; however, by using a powerful sensing device, real-time data, and virtual medical advice, Martha was able to manage her daughter's fever appropriately.

In Henry's story, advances in genetics, electronic medical records, and mobile health applications helped him receive more personalized treatment options and guidance from his doctor. Virtual social tools also provided support from others

who were dealing with a similar diagnosis, helping him manage his condition both emotionally and physically.

Today, we are witnessing the birth and evolution of a range of technologies, behaviors, and systems that will radically transform how we think about and manage health. Recognizing the overall shape and scope of the changes to come will require a big picture perspective on how these technologies will work together (and separately) to influence each of us in positive and negative ways. This will happen regardless of our background, proficiency with technology, temperament, and status (e.g., patient, caregiver, or observer).

The goal of this book is to share 15 trends that are poised to fundamentally change the way health and medical care is delivered and received in the near future. Rather than focus primarily on new technologies, our approach is decidedly human-centric. We look at how people will start to think and act differently in health, and position technology as an enabler for some of the changes to come.

As we outline these trends, we will share information about the process we used for identification and quantification, which included a combination of original research and curation, plus analysis of existing innovations and activities from pioneering medical systems and startups around the world. In the process, we uncovered the fact that these trends naturally aligned around several themes that are emerging because of three big challenges the health industry faces today:

- **Problem #1: Skyrocketing Medical Costs** - Thanks to the growing need for medical care, changes in legislative policy, and more costly treatment options—expenses related to medical care are dramatically increasing day by day.
- **Problem #2: Generic Medicine** - The standardized models that encourage universal treatment courses for patients are widely understood to be lacking; yet these approaches still dominate how medical care is delivered.
- **Problem #3: Limited Social Support** - Dealing with diseases or conditions (particularly when they are more rare) can be a solitary experience and support from outside the medical community from family, friends, and other patients can often be missing or lacking coordination.

Later in this book, we'll outline each of these problems in more detail, as well as the associated themes that describe how people have responded to these issues; however, first we'll briefly describe these themes below to provide you with additional context.

THEME #1 - HEALTH HYPEREFFICIENCY
Innovations in computing technologies are helping to make health and medical care more efficient, safe, and effective for all patients.

THEME #2 - THE PERSONALIZED HEALTH MOVEMENT
A philosophical and operational shift that considers the unique genetics, behaviors, and medical histories of individuals—instead of treating them based on inflexible or non-personalized guidelines and traditions.

THEME #3 - DIGITAL PEER-TO-PEER HEALTH CARE
A range of Web, social, and mobile tools are helping patients collaborate on things like navigating the new health insurance landscape, selecting providers, assisting in their own care, and providing emotional support.

What Are the 15 Trends?

Of course, describing the impact of technology on health at a macro level is only the first step. An outgrowth of the deep research and analysis conducted for this book was our identification of 15 unique trends that illustrate exactly how health care is changing on all levels.

Some trends are directly related to how patients experience care and the new and unique ways they are managing their treatment. Other trends illustrate the impact of technology on age-old medical traditions and practices. Below are the 15 trends (including the theme they fall under) and a short summary of each.

HEALTH HYPEREFFICIENCY
(How Technology and Computing Are Making Health Care More Efficient, Safe, and Effective)

Trend #1 – Empathetic Interfaces: Health technology moves beyond focusing mainly on accuracy and functionality to incorporate more intu-

itive design and processes aimed at making digital tools more responsive to emotional needs, or more human-like.

Trend #2 – Unhealthy Surveillance: New surveillance technologies combine large amounts of digital, clinical, and behavioral data to track the health of individuals or groups and also raise significant privacy and security concerns.

Trend #3 – Predictive Psychohistory: Big Data, in combination with powerful computers, are increasingly being used to make large- and small-scale predictions about individual and population health.

THE PERSONALIZED HEALTH MOVEMENT
(How Technology is Helping Health Become More Individualized and Relevant to People's Needs)

Trend #4 – The Over-Quantified Self: As the volume of clinical and health information collected from wearable computers, passive sensors, and more increases, consumers will struggle to find true actionable value beyond "feel good stats" in this flood of data.

Trend #5 – Medical Genealogy: Genomics and advances in genealogy will combine to allow patients (and providers) to use ancestral history and genetics to predict the risk of disease, how they may respond to medications, and more. Over time, this valuable data may be passed on to future generations.

Trend #6 – Augmented Nutrition: A growing number of tools and technologies provides instant access to detailed nutritional information to help consumers make healthier choices in real-time about what to buy in stores or consume in restaurants.

Trend #7 – Healthy Real Estate: Increasing awareness of the role communities play in health and wellbeing will influence where people choose to rent or buy homes. Key considerations will include whether streets are walkable, the quality of nearby care, and access to social or religious institutions.

Trend #8 – The Device Divide: An outgrowth of the digital divide (disparities in access to digital technologies), financial considerations may prevent patients, providers, hospitals, and clinics from accessing the latest technological innovations in health.

Trend #9 – Multicultural Misalignment: Health technologies will be less effective if they are not optimized to account for differences in age, ethnicity, culture, and more. A range of organizations and businesses will work to provide unique and effective digital health tools to diverse populations.

Trend #10 – Natural Medicine: New science will continue to validate old beliefs about the value of spices, tonics, and herbs. This will result in more mainstream credibility for natural remedies that were once dismissively called "alternative medicine," but now have a body of tangible results to prove their value once and for all.

Trend #11 – MicroHealth Rewards: Inspired by federal legislation and a deeper understanding of behavioral science, insurers, corporations, health providers, and others will apply game theory to encourage people to adopt and sustain healthy behaviors by offering them tangible rewards (or punishments) as incentives.

Trend #12 – Neuro-Influence Mapping: Advances in brain imaging technology offer new insights into patients' behavioral profiles to support the development of unique personalized treatment programs that factor in which method of influence (fear, authority, conforming, etc.) may be most likely to work. These tools are also being used to shape marketing efforts in advertising and beyond.

DIGITAL PEER-TO-PEER HEALTH CARE
(How Digital Tools Are Enabling Enhanced Collaboration and Peer Support)

Trend #13 – Virtual Counseling: Seeking emotional and logistical support, people forge one-to-one relationships online to offer assistance with navigating the new health insurance landscape, provide virtual moral support, "sponsor" one another, and share unique knowledge about conditions, ailments, and caregiving.

Trend #14 – CareHacking: Forced to increasingly take responsibility for their own care in a complex system, digitally savvy health consumers combine information from doctors, the Web, electronic medical records, and other sources to "hack" the health system in an effort to educate themselves, navigate loopholes, and ultimately get better, lower cost, and faster care for themselves and those they love.

Trend #15 – Accelerated Trial-Sourcing: Patients with chronic diseases and other conditions use digital tools to find one another, complete the usually costly and complex first stage of discovery for a clinical study, and then recruit the right pharmaceutical firms or other researchers to conduct the research.

In the next chapter we will outline our process for identifying the trends and share more on our method for quantifying and measuring each.

Much of this book will be devoted to detailing the trends—one per chapter. We'll also look at some of the fundamental forces shaping each trend. In addition, we will share original insights from the research we conducted in preparing this book. Finally, for each, we will share examples and case studies of how companies and entrepreneurs are already leveraging each trend to create new businesses, drive innovation, and improve health.

While we have written this book to be read in sequence, it is our assumption that some of you may skip to the trends you find particularly interesting or relevant. It's okay, we're not offended. Unlike a great piece of fiction, this book allows for flexibility and we encourage you to read it in the way that is most valuable to you.

Some Basic Definitions

Before continuing, we think it's important to spend a few moments defining a few critical health technology terms that are used throughout this book. (We'll define ePatients in the next chapter.) While many of you may be familiar with these terms, explaining them will help ensure clarity, including how we'll use them and why. You'll note that these terms are related and, because of this, we'll use them interchangeably throughout this book.

- **Digital Health:** The definition of this term is still evolving. Overall, it refers to how a range of technologies, including mobile, games, genetics, and social media are, according to Wikipedia, "empowering us to better track, manage, and improve our own and family's health." [1]
- **Health 2.0:** Like the term digital health, Health 2.0 refers to the use of mobile, electronic medical records, social media, and other technologies in health and wellness.
- **Health Technology:** We use the term health technology when referring to the use of digital tools such as social media, data analytics, mobile, and more to monitor, enhance, promote, and predict health.

In the next chapter, we talk about what makes an ePatient, our research and writing process, more on what this book is designed to achieve, and how it can help you.

The Background

How This Book Was Curated, and Why ePatients Matter

"We are the Gallery that walks. We are the Patients that wear our stories on our backs. Soon we shall come to a city near you and create gallery space in moments." – Regina Holliday, Patient Advocate and Artist [2]

ePatient Mom, 2012 by Regina Holliday, Used With Permission

There is a quantifiable moment when people become ePatients. For some, it's during the process of being confronted with a difficult diagnosis and turning to the Internet for answers. For others, it's within the process of caring for a loved

one who is struggling with a condition, and later dealing with the emptiness that comes after he or she passes away.

Regina Holliday is an artist and activist who well knows the world of ePatients. Forced to navigate the inefficient care system on behalf of her late husband Fred, she became a leading advocate in the movement for clarity and transparency in medical records after he passed away. Today she gives over 70 speeches a year at conferences and private summits. In many of those speeches, she shares the story of one of her most powerful projects: the "Walking Gallery."

Inspired by a single request to paint one of her murals on the back of a jacket of another ePatient, the Walking Gallery evolved as a collection of these jackets that visually tells various stories of patient empowerment. When someone wears one to an event, she describes the moment as one of disconnection. People stare at you. You enter the world of the "ostracized." And, for those who are not ePatients, it may be the closest experience to that of an actual patient traveling through a sometimes-heartless medical system.

Holliday started painting the jackets to offer a visible voice to the silently suffering. Her jackets are a symbol of that, but they also signify a greater movement, a movement where patients are no longer willing to silently suffer or blindly follow directions; instead, they are participating. They are making demands to control their destinies and data. They are empowered.

This empowerment is the fundamental emotion at the heart of this book, and has been well documented for some time now.

In November 2000, Susannah Fox and Lee Rainie of the Pew Research Center released the results of a first-of-its-kind survey examining how Americans were using the Web to seek health and medical information. Pew's report, *The Online Health Care Revolution: How the Web Helps Americans Take Better Care of Themselves*, helped to shed light on how the Internet had become a vital source of on-demand health information for many and was shaping people's medical decisions. [3]

While Pew's report helped to quantify the impact of the Web on Americans' health, they weren't the only ones to examine how patients could use the Internet for medical and wellness purposes. The late Tom Ferguson, MD, had long been a proponent of using digital resources to improve the doctor-patient relationship and helped to educate others on this topic. His book, *Health Online: How to Find Health Information, Support Groups, and Self-Help Communities in Cyberspace*, published in 1995 became a vital resource for people seeking informed guidance on how to use the Web to forge connections and find information. [4] Ferguson also coined the term ePatients, or "individuals who are equipped, enabled, empowered, and engaged in their health and health-care decisions."[5, 6]

Pew's report and Ferguson's book sparked a national conversation about the Web's role in patient education and empowerment and advanced our understanding of the ePatient revolution in other ways. Most importantly, the Robert Wood Johnson Foundation asked Ferguson to convene a research project designed to analyze how ePatients were influencing multiple aspects of the health system. In response, Ferguson convened a group of researchers, experts, and others into what became the ePatient Scholars Working Group.

In 2007, after Ferguson's untimely death from multiple myeloma, the Working Group published a groundbreaking white paper, e-Patients: *How They Can Help Us Heal Health Care*. [5] The paper, conceived and shaped by Ferguson, achieved several important milestones; it:

- Explored the growing ePatient movement
- Helped to put a human face to the ways people were using technology for health
- Charted how the Web was challenging and redefining many aspects of the patient-physician relationship

Since the ePatients white paper was published, the world has changed. The act of using the Web to find health information is no longer a novel concept. Mobile devices have helped to greatly expand Internet access (especially among African Americans and Hispanics) while making health information more accessible to people looking for support and ed-

ucation on the go. [7] We are about to enter an age where wearable devices such as watches and glasses, packed with sensors that can track heart rate, blood pressure, and other aspects of our health, will become the norm.

Are They Still ePatients?

In the midst of these profound technological changes, some have questioned whether it is still appropriate to use the term ePatient. [6] We believe it is. Just like in the early days of the Internet, we are beginning to see a new class of health consumers (patients, caregivers, and others), or ePatients, embrace novel technologies that:

- **Equip** them to monitor and analyze a range of sophisticated information about their health and wellbeing. For example, the Scanadu Scout, a new sensing device targeted toward the consumer market, measures pulse wave transit time (PWTT), or the "time it takes for a beat from [the] heart to reach somewhere else in [the] body." [8] PWTT can help determine the extent and severity of high blood pressure and is normally measured in the hospital, clinic, or other health institution.
- **Empower** them to take more control of the shape and scope of their care, from selecting procedures based on quality and cost, to using personal genetic information to understand whether a medication will be helpful or harmful before it is prescribed.
- **Engage** in their own wellbeing via technologies that provide them with constant feedback on how personal decisions (such as whether to eat a greasy hamburger or skip the gym) influence short- and long-term health.

How the ePatient Movement Evolved Beyond the Web

Traditionally, discussions about the ePatient movement have focused on how consumers are using the Internet to manage their care. For example, in 2007 Dr. Scott Haig wrote an infamous essay for *Time* relating the tale of "Susan," a patient he believed had been harmed by Dr. Google. Haig described her as full of "mispronounced words and half-baked ideas" she'd gotten from the Internet. [9] Haig's response to medical Googlers is similar to other physicians who feel

threatened or frustrated by patients seeking to engage their doctors using sometimes inaccurate or incomplete information they gather from the Web.

Today, physicians and other health providers are far more comfortable interacting with Internet-using patients. [10] In fact, an increasing number of well-funded new organizations such as the Bucksbaum Institute are devoting themselves to fostering better doctor-patient communication. At the Institute, the focus is on helping medical students "preserve the sense of kindness . . . [before technology and process beats] it out of them." [11]

Yet, a host of technologies beyond the Web are poised to test the physician-patient relationship anew. What will happen, for instance, when patients begin to engage in conversations about whether a medication is safe and effective based on data gathered via genetic testing or a sensing device? Will physicians and other health-care providers react positively or negatively?

The time has come to expand our definition of ePatients beyond the Internet, and even mobile and social media, which have been major areas of focus over the past several years. [12] Instead, we need to consider how:

- Consumers will collect, share, and use information shaped by devices that allow them to continuously monitor their bodies
- Patients' treatment will be influenced by technologies they may know little about, but provide health-care providers and others with the power to predict and affect how they think and act in unanticipated ways
- ePatients' health data exhaust may benefit or harm them, this is especially important in an era where new organizations—many of them unfamiliar with health and medicine—begin collecting and analyzing vast amounts of medical information
- A new group of digitally savvy caregivers (taking care of their parents or others) will continue to grow
- The social connections patients forge through technology will influence how we conduct medical research, manage care, and more

Here's the bottom line: A more powerful, knowledgeable, and savvy ePatient is

emerging. Our goal is to help you anticipate, understand, and perhaps even become this new ePatient—whether you work with (or for) one, care for one, or become one in the near or far future.

Why We Wrote This Book

Together, we (Rohit and Fard) possess close to three decades of experience working with patients, health-care professionals, insurance companies, hospitals, and others across the health system. During this time—especially in the last decade—we have seen a range of technological tsunamis strike the health industry, from the Internet to social media and now mobile. Each time, few in health have been prepared for the changes caused by these technologies. Most have been left scrambling to figure out how to navigate the new world they suddenly find themselves inhabiting. We believe avoiding "digital health shock" requires spending more time thinking ahead about the scope, implications, and role of technology.

Another phenomenon we've witnessed is the fact that conversations about health technologies are often divorced from the broad human and environmental (political, economic) factors that make them relevant and powerful. Fundamentally, we see five reasons for this gulf:

1. **Focus on Economics, Not Health Care:** Thanks to political and policymaking changes in the U.S. and elsewhere, there is global attention on not only the costs of health care, but how expenses can be contained and who should pay.
2. **Focus on Machines, Not Humans:** Sometimes we forget that people are at the center of health. Health and medical care is always going to be about how humans use digital tools to extend life, improve wellness, and accelerate happiness.
3. **Focus on Data, Not Motivations:** We tend to be much more interested in statistics about how many people are downloading mobile health applications rather than questions such as why we track our diet and exercise status using smartphones in the first place.
4. **Focus on Technology Trends, Not Health Industry Trends:** It's exciting to talk about how much venture capitalists have invested in certain startups and

new digital health tools; however, we'd have a better appreciation of why these firms and technologies are important if we were to examine the large-scale industry trends (e.g., increasing cost pressures, our aging population) contributing to their development and evolution.

5. **Focus on Digital Health Silos, Not Synergies:** In our multi-screen, multi-channel world, it has become clear that people are using many different technologies simultaneously for entertainment, education, and more. The same thing is happening in health as people use a combination of mobile applications, wearables like the Fitbit, and more to monitor and manage their health. Despite this, we don't spend enough time thinking about how a variety of digital health tools are (or can) be used together to educate, inform or change how people behave.

It is this missing conversation we want to help drive—by making a deeper connection between the effects of technology in health care and the fundamental changes in how patients, caregivers, and others think about, act on, and are informed about health.

Who Should Read This Book?

Given the intense interest in digital health, we know many different people may read this book. In particular, here are a few audiences we expect may find value in this publication, including some details on what each should expect to learn:

- **Patients and Caregivers:** Possess a road map that can be used to understand the technological resources that will become widely available, the forces shaping medical care, and people's motivations for selecting and using certain digital tools for health
- **Entrepreneurs:** Understand the broad forces shaping how ePatients are using digital tools to navigate health in order to develop better products and services
- **Physicians and Other Health-Care Providers:** Recognize how ePatients will soon have access to a broader array of health information sources beyond the Web; some of the information people will start bringing to doctors will be more personalized and enhanced by in-depth medical data
- **Health Executives (from Pharmaceutical Companies, Insurance Firms,**

Hospitals, etc.): Appreciate how technology will empower consumers to make more informed choices about the treatments and drugs they select

- **Health Communicators and Marketers:** Be informed about consumer activities, motivations for selecting and using digital health technologies, and broad industry trends that will influence how people are informed about health and wellness

Overall, our focus on big picture issues in health shaped our analysis of the 15 ePatient trends (lightly or heavily influenced by digital technologies) we outline in this book. In some cases, we examine emerging movements such as health self-tracking (quantified self), or the act of monitoring health indicators such as blood pressure and heart rate, and ask if there is a dark side to these trends. In others, we look at what it will mean if we have powerful computer programs that can collect and analyze vast amounts of health data in order to make predictions about people's individual future health.

Our discussion about these trends will feature not only quantifiable research and analysis of the positives and negatives, but will also highlight tangible examples of how they are playing out through real-life stories and examples.

How Did We Identify the Trends Outlined in This Book?

In previous books such as *Likeonomics* as well as his popular annual Trend Report, Rohit described his research process as being heavily focused on curation, multiple conversations with visionary people, and being informed by his work with some of the largest brands in the world. Fard's insights are influenced by the in-depth research he has conducted with health consumers for nearly a decade, experience defining and describing the digital health future for large and small health organizations globally, and work with a variety of health and wellness brands.

For this collaboration, we have combined our research styles to identify and explore the trends described in this book in four important ways:

1. **Filtering Signal from Noise:** We have collected and analyzed dozens of individual digital health trends, from augmented reality to wearable computing, and filtered them according to a single criterion: How will these tools and technologies work together to help ePatients achieve specific goals related to their health and wellbeing?
2. **Conducting Original Research With ePatients:** In late 2012, Fard's firm Enspektos launched a unique research project called digihealth pulse. One goal of this study is to uncover new information on how digitally active ePatients (those who turn to the Web and social media regularly and also have used the Internet to search for health information) view and use a range of emerging digital health technologies. Another objective is to look at how ePatients react to digital health content when they are being passively observed using the Web and social media. A range of data from digihealth pulse (most of it collected by Enspektos in late 2013 specifically for this book) is provided throughout this publication. See Appendix I for more information about digihealth pulse.
3. **Picking Experts' Brains:** In addition to curation and original research, we conducted interviews with patients, entrepreneurs, and others. We are grateful for their participation, as they helped us to further understand the scope and implications of these trends.
4. **Analysis of Funding Activity:** We also looked at recent professional and consumer investment activity in the digital health space. Since 2012, health technology funding has increased, especially for products and services targeted toward consumers, tools that enable remote patient-provider interaction, and devices that help people track their health status. [13, 14]

As you have learned, ePatients are not only still relevant, but beginning to use a range of technologies and tools that are providing them with greater insight and information about their health. In the next chapter, we take a step back to examine key big picture problems, patterns, and more that are helping to drive the evolving ePatient movement.

The Big Picture:
How Three Big Themes Describe All of the Trends in This Book

Humans are notoriously bad at anticipating change. And once change happens, getting large groups of people to react and adapt to it is an even tougher challenge. In response, those who have the privilege (and burden) of leading change will try almost anything to make the process work just a little bit faster.

Expert communicators and politicians will use powerful stories to tap into and ignite our emotions. Economists will try to motivate and predict behavior change by applying various incentive and reward models. And, change management consultants will turn to one of their favorite methods: stories about frogs.

Actually, one frog story in particular gets more than its fair share of mentions. Perhaps you've heard it before . . .

If you place a frog into a pot of boiling water, it will jump out. If you put it in a pot of cold water and slowly heat it, the frog won't react and will boil to death.

This story has become the ultimate anecdote to explain the dangers of complacency and why change is essential. There's only one problem with this tale of slowly boiling frogs: it isn't true.

Back in 1995, *Fast Company's* (unfortunately) fictional "Consultant Debunking Unit" took a closer look at the boiling frog story. [15] The magazine asked a question that would occur to any good scientist: What would a frog actually do

in this situation? To find out, *Fast Company* shared this story with Dr. George R. Zug, a longtime curator of reptiles and amphibians at the National Museum of Natural History, and asked him to rate its accuracy. Zug replied: "Well that's, may I say, bullshit. If a frog had a means of getting out, it certainly would get out." [15]

In addition to seeking colorful expert commentary, *Fast Company* conducted its own experiment. Perhaps deciding against immediately killing an innocent frog by placing it into a pot of boiling water, magazine staffers tested how long it would take two frogs to react to being placed in slowly warming liquid. "We [put] Frog A into a pot of cold water and applied moderate heat. At 4.20 seconds, it safely exited the pot with a leap of 24 centimeters. We then placed Frog B into a pot of lukewarm water and applied moderate heat. At 1.57 seconds, it safely exited the pot with a leap of 57 centimeters." [15]

We share this tale of the "underestimated frog" to underscore an important point about the philosophy and approach behind this book. We know that stories can be helpful to illustrate ideas, but they lose credibility without the right foundation in facts and research. Throughout this chapter (and book), we will also share stories to bring our ideas to life, but whenever we do, you can be sure that they are backed up with plenty of evidence.

So, let's get started by turning our lens towards three critical problems facing the health industry today and the major shifts these issues have inspired.

3 Major Problems and Shifts in Health

The quest to solve several major health system problems has contributed to the rise of three digital health themes that describe how ePatients use technology, receive treatment, are informed about health, and more. These problems, and their associated themes, are illustrated in Figure I and described below.

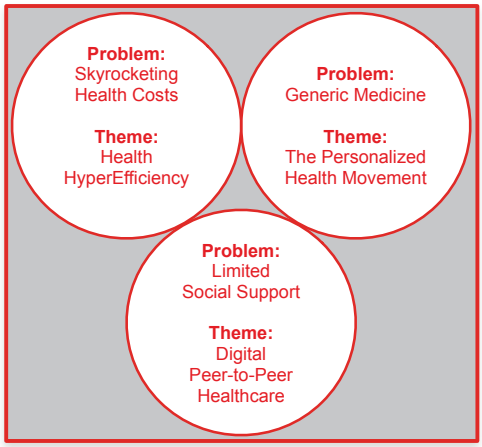


Figure I:
Significant Problems
Contributing to the Rise of
Major Health Technology Themes

Problem #1: Skyrocketing Health Costs

Many discussions about the high cost of health care begin by citing the trillions of dollars, euros, pounds, and other currencies spent each year on medical procedures, prescription medications, and more. While these statistics may be shocking, they are too abstract for most people to comprehend. We're going to bring things down to earth by focusing the cost discussion on two common stages of life that many can relate to: having a baby and getting older.

In June 2013, the *New York Times* published the second in a yearlong series of articles focusing on skyrocketing health expenses in the U.S. [16] Elisabeth Rosenthal, the author of the series, focused on what it costs to have a baby, especially for people whose insurance plans do not cover maternity care. When Renée Martin (who Rosenthal profiled in the article) asked her hospital to estimate the cost of her maternity care, she was given a very wide range of fees, between $4,000 and $45,000.

One reason for this wide disparity in costs is the fact that hospitals charge different rates to patients, health insurance companies, and government. It has become common for hospitals to send patients invoices and billing statements showing the list prices associated with various medical services; however, insurance firms and government don't pay retail. Doctors, hospitals, and others are reimbursed based on a much lower negotiated rate. On the other hand, uninsured or under-

insured patients like Martin pay much higher rates, mainly because they do not have the power to negotiate lower fees.

Although large, so-called third party payers like insurance firms and government pay lower rates, they are also experiencing sticker shock from childbirth costs. According to an analysis published by Truven Health Analytics in 2013, expenses associated with maternal care increased by over 40% between 2004 and 2010 for women with private insurance. In addition, Medicaid paid on average, $4,000 more for babies born by C-section versus newborns delivered vaginally. [17] In fact, it costs more to have a baby in the United States than anywhere else in the world. [16]

Childbirth is but one area where rising health-care costs are a concern. As the U.S. population ages, some experts anticipate spending to increase significantly, partly because seniors are living longer with chronic diseases like diabetes and high blood pressure. [18] For example, Dr. Rhonda Randall, chief medical officer of UnitedHealthcare Medicare & Retirement, told *USA Today* in May 2013, "As generations move into retirement, they become greater consumers of health care. But those turning 65 today 'are more likely to live longer than their parents and grandparents, and much more likely to live sicker for a longer period of time.'" [18]

Also, while medical spending is higher for older Americans overall, it skyrockets at the end of seniors' lives. [19] According to the authors of a 2010 report published by the National Bureau of Economic Research, out-of-pocket costs associated with medical care "represent a numerically large and potentially important drain on financial resources, particularly for households as time of death nears." This may have an influence on how elderly people may spend their earnings as they "continue to hold (or even accumulate) wealth as a hedge against uninsured costs surrounding expensive end-of-life care-giving for themselves or their spouse." [19]

The good news is that innovations in health care are being developed that may enable us to more successfully tackle the cost problem, which explains our first big theme . . . Health HyperEfficiency.

WHAT IS HEALTH HYPEREFFICIENCY?
Innovations in computing technologies are helping to make health and medical care more efficient, safe, and effective for all patients.

Inside the Impact of Health HyperEfficiency

While there are many factors contributing to the rise in health spending, the examples of childbirth and aging outlined above help us focus on two, as they are very relevant to our discussion:

- **Increased Demand for Health Services:** An aging population will always require more medical resources. Added to this, we are seeing younger people require more health care due to conditions such as childhood obesity and early onset of many preventable conditions such as type II diabetes and high blood pressure.
- **Limited Price Transparency:** With little information on the true costs of health care (and significant differences in what health institutions charge for the same procedures), it is difficult for consumers and others to limit spending or shop for high quality, less expensive treatment.

Over the years, businesses, legislators, consumers, and others have used a range of tactics to reduce medical spending; however some, such as limiting (or rationing) treatment, or releasing data on health costs (such as what hospitals charge the government) remain controversial.

Some see a possible answer to the problem of skyrocketing costs in digital health innovations. The potential value of digital technologies is twofold:

1. **Reduce the Demand for Health Services:** When technology is used in smart ways to track people's health, it can also be leveraged to make predictions about who may likely need care in the near and far future and offer data to help prevent sickness and death. In addition, the devices we use (mobile, etc.) can help to deliver more responsive, human-like experiences that do a better job of educating people on their health, helping them make better decisions,

and avoid costly medical care.

2. **Help People Select Cost-Effective and High Quality Care:** Digital technologies can automatically mine a range of health data on the quality of care, the cost of medical procedures, medications, and other factors. This information may be delivered to consumers, hospitals, insurance firms, businesses, and others to help them choose health products and services that are both cost-effective and high quality.

We refer to the group of digital tools offering these benefits and thereby helping to reduce health costs as *hyper-efficient* technologies[1]. In contrast to traditional tech, hyper-efficient tools can be used alone or in combination to:

- Collect and analyze large and diverse data sets (e.g., images, video, text, medical data, and more) faster and more accurately
- Make predictions about human behavior such as whether someone will become sick in the near future
- Enable people to engage with computers in ways that resemble how humans communicate with each other

In our discussion of future ePatient trends related to the Health HyperEfficiency movement, we will reference a range of technologies, which are described in Table I.

Table I: Technologies That Make Health HyperEfficiency Possible

Overview: Key Hyper-Efficiency Related Digital Technologies
Big Data: Over the past decade, the volume and types of data we are gathering about our bodies, the environment, digital activities (e.g., Web surfing), and more has vastly increased. The term Big Data traditionally refers to large and diverse data sets that are being generated and collected more quickly each year. It is also used in the context of tools, techniques, and technologies used to accurately analyze this information. [20] In health, Big Data is being used for a range of purposes, including helping doctors diagnose disease more accurately and delivering highly relevant and personalized health information to people.

Predictive Analytics: We are collecting large amounts of information about people's perceptions and past behaviors (e.g., the Web sites they visit, what they buy, who they vote for, their digital social connections, and more). This data can be analyzed to find patterns and correlations that suggest how people may think and act in the future. The art and science of predicting future actions using data is called predictive analytics. [21]
Health Surveillance and Sensing Technologies: A range of companies are producing technologies that allow us to monitor and measure our bodies in real-time, including Scanadu and Jawbone. These sensing devices are collecting information on many aspects of our health, including blood pressure, blood sugar, heart rate, cholesterol levels, and even whether we are taking medications as prescribed. From a surveillance perspective, monitoring and mining digital health content for insights has become a major business activity, especially within the pharmaceutical industry. [22]
Social Media and Social Networks: The rapid growth of social tools has enabled patient collaboration on an unprecedented level, which is allowing for everything from shared reviews of medical providers to patients sharing highly tactical advice on how to navigate the inefficiencies of the health care system.
Artificial Intelligence: Computing and programming power has advanced to the point where we can develop machines (from robots to mobile devices) that act in more human and responsive ways. Making computers more like people is what those advancing the field of artificial intelligence are working to achieve.

Problem #2: Generic Medicine

Over the past century or so, American health care has undergone many changes, especially in the area of personalized medicine; however, this meant something entirely different in the late 19th century. During that period, personalization referred to the fact that U.S. physicians would tailor their treatment strategies according to the needs (and whims) of individual patients, in contrast to their European counterparts. [23]

For example, the practice of medicine was heavily influenced by folk traditions, regional customs, and the use of cures passed down over many generations. In addition, almost any man of European ancestry could set up shop in a community and call himself a doctor. Because doctors relied on their clients for income and many were misinformed about the true causes of disease, medical care was both highly personalized and varied depending on the region, or even the person delivering care. [23] In many respects, personal relationships rather than medical knowledge or skill determined the fate of physicians practicing during this period. [23]

Over time, especially in the beginning of the 20th century, medical care became significantly less tailored toward the individual and based on standard scientific principles. By the 1920s, physicians were required to be licensed to practice medicine and using "natural" or homeopathic remedies fell out of favor among medical professionals. [24]

Standardization resulted in many benefits, including making medicine safer and more effective. This was mainly due to the fact that many patients began to be treated using a range of standardized criteria developed based on what came to be known as evidence-based medicine; however, standardization also had negative consequences. [25] For example, prior to recent times, much of the research used to shape treatment strategies was limited or flawed because it was based on medical studies that were conducted primarily with white men and excluded or under-represented women, ethnic and racial minorities, people with rare conditions, and others. [26] This is important because over time researchers have learned that certain medications are more or less effective due to a number of factors such as:

- **Patients' Backgrounds:** Some drugs are absorbed or processed differently by people of various ethnic and racial backgrounds [27]
- **Personal Genetic Factors:** Certain medications work differently depending on specific genetic characteristics shared by groups of people [28]

Another drawback of standardization and changes in the structure and financing of medicine is that patients have steadily received less personal attention from physicians over time. For example, a study cited by the *New York Times* in 2013 revealed that new physicians spend an average of just eight minutes speaking face-to-face with patients. [29]

The combination of lack of personalized attention from physicians and the limitations of medical research have contributed to a problem we call generic medicine. Note that we are not referring to the use of generic medications here, but rather to the misguided beliefs (below) which have led directly to the rise in generic medicine:

- **One-size-fits-all health management strategies** that do not account for preferences, genetics, environment, family situations, or other personal factors
- **Limited price transparency and tools** that enable patients to select providers and care, based on cost and quality factors
- **Dismissal of alternative or non-Western medical practices** based on a lack of knowledge about research examining whether these treatments are safe and effective
- **Failure to deliver health content and incentives** that are relevant and meaningful for individuals rather than broad groups

The good news is the medical community is moving away from generic medicine, which explains our second big theme . . . The Personalized Health Movement.

> WHAT IS THE PERSONALIZED HEALTH MOVEMENT?
> A philosophical and operational shift that considers the unique genetics, behaviors, and medical histories of individuals instead of treating them based on inflexible or non-personalized guidelines and traditions.

Inside the Impact of the Personalized Health Movement

Generic medicine has been ascendant for many decades, but there are signs of hope that this approach to health care may be starting to wane. In 2011, the members of a Kauffman Foundation-funded research group published an extensive paper, *The Personalized Health Project*, documenting the evolution of the personalized health movement. [30] They defined personalized health as including "predictive tests and technologies for individuals and for society, and also science-based strategies to prevent or mitigate disease and poor health." Interestingly, they characterized personalized medicine, as a "subset of personalized health" referring to it as "therapies that can be tailored to an individual's own genetics and physiology."

The authors of the Kauffman-funded report included the rise of the patient consumer within the broader personalized health movement. Not only are patients using a range of social tools to connect, but they are also shaping the future direction of medical research. For example, PatientsLikeMe has conducted a number

of patient-centered studies examining the safety and effectiveness of medications and various treatment strategies. [31]

The personal health movement is still evolving. Despite this, a growing number of patients, researchers, medical professionals, and others are investigating, developing, and implementing personalized health tools, techniques, and strategies that are outlined in Table II. We will discuss these further when describing ePatient trends related to the personalized health movement.

Table II: Technologies Associated With the Personalized Health Movement

Overview: Key Digital Technologies and Tools Powering the Personalized Health Movement
Genetic Profiling and Testing: In his book, *The Creative Destruction of Medicine*, Dr. Eric Topol outlines the pros, cons, and history of personal genomics, from the genetic tests offered by companies like 23andMe, to ongoing efforts to improve medication effectiveness by administering drugs based on patients' genetic profiles. [32] Today—especially as the cost of genetic testing decreases—more Americans are purchasing genetic tests for themselves and their families designed to help them understand their risk of disease.
The Internet, Mobile, and Wearable Health Devices: First widely introduced in 2003 by Stanford Professor B.J. Fogg, the theory of captology, or why human-computer interaction can help influence behavior, helped to increase understanding of how computing devices can be used to shape health and wellness. [33] Partly because of Fogg's work, we have a better understanding of how computers, mobile devices, the Web, and other tools can be used to deliver highly personalized health experiences designed to inform and persuade. The Internet and other technologies have become essential parts of many people's health and wellness experiences.
Ubiquitous Sensors: In her wide-ranging report, *Making Sense of Sensors: How New Technologies Can Change Patient Care*, Jane Sarasohn-Kahn outlined a future in which devices, or sensors that automatically collect a range of health data internally and externally, can help patients and doctors monitor health.[2] [34] Since Sarasohn-Kahn's report appeared in February 2013, sensors have attracted significant attention, as suggested by recent investment activity. If utilized appropriately, sensors may become a vital component of efforts to use personal health data to provide individualized care, prevent disease, and more.

Augmented Reality: Wikipedia characterizes augmented reality as the use of "computer-generated sensory input such as sound, video, graphics" or other data to enhance real world imagery. [35] For example, virtual information can be incorporated onto a photo of a famous landmark, including when it was built and the materials used to construct it. In health, augmented reality can be used for a number of tasks, including providing safety tips on how to properly use children's over-the-counter medicines when the product is viewed via a mobile device. Augmented reality can also help people make better food choices, such as providing nutritional information on top of an image showing a popular fast food item.
Brain Mapping: For centuries, the brain was the ultimate black box. We knew that information went in based on what we saw, tasted, touched, and felt, but little about what sensory input does to the brain. Today, neuroscientists have developed tools, such as functional magnetic resonance imaging and electroencephalograms that help us map conscious and unconscious responses to internal and external stimuli. Psychologists aren't the only ones using these tools. Marketers have been employing brain-scanning technologies to map and predict the influence of advertising and more. [36] Later, we'll also describe how neuroscience is being used to personalize health care, including in the area of mental health and addiction treatment.
Social Media: Social media tools, such as blogs, Facebook, and Twitter have steadily become more important to people seeking health and medical information. In fact, according to a Kantar Media study released in 2013, consumer use of social media sites for health research has increased by 21 percent since 2011. [37] Social content—especially if it is generated based on personal data, preferences, and requests—can aid in the delivery of individualized health information and care.

Problem #3: Limited Social Support

For years the social side of treatment and recovery remained underappreciated. The severe impact of debilitating mental conditions such as depression were minimized; emotional suffering was never given the same level of concern by the medical community as physical pain and suffering. This is all changing, and nowhere is it more apparent than in the world of caregiving.

Amy Goyer has worked in the field of aging for more than 30 years, but in many ways she was completely unprepared for the immense challenges she would face when she decided to become the primary caregiver for her two aging parents. Goyer, who serves as AARP's home and family expert, is often featured in the media speaking candidly about her caregiving experiences. One topic she frequently discusses is the social isolation she feels as she juggles caring for her

parents and maintaining a career.

How does she cope? Goyer says she relies on digital tools such as the Web and social media to stay connected with others and receive support. In an August 2013 post published on the AARP blog, she related how e-mail helped her get through a particularly tough moment. She wrote: "Eight months after I'd relocated to Phoenix to help my parents, I found myself frozen, unable to drag myself out of bed and face my to-do list . . . I leaned out of bed far enough to reach my laptop and e-mailed some friends. Dorothy e-mailed back, "Do not succumb to the bed!!!" Her message made me laugh in spite of myself . . ." [38]

We recognize that many people coping with health issues have a hard time finding and receiving emotional and social support; however, we're highlighting caregivers because they face a unique burden. Caregivers must figure out how to take care of their loved ones and maintain their own wellbeing with limited resources. Lack of knowledge about the educational and social tools available to them provided by organizations such as AARP compounds the problems they face.

Over the coming years, many more Americans will face the challenges associated with caregiving, including social and emotional isolation. According to the Pew Research Center, thirty percent of U.S. adults defined themselves as caregivers in 2010. [39] In 2013, Pew reported that the caregiver population had increased by nine percent. [40] The number of caregivers is expected to continue increasing as the population gets older and age-related illnesses like dementia become more prevalent. [41]

The good news is that increasing numbers of caregivers are no longer facing this burden alone, which explains our third and final theme . . . Digital Peer-to-Peer Health Care.

WHAT IS DIGITAL PEER-TO-PEER HEALTH CARE?
A range of Web, social, and mobile tools are helping patients collaborate on things like navigating the new health insurance landscape, selecting providers, assisting in their own care, and providing emotional support.

Inside the Impact of Digital Peer-to-Peer Health Care

Ask Susannah Fox of the Pew Research Center, and a self-described "Internet Geologist" about the digital innovation that excites her most and she'll tell you it's "people talking with each other." [42] Communicating via e-mail, the Web, and social media (or simply face-to-face) may not be as sexy as Big Data or body sensing technologies, but Fox believes it's going to have a bigger impact on health.

In a 2013 post published on her personal blog, Fox explains why: "[T]echnology allows us to widen the network of people we can talk with, increase the velocity of these conversations, inject them with more source material, then archive and make them searchable." [42]

The Pew Research Center defines the phenomenon of digital technologies helping to forge connections between people as "peer-to-peer health care." [43] We've tweaked Pew's language slightly by defining this health trend as *digital* peer-to-peer health care, as our focus is on how tools like the Web and social media can help reduce patients' and caregivers' social isolation while improving their emotional wellbeing. In Table III we describe some of the technologies driving digital peer-to-peer health care.

Will digital peer-to-peer health care change the world? *It may already have*. Because of the Internet, countless patients, caregivers, and others have forged lifelong connections that have benefited their physical and mental health. Medical data shared by patients is helping to transform long-standing beliefs about how we test medications and whether they are truly effective in the real world. And, from an individual perspective, Amy Goyer is testament to the fact that digital technologies have become integral to health, partly because of the bonds they help us form and maintain.

Table III: Technologies Powering Digital Peer-to-Peer Health Care

Overview: Key Digital Technologies and Tools Driving Peer-to-Peer Health Care
The Internet and Social Media: Over the past decade, the Web has become a significant source of social and emotional support for caregivers and patients, especially those with chronic conditions. Pew reports that caregivers are "heavy technology users," and highly likely to go online to gather health information and use the Web (and face-to-face conversations) to seek advice and support. [40] As for people with chronic diseases such as cancer and diabetes, while lower numbers possess Internet access, they are more likely to use it to search for health content and frequent social networks and other sites. [44]
Open Patient Networks: A growing number of patient-oriented networks are becoming *de-facto* trusted sources of information on particular disease conditions, displacing even authoritative peer-reviewed content that may be available online. These real-life melting pots of patient experience, such as PatientsLikeMe, are enabling anyone to share their stories within an established community, no matter where they happen to be in the world.
Mobile Health Applications: As mobile has become more popular in health, a number of organizations are developing mobile applications targeted toward patients and caregivers. For example, in July 2013, the U.S. Department of Veterans Affairs launched a pilot project in which it provided 1,000 iPads to veterans' caregivers pre-loaded with 10 customized applications. [45] There are thousands of medical mobile apps designed to help patients manage their care and U.S. federal regulators are taking steps to guide their development and even allow doctors to prescribe them. [46]

A Health-Care Theme Recap

In this chapter, we outlined three health-care themes that are emerging as people try to solve a number of major problems faced by patients, providers, caregivers, and others. As a short recap, here are the problems as well as the themes.

Problem: **Skyrocketing Health Costs**	**Solution –** **Health HyperEfficiency:** Innovations in computing technologies are helping to make health and medical care more efficient, safe, and effective for all patients.

Problem: **Generic Medicine**	**Solution –** **The Personalized Health Movement:** A philosophical and operational shift that considers the unique genetics, behaviors, and medical histories of individuals instead of treating them based on inflexible or non-personalized guidelines and traditions.
Problem: **Limited Social Support**	**Solution –** **Digital Peer-to-Peer Health Care:** A range of Web, social, and mobile tools are helping patients collaborate on things like navigating the new health insurance landscape, selecting providers, assisting in their own care, and providing emotional support.

Now that we have outlined major health industry issues influencing the evolution and use of technology, let's turn our focus to discussing the unique ways ePatients are being impacted by these themes. After pausing for a brief interlude, we'll begin our analysis in Part I, starting with Health HyperEfficiency.

[1] While our primary focus has been on how these tools can be used to reduce spending, we will discuss other use cases throughout this book.

[2] While sensors that allow patients and providers to monitor health externally are well known, a new class of devices that can be embedded into prescription medicines, such as one developed by Proteus Digital Health, are gaining increased attention.

Interlude:
How the Trends Are Organized and Described

The rest of this book will take you on a journey inside the 15 major trends in health care that are changing the ways consumers (patients, caregivers) receive treatment, consume information, and support one another.

Each of these 15 trends represents technologies and issues that our research and analysis indicates will become increasingly important between now and 2015 (as well as beyond).

For each trend, we will provide context to help you understand why it is important and examples of how this trend is taking shape today. In particular, we will use the following format to describe each trend:

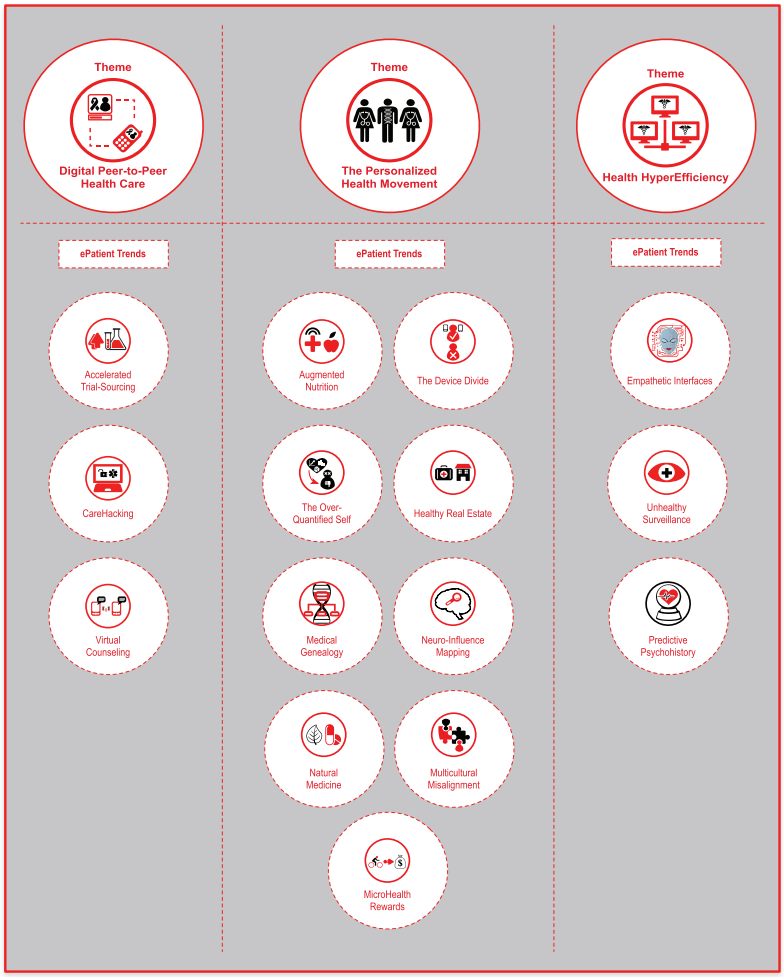
- **Organizational Framework:** The 15 trends are grouped based on the themes (Health HyperEfficiency, Digital Peer-to-Peer Health Care, the Personalized Health Movement) described previously (see Figure II).
- **Trend Summary:** We summarize each trend and provide additional background information on its history, scope, and importance.
- **digihealth pulse ePatient Data Analysis:** For certain trends, we feature data collected via Enspektos' digihealth pulse research initiative (see Appendix I for more information about digihealth pulse).
- **Stories:** For most trends, we provide examples of companies and other organizations either helping to advance these trends, or solving problems associated

with them.

As you review these trends you'll note that we've also highlighted some of the negative consequences of health technologies. Some may hesitate to examine digital health's shortcomings, but we feel doing so is vitally important if we are to fully appreciate its impact.

We will also offer insights on how and why these trends matter, both from the perspective of engaged patients, and others who are part of the health industry.

Figure II: Emerging ePatient Trends Related to the Themes Introduced Previously



After you absorb these trends, some of you may be looking for advice on what to do about them. For example, how should people protect sensitive health data or prevent information overload? We do offer some high-level guidance in the final chapter on these questions; however, the answers heavily depend on what audience category you happen to fall into. As a result, we don't focus as much on tactical advice in each trend, but rather on providing you with the context and research behind it so that you can begin to develop your own plan of action for how to utilize the information we provide independently.