

What is an exceptional case? Is it the same in all states? Should it be? Although the Committee on Ethics of the American College of Obstetricians and Gynecologists endorses the “extraordinary circumstances” approach, even it “cannot currently imagine” what that scenario could be.<sup>5</sup>

The Illinois approach — to respect informed refusals — should be the rule for courts, hospitals, and physicians. Physicians should discuss and revisit the risks, benefits, and alternatives of recommended care, and they should adequately document an informed refusal. But they should not involve courts. These cases begin at the bedside, and that is where they should end.

Physicians who seek judicial intervention should disclose that practice so patients can seek care elsewhere. For many, though, alternatives are illusory. In Tallahassee, there may be no safe harbor. In 1996, after laboring at home and becoming dehydrated,

Laura Pemberton sought intravenous fluids at TMH, but physicians conditioned her medical care on agreement to a cesarean section. She declined and left. TMH then obtained a court order to retrieve her from her home (she was found laboring in her bedroom) and bring her to TMH by ambulance, where she was forced to undergo an apparently unnecessary cesarean section.

In 1976, a man dying of aplastic anemia sued his cousin, asking a court to order the forcible extraction of his potentially matching — and lifesaving — bone marrow. The court refused and explained, “For our law to *compel* defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual” and “raise the spectre of the swastika and the Inquisition, reminiscent of the horrors this portends” (*McFall v. Shimp*).

Those horrors are no less salient here. Forced interventions undermine the liberty, privacy, and equality of pregnant women. But they are far more insidious. Because they betray foundational legal principles of our free society, they endanger the liberty of us all.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

From the UCLA School of Law, Los Angeles.

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## Escaping the EHR Trap — The Future of Health IT

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

It is a widely accepted myth that medicine requires complex, highly specialized information-technology (IT) systems. This myth continues to justify soaring IT costs, burdensome physician workloads, and stagnation in innovation — while doctors become increasingly bound to documentation and communication products that are functionally decades behind those they use in their “civilian” life.

Even as consumer IT — word-

processing programs, search engines, social networks, e-mail systems, mobile phones and apps, music players, gaming platforms — has become deeply integrated into the fabric of modern life, physicians find themselves locked into pre-Internet-era electronic health records (EHRs) that aspire to provide complete and specialized environments for diverse tasks. The federal push for health IT, spearheaded by the Office of the National Coordinator for

Health Information Technology (ONC), establishes an information backbone for accountable care, patient safety, and health care reform. But we now need to take the next step: fitting EHRs into a dynamic, state-of-the-art, rapidly evolving information infrastructure — rather than jamming all health care processes and workflows into constrained EHR operating environments.

We believe that EHR vendors propagate the myth that health

IT is qualitatively different from industrial and consumer products in order to protect their prices and market share and block new entrants. In reality, diverse functionality needn't reside within single EHR systems, and there's a clear path toward better, safer, cheaper, and nimbler tools for managing health care's complex tasks.

Early health IT offerings were cutting-edge,<sup>1</sup> but contemporary EHRs distinctly lag behind systems used in other fields. In 1966, members of Octo Barnett's laboratory at Massachusetts General Hospital invented a highly efficient programming language for the earliest EHRs; the Massachusetts General Hospital Utility Multi-Programming System (MUMPS) partitioned precious computer memory so parsimoniously that with only 16 kilobytes, the earliest personal computers could run an EHR supporting multiple users. But nearly a half-century later, most EHR vendors not only have failed to innovate but don't even embrace existing modular architectures with interfaces that allow extension of product capabilities, innovative uses of data, and interoperation with other software.

Loss of technological leadership reflects apathy and even opposition by EHR vendors to promoting liquidity of the data they collect. This attitude has thwarted medicine's decades-long quest for an electronic information infrastructure capable of providing a dynamic and longitudinal view of the health care of individuals and populations. EHR companies have followed a business model whereby they control all data, rather than liberating the data

for use in innovative applications in clinical care.

Conducting a Google-style search of an EHR database usually requires involvement of a clinician's information services department and often the specialized knowledge and cooperation of the vendor's technical teams. In reaction, scores of academic medical centers have exported data into a common open-source system where population-level analytics are managed outside the

entrenched in "legacy" approaches, threatening other vendors' viability. A healthy IT marketplace would favor disruptive innovations (simple products and services that initially serve the bottom of a market and then move up to displace established competitors)<sup>5</sup> for improving patient engagement, communication, and care coordination. Improved population health obtained at a lower cost would result. Just as consumers select and manage myriad

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vendor, and results shared across sites.<sup>2</sup>

Commercial EHRs evolved from practice-management (i.e., billing) systems, and in response to the patient-safety movement, vendors tacked on documentation modules and order entry for physicians. Since each EHR product has been built as an isolated silo, the market for any good innovation is fragmented.<sup>3</sup> Additional problems arise when complex software that was never engineered adequately<sup>4</sup> must be reimaged, reinvented, and reimplemented repeatedly.

Although EHR vendors have proliferated — more than 700 vendors now produce about 1750 distinct certified products — their systems' inability to work together has not helped doctors or patients. Furthermore, despite this sprawl, a few companies controlling much of the market remain

technologies — Facebook for social networking, Twitter for microblogging, Google for search, iTunes for music — so should physicians. Only a small subset of loosely coupled information technologies need to be highly specific to health care. Many components can be generic.

One such component is secure private storage. Many industries depend as much as health care does on the security and confidentiality of their data. Local or cloud-based storage like that provided by EMC and Amazon is highly adaptable to health care if it's accompanied by strong, compliant privacy policies. In contrast, each current EHR installation relies on a locally assembled IT support team — or, in small offices, even on practitioners themselves — so data security varies widely.

Second, communications

among providers or between providers and patients are not unique and can be addressed with existing secure, flexible products and protocols. For example, the ONC-initiated Direct Project promotes a secure communications system for health care based on SMTP (Simple Mail Transfer Protocol), the decades-old store-and-forward e-mail standard. The Direct Project exemplifies the way in which highly effective general technologies can be adapted to health care in an open, standard, integratable fashion.

Third are documentation tools. Text-processing and other software that supports task-oriented group processes in multiple industries easily outperforms EHR systems. To give just one small example, many EHR text processors fail to offer spell checking. Other industries use highly adapted project-management software to manage complex processes, as well as advanced tools such as Teambox, Basecamp, and Huddle to record extended interactions.

Fourth, although analytic approaches to managing individuals and populations are often specific to health care, the tools for loading, graphing, mapping, and analyzing data are not. Some, like Google Maps and the R statistical package, are free and open-source. Others, such as ArcGIS and SAS, are proprietary but have public programming interfaces for integration into the workflow of heterogeneous users across disciplines. All these tools cost a fraction of 1% of the typical EHR system.

Health IT's unique features include the content of medical rules and clinical decision-support

systems. Nevertheless, software for rule-based systems is generic and commercially available. Because EHRs are not designed to integrate with third-party applications, each vendor must create its own rule system, limiting users and necessitating that rules be specified myriad times.

Some types of data used in health care are stored and used in ways that are unique to the medical field, but the field is not unusual in its need to share data across diverse electronic systems; for a key subset of their data, banking and airline-reservation systems have addressed this problem at a global level. Data systems in these industries, too, started as isolated, complex systems with thousands of distinct data elements, but their developers eventually added highly functional, real-time interoperability. Furthermore, across industries, the underlying database-storage and data-query systems, whether built on Oracle, SQL, or Hadoop, are broadly standardized.

And although human-computer interfaces for physicians and patients require deep customization to support complex and unique health care workflows, the interfaces themselves can be created using flexible and generic toolkits.

The IT foundation required for health care is the core set of health data types, the formalization of health care workflows, and encoded knowledge (e.g., practice guidelines, decision-support tools, and care plans). With those ingredients, existing free and flexible software can support the automation of biomedical processes. Many businesses have

adopted large-scale, transindustry platforms to support customer relations, Web applications, and secure cloud-based data storage. Health care is ripe for this approach.

Health IT vendors should adapt modern technologies wherever possible. Clinicians choosing products in order to participate in the Medicare and Medicaid EHR Incentive Programs should not be held hostage to EHRs that reduce their efficiency and strangle innovation. New companies will offer bundled, best-of-breed, interoperable, substitutable technologies — several of which are being developed with ONC funding — that can be optimized for use in health care improvement. Properly nurtured, these products will rapidly reach the market, effectively addressing the goals of “meaningful use,” signaling the post-EHR era, and returning to the innovative spirit of EHR pioneers.

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From the Children's Hospital Informatics Program; the Harvard-MIT Division of Health Sciences and Technology; and the Center for Biomedical Informatics, Harvard Medical School — all in Boston.

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