approach tailored to the particular clinical realities of target populations.

Such tailoring will complicate strategic planning and investments in population health management and accountable care capabilities. Even for health systems that have experience with alternative payment models, assuming responsibility for new populations will require an in-depth understanding of the clinical characteristics and care-utilization patterns of high-risk subgroups and identification of evidence-based programs and tactics for managing their care. The required up-front investments will be substantial. Thus, it will be important for payers to understand that demonstrated competence in caring for specific high-risk populations does not obviate the need for contracts to provide adequate financial incentives and security to support investments in new care-management capabilities.

The implications for the roles of individual physicians are quite different. Depending on their specialty and panel composition, physicians may see patients ranging from the full spectrum of their health system's high-cost patients to a single subgroup. Physicians in ACOs, therefore, have a critical role in engaging patients and matching them with specific programs according to clinical need. Furthermore, front-line clinicians can help system leaders identify and test new strategies for high-cost patients and provide insights into care needs at a level of nuance and granularity that cannot be gleaned from claims or electronic health data.

Focusing on high-cost patients has become an attractively simple approach to improving care and reducing costs. But this policy panacea is challenged by the reality that patient demographics, health needs, and utilization patterns vary substantially among populations. Optimizing investments in this area will require improving analysis of which patients are amenable to care-delivery interventions and prioritizing interventions according to the specific needs of subpopulations.

The views expressed in this article are those of the authors and do not necessarily represent the views or policies of their institutions.

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Time for a Patient-Driven Health Information Economy?

Kenneth D. Mandl, M.D., M.P.H., and Isaac S. Kohane, M.D., Ph.D.

As patients strive to manage their own health and illnesses, many wonder how to get a copy of their health data to share with their physicians, load into apps, donate to researchers, link to their genomic data, or have on hand just in case. To seek diagnosis or better care (see table), many patients are taking steps outside traditional doctor–patient relationships. Some join 23andMe to obtain genetic information. Others bring data to the Undiagnosed Diseases Network at the National Institutes of Health (NIH). Patients are coalescing with others with the same disease in what the Patient Centered Outcomes Research Institute calls patient-powered research networks. But such patients have found no easy way to get copies of their electronic health records (EHRs).

In 1994, when the World Wide Web was only 2 years old, Massachusetts Institute of Technology computer scientist Peter Szolovits, presaging the consumer health information technology (IT) movement, proposed, in the Guardian Angel Project, using the Web for patient management of health and health data. Yet getting patients electronic copies of their health records has remained an elusive goal. Industry giants have scars to show for their attempts. Why have the barriers been so high? And what is the path to a patient-driven health information economy?

In 1998, we developed the Personal Internetworked Notary and Guardian (PING, later called Indivo), an NIH-funded system for automatically and continuously updating a patient-controlled data repository.[1] Indivo downloaded

Selected Reasons for Pursuing Patient-Controlled Data.

Need or Purpose	Explanation
Complete data	A patient-controlled health record, updated after each health encounter, would provide a complete view of the patient (in contrast to that available in institution-specific electronic health records).
Data sharing for coordinated care	In the absence of other effective mechanisms, patients may be the best vehicle for making data available to their clinicians and family.
Use of data by intelligent software or apps	Patient-controlled data repositories, properly configured, could be the nexus of patient-facing apps for care management, participation in research, and data sharing.
Support of diagnostic journeys	Patients and families with undiagnosed or difficult-to-treat conditions are now manually assembling complex data sets, including genomic data, to present to researchers and clinicians.
Data donation	Under myriad consent and authorization models, patients are increasingly figuring out how to contribute data to research.
Patients as reporters	The patient is a source of data that are complementary to the information found in institutional records; bidirectional data exchange with patients could become a cornerstone of the medical record.
Additional pairs of eyes	Patients can identify and correct errors in the medical record.
Social networking	Health data are a basis for finding other patients with similar conditions or genomic variants.

automatic updates from EHRs and enriched them with patient annotations. These repositories, controlled by patients and sharable with others, were meant to drive an ecosystem of third-party apps.[2] After we demonstrated Indivo to technology companies in 2006, Google and Microsoft launched similar personally controlled health records — GoogleHealth and Microsoft Healthvault. Walmart and other employers offered Indivo as an employee benefit. Yet today most U.S. patients still don't have electronic copies of their records.

One explanation is the wider adoption of a competing technology: patient portals, offering a view of a subset of EHR data.[3] Many portals are "bolt-on" features from EHR vendors; others are homegrown. In its criteria for achieving stage 2 "Meaningful Use" of health IT, the Office of the National Coordinator for Health Information Technology attempted to promote data access by requiring health care organizations to provide 50% of their patients with timely access after health care encounters. Patients were invited to use portals at all their providers' practices (a solution that caused a condition sometimes called "hyperportalosis"). Since the measure of success was that 5% of patients "view, download, or transmit" their health information, most implementations defaulted to view-only. Hence, the data are unavailable to patients, other providers, and third-party apps; virtually no apps in the Apple or Google stores have access to health system data.

Federal regulation defining a patient's right to health data has failed to ensure access. Since 1996, the Health Insurance Portability and Accountability Act (HIPAA) has required health care organizations to provide patients with access to any data that are "readily producible," in the format the patient requests. Organizations haven't responded. Ironically, HIPAA is one of the most commonly cited reasons for *not* transmitting patient data. The patient right was reasserted under the Health Information Technology for Economic and Clinical Health Act — with a similarly negligible effect on data sharing.

"Data liquidity" — flow among data generators and customers — carries risks. Competitive intelligence might be released about, for example, high-value markets or hospital-acquired infections. Some organizations fear security breaches or leakage of patients from their provider network. Transferring data to another product may jeopardize the EHR vendor's business model, as vendors may have trouble retaining customers if exclusivity is broken.

And technological approaches have fallen short. Under the Meaningful Use program, the intended lingua franca for data liquidity was the Consolidated Clinical Document Architecture, but it was never sufficiently standardized to support robust document exchange.[4] The Blue Button, a Veterans Health Administration technology that allowed veterans to easily download their EHR data, was ably marketed but never matured.

Now, intersecting trends have set the stage for a fresh start. Nearly two thirds of Americans own smartphones, with online access, apps, and both local and cloud storage of data. As health care reimbursement shifts toward risk-based contracting, providers seek to understand the totality of patients' experience, which requires aggregating data across

Steps toward Creating a Patient-Driven Information Economy.

1. Both the Centers for Medicare and Medicaid Services and private insurers can offer strong incentives for health care organizations to provide data to patients after encounters through a standardized electronic mechanism — initially one encounter at a time, but eventually with automatic updates.
2. Federal health IT policy can promote, and health systems purchasing IT can demand, a uniform, standard, public API for health data that can catalyze the development of an ecosystem of apps, for both clinicians and patients, that run on health data. The Meaningful Use Stage 3 Final Rule is the first major step in this direction, requiring certified EHR technology to provide an API through which patients can have access to their EHR data in a timely fashion.
3. The research community and regulatory agencies can vet a set of online reference tools that define, by demonstration as well as specification, how consent can be delivered for global or narrowly defined transfer of patient data to and from patient-controlled data repositories; essential functionality will include roles for guardians and proxies as well as easy ways to change the scope of, or revoke, consent.
4. The health care system can adopt a rigorous authentication framework, borrowing approaches from other sectors of e-commerce, so that we can identify patients and allow them to obtain and use their data.

care silos. As the clinical research infrastructure accommodates pragmatic studies and incorporates patient-centered outcomes in therapeutics development, patients are increasingly asked to report on adverse events and end points and donate health data to trials. Fortunately, the belief that it's dangerous to allow patients access to health data is slowly dissolving, with the advent of programs such as Beth Israel Deaconess Medical Center's Open Notes, in which doctors and patients jointly read and create chart entries.

Moreover, there's now a huge amount of electronic data (albeit a subset of what's needed); 95% of U.S. hospitals and 54% of office practices use certified health IT. And EHRs and hospitals are implementing data-access standards such as the Fast Health Interoperability Resources (FHIR) and the Substitutable Medical Applications Reusable Technologies (SMART) Health IT apps interface. Finally, large-scale undertakings such as President Barack Obama's Precision Medicine Initiative are promising to return participant-level data to study subjects.

Sensing an opportunity, Silicon Valley has picked up the gauntlet. In 2015, Apple released HealthKit, which provides a simple interface for devices including heart-rate monitors and pulse oximeters, creating a de facto data repository under patients' control. Companies such as We Are Curious are creating communities of people seeking answers to health questions. Amazon, Microsoft, and Google are collaborating with health care systems to store big data in the cloud.

Patient expectations have finally caught up with Szolovits's aspirations for a "guardian angel" digital assistant that cares for a patient over a lifetime. Consumers expect to have their data available and sharable. Other industries have embraced similar principles: in response to customer demand, for example, Facebook now enables users to download their own data.

A patient-controlled health-record infrastructure can support the development of highly desirable health system qualities. First, it allows a patient to effectively become a health information exchange of one: as data accumulate in a patient-controlled repository, a complete picture of the patient emerges. If patients can obtain their data wherever they go, they can share them with physicians as needed — rather than vice versa. We believe the Meaningful Use program would have been more successful if it had rewarded clinicians for storing data in patient-controlled repositories rather than in EHRs that fragment data across the health care system.

The need for a copy of one's data is most obvious in life-and-death situations in which patients have failed to find answers in their health care system. Journeys like Matt Might's search for a diagnosis of his son's genetic condition suggest that patients may be among the most sophisticated users of health data.[5] Might, a computer scientist, connected with a research team using whole-exome sequencing to discover that his son had two different mutations in the *NGLY1* gene. Those invaluable sequence data were extremely difficult to obtain and share.

Such activated patients, however, represent the tip of an iceberg of dissatisfaction with health care and need for greater data access and control. The requisite technology is no longer mysterious or expensive; it's a set of commodity-level toolkits for data exposure, transfer, and storage. Successful translation of these technologies into a productive health information economy awaits only cooperation from data producers and purveyors.

The government can help stimulate such participation, and Meaningful Use 3 does require providers to make data available for patient access over an application programming interface (API). But whether or not the Meaningful Use program survives the backlash against it, IT purchasers can demand uniform, useful implementation of an open API. Health care providers and patients can advocate for and collaborate

in developing key enabling policies and toolkits (see box) that leverage an API for patient data access.

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Gifts

Anna Reisman, M.D.

We buried my sister Deborah quickly, in accordance with Jewish tradition, two states away in the family plot in New Jersey. A handful of us gathered around the rectangular hole by the graves of grandparents and great aunts and uncles, recited the prayer for the dead, trudged through blowing brown leaves, ate sandwiches at the diner next door, and drove back to Connecticut. My sister Lisa said it felt weird to be leaving her behind. But she won't really be alone, I said, and we giggled at the idea of Deborah there amidst all those arguing relatives for eternity.

Deborah's voice, however, wouldn't be part of the arguments. Born with tuberous sclerosis, which causes benign brain growths and, in her case, seizures and severe intellectual disability, Deborah never learned to speak. For the last 25 years of her life, she lived in a group home in Connecticut, spending most of her time sitting on a favorite brown leather chair, legs tucked under her, eyes focused on nothing in particular.

Deborah was elegant in her own way, slim with thick, shiny, dark hair. In her skinny jeans and Aeropostale sweatshirts, she looked like a pretty teenager even in her 40s. Sometimes she was willing to interact with family, housemates, and caregivers — clapping her hands excitedly in imitation of me or one of my kids, tolerating a game of catch (from her armchair, with a half-deflated yellow basketball), or standing and grasping my forearm en route to the snack cabinet.

Most of the time, she avoided eye contact. Though she'd bend her head down to accept a kiss, she wasn't comfortable being touched. After one visit involving a chocolate doughnut and some hand holding and ball tossing, my son, then 13, confided in me his belief that if he tried hard enough to connect with her, she'd snap out of it and start talking. I knew that feeling; I'd had it pretty much my whole life.

When, a few days after the burial, Lisa told me she was ready to start planning a memorial service, I balked. It had been an awful few months — really, an awful year — and I wanted to move on. Over the spring, through the summer, and into the fall, an aggressive and ugly cancer had sapped Deborah's energy, and nobody knew how to interpret her howls and moans. Was this pain? Should we give her more morphine? Was she anxious, or constipated, or hungry? She rattled her primary care doctor, who would call me when something was wrong and talk, doctor to doctor, sparing no grisly detail. One morning, I paced in an empty parking lot in the glaring sun outside a conference center, trying to get cell-phone reception; the doctor's voice was coming in choppy, something about bleeding and oozing, and I remember feeling a cloud of anxiety expanding painfully in my chest and wondering if this was the beginning of the end. But it wasn't, for quite a while — until it was.

When home hospice wasn't enough to ease Deborah's pain and agitation, we moved her to inpatient hospice. She faded quickly. The muscles of her hands shrank and flattened. She slept a lot, her mouth wide open. Oddly, she seemed more comfortable making eye contact than ever before. Perhaps it was the morphine or the Ativan.

Still, it was hard to imagine how the drugs could sufficiently dull the frustration and puzzlement she must have felt over her inability to get out of bed. Simply grasping a spoon of lemon ice