This book describes an overlooked solution to a long-standing problem in health care. The problem is an informational supply chain that is unnecessarily dependent on the minds of doctors for assembling patient data and medical knowledge in clinical decision making. That supply chain function is more than the human mind can deliver. Yet, dependence on the mind is built into the traditional role of doctors, who are educated and licensed to rely heavily on personal knowledge and judgment. The culture of medicine has long been in denial of this problem, even now that health information technology is increasingly used, and even as artificial intelligence (AI) tools are emerging. AI will play an important role, but it is not a solution. The solution instead begins with traditional software techniques designed to integrate novel functionality for clinical decision support and electronic health record (EHR) tools. That functionality implements high standards of care for managing health information. This book describes that functionality in some detail. This description is intended in part to be a starting point for developers in the open source software community, who have an opportunity to begin developing an integrated, cloud-based version of the tools described, working with interested clinicians, patients, and others. The tools grew out of work beginning more than six decades ago, when this book’s lead author (deceased) originated problem lists and structured notes in medical records. The electronic tools he later developed led him to reconceive education and licensure for doctors and other health professionals, which are also part of the solution this book describes.

ABOUT SYNTHESIS
This volume is a printed version of a work that appears in the Synthesis Digital Library of Engineering and Computer Science. Synthesis books provide concise, original presentations of important research and development topics, published quickly, in digital and print formats.
Ending Medicine’s Chronic Dysfunction: Tools and Standards for Medical Decision Making
Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies

Editors

Ronald M. Baecker, University of Toronto
Andrew Sixsmith, Simon Fraser University and AGE-WELL NCE

This series provides state-of-the-art overview lectures on assistive technologies. We take a broad view of this expanding field, defining it as information and communications technologies used in diagnosis and treatment, prosthetics that compensate for impaired capabilities, methods for rehabilitating or restoring function, and protective interventions that enable individuals to stay healthy for longer periods of time.

Each overview introduces the medical context in which technology is used, presents and explains the technology; reviews problems and opportunities, successes and failures in the development and use of technology; and synthesizes promising opportunities for future progress. Authors include significant material based on their own work, while surveying the broad landscape of an area’s research, development, and deployment progress and success.

Ending Medicine’s Chronic Dysfunction: Tools and Standards for Medical Decision Making
Lawrence L. Weed (1923–2017) and Lincoln Weed

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Ending Medicine’s Chronic Dysfunction: Tools and Standards for Medical Decision Making

Lawrence L. Weed (1923–2017)

Lincoln Weed

SYNTHESIS LECTURES ON ASSISTIVE, REHABILITATIVE, AND HEALTH-PRESERVING TECHNOLOGIES #16
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KEYWORDS
problem-oriented, electronic health records, clinical decision support systems, artificial intelligence, clinician role, licensure
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... the avoidance of reality is much the same everywhere… To see what is in front of one’s nose needs a constant struggle. — George Orwell

1.1 WHAT IS THIS BOOK ABOUT?

Soon after outbreak of the COVID-19 pandemic in the U.S., the supply chain for essential medical equipment reached a breaking point. Medicine has yet to recognize a similar, older, and larger problem: constant failures in the supply chain for health information. Unlike equipment for a pandemic, health information cannot be mass produced in advance. Patient care requires constant assembly of information, both knowledge and data. That information must be selected, distilled, and organized for patient-specific, problem-specific use in every case. As the assembled information is used for decision making, maintaining the supply chain requires meticulous, organized recordkeeping and follow-up over time.

Constant failures in these supply chain activities compromise decision making across the board. And quality failures occur with not only medical decisions (missed diagnoses or misguided treatments, for example) but execution of decisions (unskilled physical examinations or surgeries, for example). Taken together, these two areas of quality failure—decision making and execution—have long caused harm and economic waste on a global scale. Continuing to tolerate these quality failures is comparable to inaction against a disease pandemic.

This book focuses on medical decision making, not execution (“doing the right thing,” not “doing the thing right”). Decision making depends on medicine’s informational supply chain. So, the book’s core subject matter is to diagnose and remedy failures in that supply chain.

2 See Mukherjee, S., “What the Coronavirus Reveals About American Medicine,” The New Yorker, April 27, 2020. Dr. Mukherjee’s article goes on to discuss electronic health records (EHRs). See Section 3.4. Dr. Mukherjee concluded that once the pandemic is over, we should do more than merely resume the status quo. “We need to think not about resumption but about revision.” This book argues that we need to think not about revision but about reconstruction from the foundation.
3 Decision making has also been referred to as planning. See the famous report by the Institute of Medicine (now the National Academy of Medicine or NAM), To Err Is Human: Building a Safer Health Care System (National Academies Press, 2000), p. 55, which explains: “This report addresses primarily … errors of execution, since they have their own epidemiology, causes and remedies that are different from errors of planning. Subsequent reports … will address the full range of quality related issues, sometimes classified as overuse, underuse and misuse”). The first of the subsequent reports was Crossing the Quality Chasm: A New Health System for the 21st Century (National Academies Press, 2001), which repeatedly referenced the work of this book’s lead author, Dr. Lawrence L. Weed (referred to below as LLW). For background on LLW, see Section 1.3 and Chapter 5.
1. INTRODUCTION

Developing an effective informational supply chain is a pathway for improving the quality of medical decisions. Improved decisions are needed for improving the economics of the health domain. And improved economics is needed to afford universal coverage without diverting resources from other urgent needs. In short, everyone in the health domain has a large stake in using this new pathway.

The root cause of supply chain failures is misguided dependence on the human mind. Yet the role of the human mind has long been venerated. The culture of medicine is thus in denial about this root cause.

The state of denial makes it difficult to recognize and remedy dependence on the mind, even now as digital information tools increasingly offer an escape. That misguided dependence, and the continuing state of denial about that problem, are the subject of Part I of this book. Solving that problem requires new digital tools for health records and decision support based on new standards of care for handling health information—the subject of Part II. New tools and standards make possible new occupational roles for doctors and other health professionals, new concepts of medical education and licensure, and new concepts of expertise for both health professionals and their patients—also the subject of Part II.

Much of the critique in Part I will sound familiar to readers engaged in health policy issues. Decades ago, this book's lead author (LLW) was among the first to recognize issues like the centrality of medical records, the need to protect against, rather than venerate, autonomous expert judgment, and the primacy of the patient’s role. Now that these insights have become conventional wisdom, the question arises—could there be something more in LLW’s work that we’re still missing? That something more is the solution presented in Part II, which has never been widely understood, much less adopted.

We addressed both the problem and the solution in our book, *Medicine in Denial* (Amazon Kindle Direct Publishing, 2011). The present book draws heavily on *Medicine in Denial* by Dr. Leslie Kernisan (the third and last post with links to the earlier ones is available here). Readers may also be interested in Weed, L. L. et al., *Knowledge Coupling: New Premises and New Tools for Medical Care and Education* (Springer-Verlag, 1991). Lincoln Weed has dozens of copies of that book, available for free. Contact ldweed424@gmail.com or text to 703-424-4408. The present book covers only a fraction of the material covered by the *Medicine in Denial* and *Knowledge Coupling* volumes.

Some readers may ask how this book relates to the sweeping critiques of the medical-industrial-academic complex presented in Ivan Illich’s prophetic *Medical Nemesis: The Expropriation of Health* (Pantheon Books, 1976) and in Seamus O’Mahony’s recent *Can Medicine Be Cured? The Corruption of a Profession* (Apollo, 2019). (See this blog post discussing both books: Richard Smith: The most devastating critique of medicine since Medical Nemesis by Ivan Illich in 1975 (February 13, 2019).) LLW, who read the Illich book, sought to develop solutions to the failings he saw in real-world problem-solving for patients. His pursuit of those solutions (not mere analysis of failings) led him to the diagnosis stated above—misguided reliance on the minds of doctors—which is a primary root cause of both patient care and system-wide failings. The human mind is the vector for the systemic corruptions in the medical-industrial-academic complex as described by Illich and O’Mahony. Unlike them, LLW focused on solutions, which deepened his insight into the failings. LLW’s solutions represent a way to harvest value for patients and society from the medical-industrial-academic complex while guarding against its exploitive tendencies.
The following case vividly illustrates the problem described in Part I, and it points straight at the solution in Part II.

1.1.1 THE CASE OF THE CRAZY SURGEON AND THE WISE PHYSICAL THERAPIST

The patient, Eric, had an unusual disease in his joints—osteochondritis dissecans. It caused Eric’s knees to go bad during his teens and by age 20 he had undergone reparative surgery on both knees. Over the next 40 years, he had to progressively curtail his physical activities as his repaired knees deteriorated. At age 62 he decided to have replacement surgery on one knee. He relied on advice from his orthopedic surgeon that he was a perfect candidate for knee replacement. The orthopedist said the only significant downside was a 1–2% risk of infection.

Two days after the surgery, Eric began the standard post-operative physical therapy (PT) protocol. But immediately something was wrong. As described by Eric:

The protocol is intense, calling for aggressive bending and extension to avoid scar formation in the joint. Unable to get meaningful flexion, I put a stationary bicycle seat up high and had to scream in agony to get through the first few pedal revolutions. The pain was well beyond the reach of oxycodone. A month later the knee was purple, very swollen, profoundly stiff, and unbending. It hurt so bad that I couldn’t sleep more than an hour at a time, and I had frequent crying spells.

Eric’s physical therapist had no solution, and his orthopedist dismissed the pain. “You should have your internist prescribe anti-depression medications,” the orthopedist said. Eric and his wife listened “in total disbelief” to this “robotic response.” Eric goes on:

That seemed crazy enough. But the surgeon then recommended a more intensive protocol of physical therapy, despite the fact that each session was making me worse. I could barely walk out of the facility or get in my car to drive home. The horrible pain, swelling, and stiffness, were unremitting. I became desperate for relief, trying everything … fully aware that none of these putative treatments have any published data to support their use.

Then Eric’s wife learned about arthrofibrosis—a disastrous complication suffered by 2–3% of patients having knee replacement surgery, which is the most common of all orthopedic operations. Arthrofibrosis causes a vicious inflammation response and profound scarring. Eric confirmed with his orthopedist that he had this condition. The orthopedist told him there was nothing to be done but wait for a year, at which point more surgery could remove the scar tissue. “The thought of going a year as I was or having another operation,” Eric wrote, “made me feel even sicker.”

Then a friend recommended a different physical therapist. She rescued Eric from his nightmare:
Over the course of 40 years, she had seen many patients with osteochondritis dissecans, and she knew that, for patients such as me, the routine physical therapy protocol was the worst thing possible. … her approach was to go gently; she had me stop all the weights and exercises and use anti-inflammatory medications. She handwrote a page of instructions and texted me every other day to ask how “our knee” was doing. Rescued, I was quickly on the road to recovery. Now, years later, I still have to wrap my knee every day to deal with its poor healing. So much of this torment could have been prevented. 

Eric believes that “a full literature review … might well have indicated that I needed a special, bespoke PT protocol,” assuming that “experienced physical therapists such as the woman I eventually found shared their data” via the medical literature. He also suggests that the information could have been shared via artificial intelligence, usable by not only his clinicians but him as a patient. But no such tool was available. In its absence, the orthopedist needed to review the literature, or consult someone else, or otherwise research the correct therapy for a patient like Eric. But he evidently failed to do so:

As it was, I was blindsided, and *my orthopedist hadn’t even taken my history of osteochondritis dissecans into account* when discussing the risk of surgery, even though he later acknowledged that it had, in fact, played a pivotal role in the serious problems I encountered [emphasis added].

Eric goes on to discuss the roles played by his orthopedist and the second physical therapist. Referring to the follow-up visit where the orthopedist had suggested an anti-depressant, Eric writes:

The idea that I should take medication for depression exemplifies a profound lack of human connection and empathy in medicine today. Of course, I was emotionally depressed, but depression wasn’t the problem at all: the problem was that I was in severe pain and had Tin Man immobility. The orthopedist’s lack of compassion was palpable: in all the months after the surgery, he never contacted me once to see how I was getting along. The physical therapist not only had the medical knowledge and experience to match my condition, but she really cared about me. It’s no wonder that we have an opioid epidemic when it’s a lot quicker and easier for doctors to prescribe narcotics than to listen to and understand patients.⁶

Tragically, Eric’s case is not an isolated occurrence. It is all too representative of decision making that is uninformed and callous. Eric writes:

> *Almost anyone with chronic medical conditions has been “roughed up” like I was—it happens all too frequently … the problem is so pervasive that even insider knowledge isn’t necessarily enough to guarantee good care. Artificial intelligence alone isn’t going to*
solve this problem on its own. We need humans to kick in. *As machines get smarter and take on suitable tasks, humans might find it actually easier to be more humane.* [Emphasis added.]

Note the mention of “insider knowledge.” Eric is an “insider” because he is Eric Topol, M.D., a distinguished cardiologist and the author of three books about the future of medicine. The above description of his case is paraphrased and quoted from the opening pages of his most recent book, *Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again.*

### 1.1.2 HOW THIS CASE EXEMPLIFIES THE SUBJECT MATTER OF THIS BOOK

What happened to Dr. Topol reveals how quality failures are built into medical practice at multiple levels. Specifically:

- The orthopedist caused four harmful breakdowns in the informational supply chain.
  1. He failed to inform his patient of the general arthrofibrosis risk and the special risk arising from a history of osteochondritis dissecans. (2) Once that special risk materialized, he failed to diagnose it. (3) That diagnostic failure led him to recommend an even harsher PT regimen and to suggest an anti-depressant. (4) These errors, together with his lack of compassion, completely alienated his patient.

- That alienation is itself a breakdown in the informational supply chain, because close communication between patient and clinician is essential to quality of care. Sometimes alienation causes patients to distrust the entire health care system. Their distrust may then deter them from seeking care when they need it—the ultimate supply chain breakdown. And, like a metastasizing cancer, the patient’s distrust may spread to family members and others who witness what happened.

- Dr. Topol’s suffering and disability came to an end only because a friend happened to recommend a physical therapist whose knowledge and experience happened to match his particular needs. This random matching falls far short of what we should expect from a scientifically rigorous system of care. Yet, randomness is inevitable if medicine’s informational supply chain depends on the clinician’s mind, with all its fallibility and idiosyncrasies. Medicine cannot be practiced as *a science,* and care cannot be provided through a *system,* until the supply chain incorporates tools and standards external to any clinician’s mind. Clinicians must be governed by standards of care assuring that the tools are used *habitually* from the outset of care to match medical knowledge with

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detailed patient data carefully selected by the tools. The minds of clinicians and patients still have a supplemental role to play, but they cannot trust their own minds to perform this matching process.

• The needed information tools, Dr. Topol suggests, should take the form of artificial intelligence (AI) software. He believes that AI “could have predicted that my experience after the surgery would be complicated” (p. 3). But advanced AI software is not necessary for a case like Dr. Topol’s. Traditional software optimized for general medical decision making, as described in Chapters 8 and 9, could have been used to identify the arthrofibrosis complication risk, the effect of the osteochondritis dissecans history, and the alternative to the standard PT protocol. This point is crucial, because traditional software already offers simplicity, reliability, and transparency that are not yet feasible with advanced AI in many contexts. Moreover, traditional software offers protections against some risks inherent in both human and artificial intelligence.

• External tools are not enough. For both traditional software and AI tools, their design and use must be governed by high standards of care for managing complex health information. The key point is that external tools make it possible to set standards of care at a higher level than the unaided human mind can attain. Hopelessly complex knowledge and data become manageable when we use external tools designed to implement high standards of care for managing health information.

• “Standards of care” are not technical standards (e.g., data, vocabulary, and interoperability specifications, which is what “standards” suggests to health IT specialists). Instead, standards of care are rules of conduct. For example, Dr. Topol’s orthopedist violated a rule of conduct that clinicians must habitually employ external tools to match general knowledge with patient-specific data. Another rule of conduct is maintaining accurate, organized records in compliance with generally accepted standards for health recordkeeping, not unlike generally accepted accounting principles for financial records. Complying with these standards of care is a matter of both scientific integrity and public safety, not to mention efficiency and productivity.

• The rules of conduct just described are process standards. Also needed are detailed informational standards, specifying the knowledge and data that must be taken into account for a given problem situation. For Dr. Topol, the initial problem situation was deciding whether to undergo knee replacement surgery and rehab. A good informational supply chain would have prompted a question on whether a candidate for knee replacement surgery has a history of osteochondritis dissecans. (Ideally, the question would be answerable by automated search of a lifetime electronic health record, with-
out the need for the patient to recall that history.) Given a positive response to that question, the informational supply chain would inform the patient and clinician of the arthrofibrosis risk and the need for a special PT regimen. In other words, everyone involved should not have had to rely on their own minds or the minds of others. Their personal ignorance or awareness should not have mattered.

- A good informational supply chain protects against conflicts of interest. Maybe Dr. Topol’s orthopedist deliberately understated the risks of knee replacement surgery to induce his patient to elect surgery and thus generate fees. Or suppose an insurer denied coverage for the surgery or the post-operative PT on the ground that neither would work in a patient with a history of osteochondritis dissecans. Or suppose Dr. Topol never learned of the physical therapist with the requisite knowledge. Safeguards against all these random contingencies are provided by the right tools and standards. Everyone involved should have been able to consult an external tool supplying the information needed.

- Clinician roles are pivotal. The informational supply chain function is so deeply embedded in the doctor’s role that Dr. Topol trusted his orthopedist’s advice. Yet, the second physical therapist, not the orthopedist and not the first physical therapist, turned out to have the expertise relevant to Dr. Topol’s needs. Why is it, then, that an orthopedist is higher in the medical hierarchy than a physical therapist? This disparity in status further manifests randomness and dysfunction in the informational supply chain. And it calls into question current notions of licensure and authority for doctors and all medical practitioners.

- It may seem surprising that Dr. Topol, as an “insider,” trusted his surgeon’s advice. But this is understandable. No one can easily find the time to second guess professional advice and conduct independent research. As a specialist himself, Dr. Topol would have known how time-consuming it might become for him to delve into a different specialty, orthopedics. And he likely trusted a fellow doctor to be as diligent and caring as he would be. So the path of least resistance was to trust the advice he received. But the reality of medicine is that such trust is too often not warranted, from both medical and economic perspectives.

- From a medical perspective, even if doctors were always diligent and caring, they are attempting the impossible. Their minds are not capable of functioning reliably as part of the informational supply chain. Were the human mind treated as a medical device for performing this function, it would never pass FDA scrutiny for safety and effectiveness.
1. INTRODUCTION

- From an economic perspective, trusting doctor advice may seem rational, particularly with specialists. Specialization normally fosters expertise and efficiency. But this principle doesn't apply if the specialist's expertise doesn't match patient needs. In medicine that mismatch is the norm, because patient needs routinely cross specialty boundaries. This point implicates medicine’s division of labor. External tools can take into account all specialties. And that expertise can be built into the tools before patient encounters, obviating the need for each clinician to reinvent the wheel during those encounters. The tools can be used by all clinicians, not just doctors, and by patients themselves, before, during, and after their encounters. An economically rational division of labor among external tools, clinicians, and patients becomes possible once the tools are available. By comparison, the current division of labor in medicine is primitive. Other fields in the domains of science and commerce have evolved away from reliance on opaque expert judgments. It is long past time for medicine to catch up.

- A better informational supply chain would relieve clinicians from the intolerable burden of constantly reinventing the wheel—a burden that contributes enormously to clinician burnout as well as negligent and callous conduct such as that of Dr. Topol’s orthopedist. Dr. Topol recognized this reality: “As machines get smarter and take on suitable tasks, humans might find it actually easier to be more humane.”

The above points detail various ways that Dr. Topol's case exemplifies the subject matter of this book. The following section further introduces the book's core concept: that medicine’s failures of quality and economy are rooted in the doctor's role.

1.1.3 A NEW DIVISION OF LABOR

Discontent with the status quo and ongoing attempts at reform have long been part of the culture of medicine. Yet that culture has never faced up to how the doctor’s role blocks true reform. What that means, and what to do about it, are the subject of this book.

Fundamentally changing the doctor’s role is an alternative outside mainstream health reform. This alternative, despite having evolved for six decades, is genuinely new—it has not truly been considered, much less accepted or advocated, by mainstream experts. Nor have they rejected this alternative; it’s not even on their radar screens. That is the case even though mainstream economists have long criticized the doctor’s role. Locked in place by medical licensure, the doctor’s role,

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8 Deep Medicine (see Note 7), p. 4. Dr. Topol later illustrates this point with a quote from Lynda Chin: “Imagine if a doctor can get all the information she needs about a person in 2 minutes and then spend the next 13 minutes of a 15 minute office visit talking with the patient, instead of spending 13 minutes looking for information and 2 minutes talking with the patient.” Ibid., p. 23.
according to this critique, is a monopolistic barrier to market forces that would otherwise generate major innovations in medical practice.  

We tend to agree with the economists’ critique as far as it goes. But it doesn’t go very far, because it doesn’t envision an alternative to the doctor’s role. The critique needs to be reconciled with economists’ traditional view of the doctor’s role as a regulatory necessity. Because that traditional view persists, mainstream health policy thinking still accepts the doctor’s role as inherent in modern medicine. It involves advanced science and technology, so everyone is socialized to believe that medicine must be practiced by, or under the direction of, highly educated, highly compensated doctors. They alone are thought to have the trained minds needed to apply medical science. Their training is thought to confer some sort of unified expertise on doctors as an occupational category.

The alternative view advocated in this book is that the doctor’s role is unnecessary to—indeed incompatible with—scientific rigor in medical practice. Without scientific rigor, medicine will continue to be practiced as an artisanal craft or a commercial endeavor, both at widely varying levels of skill and quality, both poorly connected to patient needs, and both far less productive and affordable than they must become.

So what exactly is the doctor’s role, and how is it an obstacle to scientific rigor? We address those questions in Chapter 2 and give detailed examples in Chapter 3.

Finally, we need to explain how this book’s subject matter fits into the Morgan & Claypool “Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies.” The series concerns “the expanding field of assistive technologies,” defined broadly to include technologies in prosthetics, rehabilitation, and protective interventions to preserve health. The subject matter encompasses LLW’s argument that everyone, patients and clinicians alike, must habitually use “assistive” information tools as a cognitive “prosthetic” to “rehabilitate” the human mind from its innate limits. This argument goes well beyond the current consensus that cognitive heuristics and biases impair medical decision making. Moreover, with recent pathbreaking advances in AI, a related issue is emerging: in what contexts should advanced AI play more than an “assistive” role? When should it supersede human intelligence?

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9 See Medicine in Denial (Note 4), part VIII.B (pp. 210–219), and Section 2.1. The reference to “market forces” should not be taken as endorsing an unregulated “free market” in health care. On the contrary, the potential of market forces cannot be realized unless medical practice is tightly regulated in very specific ways. Those specific ways were the subject of the lead author’s work for six decades.

10 This traditional view was articulated by the late Kenneth Arrow in a seminal 1963 article, which we have discussed elsewhere. See Note 121.
1. INTRODUCTION

1.2 WHO IS THE AUDIENCE?

Without the necessary information tools, the reforms envisioned in this book are powerless to be born. So this book’s most immediate audience, though not the only one, is those who are best positioned to start building the necessary tools—developers in the open source software community. This is not limited to specialists in health IT. Open source developers outside health IT may have fresh perspectives and relevant experience.

Health IT differs somewhat from other fields where software developers work. Developers normally lack expertise in the functions to be performed by the tools they build. So they normally rely on guidance from subject matter experts in those functions. The authoritative subject matter experts in medicine are doctors.

Yet, this book is in part a critique of the doctor’s role, including mainstream doctor practices and orthodoxies in medical decision making. If our critique is right, then the doctor’s role poses a dilemma for software developers. Their dilemma is that they must combine a healthy respect for the firsthand clinical experience of doctors with a healthy skepticism of guidance from doctors on designing digital tools for clinical use. In other words, developers cannot rely on guidance from doctors in the way they would normally rely on guidance from subject matter experts.

Doctors are not the only subject matter experts who health IT developers work with. Others are non-doctor clinicians, business/administrative managers, academic specialists, and regulators (not to mention patients, who have personal expertise, as we discuss elsewhere). But, like doctors, all these experts have perspectives that do not always work as guidance to health IT developers. Moreover, the agendas of medical and non-medical experts may come into conflict.

A prime example of conflict is electronic health record (EHR) tools. Clinicians rightly believe that EHRs have been subverted by an economic agenda—generating documentation to maximize billing and reimbursement. The result is that doctors bitterly criticize EHRs as hard-to-use, clinically dysfunctional, and thus extraordinarily burdensome. This mismatch between clinical and economic agendas in EHR design is indeed a serious problem, so much so that cumbersome EHRs are a major contributor to clinician burnout.11 This is one of the mainstream failings that the open source software community can help address.

All this means that software developers should not accept on faith the directions or guidance they receive from clinicians and other subject matter experts in health care. The open source software community, indeed everyone in the health domain, should not uncritically buy into either mainstream orthodoxy or the contrary views stated in this book. Instead, everyone can independently think through how the health care system can be reformed, taking into account their

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11 See Section 3.4.4, which cites recent articles written for the general public. Countless more descriptions can be found in the medical literature and blog posts.
personal experiences in the health domain and in their own professions. Unlike everyone else, however, software developers are positioned to bring to life essential information tools.

Moreover, developers have special expertise in what it takes to translate work processes of many kinds into step-by-step procedures capable of being executed by traditional software tools. They also have expertise in structuring database repositories in the cloud for use by various parties in disparate contexts. And they are developing expertise in advanced artificial intelligence, including machine learning. Those kinds of expertise are highly relevant.

In short, we hope this book elicits interest among software developers in building essential information tools on an open source basis. Some of those readers may wish to jump ahead directly to Part II of this book. The portions most directly relevant are Section 8.3 (discussing a seven-step sequence to be implemented in clinical decision support tools), Section 9.1.2 (discussing medical record structure and data categories), Section 9.2 (discussing a consolidated record in the cloud with a common data model for patient data and care processes), and Section 9.3 (discussing one company’s important work on integrating clinical decision support with electronic health records). That said, the entire book is relevant to software developers, who need some understanding of the clinical and policy issues involved.

Although the software developer audience is primary, that is certainly not the only audience. Building and using the tools ultimately requires a common understanding among developers, clinician and patient users of what they develop, institutional providers, third-party payers, regulators, researchers, health policy analysts, and other stakeholders in the health domain, regardless of political orientation. They all can think through the ideas presented, and seek to arrive at some common understanding. In particular, they can think through what the essential information tools involve, in terms of purpose, design, proper and improper uses, limitations, and potential effects, in relation to existing health IT. Most of all, individual consumers/patients and health professionals need to understand how they can jointly use the tools to meet individual health needs.

Accordingly, this book is written for a broad audience. That means the book includes some basic material unnecessary for some readers—for example, basic concepts familiar to software developers in the health IT field and basic medical concepts familiar to clinicians. It also means the book is intended to be accessible to readers from a wide range of educational levels and occupational backgrounds.

1.3 WHO ARE THE AUTHORS?

The lead author, Dr. Lawrence L. Weed (referred to below as LLW), died in 2017. Although he did not participate in the actual writing of this book, he is named as the lead author for two reasons.

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11 See his New York Times obituary, this tribute (“Remembering Larry Weed”) by Art Papier in MedPage Today, this tribute (and the links therein) by Dr. Papier to the Society for Improving Diagnosis in Medicine, this tribute by Harlan Krumholz in the Health Affairs blog, and this 2005 article in The Economist.
1. INTRODUCTION

First, LLW originated all the core ideas, spearheaded development and use of the tools and standards described, and inspired immense work by many others over more than six decades. Second, this book draws heavily on the 2011 book *Medicine in Denial* (see Note 4), of which LLW was the lead author. See Chapter 5 for further discussion of LLW’s background and influence.

Lincoln Weed is a son of LLW. He is a retired lawyer who, for most of his career, specialized in employee benefits, including health benefits, working initially at a federal agency, and then at law firms in Washington, D.C., and finally at a consulting firm where he focused on health privacy issues for several years. His health benefits work intersected with LLW’s work, which led to co-authoring some publications with LLW beginning in 1994, including the *Medicine in Denial* book.

Disclosure: Lincoln and his four siblings inherited LLW’s small financial interest (of highly uncertain value) in the buyer of LLW’s company, PKC Corp. In addition, Lincoln has a very small interest in another company affiliated with a company developing a decision support and medical record platform related to LLW’s work (see Section 9.3). In addition, Lincoln became a member of the non-profit Health Record Banking Alliance (HRBA) and started working with an HRBA committee in early 2020. See Section 9.2 (no compensation is received for working with the HRBA). In addition, LLW and Lincoln have long known the CEO of the company discussed in Section 8.4 but have no financial interest, direct or indirect, in that company.

1.4 BASIC CONCEPTS AND TERMINOLOGY USED IN THIS BOOK

**Health** and **medical/clinical**: We generally use the adjectives *medical* and *clinical* in reference to the health care system, and the term *health* (as an adjective) in reference to the health domain.

**Health care system** and **health domain**: We use the term *health care system* to refer to the combined social systems through which health care professionals provide care to patients, professional services are paid for, health care activities are regulated, health-related research is conducted, etc. The health care system is a subset of the health domain. The health care system influences, but does not govern or control, the entire *health domain*.

**Health information**, **medical/health knowledge**, and **patient data**: *Health information* as an umbrella term covering both general knowledge and patient-specific data. This binary distinction between knowledge and data is useful in many contexts, but is ultimately an oversimplification, as discussed in Section 3.5.

**Patient**: People act in a *patient* capacity when receiving care within the health care system, and they act in a personal capacity when otherwise engaging in behaviors and pursuits outside the health care system that affect their health. For convenience, however, we sometimes use the term “patient” loosely without intending to distinguish between patient and personal roles, which may be intertwined.
Problem-oriented medical/health record (POMR, POHR) or problem-oriented record, and problem-orientation: These concepts are explained in Chapter 7. See also Section 3.4.1 at Note 98.

Social determinants/drivers of health (SDoH): SDoH are factors such as housing, nutrition availability, financial status, social stresses, environmental conditions, access to health care, and more, that affect health. Recently, some have substituted the term “drivers” for “determinants,” because social factors are not the sole determinant of health.

SOAP notes: The are progress notes in POHRs. SOAP is an acronym for Subjective, Objective, Assessment, and Plan, the four main components of a SOAP note. See Section 9.1.2.2.
PART I: THE PROBLEM
CHAPTER 2

Nature of the Problem

2.1 ROOT CAUSE OF THE PROBLEM

*Neither the bare hand nor the understanding left to itself are of much use. It is by instruments and other aids that the work gets done, and these are needed as much by the understanding as by the hand. … There is a single root cause of nearly all the evils in the sciences, namely, that while we wrongly admire and extol the powers of the human mind, we fail to look for true ways of helping it.*

— Francis Bacon (1620)

Patient care decision making depends heavily on the information taken into account. So decision making can be conceived in two stages: (1) assembling the right information in maximally usable form; and (2) making decisions after taking into account that information with the patient’s preferences and values. The first stage is where the supply chain operates. Assembling information involves retrieval from the medical literature and other stores of knowledge, using that knowledge to select what patient data to collect and determine what the data mean for purposes of solving a medical problem as initially presented, organizing the results, delivering the results when needed, and recordkeeping to manage these processes and follow-up over time. All this must be individualized to the needs of each unique patient.

The primary vehicle for these supply chain activities has always been the doctor’s mind. That role for doctors continues to a large extent even now that health IT is widely used. Yet, that role demands more than doctors’ minds can deliver. This gap increases with advances in science and health IT. The advancing science increases the volume and complexity of medical knowledge exponentially. Corresponding increases in patient data arise. Health IT then worsens this overload on the mind by making access to information almost limitless and instantaneous. In short, the gap between the mind’s limited capabilities and an effective informational supply chain has grown wider and deeper.

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13 Bacon, F., *Novum Organum* (1620), Summary of the Second Part, Aphorisms Concerning the Interpretation of Nature and the Kingdom of Man, Book I, Aphorisms No. 2, No. 9 (translated and edited by Urbach, P. and Gibson, J., Open Court Publishing Co, 1994). (Online versions of *Novum Organum* (in different translations from Latin) are available at various sites.) For a clinical psychologist’s recent commentary on *Novum Organum* at the 400th anniversary of its publication, see Weinfurt, K., Francis Bacon’s 400-year-old list of scientific foibles holds lessons for modern scientists. *Science* (March 17, 2020).
As this gap increased over time, it was never clearly recognized or planned for. “Most of the technologies and ways we do things in medicine were never designed with human limitations in mind,” David Bates and Atul Gawande have written. “Indeed, most medical processes were never consciously designed at all; rather, they were built with a series of makeshift patches.”14 This point applies in spades to the informational supply chain. The outcome is ongoing failures of quality and economy on a pandemic scale. These failures have always been with us, so that we don’t even recognize them as failures.

This state of affairs persists because the doctor’s traditional role persists. Doctors are still seen as indispensable links in the informational supply chain.

The doctor’s role is built into law (doctors have a legal monopoly over medical practice) and culture (we all are socialized to trust doctor expertise and authority). Moreover, the doctor’s role distorts development and use of health IT. For example, doctors tend to use clinical decision support (CDS) tools selectively, when they feel the need for help with a puzzling case, not habitually, which is what scientific rigor requires. This tendency is the natural outcome of medical education and licensure, which implicitly teach pride in personal knowledge. Doctors are not trained to systematically recognize the inevitable discrepancies between accepted knowledge and problem solving for unique patients. Moreover, doctors are socialized to value professional autonomy. This makes them resistant to high standards of care for managing health information, which they see as bureaucratic interference in their autonomy.

Escaping this predicament means reconceiving the doctor’s role and everything built around it, including standards for design and use of health IT.15

Think of the health care system as a network of nodes, human and organizational, playing their accustomed roles. This network is dysfunctional because its human nodes, doctors in particular, are severely underpowered and poorly connected.

The connectivity problem—poor interoperability among electronic systems—is well recognized. Less recognized is that doctors are underpowered for functioning as network nodes—their minds cannot reliably handle the information retrieval and processing functions required in ordinary medical practice. At the same time, doctors have a legal monopoly over medical decision making. Changing the division of labor is thereby blocked. Yet, all other nodes in the network continue to depend on doctors. That dependence threatens to become even more harmful to the extent that

15 Although we thus advocate a large paradigm shift, we do not deny the potential for important advances within the current paradigm. See, for example, the impressive initiatives being disseminated by Dave Chase (as described at https://healthrosetta.org/ and his most recent book, Relocalizing Health: The Future of Health Care is Local, Open and Independent; the systemic accomplishments at the Geisinger health system as described in the book, Steele, G. and Feinberg, D., ProvenCare: How to Deliver Value-Based Healthcare the Geisinger Way (McGraw-Hill, 2019); and the management approaches described in the book, Emanuel, E., Prescription for the Future (PublicAffairs, 2017).
better interoperability increases data sharing. That would worsen the information overload that already burdens doctors intolerably.

With the right tools, so much of medical knowledge can become a network of interconnections, navigable by everyone as a map to the medical landscape. And so much of what doctors do with clinical information can be done better by clinicians and patients jointly equipped with the right tools. No machine learning or other AI is required; the tools simply perform transparent, pre-defined, step-by-step processes. Specifically, diagnostic and treatment decision making can be broken down into seven distinct steps, six of which can be automated in a completely transparent manner, using knowledge incorporated in the tools before patient encounters (see Section 8.3). No longer must medical practice be hidden inside a black box of “clinical judgment.”

Doctors now recognize that they cannot rely solely on their own intellects for knowledge retrieval. But they still view themselves as key to the informational supply chain. Although tools external to the mind lessen the need for memorized knowledge, doctors believe that their minds are still required for applying that knowledge to unique patients. They believe their training and experience instill “clinical judgment”—a black box that no one outside the profession can open, a mysterious amalgam of science and art, based on acquired knowledge, intelligent analysis, and subtle intuition. And those judgments are sometimes impressive. The authority of doctors thus seems inherent in scientifically advanced medicine.

But this traditional role introduces constant breakdowns. Clinical judgment is a euphemistic term for doctors’ on-the-fly, idiosyncratic, opaque cognitions, good or bad. Retrieving knowledge and matching it with patient data can occur reliably only if handled by tools external to the mind, before clinical judgment operates. Moreover, those tools avoid the waste inherent in requiring clinicians to reinvent the wheel for each patient, which is what happens when human minds perform information retrieval and processing that external tools could readily accomplish. That unnecessary burden on clinicians is not only wasteful but harmful, because it undermines their performance and their relationships with patients.

In short, habitual use of external tools should be an enforceable standard of care. There should be accountability for misplaced reliance on the minds of doctors. Human judgment has an essential role, but not as part of the informational supply chain—except in a limited, supplemental way, as discussed below.

Basic supply chain activities (knowledge retrieval and matching with patient data) are part of complex processes of care over time. Managing those processes is another part of the informational supply chain. It too requires external tools and standards of care for medical recordkeeping. Yet only fragments of the necessary standards have ever been recognized or implemented in paper or electronic records. The outcome is that current electronic record tools are in many ways dysfunctional (see Section 3.4).
2. NATURE OF THE PROBLEM

Tools external to the mind offer not just transparency but productivity. Traditional reliance on the human mind in medicine is like a carpenter working without power tools. Power tools for carpentry offer not just speed and capacity but reliability and precision not possible with hand tools. Much the same can be said of digital information tools for handling medical knowledge and patient data. Moreover, digital tools for recordkeeping can be designed to structure and guide and coordinate the functioning of multiple users. They include not only doctors but other medical practitioners, consumers/patients/families, and third parties.

It follows that software developers need a healthy skepticism of the guidance they receive from doctors on the tools to be developed. Developers and users need to think in terms of new, higher standards of care than doctors are trained to deliver. Those higher standards must inform the design and use of the software tools to be built. The tools and standards are the subject of Part II of this book.

Skepticism of doctors is warranted because medicine’s doctor-centric culture is anomalous. Unlike medicine, most fields in the domains of science and commerce have, over centuries, evolved away from reliance on opaque expert judgment.¹⁶ The vulnerabilities of human judgment, and the importance of moving from subjective to objective knowledge, were recognized long ago in philosophy and psychology (see Chapter 6). Now, with digital information tools, the doctor’s traditional role is a greater anomaly than ever. Until we face that reality, medical practice will continue to lack the rigor of scientific practice. And without that rigor, medicine’s humanitarian ideals are hollow.

2.2 DENIAL OF THE PROBLEM

Four centuries ago Francis Bacon (see Note 12 and Section 6.1) recognized how human judgment naturally tends to misfire. Beginning a half century ago, that issue became the focus of research in cognitive psychology and then behavioral economics. In the late 1970s, LLW became aware of this psychology literature, discussing it in his writings, including a key 1981 article¹⁷ and his 1991 book.¹⁸ Within the past three decades, doctors belatedly started paying attention to the psychology literature. Now clinicians regularly use terms from cognitive psychology such as heuristics, confirmation bias, recency bias, anchoring, premature closure, and the like—labels for the various ways that human judgment goes wrong.

¹⁶ See Medicine in Denial (Note 4), Part V, especially pp. 106–112 and 120–129.
But LLW diverged sharply from other doctors in the conclusions he drew. LLW concluded that cognitive psychology pointed in the same direction his work was headed. We cannot fully control how our innate tendencies compromise our judgment, but we can control how judgment is informed. The informed judgment of an ordinary mind may be superior to the uninformed judgment of a genius. So LLW found that we must bypass the human mind, replacing it with external tools, for the first stage of decision making—assembly of information(as explained in opening of Section 2.1). Our current reliance on the human mind for the first stage, where the informational supply chain operates, will come to seem as primitive as bloodletting.

In contrast, doctors conceive human judgment as if they can somehow learn to overcome its innate vulnerabilities. They are educated to rely on their own recall and reasoning powers to assemble the information they need. They are socialized to believe that “proficiency in clinical reasoning … is … the clinician’s quintessential competency.”\(^{19}\) So now they have added cognitive psychology to their reasoning powers. Faith in the human mind thus remains deeply embedded in the culture of medicine.\(^{20}\)

Dr. Sherwin Nuland articulated that faith, describing an ideal of intellectual virtuosity:

> To understand pathophysiology is to hold the key to diagnosis, without which there can be no cure. The quest of every doctor in approaching serious disease is to make the diagnosis and to design and carry out the specific cure. This quest I call The Riddle, and I capitalize it so there will be no mistaking its dominance over every other consideration. The satisfaction of solving The Riddle is its own reward, and the fuel that drives the clinical engines of medicine’s most highly trained specialists. It is every doctor’s measure of his own abilities; it is the most important ingredient in his professional self-image. … Our most rewarding moments of healing derive not from the works of our hearts but from those of our intellects—it is there that the passion is most intense.\(^{21}\)

Relying on personal cognition to solve The Riddle is a false ideal. The falsity is that the ideal promises more than the mind can reliably deliver in real-world practice conditions. Not only does this ideal cause enormous medical and economic harm—it also contributes to toxic stress and burnout for clinicians. Beyond that, the ideal fosters harmful reward systems and blocks key regulatory and market reforms. Medicine’s culture of denial is thereby perpetuated.

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\(^{19}\) National Academies of Sciences, Engineering, and Medicine. 2015. Improving Diagnosis in Health Care. Washington, DC: The National Academies Press, p. 53. [https://doi.org/10.17226/21794]. This same report observed that “clinical reasoning processes are difficult to assess because they occur in clinicians’ minds and are not typically documented” in medical records (p. 94). It follows that “doctors’ quintessential competency” is inherently resistant to scrutiny and continuous improvement by market and regulatory forces—a conclusion that the report did not articulate, which further evidences a state of denial.


A useful comparison is the culture of software development. Developers initially resisted the use of debugging tools, believing them to be merely a crutch that capable people should not need. But it rapidly became apparent that even the best developers needed these tools to cope with the complexities they faced. Use of the tools thus became standard practice in the software industry. In contrast, the medical profession has yet to establish comparable practices for medical decision making. This is true even with tech-savvy younger clinicians. Although they commonly use EHRs and clinical decision support software, they have never been subjected to the disciplined standards implemented in LLW’s health record and CDS tools.

The persisting culture of denial is evident from “Lost in Thought,” a 2017 *New England Journal of Medicine* (NEJM) article. The authors lucidly describe how information overload has escalated in recent years. Yet their article still displays denial of a simple reality—that medicine’s complexity overtook the human mind long ago. The authors state, for example, “The complexity of medicine now exceeds the capacity of the human mind” (emphasis added). This is rather like saying, “The demands of transportation now exceed the capacity of horse–powered vehicles.”

The authors similarly misstep in stating, “computers will tomorrow be able to process and synthesize data in ways we never could do ourselves” (emphasis added). Again, the reality is that computers have long had greater capacity than the human mind to “process and synthesize” data and knowledge in certain basic ways. This does not mean that computers can replicate the human mind—far from it. It means only that computers far exceed the human mind in reliability, speed, capacity, and precision when exhaustively performing determinate, definable tasks for purposes of information retrieval and processing. See Section 3.3.4.1.

The authors rightly point to recent advances in computer algorithms, machine learning, and data science, which enable new tools for pattern recognition and other indeterminate tasks. These tools are generating new clinical insights and approaches never before possible. But that focus neglects simpler capabilities that computers long since made possible. This neglect is part of medicine’s culture of denial.

A key reason for such denial, not specific to medicine, has been stated by the cognitive psychologist Robyn Dawes:

> The greatest obstacle to using [external aids] may be the difficulty of convincing ourselves that we should take precautions against ourselves … . Most of us … seek to maximize our flexibility of judgment (and power). The idea that a self-imposed

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23 “Medical knowledge is expanding rapidly, with a widening array of therapies and diagnostics fueled by advances in immunology, genetics, and systems biology. Patients are older, with more coexisting illnesses and more medications. They see more specialists and undergo more diagnostic testing, which leads to exponential accumulation of electronic health record (EHR) data. Every patient is now a ‘big data’ challenge, with vast amounts of information on past trajectories and current states.”

external constraint on action can actually enhance our freedom by releasing us from predictable and undesirable internal constraints is not a popular one. ... The idea that such internal constraints can be cognitive, as well as emotional, is even less palatable.25

Another part of that culture of denial is rationalizing outright misdeeds, notwithstanding the serious harm they may cause. Misdeeds are committed by doctors and other elites in the health domain, just as corporate executives commit misdeeds in the business world. But these “familiar villains ... are not the fundamental problem,” argues Dr. Robert Pearl. “They’re what we call in medical practice “opportunistic infections,” problems that turn up in the context of other diseases. Ridding the system of their misdeeds is not the ultimate solution. It won’t significantly change the underlying pathology.”26 The underlying pathology involves imposing unbearable cognitive burdens on doctors while leaving them unconstrained by a system of accountability.

Dr. Pearl goes on to discuss classic research in psychology, showing

... that our environment has a far greater impact on our actions than our upbringing or personal beliefs. ... context—the circumstances we find ourselves in, the instructions we are given, the threats made against us, and the rewards we are offered—can and often do shift our perceptions of reality without our even recognizing that a shift has happened. Context has a profound impact on what we see, hear and feel. It has the power to change our behavior.27

Part of the context of medical practice is the absence of protective tools and standards external to the mind. This context is rooted in medical education and licensure for doctors.28 The resulting environment fosters the “opportunistic infections” that Dr. Pearl speaks of—not just misdeeds by familiar villains, but constant missteps and shortfalls by everyone.

Denial is evident in an especially expensive arena for missteps—diagnostic testing procedures such as lab tests and imaging (CAT scans, MRIs, and others). Dr. George Lundberg has estimated that “about 80% of the tests carried out in the laboratories I oversaw in academic medical centers did not need to be done.” He also cites studies of arbitrary doctor ordering behavior and observes: “doctors’ examinations are now almost superseded by batteries of tests. When we look at why physicians order tests, we discover a wide variety of reasons, but few of them have anything to do

27 Ibid. After discussing the psychology literature on terrible behaviors in non-medical contexts, Dr. Pearl goes on to provide various examples from medicine (pp. 15–19).
28 See *Medicine in Denial* (Note 4), part VIII.
A 2016 article estimates, “30% of laboratory tests and 20% to 50% of ‘high tech’ radiologic imaging ordered by health care providers may not be of value to the patient.”

As to imaging technologies, they are used promiscuously, with little forethought. Indiscriminate use is driven in part by vendor marketing and fee-for-service incentives, but also by analytical sloppiness and lack of transparency in “clinical judgment.”

Beyond cost, the most obvious downside of imaging overuse is unnecessary radiation exposure for patients (depending on the technology involved). Other downsides involve clinicians not comprehending the fallibility of imaging results, not appreciating the enormous value of carefully selected, traditional data sources, and thereby becoming distanced from their patients and basic clinical data—not to mention losing (or never learning) important clinical skills.

The very multiplicity of diagnostic approaches (imaging alternatives, traditional testing, basic clinical observations, and new genomics and other testing at the molecular level) make it difficult to know or recall the tests relevant to a given problem situation or to decide what tests to use when. Equally difficult is comprehending all the data generated. Yet, these difficulties could be greatly diminished by basic CDS tools of the kind described in Chapter 8.

Denial also takes the form of vested interests defending the status quo. A prominent example took place with an important publication about failures of quality. In late 1994, the *Journal of the American Medical Association* (*JAMA*) accepted for publication an article by Dr. Lucian Leape, “Error in Medicine” (now considered a classic). But the *JAMA* editor, Dr. George Lundberg, was nervous. “I wanted to publish the paper for the profession but feared that I would lose my job if the public media hit hard on it.” So Dr. Lundberg included the article in a *JAMA* issue published during the holiday season in late December, knowing that “holiday issues are the least read and covered.” His tactic worked for a few weeks. Then “all hell broke loose. Hate mail began pouring in. I was accused of being on the side of the lawyers, of being a damned turncoat and traitor to the cause. An intensive lobbying campaign to get rid of me began” (but did not succeed at the time).

Meanwhile, 18 days before the date of the *JAMA* article, unbeknownst to Dr. Leape and Dr. Lundberg, a shocking medical error had taken place:

Betsy Lehman was a nationally recognized *Boston Globe* health columnist and mother of two young girls when she died of a massive overdose of chemotherapy while being...
treated for breast cancer at the Dana-Farber Cancer Institute on December 3, 1994. ... Betsy Lehman’s death catalyzed a movement to recognize that patient harm is not always caused by an individual clinician’s negligence. Rather, preventable medical harm can be viewed as a consequence of institutional systems and culture that had not kept pace with the complexities of modern health care. The challenge and the opportunity, then, would be to apply interventions developed by other complex, high-risk industries that had succeeded in achieving high levels of safety and reliability.  

Subsequent reporting of this incident combined with Dr. Leape’s JAMA article began to break through medicine’s culture of denial. Health care providers and the media increasingly recognized threats to patient safety and the need for “institutional systems and culture” changes to better cope with medicine’s escalating complexity. This was soon followed by increasing recognition of the human mind’s vulnerabilities as shown by cognitive psychology. But this recognition went only so far. It did not extend to re-thinking medicine’s occupational hierarchy with the minds of doctors at the top. On that front, denial goes deep. See Chapter 10.

A doctor-centric culture is naturally in denial that the doctor’s role is itself a problem. And every year, the culture receives an infusion of newly minted doctors who have been indoctrinated and licensed to perform the doctor’s role while being insulated from real competition. The effect is to block demand for solutions that might otherwise be rapidly embraced. The culture is thus self-reinforcing.

The culture of denial extends to patients. “Some people don’t want to hear about medical mistakes or don’t believe they can happen. One person says, ‘People put a lot of wishful thinking into their doctor and the system, and they don’t want to hear about what can go wrong.’” To hear what can go wrong is to hear “stories of people who have lost a part of themselves. That part may be a loved one, or a physical part of their body, or their identity and sense of self.” Hearing such stories hardly generates demand to hear more.

Denial also occurs in the health IT world, where software developers are expected to satisfy doctors or business executives or both. This environment has led to a health policy consensus that does not threaten the doctor-centric status quo. The consensus is that health IT specialists need to fix poor “interoperability” among different computer systems. This is indeed a major concern—without sufficient interoperability, electronic documents and data transmitted from one system to another are not “computable” by the receiving system and thus less easily usable by clinicians and

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34 Betsy Lehman Center for Patient Safety: The Financial and Human Cost of Medical Error ... and How Massachusetts Can Lead the Way on Patient Safety (June 2019), p. 5 (emphasis added). The medical error in Betsy Lehman’s case (a chemo overdose) was not an error of decision making (the subject of this book) but an error of execution (largely outside the scope of this book). See Section 1.1 and Note 3.

But many seem to hope that interoperability alone will somehow enable new, self-organizing solutions to medicine’s manifold problems. Such hopes for interoperability reflect denial of a broader and deeper problem—defective information processing by the human minds at both ends of interoperable information exchange, those who generate the information and those who request and receive it.

An example is doctors’ thoughtless ordering of diagnostic testing procedures such as lab tests and costly imaging, discussed above at Notes 29 and 28. Interoperability does help reduce duplication of these procedures by different providers, but that’s not enough to assure that ordering of these procedures or use of the results is rational.

As a further example, suppose a doctor uses interoperable medical record systems to request transmission of the problem list from some former doctor’s EHR. Interoperability might assure that the receiving record system properly adds this data transmission to the problem list in the receiving doctor’s record for the right patient. But the transmitted list must be reconciled with the problem list already maintained in the receiving record—an issue that interoperability does not address. Nor does it address a more fundamental issue: no one has assurance that either doctor’s problem list is complete or the problems carefully defined. The underlying failure is that standards of care for problem lists have yet to be generally accepted, much less enforced. Medicine persists in denial of the reality that enforcing those standards with corresponding tools is needed to “take precautions against ourselves.”

We recognize that unaided clinical judgment is sometimes remarkable, in terms of both analytic insight (thoughtfully applying first principles to novel situations) and intuition (pattern recognition at the unconscious level). This typically happens when well-trained, highly experienced, meticulous, intelligent clinicians bring their minds to bear on difficult cases, especially those that happen to match well with the clinician’s personal expertise. But clinicians of that caliber are costly. There will never be enough of them. Moreover, they tend to be so overburdened that they lack time to meticulously apply their expertise. In any event, they are still fallible, and matching their expertise with each patient’s needs is essentially random. Capable doctors are no substitute for a true system of care.

No system can capture all the human intangibles involved in caring for patients. But a well-conceived system would capture and disseminate and continuously improve much of what the best doctors—and other clinicians—collectively have to offer. Recall the wise physical therapist whose special knowledge rescued Dr. Topol from the nightmare with his orthopedist.

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36 What should be accepted as sufficient interoperability is a matter of debate. For a valuable recent discussion of the excruciating complexities involved, see Adler-Milstein, J. et al., Improving Interoperability By Moving From Perfection To Pragmatism, Health Affairs Blog, Jan. 13, 2021. DOI: 10.1377/hblog20210105.661344.

37 Dawes, Note 25.