Proceed With Caution

I.T. security concerns, a host of other issues have kept mental health data in the shadows.

By Elizabeth Gardner

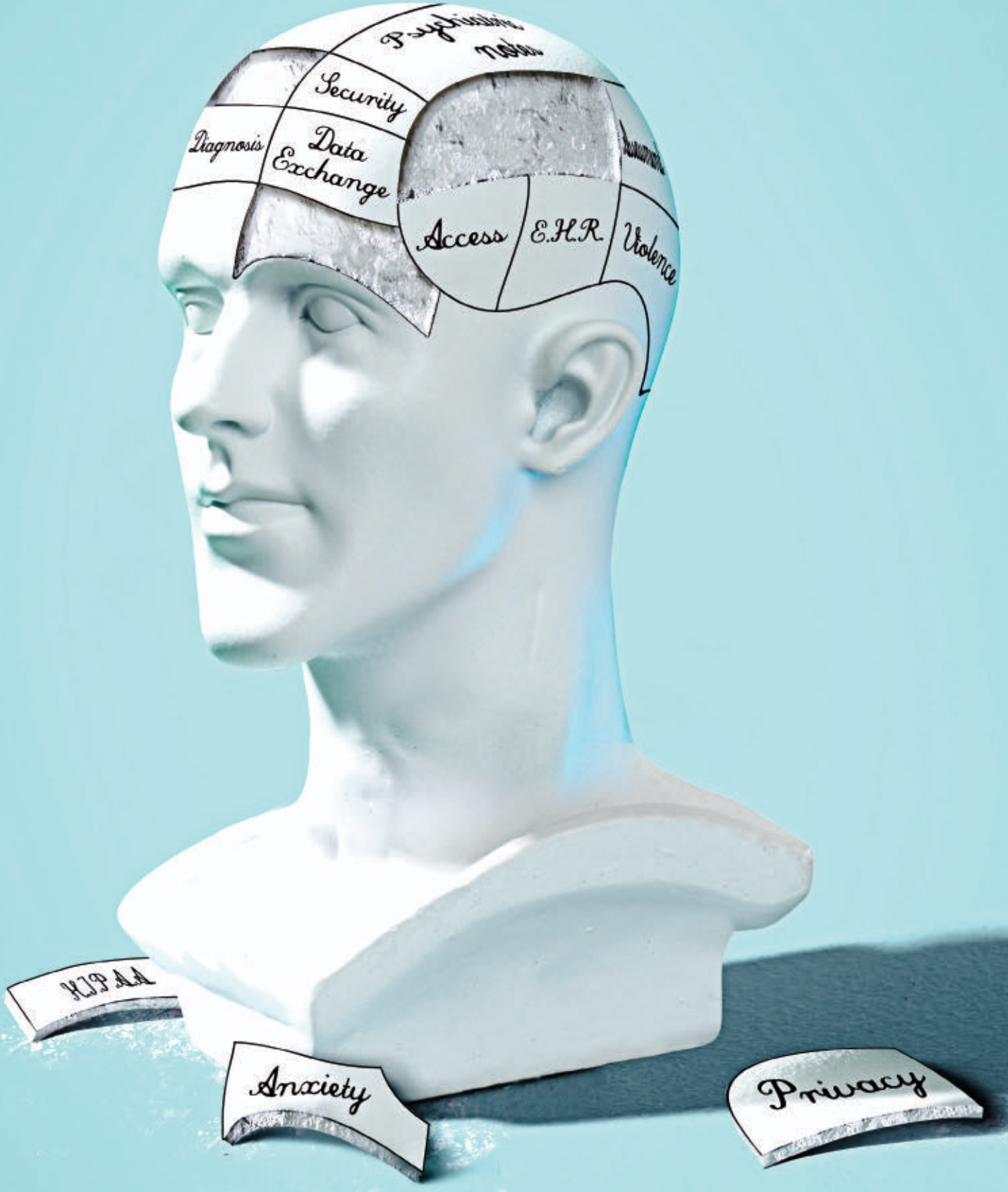
Adam Kaplin, M.D., chief psychiatric consultant at Johns Hopkins Hospital in Baltimore, wants everyone to be aware that depression is the biggest killer of heart attack patients during the year after their surgery. Not smoking, not high cholesterol, but an insidious mental illness that, like other mental illnesses, has serious physical repercussions.

"Cardiologists should know that they need to pay extra attention to depressed patients because they're at much greater risk, since these diseases interact with each other," Kaplin says.

But how do they know which patients are depressed? Often they don't, unless the patients tell them.

Kaplin has struggled to share his patients' information with the other doctors who care for them, but has found institutional reluctance to facilitate that kind of sharing, even with an electronic health record system available.

And Johns Hopkins is not alone. Kaplin and fellow Hopkins researchers recently surveyed whether mental health information is being shared at the top 18 hospitals on the 2012 U.S. News and World Report ranking. Only 44 percent were storing their psychiatric records electronically at all, and only 28 percent were sharing those records with physicians outside psychiatry.


Security
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Violence
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Anxiety
Privacy

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Moreover, the team found that sharing psychiatric information correlated with significantly lower patient readmission rates. Their study was published online in December in the International Journal of Medical Informatics.

If sharing is that rare at the top hospitals, despite the apparent favorable impact on care, it's safe to assume it's even rarer at the average hospital, Kaplin says. "There's still a tremendous stigma surrounding mental illness, and the only way we'll move forward is to start treating it like other somatic illness," he says. "We psychiatrists know that these illnesses are no different than hypertension or diabetes. They're chronic conditions, not personal weaknesses, and there is a biological basis to them."

The direct and indirect costs of mental illness and substance abuse are a huge toll on the overall health of the country. The National Alliance on Mental Illness estimates that the mental illness costs the economy $79 billion annually, including $63 billion in lost productivity. If indirect costs are included—for example, mentally ill people who lose their jobs, are underemployed or unemployed, the costs may be as much as $193.5 billion. The U.S. spends about $135 billion treating mental illness and addiction every year, not counting dollars spent on physical illnesses that are complicated by mental illness.

Until recently, behavioral health information (a blanket term covering both mental health and substance abuse treatment) has been sequestered by both law and common practice, and behavioral health professionals have guarded it jealously. With good reason: Patients who aren't assured of confidentiality might not be honest with their providers, or might avoid seeking treatment at all, because of the stigma surrounding problems of the mind.

"You could put my entire medical history on a billboard and I wouldn't care, but people with psychiatric conditions are in the worst position to understand what should be shared about their care," says John Houston, vice president of privacy and security at University of Pittsburgh Medical Center. "Lots of people with serious psych disorders are being appropriately cared for and able to be productive, but they are very concerned about people knowing they have some disorder or issue." His wife runs a large psychiatric hospital, which makes him unusually aware of the quandary inherent in sharing such sensitive information.

> **"We've been so far behind our brethren disciplines."**
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> —Adam Kaplin, M.D

However, the need for coordinated care is overtaking the impulse to be secretive. Both the Office of the National Coordinator and the Substance Abuse and Mental Health Administration are funding projects to facilitate the sharing of behavioral health data with other providers.

ONCHIT sponsors the Behavioral Health Data Exchange Consortium, to pilot the interstate exchange of behavioral health treatment records using Direct secure messaging protocols. The participating states—Alabama, Kentucky, Florida, New Mexico, Nebraska, and Michigan—are creating draft policies and procedures for exchanging behavioral health treatment records.

Colorado's RHIO released a detailed plan last year for including behavioral health information in its statewide HIE. More than a third of Colorado adults report poor mental health.

In Illinois, the Behavioral Health Integration Project, part of the statewide health information exchange, is working with the state legislature to modify its unusually stringent confidentiality provisions. Harry Rhodes, directory of HIM excellence at AHIMA, who's on the HIE's privacy and security committee, says its research revealed that the process for a new patient evaluation can take up to 10 days because cautious providers exchange information via courier. "A lot of behavioral health is done by teams, so there's a lot of exchange," he says. When several providers tried using Direct protocols instead, evaluation time was reduced to two or three days.

Why has it been so difficult to share behavioral health data? The main reason is that it's hedged with legal safeguards. The laws are designed to maintain patient privacy except in life-or-death emergencies, but they also have had the effect of discouraging the use of computers to store information pertaining to mental health and substance abuse treatment.

Psychiatry and psychology are among the least automated sectors in health care. Solo and small practices are the norm, and most treatment involves listening and writing prescriptions. "The technology for psychiatry is a pen and an [electroconvulsive therapy] machine," Kaplin says. "We've been so far behind our brethren disciplines."

Glenn Martin, M.D., appreciates the irony that he is the head of the Interboro RHIO, a health information exchange for New York City and surrounding communities, while refusing to have electronic records in his small private psychiatry practice. "I'm happy to be a glutton for information," he says. "I will download but not upload," though he is willing to let his patients' primary care providers know when he has prescribed a medication.

Steven Daviss, M.D., chair of psychiatry at Baltimore Washington Medical

Center and head of the EHR committee for the American Psychiatric Association, says many psychiatrists don't have enough Medicare and Medicaid patients to make it worthwhile to try to pursue federal EHR incentive payments. If they use a computer at all for the clinical side of their practice, it might be as simple as a Word document for each patient. And the upside of using a certified EHR—for example, the ability to quickly identify which patients are due for a medication check—is far outweighed by the fear of a security breach.

"Psychiatrists think more about data breaches than other physicians do," Daviss says. "We hear about breaches every day, and there's a concern that the technology is still too early to guarantee safety."

The APA backs electronic records for mental health, but only if patients have at least as much control over them as they do over paper records, and aren't forced into an "all or nothing" situation. "Electronic health record design and implementation should leverage technology to give more flexible approaches to access for sensitive information," according to the organization's position statement.

Within Daviss's institution, all providers have access to their patients' psych records. "Frankly, it would be hard to understand how a facility could do the work it needs to do if everyone can't access the information," he says. For example, a physician doing a diabetes evaluation would benefit from knowing that the patient has lost 20 pounds in the past month due to depression.

The University of Pittsburgh Medical Center also shares its psych data within the institution. Dealing with several layers of patient consent has been one of the most challenging issues, says Houston. In Pennsylvania, patients must give specific consent for each provider to see their information, and under the law they can also choose which information is disclosed. Because the EHR can't segment information that way, UPMC treats everything in a psych encounter as sensitive data. Houston isn't happy with that solution, but it's the best he can do for now. He would like to be able to distinguish truly sensitive information from information that ceases to be sensitive when taken out of the context of a psych encounter.

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"It's important to know that a patient is being prescribed a drug, but the acute care setting doesn't need to know why," he says. "Methadone can be a painkiller as well as being used to treat addiction." All-or-nothing is a persistent problem, says Michael Lardiere, vice president for HIT and strategic development for the National Council for Community Behavioral Health, which is participating in several state pilots of behavioral health information exchange. "If you're a medical patient, you can't say, 'Send all my information except for the lab work from yesterday,' but laws allow patients to make that kind of decision about their behavioral health data. At this point, these systems don't give patients the granular control that the law says they can have."

"Many of the systems being built to facilitate sharing are leaving mental and behavioral health data out altogether, and that creates an issue," says Deven McGraw, director of the health privacy project at the Center for Democracy and Technology, Washington. While struc-

tured data fields could be flagged or blocked, much behavioral health data is in free text and difficult to flag.

One of SAMHSA's initiatives, Data Segmentation for Privacy (DS4P), is intended to address this issue, and it is testing the concept with the Department of Veterans Affairs, using metadata to signal the privacy level of behavioral health and other sensitive data.

Martin acknowledges that technology is lagging, but questions how much it matters, because if medical provider has enough information to coordinate care—for example, a complete medication list—he or she also has enough information to deduce a great deal about the patient's behavioral health situation. "The state of the art means that data granularity can't be guaranteed, but even if it could, who cares?" he says. "Once they see you have a lithium level, the cat's out of the bag."

Behavioral health, HIE

Regardless of those concerns and challenges, psychiatric data exchange is moving forward on some fronts. In March, Rhode Island's CurrentCare became the first statewide health information exchange to share behavioral health information, uploading data from two mental health and addiction treatment centers. And if its early experience is any guide, the patients will be the least of the challenges.

"What I'm hearing from [the facilities] is that the patients are not that different from the rest of us—they are us," says Laura Adams, president of the Rhode Island Quality Institute, which runs CurrentCare. "They don't want to have to remember all their meds or carry them around in a paper bag, and they don't want an ED treating them without full knowledge of all the prescriptions they take." Even though patients have a choice of three levels of access—emergency only, certain providers only, or all providers who treat them—95 percent, so far, are choosing the "all providers" option.

The addition of behavioral health data to CurrentCare is part of a five-state, $3 million pilot program funded by the Substance Abuse and Mental Health Administration and the Health Resources and Services Administration through their joint Center for Integrated Health Solutions. The other states are Kentucky, Illinois, Maine, and Oklahoma.

SAMHSA has made information sharing a top priority, says Kate Tipping, SAMHSA public health advisor.

"With Medicaid expansion and primary care under reform, we need to ensure that mental health and substance abuse treatment information can be shared to provide whole-person care," she says. "A lot of the HIEs don't have the capability to exchange behavioral health data in compliance with the law because the systems don't have the capacity to manage consents or control redislosure as required by the law."

Rhode Island is the first state to go live. It's the perfect lab for such a venture: small enough to have a manageable number of potential participants, and, unfortunately, the state with the highest rate of mental illness in the country, according to SAMHSA. Almost one in four Rhode Island residents has a mental illness of some kind (compared with one in five in the U.S. as a whole), and 7.4 percent have a serious mental illness (compared with 4.6 percent nationally).

CurrentCare started in 2010 with funding from the American Recovery and Reinvestment Act. It has been "opt-in" since the beginning, which has greatly simplified the transition to sharing mental health and substance abuse records, say Adams.

"A lot of people thought it would be hard and expensive [to get opt-in permission] and that the exchange wouldn't have a lot of data in the beginning, and all that was true," she says. "But this is what our community wanted—patient control over the data." The compromise was that patients had to agree to include all of their data in the exchange.

That first opt-in level of permission gets the patient's data into the exchange, regardless of source. But behavioral health patients have to do a second level of permission to allow providers to look at that data. "We had to re-do the viewer so it had a firewall where that data would be partitioned," Adams says. Both types of permission have to be in place before behavioral health providers upload the data.

The data itself, in the form of XML-based continuity of care documents, is exchanged by Direct secure messaging protocols. "It was a very clever way to take care of secure transport," says Bill Cadieux, CIO of The Providence Center, one of the first two behavioral health providers to upload data. (For more from Cadieux, see "Executive Session," page 40). He says the protocols are strong enough to allay fear of breaches, but inexpensive to implement. "Behavioral health is always on a shoestring budget."

For their part, behavioral health providers can access patients' medical histories through CurrentCare, including medication histories that capture any prescrip-

You May Find This Useful

- Software and Technology Vendors Association: *www.satva.org*
  Trade organization for vendors of behavioral health and human services software.
- Substance Abuse and Mental Health Administration:
  www.samhsa.gov/healthIT/
  Visit this page for information about SAMHSA initiatives
- National Council for Community Behavioral Health: *www.thenationalcouncil.org*
  The "Behavioral Health IT" page has useful background on including behavioral health providers in the meaningful use incentive program, and a recent survey on I.T. adoption by NCCBH members.

tion filled in a Rhode Island pharmacy.

Providers who access substance abuse treatment information will get an extra reminder of the federal regulation forbidding them to redisclose the information without permission, says Linn Freedman, an attorney with the Rhode Island firm Nixon Peabody who advised RIQI on the project. "Once we came up with the model and were able to identify the data feed, we paid the vendor to set up the pop-ups and audits," she says. "I give the RIQI team credit—they spend a lot of resources and effort figuring this out."

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Mental health vs. substance abuse

There are two distinct categories of behavioral health data, governed by different sets of laws. It's confusing enough to make anyone err on the side of extreme caution, but experts say the important thing is to maximize the level of sharing within the limits of the law, not to lock down information unnecessarily.

Mental health records are generated by psychiatrists, therapists, social workers, and others who treat mental illnesses such as depression, anxiety, bipolar disorder and schizophrenia, and by other clinicians who may prescribe or refer for such treatment.

Mental health records are governed by state laws that vary widely in their degree of strictness and level of detail. Some are much stricter than HIPAA. North Carolina and Wisconsin set out several specific contexts for sharing mental health data. Some, such as South Carolina and Oklahoma, allow disclosure to any party with a treating relationship to the patient. Some require the patient's permission for that disclosure, but patients can give a blanket consent for access to their mental health data by any clinician with whom they have a treating relationship. Others require patients to give permission specifying which providers are permitted to share, and which information they want shared.

"Practically every state is different in what rules they have, so if you're a vendor and want to make sure you capture and manage mental health information, you would have to make sure your product could deal with intricacies across all 50 states," says Daviss, who serves as the chair of the American Psychiatric Association's Committee on Electronic Health Records. "That's the biggest challenge for EHRs, which generally don't have special recognition for different categories of information, except maybe a flag saying 'This is sensitive.'"

Daviss, who serves on legislative committees for several professional organizations, says the shootings at Sandy Hook Elementary School in Newtown, Conn., have prompted many state legislatures to reconsider mental health legislation generally, and he recommends keeping a close eye on developments in your state.

Substance abuse treatment records generated by certain facilities and providers are governed by a federal regulation, 42 CFR Part 2. (English translation: Code of Federal Regulations, Title 42: Public Health, Part 2: Confidentiality Of Alcohol And Drug Abuse Patient Records.) The regulation doesn't apply to all providers—only formal drug and alcohol addiction programs operated or funded by the government. Records arising from treatment at such facilities can't be disclosed to anyone without specific permission from the patient, and even parties who have permission are prohibited from redisclosing it without the patient again giving permission.

"Even a doctor can't disclose this information unless it's a treatment emergency, or you have a court order, or the patient has given consent," says Freedman.

The attorney advised the Rhode Island HIE on how to include substance abuse treatment data Even if one of those conditions is met, the doctor or hospital has to promise not to redisclose the information to anyone else, except under the same set of conditions.

Substance abuse treatment records aren't the same as records of substance abuse history, which are not specially protected by this stringent law but might be covered under state mental health record laws and are still covered under HIPAA. Treatment for substance abuse that's not given not as part of a formal addiction program may not be covered either.

This legal patchwork can create puzzles for a health information exchange, says Martin, a psychiatrist who also serves as director of medical informatics for Queens Health Network in New York and medical director of Interboro RHIO, a clinical data exchange serving the city and surrounding communities.

"If you come into my ED dead drunk, your alcohol level in the ED isn't protected under anything but standard law, but if you then go to a detox unit, it's extraordinarily protected," he says. "If you then go to a psych unit your information is covered by another set of laws, and if you end up back in medical treatment for cirrhosis, it's yet another set." ■