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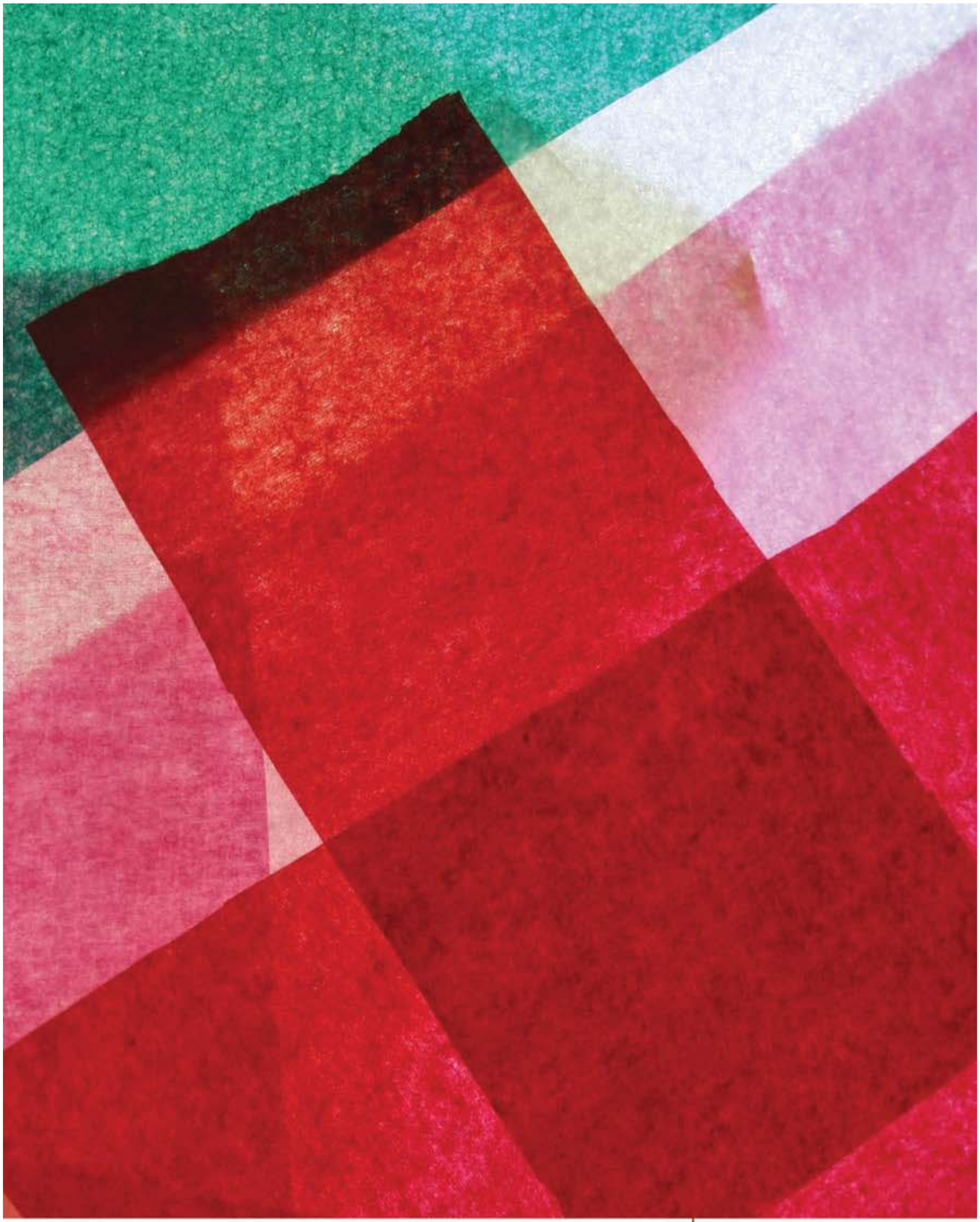

DESIGN FOR CARE

Innovating Healthcare Experience

by **PETER H. JONES** foreword by John Halamka, MD

Rosenfeld

DESIGN FOR CARE

INNOVATING HEALTHCARE EXPERIENCE

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Brooklyn, New York

Design for Care: Innovating Healthcare Experience

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DEDICATION

To Patricia, my own favorite writer, who kept me healthy while writing for three years

To my mother, Betsy, whose courage and insight in her recent passing from a rare cancer gives me empathy for the personhood of every patient

And to my father, Hayward, whose perpetual resilience shines through after surviving two cancers and living life well

HOW TO USE THIS BOOK

Design for Care fuses design practice, systems thinking, and practical healthcare research to help designers create innovative and effective responses to emerging and unforeseen problems. It covers design practices and methods for innovation in patient-centered healthcare services.

Design for Care offers best and next practices, and industrial-strength methods from practicing designers and design researchers in the field. Case studies illustrate current health design projects from leading firms, services, and institutions. Design methods and their applications illustrate how design makes a difference in healthcare today. My hope is that you will adapt the lessons, methods, and insights in this book to a product, organization, or service system in your own work.

Who Should Read This Book?

Design for Care was written for three audiences: designers and design researchers in healthcare fields; healthcare professionals and clinical practice leaders; and service, product, and innovation managers in companies serving healthcare.

Healthcare is complex, and learning even one vertical slice of a vast field is a significant undertaking. Learning and working across a second sector is a career challenge. Working effectively across sectors is unheard of. Designers, researchers, and practitioners across all three audiences typically work within a single sector—for a hospital, an information technology (IT) company, a medical products company, or a service provider. This book aims to inform design professionals across sectors (and design disciplines) and to contribute to their ability to design for the continuous life cycle of patient-centered service experiences. To ensure quality and manage costs across the whole system, a holistic view of healthcare and design is necessary.

For service designers, product, and innovation managers, I cover the most compelling information and service opportunities in healthcare with case studies and informed research. There are few guides for product managers in healthcare. Although this book does not specifically focus on product and project management, it weaves together many missing pieces overlooked in product and service innovation.

Most care providers work in one sector as well, deeply focused in a practice and an organization. This book helps inform clinical leaders of innovation methods, and encourages their understanding of the value of design thinking in health services, informatics, and organizational practice. Effective and ethical system design is not just making things work better for end users. Design leadership requires a collaboration at the practice level to contribute organizationally and systemically. I introduce health leaders to design and systems thinking approaches to help them innovate patient-centered service.

With the increased focus on improving the user experience in health websites and services, many designers new to the healthcare field will be learning about these users while on the job. *Design for Care* explores cases and methods for bettering human experience on both sides of the care experience, for both the patient and the care providers. It speaks to both new and experienced practitioners, and should be especially useful for those in transition between fields. For healthcare providers and those already managing projects "inside the system," adaptation of successful methods and patterns is encouraged between different cases and uses.

What's in This Book?

Part I: Rethinking Care and Its Consumers

The three chapters in Part I focus on the healthcare consumer. **Chapter 1: Design as Caregiving** presents a perspective on design as a way to provide care and addresses the problem of the fragmentation of design practice and engagement across the different healthcare sectors. **Chapter 2: Co-creating Care** focuses on design for health information seeking as a way of co-creating value in immediate care situations. **Chapter 3: Seeking Health** examines personal health decision making.

Part II: Rethinking Patients

The two chapters in Part II make the transition from health seeker in a consumer context to a patient-oriented perspective. **Chapter 4: Design for Patient Agency** presents agency and connectivity as alternative design factors to balance the traditional healthcare default perspective of *patiency*, which often treats patients as passive participants in their own care process. **Chapter 5: Patient-Centered Service Design** presents a systems approach to service design, and attempts to resolve differing concepts found across health service approaches. Human-centered approaches to service design focus on the primacy of patient experience, improving the touchpoints of care along the continuum of service responsibility.

Part III: Rethinking Care Systems

The four chapters in Part III look at care-centered service design in the complex systems of clinical healthcare and information-based work practices. **Chapter 6: Design at the Point of Care** is a service design approach to clinical decision making, medical education, and the four stages of clinical service design. The focus on medical education connects physician training, clinical work, and the care organization as designable services in a whole system. **Chapter 7: Designing Healthy Information Technology** looks at health IT as both innovation and system infrastructure at both the enterprise and practice levels. Lessons learned from electronic medical records and meaningful use provide a context for designing improved IT in clinical practice. **Chapter 8: Systemic Design for Healthcare Innovation** develops a systems thinking approach to designing service and organizational innovation in healthcare. **Chapter 9: Designing Healthcare Futures** presents methods and models for reimagining healthcare service from near- and long-term future perspectives, to enable strategic and socially responsive innovation.

What Comes with This Book?

You'll find additional content in this book's companion websites (http://designforcare.com and www.rosenfeldmedia.com/books/design-for-care/). Its diagrams and other illustrations are available under a Creative Commons license (when possible) for you to download and include in your own presentations. You can find these on Flickr at www.flickr.com/photos/rosenfeldmedia/sets/.

FREQUENTLY ASKED QUESTIONS

Who are the stakeholders for this book?

The book is written to ultimately help health seekers—the patients and people who seek information, health services, and care from today's fragmented healthcare systems. We all rely on healthcare at some point, for ourselves and those we care for; therefore, everyone can be a stakeholder.

"We" are the user experience and service designers in healthcare, care providers improving healthcare service, and product and project managers in health industries. We are the ones who will ultimately employ design in healthcare transformation. Other stakeholders include design and medical educators, management of hospitals and companies providing healthcare applications, and policy makers.

How do you resolve the different terminology used in different design disciplines?

Throughout the book, references are made to concepts and terms that have distinct meanings in their own fields. Because the book presents a convergence of design methods and human research across the sectors of healthcare, a collision of perspectives is to be expected. The design disciplines have variations in design practice, research methods, and artifacts that cannot be resolved in one book. Research and medicine are divided by discipline, method, and legacy.

The intention of this book is to raise crucial issues of which designers should be aware. The common bond among all these disciplines is the compelling requirement to solve complex problems in effective and sustainable ways. See page 12.

What is health seeking?

The health seeker is any person aware of his or her motivation to improve his or her health, whether sick or not. Health seeking is the natural pursuit of one's appropriate balance of well-being, the continuous moving toward what we call "normal" health. For some, normal is just not feeling any symptoms; for others, it may be achieving the physical performance of an Olympian. See page 15.

What is Health 2.0 and Medicine 2.0, and is there a difference?

These designations are applied to coherent trends in Internet-enabled IT in healthcare and medical innovation. The implication of the release number

"2.0" signals consensus among IT vendors and innovators that a technology regime shift is being organized, similar to Web 2.0. Health 2.0 ranges from the conceptual shift in the management of patient care using online technology, to healthcare IT start-ups and Web services for health management. Medicine 2.0 was inspired by the shift in IT and data resources from academic medicine and biomedical sciences. See page 100.

How are design and medicine alike?

These two fields are similar in many ways. Both are performed as an expert-informed skilled practice that is learned by doing. And both are informed by observation and feedback, by evidence of their beneficial effects. Both disciplines are motivated by a deep desire to help people manage and improve their lives, individually and culturally. Modern medicine is guided by scientific inquiry much more than design, but then designers and engineers in healthcare often have scientific backgrounds. In medicine, evidence of outcome is gathered by measures of health and mortality, controlled experiments, and validated in peer-reviewed research. For clinical practice and organizational change, however, validation is often based on the social proof of adoption in practice. Design interventions in healthcare are often assessed by the analysis of empirical evidence, but in few cases would experimental validation be appropriate for service or interaction design. Different evaluation methods are valid in their contexts, a proposition that may not yet be acceptable across healthcare fields. See Chapter 6.

Why do you say "There is no user in healthcare"?

The designation of "user" privileges the use of a particular system and its functions, which promotes a language of efficiency based on "user tasks." It biases design toward optimizing for a specific set of use cases based on a strong representation of a primary user of IT. Healthcare is a huge social system with many participants and roles dedicated toward the recovery of individual and social health. Few of these roles actually require IT for their performance. A user-centered perspective risks isolating a single aspect of use and interaction, when nearly everything involves more than one of the primary participants: consumers, patients, and clinicians. If we take an empathic view, it becomes clear that *users* and even *patients* are names of impersonal convenience. The term *health seeker* is proposed as an unbiased way of understanding the person seeking care as a motivated actor making sense of a complicated system to achieve health goals. See page 13.

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FOREWORD

In 2012, my wife and I were partners on a cancer journey. She was diagnosed with stage IIIA breast cancer in December 2011, and the cycles of chemotherapy, surgery, and radiation therapy filled the first seven months of 2012. As a clinician, I reviewed every order, every note, and every plan in her Beth Israel Deaconess online medical record. As a patient, she viewed everything written about her in her Beth Israel Deaconess PatientSite personal health record. I cannot imagine how care coordination, shared decision making, and communication would have been possible without ubiquitous patient–provider access to all the data, knowledge, and wisdom related to her care.

In *Design for Care*, Peter Jones outlines the critical role of design in the wellness care of the future, ensuring that every provider and patient is empowered with the services and tools they need for healthcare quality, safety, and efficiency. His thoughtful analysis includes all the core concepts that are driving the US healthcare IT stimulus—policies and technologies that engage the patient, eliminate disparities, protect privacy, and prevent avoidable harm.

When I mentioned that my wife's care required universal access to data, knowledge, and wisdom, what did I mean? *Data* includes the simple facts about her care—an appointment is made, a medication is given, a lab test has a result. *Information* is the interpretation of her data in a manner that is relevant to her care—her hematocrit at baseline is 39, and after chemotherapy it is 30. Her medications have caused side effects that may outweigh the benefits of the drug. *Wisdom* is applying decision support rules to her information that optimizes her care. Because her tumor is estrogen positive, progesterone positive, and HER2 negative, the best therapy is Cytoxan/Adriamycin/Taxol. Her accumulated radiation dose from all the mammograms, CT scans, and other studies is concerning, and thus ultrasound should be used when possible.

We clearly need better ways to move between data and information to knowledge and wisdom in today's complex healthcare world. This book illustrates these points and emphasizes the need for patients and providers to embrace a wise integration of technology into healthcare service.

Meaningful use and care improvements through universal adoption of electronic tools is just one of the major trends in the era of healthcare reform. "Patient-centered medical homes," "accountable care organizations," and "population health" are the new buzzwords. We need to rethink and actually design the new models of service, institutional practice, and patient engagement that ensure these new institutions become innovative alternatives to the care model, and don't simply replicate business as usual. The new concept is that care is no longer episodic, but continuous. Patients are engaged in their daily lives, and the emphasis is no longer on the treatment of illness but the preservation of wellness, maximizing functional status and care according to the preferences of the patient.

Peter Jones examines the kinds of innovations that are moving care away from academic health centers and into the community and homes. This trend is essential—healthcare in the United States consumes 17% of the gross domestic product. It is a poor value, with significant cost and less than stellar outcomes. To bend the cost curve and create high-value care, it is wise to follow the recommendations outlined in this book. Embrace technology, but design it well and consider its future trajectory and how it affects safety and interaction with patients. Engage the patient and innovate in ways that focus on longitudinal wellness rather than episodic encounters for illness.

I am confident you will find this book a helpful road map to guide your own journey to improve health and healthcare.

—John Halamka, MD
Chief Information Officer,
Beth Israel Deaconess Medical Center, Boston

INTRODUCTION

Care, and healthcare, is about taking care of humanity. Health is personal and universal—it may be the one value everyone cares about. Healthcare is the most hands-on of professions and services, and yet is extremely technical. As the industry intensifies the adoption of digital and electronic technologies, deeply informed design of services and systems becomes a pressing and critical need. At the same time, healthcare design does not yet fit into the conventional clinical organization, and institutional practices have not established meaningful positions for design. However, considering the increasing role of technology, the risk of errors induced by poor design, and the complexity of healthcare itself, designers from specialized disciplines should play critical roles in all technology decisions.

Healthcare in the United States is a mess. Technically, a "mess" is a complex set of problems with inextricable interdependencies. The overall system of healthcare—from services to payment to policy—has grown so complicated that a redesign of its components would not change the system substantially. New design thinking is called for, yet where do we start? Designers have no access to the system levers, and most of our work today is aimed at making the components run better and safer.

Healthcare has always organized itself around the patient encounter. Each human being with a healthcare need must be engaged in person and with respect to his or her unique biological and environmental circumstances. Healthcare services are designed to manage the flow of people from need to outcome, generally one at a time, according to the encounter formula. Services are aggregated into "big box" clinical solutions—hospitals and clinics—that serve as our "care malls" for full-service healthcare. Big box care is aggregated at the system level to regional and payer networks.

Healthcare is changing rapidly, attended by the increasing complexity related to its information glut. Consumer access to highly credible health websites has irreversibly altered the traditional equation, changing once-passive patients into stakeholders in the healthcare business. Their awareness of and access to health information challenges the hegemony of institutional practice. But innovations in healthcare and open information are also balanced by the inherent risks of institutional care, its systemic risk aversion, and its regulatory environment. As healthcare services undergo constant change, do we know how the numerous information systems are cooperating, and how different views of patient data are shared? How will new information infrastructures, systems, and configurations affect practice? How will changes in practice affect patients?

One intention of this book is to enable better communication, understanding, and knowledge transfer between healthcare fields and work experiences. The chapters are organized to reflect the human health experience and to discuss issues at the points of interaction where people seek and receive healthcare.

Designers (in general) perform systematic problem solving to formulate better ways for humans to interact with technology and services. Many designers work on systemic "big box" problems such as process workflow, information displays, and wayfinding; or behind the scenes on medical devices, health IT, or Web interfaces. As in the field itself, few designers are able to contribute in more than one healthcare sector. Therefore, better understanding between sectors will enable us to design better end-to-end processes and whole systems. This book aims to create awareness across these segments and sectors by indexing representative issues and powerful methods from successful applications.

Design, in all its disciplines and methods, is finally emerging in new and influential roles in all types of healthcare services. Medicine is not, in practice, an online and digital field, but the rapid development of digital technologies in care delivery and education is drawing new designers into all healthcare sectors, from consumer websites to clinic design. *Design for Care* speaks to these designers and health professionals about how, where, and why their fields connect at the many points of care and service.

Designing for Care Experiences

Care is a powerful value, one we all take seriously. When a friend announces that he or she is taking time off from work to "take care of" a spouse or other family member, we understand the empathic response to a life-changing situation that takes priority over other values. Care is not just a response in the present. We project concern and hope into a shared future, and hold both memory and expectation for the cared for. Caring extends over time, unlike the immediate empathy needed to understand user experience, for example.

Yet caring is not just temporal, based on need, it is considered an enduring and authentic characteristic of a person. People take care of the others in their lives. Direct design implications are revealed in this observation. There may not always be a single "user" for health information and services. The single-user persona may need to be updated to a family scenario and the "best-friend search" use case. As some informatics researchers are now pointing out, the health-seeking experience is a multiparticipant, multiuser circle of care. It is often familial, and inherently and intimately social.

The verb *care* has acquired different meanings in different health and caring professions, and each profession related to health and human development may subscribe to a different definition and view of care. When settling these differences in meaning and not just discourse, the problem becomes ontological, a question of the reality of caring. This is not simply a conversion of meanings from one field to another. The very meaning of care and caring differs between providers (health practitioners) and between providers and recipients (patients). Design has not yet taken a clear stand in the matter of care. Perhaps we recognize that we cannot own the core when we ourselves still live and work at the periphery.

Philosopher Milton Mayeroff defined caring as acting on empathy, as being able to understand another's world as if you were that person. Caring requires knowing, trust, patience, humility, honesty, and the primacy of life's rhythms. According to Mayeroff, for caring to take place, "there must also be developmental change of the other as a result of what I do; I must actually help the other grow."[1]

How the Design Industry Must Change

Design has never been a serious contender for service as a caring profession. Across the full range of design fields, from communications and visual design to fashion and product design, designers are recruited to enhance campaigns that oppose values of caring. The recent vogue of design thinking does nothing to alter the technological affinity of the design professions. Design, more than the sciences even, has been steered toward a values-neutral practice of creative product and service development. There are no core ethics of design thinking, no inherent barriers of duty or conscience that keep designers from switching from healthcare "content" to beverage industry clients. Design thinking's crucial test is not merely surviving the merger of design and business with its soul intact, but in transforming organizational practices by continually repositioning real human beings in the center of design and service management decisions.

Learning from empathy is a first step toward caring, by allowing us to understand how other people experience the situations we are committed to improving. Given the interest in emotional design and empathic research methods in recent years, this step may not be in doubt. Responding as professionals to the call of caring marks the current bright line between the caring professions and supporting disciplines, such as design, IT, and human research, that are not called to patient care.

The call to care suggests a possible primary design position. Caring confronts us directly with a question of human valuing that we—designers and health professionals—may believe we are already fulfilling in some way. As with all values, the way it is understood can and will differ significantly between people.

We might start from the assumption that, as designers, we do not know (yet) how the values of care are lived and acted upon. We must interpret without (yet) being expert. *Design for Care* presents scenarios for designers to consider the human and social value of caring, the various ways care shows up in health seeking and health making, and the systemic role of care.

Finding Your Place in the Story

Healthcare is a massively complex system that deals with at least two irreducible sources of complexity: the institutional (distributed provider systems and hospitals) and the personal (the biological and social setting of the human body). Furthermore, these realms cannot be isolated, because the purpose of the institution is to serve individuals. An infinite variety of possible problems arise in the relationships between these two spheres of purposeful behavior. The opportunities for design to have an impact are everywhere, from effective comprehension of materials and wayfinding to improving education and information resources. Healthcare systems provide designers a constant, endless challenge in helping clinicians and patients navigate complex situations. Where is your place in the larger story?

Design (of all disciplines) is not yet showing its impact in health services. For the most part, designers remain on the sidelines in institutions and practice, unsure of where and how to step in to make a difference. Compounding this position is the difficulty that designers are often not given the latitude to practice creatively and meaningfully in healthcare institutions. The medical and institutional care traditions do not offer a ready berth for design, and our traditional positions have little systemic impact if employed without strategic intent. Until we prove to be valuable contributing members of the care team, we risk being seen as specialists and even marginal players in the story of care.

User experience won over every other application field, after a decade or more of commitment to business and IT. But change and innovation happen differently in healthcare than in other sectors—the risks are higher, the funding is regulated, and the "users" are not paying (or complaining) directly. IT is not the front line of patient care. If we are not working together with a systemic strategy, we may be contributing to the fragmentation of the field by optimizing narrow bands of practice that sustain old habits. We have no way of knowing without reaching agreement on a common design language that aligns the levels of care, the organization, and its system.

"Designing for care" has several meanings. Each chapter in this book focuses on a different aspect of human-centered design for care practice, identifying design approaches for the activity. A critical opportunity for designers is to transform the value available at the front lines of healthcare practice. Healthcare is changing rapidly, dramatically, and somewhat chaotically, as any change pushes ripple effects through the complex system. Healthcare reform, creating better care services around the patient experience, and humanizing IT are opportunities for design to contribute as a field.

PART I

Rethinking Care and Its Consumers

The rapid diffusion of hundreds of Web resources for health purposes has created a gap between information quality and user expectations. Consumers can now pursue their own research into health issues by searching the vast collections of consumer-oriented health information on the Web. They cannot be expected to understand the complexity of health issues, but do expect health information to be truthful. Yet more information does not yield better information. In fact, quite the opposite may be true. Part I focuses on the health-seeking activities of the healthcare consumer.

Health-Seeking Experiences

A person's health seeking is a continuous process of taking steps toward better health—before, during, and after any type of encounter with traditional healthcare service. Health seeking, as with other human motivations such as pleasure seeking or status seeking, represents an individual journey, in this case toward relatively better health. For a very healthy person, the ideal of perfect fitness may be an authentic health-seeking journey. For a cancer sufferer, relative health may be a matter of surviving treatment and fighting for gains in remission. These are health-seeking behaviors with quite different personal struggles, achievements, care needs, and support requirements. Seeking health covers a set of fundamental human needs. Every person is a health seeker in their own way, even if not a "patient" or a fitness buff.

A person's progress in health seeking is measured by points of feedback sensed from their everyday lives and received from professionals. People with chronic health concerns such as diabetes need continuous feedback. Those in "normal" health may find health feedback only marginally helpful. (For example, I may measure my workout progress, but I weigh myself on a scale maybe only twice a year.)

People also have different timeframes of health feedback. Think of the health-seeking journey as occurring over a lifetime, a continuity that proceeds through youth, adulthood, and older age. The individual and his or her immediate circle of care (spouse or partner, family, friends) are co–health seekers in many ways (though never "co-patients"). Everyone travels this journey together with parents, children, friends. The health journey includes a lifetime of other encounters and experiences that can enhance responsible healthy behaviors.

Yet healthcare providers have little insight into the continuous health-seeking journey. Although doctors may see dozens of individual "cases" on any given day, they have little time and usually no formal payment mechanism to follow an individual's health journey after a professional medical encounter. Their brief touchpoint is but one opportunity for improving an individual's health among dozens in a given day. There are certainly different types of practices, and some do track and manage longitudinal health outcomes. Yet an individual's health seeking is his or her own journey.

For more than a century, Western healthcare has treated people as patients, as passengers in a complicated and mysterious train on rails governed by seemingly unknowable biological forces. Any degree of pathology is relative to a normal ("healthy") standard and to a person's own experience, which may be unknowably limited and limiting. The normal condition is one of relatively balanced health in a constant motion toward homeostasis. When facing conditions that require medical intervention, people are motivated to seek health as an end in itself, as well as supporting all other goals in life.

Clinicians might find the current mandate to improve the patient experience as the perfect entry point to engage design practices as full partners in providing better care. Designers have the advantage of not being doctors—they are not professionally bound to the same legal responsibility to treat people *only* as patients, subject to clinical intervention. By repositioning the individual health seeker as a deciding and knowing agent of his or her own experience, health services can be designed to facilitate a whole-person approach to health. Improving patient experiences is the just the first step in a cultural and historical shift. A person is a patient for a limited period, but the experience of seeking health is a continuous process throughout life. Care providers and resources can help restore natural and supported functions of life.

Health seeking is not just a "journey to normal" because there is no final state of health. People live with multiple conditions of relative health in a balancing system. Measures and indicators of "healthy" are not optimized; they are better or worse compared to an individual's own baselines. People may lose weight by dieting but not improve cholesterol levels; they may recover from a viral infection but have a cough for weeks. No health measures are static, and the numbers of good measures are not as "objectively healthy" as people might think.

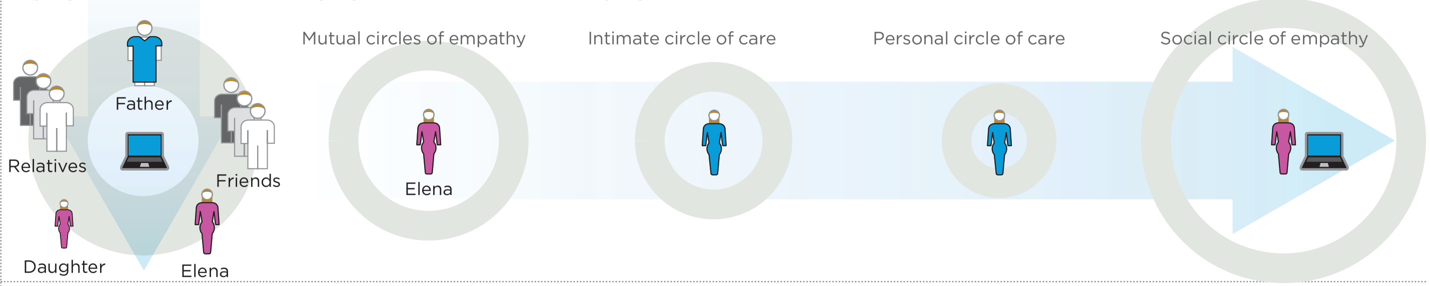
Health journeys are *self-educating*—people evolve as they learn in stages of struggle, understanding, acceptance, and self-management. Health seeking is an evolutionary act of self-discovery, of sustainable improvements of behavior and experience that claim a personal stake in one's present satisfaction and future thriving.

The Health Seeker in Context

Beginning in Chapter 2, each chapter advances the scenario of a persona character, Elena, as she navigates complex health issues and pursues health outcomes over a series of setbacks and healthcare encounters. Her story serves as a baseline narrative to observe human responses to events, touchpoints, and likely decisions for care services. This health-seeking journey is loosely aligned with each chapter's content.

Health Seeking | Elena’s Journey

Situation	Caregiving 2 Years	Health Incident 2 Months	Diagnosis 2 Weeks	Treatment 2 Days	Living With Future
Information Resources	Consumer websites (Everyday Health, WebMD, Mayo Clinic)	Consumer websites, physician references	Consumer/professional resources (Medscape, HealthKnowledge)	Physician references	Health communities and personal social media
Touchpoints	Web, e-mail, workplace, home	Doctor’s office, Web, home Mutual circles of empathy	Specialist center, Web, home Intimate circle of care	Hospital, Web, home Personal circle of care	Web, home, e-mail Social circle of empathy
Journey	Seeking family health	Focus on personal health	Significant health concern	Seeking treatment	Helping others
Motive	Harmonious home and family	Sustain personal productivity	Recover health to at least former level	Best survival outcome	Share lessons learned
Chapter	2	3 4	6	7 8	9



Elena's scenario is not unlike a service journey map, except from the perspective of the health seeker, whose shifts in role and identity are based on health condition and goals. The journey map is based on a typical method for portraying the navigation of health seeking and clinical encounters (Figure I.1). Notice that over the entire span of roughly two years, significant health events happen in brief intervals of two months or less, with significant impact on future health and life outcomes.

Physiological measures indicating relative health are not shown on this timeline, but are suggested in other contexts to indicate correspondences between measures, acute incidents, and recovery. Design goals for the health seeker in this journey view might include:

- Connecting Elena to her immediate family to support her caregiver role (through electronic media, printed artifacts such as notes and reminders, and multisensory media).
- Giving her direct support to inform and manage her family's health needs, and connecting her with any services for which she has regular touchpoints.
- Providing her with emotional support as a caregiver to help sustain her motivation and keep track of health progress.
- Enabling her to easily update and track her interactions with clinical services and healthcare systems.

Part I, with its focus on consumer contexts, describes Elena's personal sphere as she seeks information, support, and resources from her immediate circle of family and community to meet her health goals. Part II describes her choices and outcomes experienced as a healthcare patient, and Part III shows her as a participant in the healthcare system.

FIGURE I.1
A health seeker's journey.

CHAPTER 1

Design as Caregiving

Can Healthcare Innovate Itself?

Whether you choose a story from your own life experience or from that of a friend or family member, or just Google "healthcare horror stories," the problems in healthcare today are clear and all too common. Urban emergency rooms are overflowing, medical devices have misleading interfaces that lead to errors, doctors order too many expensive and unnecessary tests, and medical records are confusing and unreadable. Private health insurance is complex, expensive, and fragmented, sometimes resulting in crippling financial difficulties. Pharmaceutical wonder drugs are pulled off the market after a few years as emerging harmful side effects show up. Healthcare has optimized every function in the system, but the system grows more complex as these functions overlap and compete. As Harvard management professor Rosabeth Moss Kanter recently wrote,

> Supposedly, everyone working in health care wants the same thing: to help people get and stay healthy. . . . The problem is that everyone can have a different view of the meaning of getting and staying healthy. Lack of consensus among players in a complex system is one of the biggest barriers to innovation. One subgroup's innovation is another subgroup's loss of control.[1]

Because healthcare problems are so complicated and messy, they cannot easily be untangled once they appear. Mike McCallister, CEO of insurance provider Humana, described the US healthcare sector as a gigantic mix of varied players that is "broken, but can be fixed. We don't actually have a healthcare system. We have a lot of different systems that are glued together."[2] Alex Jadad, founder of Toronto's Centre for Global eHealth Innovation, calls for immediate innovation in person-centered healthcare and collaborative development of IT to help Canada's high-functioning but stressed healthcare system: "This technology can help us transcend our cognitive, physical, institutional, geographical, cultural, linguistic, and historical boundaries. Or it can contribute to our extinction."[3]

Designing for care brings a holistic and systemic design perspective to the complex problems of healthcare. We are already improving services by designing better artifacts, communications, and environments. What remains missing is the mindset of professional care in designing for people, practitioners, and societies. Like clinicians, designers in the health field can take responsibility for helping people and societies become healthier in all aspects of living.

Technology Will Not Save Healthcare

Technologists advocate for disruptive innovation in healthcare, a call that envisions radical change for consumers as well as the largest institutions. The two targets of disruption are typically hospital-based institutional healthcare and the medical care model itself. The cure is envisioned to be a future of low-cost networked computer technology owned by consumers, not clinicians. A kit can be imagined consisting of embedded sensors connected to a handset, cloud-based data collection with instant analytics, and continuous-learning algorithms that diagnose individual conditions based on rapid sensor tests and genetic analysis. Possible new treatments are not described clearly, but still an accountable person will be needed to administer injections and judge the appropriate therapy and medications. A problem with such scenarios is that they project a future driven by technological determinism—because it can be done, it will be done.

The decentralized "future of medicine" scenarios articulate radical changes in technology but fail to address changes in cultural meaning. As pictured by Silicon Valley, healthcare could be decentralized and fragmented into defined care streams that the "user" (the patient) would navigate as self-service interfaces. In effect, these scenarios shift care decisions to "consumers" who might be existentially vulnerable to their own poor decisions (as well as to new types of usability risks). If patients are forced by economic changes to trust a technology instead of a physician, the ethics of "brave new healthcare" scenarios become socially problematic.

The technologically determined scenarios suggest a sociological change more radical than any other system designed in human society. Healthcare is the world's largest employment base, with national health systems among the largest employers in their respective countries. Such a disruption would ignore the sociotechnical foundation of healthcare that underlies practice, education, policy, employment, and the very meaning of care. It risks replacing medicine with a new corporate system devoid of human socioculture or caring, treating diseases as functional states mediated by robots. Although the enabling technologies can and will be developed, their implementation will look very little like the visions of computational "personalized" medicine imagined by technological utopians (and investors standing to benefit).

Another focus of disruptive change is the US private insurance model, which turns on policy innovation and not technology. Innovation in insurance-managed payments to guarantee equitable care services might make the single largest difference in people's everyday lives. If patients did not have to worry about going bankrupt to pay for the noncovered costs for healthcare services, they would view their health and self-care differently. Although not a perfect policy for either citizens or providers, the Affordable Care Act (Obamacare) established a new framework for policy innovation to occur, to meet the goals of covering uninsured Americans and managing aggregate costs. If the system were not based on profit-seeking business models, innovative new care practices would be designed and implemented. In the United States today, however, with multiple layers of cost accounting and payment review, stakeholders distrust one another, and patients lose out. Unfortunately, the ultimate fix is not technological but political, the results of policy innovation to ensure universal coverage and appropriate technology support.

Major policy changes will be necessary to encourage the risk-averse health industry to accept system-wide innovation. Today, healthcare systems and their management are the biggest barriers to meaningful innovation, as they have so much to lose in a paradigmatic shift.

Even the most radical breakthrough technologies often demonstrate only incremental improvements to the service and experience of care. As new clinical services are developed around emerging medical technologies, the form and function of current practice will change only modestly, perhaps not even perceptibly to patients. Due to culture, risk, payment, generally accepted practices, and other systemic factors, technological change is often not leveraged as an opportunity to change policy and practice.

Both of these envisioned "disruptions" shift profits and costs, winners and losers. Only the disruption of the insurance industry guarantees a beneficial cost shift to consumers in the near term. There are no guarantees that technological disruption will pass end savings to consumers. Though low-cost systems can be developed, there are no social provisions for regulating the resulting business models and new corporate entities that could manage health technologies. If the pharmaceutical industry (which is rarely mentioned as a target for disruption) cannot innovate new business models, it seems misguided to believe that emerging technologies slated to replace physicians will be priced any differently than pharmaceutical products.

In a market-based system, disruptive innovations create real competitive value by making long-established services obsolete. But even if many healthcare services are profit-based, should innovation best be envisioned as enabling a competitive economic outcome? How does disruption help healthcare? Human lives are at stake, not merely profits.

Innovation of Human-Centered Care Systems

All-out radical technological change is not the only way to create value for health seekers and reduce exponential costs. A better way to innovate might be found in designing human-centered care systems.

The human-centered design of healthcare has never been more necessary. Leading innovation provocateur Don Norman, with designer and author Roberto Verganti, proposed a concept and solution to the paradox of "merely" incremental innovation from human-centered design.[4] They position radical and incremental *technology innovation* against radical and incremental *innovation of meaning*. The position emerged from Norman's observation that only new technologies were found to trigger radical change. And yes, he found that human-centered design research (studying users in their native habitat) rarely, if ever, led to disruptive innovation. Though essential to incremental improvements in technological systems from airplanes to software, design research fails to find breakthroughs, due in part to the fact that radical changes cannot be extrapolated from observing practice. Further, user evidence tends to reinforce the very practices being studied, as user behavior is defined by its goals and productivity, not the experimentation that might lead to completely new practices.

The shift to cultural and practice innovation is found in the other half of the Norman-Verganti equation: the radical innovation of meaning. What Verganti calls design-led innovation involves redefining the socially recognized meaning of technology or a practice. Sociotechnical practices in healthcare may be reframed (without radically changing technologies) to shift the social purpose. The accountable care organization (ACO) model promoted by new US legislation carries the seeds of new value propositions that have yet to be tested. The essential meaning change is that of localized care centers with more attention to patient life needs to reduce readmittances. Although ACOs might become radically patient-centered, perhaps the most significant value will emerge in the social meaning change, with new types of care practices being envisioned that reinvent the relationship of providers and health seekers. These practices and their business models offer fertile ground for the new types of designers being trained in socially aware innovation.

Disruptive innovations that we see in other industries may have less of a role in healthcare, even though the opportunities for new technology are clearly present. Healthcare facilities are not early adopters. New software, devices, and systems take time to learn and socialize, and the investment of professional time and budget in training and ramp-up is quite expensive. The expense of these social costs can outweigh the benefit of adoption. For example, desktop computers took years to infiltrate hospitals, and by the time they were ubiquitous in the clinic, they had become common in homes. Minimal training was necessary because the technology was already pervasive. The use of mobile devices is following the same late adopter cycle, allowing for a more natural (less forced) introduction of new devices into high-performance, high-risk clinical environments.

Even information systems require mammoth projects for system-wide implementation. The *adoption* of new services and systems is by no means a given. Breakthrough medical technologies are also not adopted immediately by institutions. New technologies, devices, and therapies require extensive review and evaluation through animal and human trials, developmental testing, and regulatory approvals. Changes in practice may take months or even years to filter through an institution or system diffused across regions and affiliation. For example, the truly disruptive da Vinci robotic surgery system did not change medical practice as we know it. It allows skilled surgeons to operate on remote and special-case patients who were previously underserved. Da Vinci signals the start of a new trend that might increase capital costs (as hospitals must all acquire it to compete) as well as lower surgery costs, potentially having a democratizing effect of equalizing the quality of routine surgeries across regions.

Da Vinci is a disruptive technology that shows significant yet incremental effects. Organizations absorb the new system into the current business model. For now at least, hospitals remain big box clinical institutions. Technology and product design have only incremental effects on the patient experience. Patients must still be prepped and undergo an invasive procedure, yet now with the much greater convenience of being able to show up at a community-based clinic in the healthcare network. Change is difficult for doctors, and adaptation to changes can be discomforting for patients.

This perspective of redesigning existing practices explodes one of the most treasured myths of innovation. Many authors suggest that disruptive interventions have the highest impact and are therefore the aim of innovation. Innovation theories celebrate the value of "disruptive" innovation as the most competitive form of innovation. Yet what are the purposes of disruptive healthcare innovation? To improve efficiencies, costs, practices, or patient experiences?

We might reframe the purposes of disruptive innovation in institutional healthcare based on the experience with platforms and devices. The da Vinci system performs operative functions that surgical teams can understand and integrate within well-defined routines. It doesn't disrupt the function of surgery, but rather the way routine operations are physically performed. Information technologies tend to disrupt clinical work in ways that may *reduce* efficiency of performance. New systems require training and ramp-up time (away from patients). Additional time must be allocated for electronic entries for the purported benefit of administration, not patients.

Consider the societal value of an innovation from the perspective of those most affected by the results. Does a simple value analysis show benefit to all direct stakeholders? Will health seekers benefit from the change?

Are There Users of Care?

Healthcare is a complicated business, and can be a complicated context for design. Multiple *stakeholders* (from consumers and patients to clinical staff, administrators, and insurers) interact with multiple *services* (from primary care to academic institutional networks) in multiple *sectors* (from clinical practice to insurance and government). Traditional user-centered design practices are insufficiently powerful to solve problems at this level of complexity. We can easily and mistakenly design a perfect product or service for "our users," yet remain disconnected from the other systems and stakeholders the service may affect.

In health contexts, the risks to health and the effects on practice are always considered. Healthcare environments require the use of far more rigorous design and development methods than the contemporary trend in user experience (UX) and service design. Involving both significant financial and human life impacts, investment decisions are based on evidence, with a strong organizational bias toward statistical evidence.

Designers face a recurring challenge in every healthcare project—to envision the scope for service sufficient to meet future needs and growing complexity. We design for situations that have multiple interacting workflows, poor integration, layers of legacy infrastructure, and highly dispersed applications. These legacies constrain the ability to design services across departments, institutions, or at any level we consider as "the system."

Healthcare is a large-scale distributed system dedicated to serving individuals with health needs but who are not the paying customer. This is a classic dilemma of service and experience design: the patient (the end user) has little decision-making power but a life-critical need; the institutional customer (who pays) has significant power but little understanding of need.

Patients and practitioners are changing the balance of power through improved transparency and access to information. But these social, human, and information interactions magnify the technical complexities because they introduce new uncertainties to decisions and transactions.

UX design advocates understanding and designing for the optimal user interaction. It often supposes an interactive product with specified uses in a work (or point of care) context. User-centered design has served as a sufficiently powerful methodology for a generation, and health informatics and technologies have improved significantly, if incrementally. A generation of experience designers has been trained to represent the interests and needs of users, and we have institutionalized "the user" as shorthand for design (user-centered) and usability (user-friendly). However, there is no single user in healthcare, and the convention of referring to users may be misleading in the context of care.

In healthcare practice and design, the vocabulary and perception of the human subject is dominated by three primary frames: user, patient, and consumer. All three designations are passive, objectified representations that constrain a person's significance as a "health actor" to a transactional role. These roles designate people as users of products (user), clients of institutions (patient), or recipients of services (consumer). If we examine critically the ways in which designers participate in projects, advise on the design of IT and systems, and select research methods, the attendant design values of these roles show up in dialogue and decision making.

A user-centered service design perspective leads us to focus on the *patient,* the recipient of care and the human actor most vulnerable to "disruptive" technology impacts. By focusing on patient outcomes and processes, design decisions are unassailable and credible. Presenting a case based on real patient needs and experience can move a room of mixed opinions to consensus agreement.

The patient-centered perspective has become a significant movement in medical practice, and is central to healthcare service design. Yet people do not see themselves as patients; it is not a persistent role or identity that people choose. The patient identity is not persistent across the continuous experience of health seeking. Also, as readily observed in healthcare institutions, not all service problems involve patient behavior. The patient is not central to every function in healthcare systems and organizations.

We have also been conditioned through years of professionalization to accept a medical view of wellness and sickness, a view in which people show up as patients within a largely corporate healthcare system. As designers, we unwittingly follow this model when we adopt a conventional approach to workflow and personas. We even risk this perspective when making claims for "improving the patient experience." That is, we are still framing a clinical encounter as a "patient experience," making the inevitable more comfortable or efficient. We risk representing a supply-side (vendor-oriented) perspective, which only simulates empathy or care, regardless of the humanizing intent of the methods. If not working within a clinical organization, we may not be able to speak with real patients in actual care situations. Designers and health professionals need better methods for understanding experience and making design claims with often limited access and data.

A market-based viewpoint defines people as customers and receivers of health or information services that others produce and supply. The *consumer* designation fixes our attention to a transactional service relationship inimical to the values of care. Critiquing the consumer persona or mindset frees up the capacity to innovate with fresh perspectives. Human health is not the result of a service transaction; rather, it flourishes in the context of care, drawing on personal, familial, professional, and community resources.

In a complex system such as healthcare, naming any persona as a *user* privileges just one role in the system. It also assumes something to use, and traditional modes of use are often not the case in healthcare. In care situations, everyone participates at some point in a human system of health seeking from which we produce care and support. By enlarging the scope of health seeking to view it as a social context of health seekers and caregivers, we expand beyond our narrow (and professional) point of view that wants to designate people as "users."

Each of these three frames (user, patient, consumer) has relevance in certain circumstances, and they are useful to indicate to designers the differences in identity and activity across the spectrum of health services. Yet real people do not experience themselves as these roles, especially in health situations.

We might actively replace the old mental models with a fresh perspective based on the *lived experience of health*. What should designing for care establish as the perspective for care-centered practices? To answer this, let's ask higher order questions: Why are people in the healthcare system? What motivates people who seek care and health?

The health seeker may not be a patient or even a consumer, but any person aware of her motivation to improve her health. A health seeker may be any person desiring better health for his own life circumstance, for a family member, or a friend. A family or community might seek health. It is not necessarily an individual experience. People do not always follow medical advice, take their prescriptions, or take the most rational steps when dealing with a disease condition. People make sense of their life concerns together with their specific questions when seeking health and health information. As such, health seeking is not just looking things up on Dr. Google. It is a process of organizing one's experience and trusted resources, including materials from the Web and advice from health professionals and family and friends, to address partially formed questions. If health seeking can be understood as a continuous lifelong process, a care-centered design orientation can span the different needs of patient, professional, and service, and help us define priorities for intervention and redesign.

A Caring Design Ethic

Caring design requires a change in meaning, as the design professions have no tradition of care practices. True care goes beyond the appreciative and participates with the personal feelings and social concerns shared by both patients and practitioners. Beyond the instrumental empathy "in order to" understand the user, care seeks to understand the senses and feelings of a person, as they really matter.

An honest, empathic interest expressed in care will be challenged by the typical organizational commitments of a designer's IT company or agency. When we use project management language to structure our product requirements and define our shared goals, we may fail to even acknowledge the other values calling for attention in a care situation. In healthcare, care design may then part ways with both the individualistic approach to creativity and the brutal efficiencies of project management in design execution.

The values and ideals promoted in a caring design ethic are drawn from the humane arts and sciences of health and medicine. These include empathic care, doing no harm, health for the whole person, and helping people live sustainable lives. Devoting a new focus of care in design practice requires an innovation of meaning for designers, and it may change our methods, tools, and engagements. The narrative for this next generation of humane design practice has yet to be formed. How will the meaning of value to clients, communities, and health seekers change?

Shifting Focus from Product to Person

New systems are not always the answer. Consider the cumulative impact of the thousands of cognitive interactions required of users for every new service, system, interface, device, or billing statement. Doctors are too busy to adopt more than a few essential services, and they often maintain older systems that are safely committed to memory, rather than invest time in learning a new system that may introduce transition risks and fail to improve care or costs. Patients may be confused by the sprawling range of Web services and competing arrays of redundant online health information.

Consider the many new products, interfaces, and tools for individual healthcare that may be innovative but have no accepted mandate. For example, personal health records (PHR), such as Microsoft HealthVault, have been available since 2007, but adoption has been hampered by the lack of basic usability, limited utility, and “understandability.” Most people do not yet understand the PHR and its possible value. Google ended the Google Health PHR in 2011 due to a lack of general acceptance and process (not just interface) usability. An application only used by individuals who *must* use it is not a basis for mass adoption.

Issues such as information privacy, caregiver accessibility, and care team collaboration are also significant design factors. Technical and usability concerns are also daunting impediments to acceptance and adoption. The early adopters of personal health technologies are people motivated to use these tools for daily needs, but patients living with significant health concerns may—due to age and multiple conditions—find it more difficult to learn and use these tools than people with less need for them.

The Case for Caring Design

Although each design discipline differs in its methods and targets, most designers work at understanding problems of human use of a thing or a system, and innovate to make effective changes that people desire. Since the dawn of medicine and physical care, people have designed artifacts to enhance practice, comfort, and communications. Nurses “designed” the Kardex documentation system, and medical librarians contributed to the formal design of medical charts. But until very recently, people trained as designers have largely been absent from the health professions, and very few programs educate designers in healthcare practices.

In the 1980s, first in architecture and then (much later) in device design human factors, specially trained designers began focusing on health applications. Human interface design for medical devices only improved after problems were reported with control interfaces in devices (such as drug infusion pumps) that had been designed by engineers with no user interface design training. With the recent explosion of informatics and health websites in the last decade, it would seem the entry point for service and experience design has finally arrived.

Design is not taught or (in practice) led from a caring perspective. Design is a creative practice that employs empathy as a method for designing better, more usable products and services. Empathy is a *temporary* caring, and becomes instrumental when invoked as a means to improving the design of things or services for sale. Although we may care about the impact of our design work, we do not usually follow and care for the lives of our users, or the patients affected by our systems. We may care about users and patients, but we are not called on to care about any particular person. How we might "care more" is a question that requires rethinking the role of design and human-centered research. The difference may entail moving from performing as contributing designers to coordinating patient-centered service projects. In these scenarios, the health outcomes of future patients are now at stake. Yet the imperative for innovation and service change means organizations will accept a higher level of creative and participatory design.

The Design Thinking Divide

Healthcare practice and institutions have no common voice, and few "whole system" advocates are followed. Ranking just after the prime directive of "help all and do no harm," institutions care about cost and risk. Because change incurs both costs and risk, healthcare has significant incentives not to change the system. These values and incentives powerfully determine the scope of design impact. Traditional UX and service design methodologies may be necessary, but are not sufficient.

Design proposals require sponsors to weigh care, cost, and risk. Institutional sponsors deal in quantitative evidence where possible, and designers make qualitative arguments based on human experience. Making matters worse in practice, design and implementation decisions are fraught with competing interests, often imposing near-term decision making on the IT team and changes in practice, and design and research professionals are often isolated in narrow bands of problem scope.

The complexity of healthcare IT applications requires that designers make a personal and usually long-term commitment to the domain, involving years of learning, practice, and patience with slow progress. In institutional or commercial healthcare IT development, designers have much less control over the delivered experience than in other fields. The opportunities for creative influence or enhancement may not be apparent (and may need to be courageously co-created in the organization). Healthcare as a domain is strongly influenced by empirical scientific tradition and evidence-based practices. Designers will be expected to understand and adapt to the language of the domain rather than the language of design and user experience.

Large-scale healthcare applications are based on enterprise IT architectures, which may take many years of development cycles to significantly change. And ethnographic or field research is hampered by limited access to the different "users," especially patients, due to privacy and immediate care considerations. Most research studies take months, not weeks, because they are carefully designed and then reviewed by ethics boards. Due to these factors and the hierarchical and highly managed healthcare culture, a design team must be committed to making a difference over the long term.

Healthcare applications—at least institutional applications—are not designed by means of creative ideation, participatory design, or even iterative prototyping. There are few national-level design advisors or advocates from the design or even the industrial engineering fields. Publications are dominated by physicians and informatics specialists, whose work is often based on tightly focused, feasible research agendas fitting institutional mandates. Conferences are highly specialized within medical or educational discipline (professional societies), technology (health IT and informatics), technology-oriented research (the Medicine 2.0 movement), and disease specialization (e.g., the American Diabetes Association). There are no regular design-oriented conferences in the healthcare field yet, and few tracks within conferences to encourage discourse between design professionals across different fields. Our current lack of standing is also evidenced by the subordination of design practice to every other field we support. Yet the situation is changing, and many new points of entry have opened.

Lost and Found in the System

How do designers build a more systemic approach? We are not typically engaged at the level of healthcare reform or practice, but serve in problem-solving teams for well-framed issues. Our points of entry to the system level are not clear. The advisors and policy advocates in healthcare are distinctly separated by problem area (disease management, medical education, health insurance reform) and separated by problem-solving approach (policy, practice innovation, patient-centered medicine, information systems).

Due to the complexity of healthcare practices and the compelling urgency of narrow-focus concerns, individual designers and design teams are often unable to design solutions to address root causes. It is rare to design any application that scales across institutions or practice areas. The Web does not count because most applications are piecemeal, insufficient, or one of many similar sites. Universal access is not a solution for scaling across domains or services.

Given the serious design risks of unforeseeable design error in health practice and the hazards of liability, designers, researchers, and engineers are obligated to understand the systemic problems in the field. Small oversights can lead to consequential errors. As a patient you may have noticed an irritating but inconspicuous oversight, such as the overly small text size on a prescription label or a long wait in an examination room. Or you may have experienced the frustration of poor information organization—or even intentional obfuscation—as you attempt to decipher your insurance coverage before phoning for an appointment. You may have been the hapless recipient of an everyday medical mistake, such as a slightly misplaced needle insertion that leaves a well-liked muscle tender for weeks. Chances are these irritants, on their own, would not be considered worthy of special design attention. Are they symptomatic of systematic problems?

From an outsider's perspective—and designers are still outsiders—the system that connects these particular incidents may not readily disclose itself. However, once inside the health-industrial complex, significant design concerns will show up that overwhelm these trivial annoyances. Do not lose sight of the seemingly minor inconveniences; frustration is one of the leading causes of innovation. Frustrations with wayfinding, communications, or documentation may reveal underlying systemic causes that have been completely overlooked.

If your intention is to apply design thinking and skills to make a difference in healthcare, start with your own history and perspectives. We are all health seekers. Uncover your personal interests and biases, your beliefs about life and health, and your positions on scientific evidence and the art of medicine. Unlike other fields of design and management, personal experiences and common sense may harness your motivation and inform a sense of genuine empathy.

Designers and researchers work with and deeply appreciate the abstract—our building blocks include information, artifacts, interaction, aesthetics, methods, templates, personas, and so on. The healthcare field, which has become automated and intellectual, is centered on embodied subjects—people with health concerns. Healthcare itself is a hands-on practice of continual and practical problem solving. In few other worlds of design do we find such a difference between our maps (our products) and the territory.

Design Thinking in Service and Policy Sectors

People working on the front lines of healthcare are overloaded with well-intentioned information services. Research has identified the prevalence of platform fatigue, when busy professionals become weary of maintaining an institution's multiple systems for patient records, billing, orders, and decision support, each of which requires access, password control, login sequences, and learning a new interface. Future healthcare problems are not solved by the introduction of a better user experience.

Scalable services—service systems—require rethinking IT, not just as an integrating resource in a whole system but as a team player that is as trusted as a human member of the clinical team. Clearly, IT has not achieved this level of reliability and resilience yet. The implementation of IT "solutions" should never become a default management decision. Multidisciplinary clinical service design teams are called for to determine the appropriate allocation of technological, organizational, and individual role functions in care service systems. At the very least, a regular practice of critical evaluations can assess that care provision is not impeded or complicated.

The societal waves of change happening now are driving the need for better design. We should expect a historically large shift from other fields into healthcare, due to the near-term political and institutional attention on implementing electronic patient records. Driven by the push of the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act in the United States, and the general mandate of ready funding for technology, health centers continue to rush to implement and integrate medical records, hospital management, billing, and insurance in massive institutional databases. These systems are complex, unwieldy, and at some point, necessary. Yet their interfaces are intended for practitioners working in hectic care settings who usually consider computers an administrative chore.

Outside of the United States, healthcare requires a complete rethinking of our experience with health services, providers, costs, and innovation. Whereas developed nations may be faced with an overabundance of choice, emerging economies require consideration of how design can help the very basic outcomes of healthcare services. In the United States, we expect an exchange of ideas and methods between the consumer and professional sectors. In global healthcare, we cannot expect to transfer knowledge and the easy fixes learned from North American successes. In developing nations, culturally appropriate innovation might require a integration of traditional practices with guidance from mainstream healthcare procedures and medications. Automation may be a helpful but secondary concern, with health centers enabled by off-the-shelf software and sufficiently reliable computers, while allowing for unreliable grid power and Internet access.

We might also acknowledge how the technological imperative is implied in innovation thinking. Not all "systems" in healthcare are computer-based; the technical work of care is performed as a hands-on human process. Diagnosis, treatment, procedures, aftercare, and care planning are not (yet) automated, and the human-to-human relationship of care never will be. Yet healthcare process and procedure generates a massive amount of data helpful in analysis and management of services. The allocation of human and automated tasks remains a moving target as IT and sensors expand the possibilities of public and individual care, and the designers of service and experience have rights to the negotiable intersection between human and information. Unfortunately for interaction and UX designers, the healthcare IT market has not matured to the point where UX factors significantly affect purchase and implementation decisions. We are only now getting a hearing, and with the rapid pace of newly installed databases, we may be appearing on the scene much too late. Yet these systems still need our help.

Wicked Problems in Healthcare Design

Healthcare is not only a "mess," it technically entails many *wicked problems*—complexities with no clear and immediate resolution. Wicked problems are generally large in scale, affecting unknown numbers of people with unknown levels of risk and effect. They include most persistent social and environmental issues that have emerged from multiple root causes over time. In truly wicked problems, original causes (such as bad regulatory decisions) evolve into new effects (corrupt agencies and regimes), interventions have no testable solution (How do you determine whether the situation has been resolved?), and the very acknowledgment of a "problem" results from the earlier effects of embedded, interconnected, complicated problems.

Systems scientist Horst Rittel reserved the term for systemic social problems that defy analytical problem solving, are not understandable by any single individual, and have no single best solution.[5] In healthcare, wicked problems are the most critical (and costly) issues, such as aging populations, multiple chronic diseases, interacting conditions in persons living longer, and rapid changes required of practice based on constant updates to (and conflicts in) research. They occur at a scale that can have devastating financial and societal impacts that increase over time. Reaching agreement on how to solve these problems remains difficult, but they also require action in the face of incomplete knowledge and limited foresight, meaning that we often do our best and then live with the consequences.

Problems that do not meet the definition of wicked are commonly framed as simple, complicated, or complex. *Simple* problems are those situations with a clear cause and a reliable response in most cases. In healthcare, these include well-understood routine conditions such as broken bones and lacerations. Many more health concerns are *complicated*, requiring iterative tests and observations. Surgical operations are complicated, with many moving parts and many ways to fail. *Complex* problems are interconnected and entangled issues with uncertain outcomes. Chronic, interacting diseases are complex, such as asthma, allergies, and many cancers or autoimmune diseases. *Wicked* problems are complex problems with uncertain interventions as well as uncertain outcomes. These can range from healthcare system reform to facial pain management.

Design Strategies

Design strategy is necessary to align any radical innovation with organizational purposes. A design strategy, spanning every role from communications to services, reframes the meaning of change to stakeholders, and creatively aligns a new concept with implementation. A design strategy determines whether managers will risk changing the meaning of healthcare services or merely adapt technology to current practices. Because the tradition of professional care has become so culturally embedded, few institutions risk taking the road to radical meaning change.

Over the last two decades, a small number of progressive frameworks for design thinking have been found applicable for the selection of strategic design options. Design theorist Richard Buchanan's orders of design is an influential schema for problem framing, as well a definitive reference to the contemporary view of design thinking.[6] He proposed four placements that designers employ to compose integrated design strategies across four classes of design targets:

- Symbolic and visual communications
- Artifacts and material objects
- Activities and organized services
- Complex systems and environments

Buchanan observed that designers draw upon placements as ways to creatively reconfigure a design concept in a new situation. All designers build their own vocabularies, as well as a set of skills and styles applicable in their domains of work. Rather than following a fixed series of orders to reach an outcome, the placements are a strategy for creative invention. An information design problem for a website might lead to a discovery of a better wayfinding information scheme by adopting the new Web information categories and shifting across types from one placement to another.

We can find a range of problem types in every healthcare sector, but things become complex when defining problem boundaries. An individual health problem can be viewed as a matter of self-care or as interacting with multiple institutional systems. Where we draw the line matters. Designers and strategists Garry VanPatter and Elizabeth Pastor defined design geographies—four essentially different design domains, Design 1.0 through 4.0, that represent an evolution of design practice, research, and education to develop new knowledge bases necessary for increasing complexity (Figure 1.1).[7]

The stages are not replacements of former paradigms (as in *Health* 2.0). They are based on observations from practice settings, and their "proof" is not theoretical but comes from application. Managing complexity is not just a matter of increasing scope. Different skills and methods apply in each domain that are generally transferable up, but not down, from one level to the next.

The four stages embody design processes for the following contexts:

1. **Artifacts and communications:** *design as making*, or traditional design practice
2. **Products and services:** design for *value creation* (including service design, holistic product innovation, multichannel, and user experience), or design as *integrating*
3. **Organizational transformation** (complex, bounded by business or strategy): design for transforming work practices, strategies, and organizational structures
4. **Social transformation** (complex, unbounded): design for transforming social systems, policies, and communities

Because of the magnitude of complexity difference in each stage, they are not interchangeable. In any given design process, the skills and orientations from *all* levels might be employed. Each higher phase is inclusive of the lower levels as the problem complexity expands from Design 1.0 to 4.0. An organizational process (D3.0) can design communications in line with the quality of the best D1.0 work. The process itself follows the methods and practices of a D2.0 service.

The four domains differ in their strategy, intention, and outcomes. Each requires skill and coordination of distinct methods, design practices, types of collaboration, and stakeholder participation. These are not fixed requirements but merely entry criteria for performing in the capacity of that "geography" in practice. The domains are described as follows (Figure 1.2):

FIGURE 1.1
Mapping design process to challenge complexity. (Courtesy of Humantific)

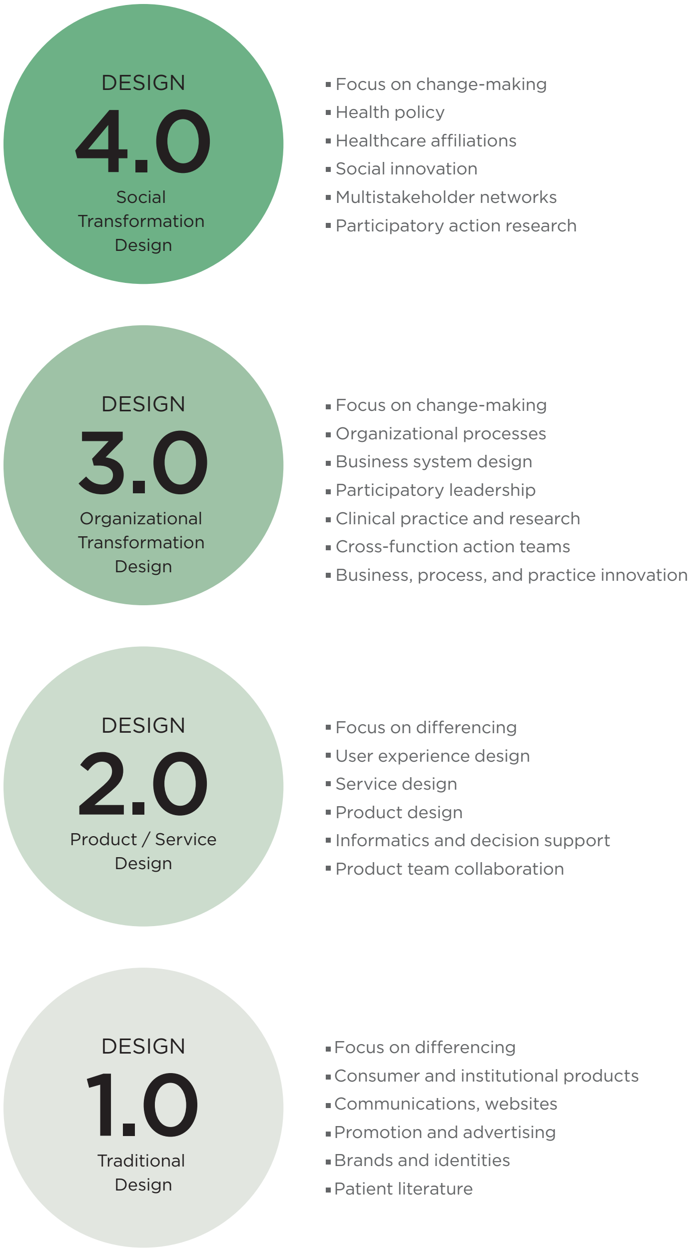


FIGURE 1.2
Design 1.0–4.0 approaches in complexity scale.

Design 1.0: Traditional craft design processes. This is a typical creative practice approach in which the design of artifacts and products is led by a designer with ingenuity and experience. This stage relies on individual design skills in form-giving, illustration, and representation to define and finish desired products, such as publications, simple websites, or advertising. It is performed as an invisible process to stakeholders.

Design 2.0: Industrial and interactive product design. This stage includes the vast majority of all design-led projects in a clinical organization, including all types of IT, interactive services, and most services design. A design and research process is published for the specific purposes of the project (such as a process and style guide). Clinical stakeholders have representation in a multidisciplinary team. User behavioral research is necessary to ensure useful and usable products for effective interaction in the intended environment.

Design 3.0: Organizational level transformation design. This stage co-creates the organizational change necessary for the increased complexity of services that change clinical work practices or institutional policy. Organizational research and workflow analysis are compatible with sociotechnical systems approaches,[8] such as activity theory and cognitive work analysis. Design 3.0 integrates health IT and practice change as part of social systems. The project teams are extended with clinical stakeholders and patient representation. Processes are not only published, they are developed by the extended team with consensus and made universal across projects. Advanced internal skills (collaborative facilitation) and design/research skills are required to lead, conduct, and communicate the full cycle of design and research for complex problems.

Design 4.0: Social transformation. This stage is the highest order of complexity, in which multiple social systems intersect. The large healthcare institution can be seen as a nested social system, with many different social systems overlapping in the cause of health and care provision. Because this stage typically has no single fixed boundary, the scope and problem are defined through socializing agreement. Even the problem definition requires mixed, multidisciplinary stakeholders. As the design intent reaches beyond the organization, research approaches informed by social systems design[9] and participatory action research[10] are compatible with this scale of design.

Design across Healthcare Services and Sectors

Shifting the target of design from a print or material artifact (D1.0) to a product or service (D2.0) may not require a significant change in design practices, but represents a shift in artifact complexity and certainly in user or organizational involvement. More stakeholders are necessary to inform design, and product teams deal with multiple competing requirements and interpretations of value and quality. An increasing requirement for stakeholder collaboration and technology integration is shifted up to each subsequent level.

Many integrated services or complex Web products have made the shift from individual to social interaction, and D1.0 and D2.0 are often combined within the same product. But healthcare practices occur in distributed settings and require more than well-designed apps. In the institutional setting, IT applications require organizational integration (D3.0), and new clinical services may address community health concerns (D4.0).

One series of transformations moves from part (function) to whole (system) up the levels of ordering. In diabetes management, for example, a D1.0 solution might entail a public service advertisement for a D2.0 diabetes information website. Moving to D3.0, a hospital might offer a specialized clinic to serve the growing demographic of patients with diabetes and related issues. Moving to D4.0 might co-create an online community organized for diabetes aftercare staffed by live clinicians for asynchronous responses to questions and even review of personal health data to minimize the burden and expenses of in-clinic appointments.

Figure 1.3 shows a relative scale of problem solving, from simple design problems to wicked social concerns, and the design strategy consistent with the needs in each problem area. As complexity increases, the demand for sensemaking of the problem itself increases. Sensemaking, considered here the consensual understanding of the functions of a problem area, becomes a critical requirement in situations of high complexity (D3.0 and D4.0). In a social design process, multiple stakeholders, managers, and experts come to agreement or make sense of the situation together.

Strange-making is a process of differentiating form to capture attention. It consumes the larger proportion of D1.0 and D2.0, where novelty and provocation is expected for product design, commercial communications, or sophisticated Web services. In a competitive consumer marketplace, the need for design differencing is absolutely clear. Distinctive value propositions are embodied with differentiating design values. In D3.0 and D4.0 contexts, however, there is no need to differentiate. These contexts share a high degree of social and process complexity and interconnectedness among problems. For organizational and social systems, deep problem understanding (through processes of collective sensemaking) comprises the majority of the design engagements over the development life cycle.

FIGURE 1.3

Design geographies and complexity scale. (Courtesy of Humantific)

The framework gives designers the ability to make a case for systemic design. Consider a consumer website such as WebMD. As a conventional Web content product, WebMD provides valuable information to searchers of health information. Yet it does not connect the individual socially to other users (D2.0); to institutions or business processes (D3.0), except through advertising or embedded content; or to larger-scale social transformations of healthcare (D4.0). Its advertising-based revenue model, although commercially lucrative, inhibits the site from growing into a broader service with institutional or societal impact.

D3.0 expands the target of design to the organization itself—one that is already structured to function as a repeatable production system. D3.0 facilitates practices within an organization that help multidisciplinary teams and functional groups reinvent their work and rethink innovation as a direct management concern. D4.0 facilitates design and innovation owned by multiple stakeholders in a complex situation, a transformative design perspective that engages people from across organizations in a much larger social system. Few design projects are defined at the level of D4.0, but some organizations face challenges that are better framed this way. The strategies of top clinics and diversified organizations such as Kaiser Permanente reach beyond the organizational boundaries to government, universities, patient groups, and clinical research, expanding the boundaries of design. They are not solely organizational programs, and can be facilitated as multistakeholder social systems problems.

Design thinking at the social and cultural scale is collaborative and cross-organizational. Designers become conveners, sharing the process and co-creating artifacts, research methods, and local decisions. The distinction between D3.0 and D4.0 is one of boundaries—when the institutional boundary of D3.0 is crossed to the societal realm of 4.0, design intent changes to policy and social action. Responsibility for the process is transferred to the stakeholders, not just for effective collaboration but as a normative practice, following the principle that social and policy design is owned by the stakeholders who live with and benefit from the outcomes.

Design thinking—and design strategy—are not development processes. Buchanan's paper was among the first to employ the term *design thinking*, and it avoided any suggestion of the popular stepwise frameworks that characterize current approaches to design thinking. His proposition was that designerly thinking afforded ways of flexibly addressing intractable (wicked) design problems through a creative process of shifting solutions through the levels he called placements. This reminds us that systemically complex problems are not "solved" as much as they are addressed through thoughtful and often disruptive interventions. The geographies model reveals that higher orders of complexity require different skills, practices, and languages.

Designing No Harm

Collaborative design attention is most needed where the probability of harm is increased by poor design decisions. Nobody dies from a bad website, but patients can and do die from information display errors and counterintuitive device interfaces. Thoughtless design is magnified greatly when it shows up in a healthcare process or medical device.

The healthcare system presents us with an ongoing and interconnected family of problems that no single person can understand and navigate. A fix for a local situation (such as online scheduling for long-term care) could destabilize the larger system in unforeseeable ways (such as increasing the demand for nursing homes when a mixed-residency alternative might be promoted instead). We are responsible for outcomes, whether or not we accounted for them in our local projects. We cannot always know in advance how systems will interact in practice, and yet we must act in any case.

Every activity in the healthcare setting is interconnected and tightly coupled to measured health outcomes and highly professionalized practices. Any artifact, document, and interaction in a care situation can introduce a systemic effect. However, we also cannot conduct institutional research or user research studies for every intervention and new product. We need new ways to learn, think, and work quickly to make sense of the human, system, and organizational problems that co-occur every day in the morass of healthcare.

The fastest growing markets are electronic health record systems, billing and management systems, and Health 2.0 start-ups (often just Web applications). This trend may draw a large proportion of talent from information architecture, interaction design, software design, and user research from other fields into the healthcare arena. These innovations give hundreds of new ideas a chance to be heard in the field.

Designers have a unique opportunity to advance local and systemic change by empowering caregivers to enhance their ability to deliver caring. Together, the possibility emerges to design and campaign new service systems that enable people to better express caring in the system.

The convergence of design research, service and UX design, and human factors has led to fusions of practice and methods. Designing for care helps improve the *experience of being human*, and not necessarily the user experience. Consider that the aim of healthcare is to free people from a disease condition and help them live with chronic situations, and at the same time to create independence from the medical system. Caring design looks for systematic opportunities to create this independence, which may then lead to new products. Aligning with the values of caring professions may lead designers to new careers that are only just now being envisioned.

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