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March 2013: Vol. 29, No. 3  
Pages 25-36

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**AHC Media**

## Predictive testing in minors: A new — and growing — ethical challenge for providers

*Direct-to-consumer tests are “game-changer”*

Virtually any predictive test that can be done on an adult can be done on a minor, from tests for Huntington's disease to breast and ovarian cancer to schizophrenia, but “the question is not whether we can, but whether we should,” says **John Lantos**, MD, director of the Children's Mercy Bioethics Center in Kansas City, MO. Lantos says the current era “will be an era of rapid change, phenomenal discovery, and large risks for children.”

While some argue that testing young people for adult-onset conditions in which no prevention or treatment is possible should be avoided until young people are old enough to make more mature decisions as adults. Others argue that for some young people, particularly those who actively seek testing, predictive testing could be beneficial from a psychosocial perspective.

“The debate about predictive genetic testing in young people has been ongoing for about two decades now. Over this time, arguments have been made on both sides of the fence,” says **Rony Duncan**, PhD, Senior Research Fellow at the Murdoch Childrens Research Institute's Centre for Adolescent Health in Victoria, Australia.

It has long been common practice that physicians did not test children for adult-onset disorders, under the rationale that since there was nothing that

## EXECUTIVE SUMMARY

Some ethicists believe that testing young people for adult-onset conditions where no prevention or treatment is possible should be avoided until they are old enough to make more mature decisions as adults, while others argue that this could be beneficial for some adolescents. Other ethical concerns:

- More often, parents are requesting genetic information about their children, even if it is unrelated to childhood diseases.
- Parents now have the option of obtaining genetic information about their children directly from a direct-to-consumer genetic testing company.
- Tests report risks and not certainties for many diseases, and the risks can be very low, making the utility of the information questionable.

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could be done during childhood, the child should have an opportunity to make an autonomous decision about whether he or she wants to receive that information when they reach adulthood, notes **Amy L. McGuire, JD, PhD**, Leon Jaworski Professor of Biomedical Ethics and director of the Center for Medical Ethics and Health Policy at Baylor College of Medicine in Houston, TX.

“Until we can add some empirical evidence to this ongoing debate, I suspect not much will change in terms of international guidelines recommending against testing. Therefore, I hope that one of the developments we see going forward is the generation of empirical evi-

dence about what *actually* happens psychosocially for adolescents who undergo predictive testing for adult-onset conditions that can’t be prevented or treated over the long term,” says Duncan. “Only in this way can our guidelines be truly evidence-based.”

More often, parents are requesting genetic information about their children, even if it is unrelated to childhood diseases, adds McGuire. “If they are refused testing, parents now have the option of obtaining genetic information about their children directly from a direct-to-consumer genetic testing company,” she says. “This is a game-changer.” Physicians will be challenged to provide appropriate education, support, and follow-up testing for children who receive results outside of the medical system, she adds.

“Although online tests are still quite expensive for many people, they do raise questions about how much longer we can control who does and who does not access genetic testing,” says Duncan.

Validity and reliability, the ability of consumers to interpret complex genetic information and multifactorial risk assessments, and how useful they are clinically are key ethical concerns with direct-to-consumer genetic testing, according to **Katherine Wasson, PhD, MPH**, director of the Bioethics & Professionalism Honors Program at Loyola University’s Neiswanger Institute for Bioethics in Maywood, IL. “Will these tests do harm to people, or will people make decisions based on false-positive or false-negative results?” she asks.

For example, a woman might decide to have a mastectomy if she receives results indicating she is at high risk for breast cancer, or might be less vigilant about preventive health measures if test results indicate she is at low risk for heart disease. “Others argue that this type of testing won’t make a strong impact on individuals one way or another,” says Wasson. “Consumers are motivated by curiosity and wanting to know about their own disease risks, but may not do much with the information.”<sup>1-2</sup>

## False positives

More predictive tests will become available in the coming months and years, and more parents will be aware of the tests, predicts Lantos. “More situations will arise in which complex family dynamics make testing seem like a reasonable option,” he says.

While research likely will identify more situations in which predictive tests have medical implications for the child during childhood or adolescence, evidence might indicate that some tests aren’t very useful or have more false positives than true positives. “Parents will think that kids are destined to develop some dreaded disease, but they will never develop that disease,” says Lantos.

Medical Ethics Advisor® (ISSN 0886-0653) is published monthly by AHC Media, a division of Thompson Media Group LLC, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Periodicals Postage Paid at Atlanta, GA 30304 and at additional mailing offices.

**POSTMASTER:** Send address changes to Medical Ethics Advisor®, P.O. Box 105109, Atlanta, GA 30348.

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### EDITORIAL QUESTIONS

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“Even with true positives, they may lead to changes in the way children are treated that are not justified by the test results.”

Since for many diseases the tests report risks and not certainties, and the risks can be very low, the utility of the information is questionable, says **Josephine Johnston**, director of research at the Hastings Center in Garrison, NY. “How much will the test really tell us? We need to be careful that we don’t ‘oversell’ these tests. We must be realistic about what they can and cannot tell us.”

Whole genome analysis opens the door to detecting all sorts of genetic risk factors in anyone tested — embryos, fetuses, children, or adults, adds Johnston. “Since we know so little about what the genetic data means — many identified genetic risk factors account for a very small increase or decrease in individual risk — we’re likely to have lots of genetic data well before we know what it really means.” Another ethical concern is what happens to the information and who has access to it. “Is there a risk that it could be used against the child now or later in life? These risks need to be taken into account before testing is performed,” says Johnston.

## Is there a medical benefit?

Minors who have a family history of a genetic condition are able to undergo predictive genetic testing for most conditions that present prior to adulthood, where there is a medical benefit to the test, says Duncan. For instance, adolescents routinely undergo predictive testing for familial adenomatous polyposis, a bowel cancer predisposition syndrome, because if they are found to be at risk, they can then undergo regular bowel screening and, hopefully, avoid ever developing bowel cancer.

“But for conditions where there is no way to prevent or treat them, predictive testing in children and adolescents is generally recommended against until young people reach the age of majority,” says Duncan.

There might be circumstances under which it is important for parents to know something about the child’s risk for adult-onset conditions, says Johnston, “but I think this needs to be really carefully thought through. Will the child be helped now by this test — and how?”

## Right not to know

Many people prefer not to know their genetic risk factors — sometimes referred to as the “right” not to know — and some testing of minors could deny them the opportunity to exercise that choice, argues Johnston.

“There is a concern about autonomy, in that if we allow mature minors to make decisions about testing before they have the full cognitive capacity to do so, we’ll be threatening their future autonomy to make a decision about testing as a competent adult, thus possibly removing their right *not* to know this information later in life,” says Duncan.

There is a concern that if children or adolescents find out they will develop a genetic condition later in life, this will be psychologically and socially harmful to them in a range of ways — not just as a consequence of their own reactions, but also because of the way that others — for example, their family or employers — might treat them differently, says Duncan.

“Emerging evidence in this field is, in fact, demonstrating a very different story though,” she says. “Interviews with adolescents who have undergone testing demonstrates that, for those who actively come forward to seek testing and do so with associated counseling, testing can relieve psychological distress and enhance life plans. Critically, evidence is also emerging to demonstrate that refusing to test adolescents who have a strong desire to know their gene status can be psychologically distressing for them.”<sup>3,4</sup> ■

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# Real-time consults meet needs of ED doctors, but rarely exist

*Bioethics' relevancy is at issue*

Ethics consults typically involve intensive care unit patients where issues can be thoroughly examined over a lengthy period of time, but what if a provider has minutes instead of days to make a decision? There is “definitely value” in providing emergency departments (EDs) with access to ethics consults, but the traditional ethics committee consultation process is insufficient to meet this need, says **Craig Bates, MD, MS, FACEP**, an attending physician in the Department of Emergency Medicine at MetroHealth Medical Center in Cleveland, OH, and a member of MetroHealth System’s Ethics Committee. “The time frames involved in the consultation process are acceptable for other units in a hospital, but not for an emergency physician with a specific question,” he says.

Bioethics consultations in EDs take three forms, according to **Kenneth V. Iserson, MD, MBA, FACEP, FAAEM**, Professor Emeritus of Emergency Medicine at the University of Arizona in Tucson and co-author of *Ethics in Emergency Medicine* (Galen Press). These are concurrent “stat” consults, retrospective reviews, and prospective policy and statute production. “Consultations during a clinical situation with ethical implications rarely occur,” he says. “The mechanism for round-the-clock ethics consults rarely exists, even in the most sophisticated institutions.”

Iserson notes that EDs have been described as “battlefields.” “This insight may help ethics consultants understand some of the differences between this medical setting — and the professionals working there — and other areas of the hospital,” he says.

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## EXECUTIVE SUMMARY

Ethics consultations typically don’t occur in the emergency department because of time constraints and the necessity of rapid decision-making, but some institutions now offer abbreviated consults in real time. Ethicists can:

- Agree to make themselves immediately available to ED clinicians.
- Reassure providers that they’re practicing ethically with refusal of treatment cases.
- Help practitioners to interpret advance directives.

“They function at a frenetic pace, and always have limited resources — the most valuable of which is time.”

## Stay relevant to clinicians

Individuals who do institutional ethics consultations rarely have the level of emergency medicine experience needed to assist clinicians, according to Iserson. In addition, emergency physicians and nurses might not immediately recognize a situation as an ethical dilemma, might not want others involved in the decision-making process, or might feel comfortable dealing with the issues themselves, as ethics has become more prominent in emergency medicine training, literature, and conferences.

Ethics consultations can promote patient-centered care and sound ethical decision-making, but their application to the ED environment can be challenging because of time constraints and the necessity of rapid decision-making, says **Catherine A. Marco, MD, FACEP**, a professor in the Department of Emergency Medicine and director of the medical ethics curriculum at The University of Toledo (OH).

“Emergency physicians are trained in, and should be facile in, applying ethical principles to ED issues, such as informed consent, refusal of care, end-of-life decisions, minors and confidentiality, and numerous others,” she says. “Institutional availability of timely ethics consultations may be a valuable asset to emergency physicians for complex or high-risk scenarios.” (See related story, p. 29, on one hospital’s “rapid response” model for ethics consults.)

Bates says that an effective strategy for ethics consults in the ED includes these components:

- **Anticipating common ED issues, so that providers have a “toolbox” of approaches to address problems themselves.**

“It is also critical that emergency care providers have a very good understanding of the relevant laws to common situations,” says Bates. These include advance directives, health care power of attorney, durable power of attorney, guardianship, surrogate decision makers, circumstances that impact autonomy of minors, and caring for prisoners or patients in law enforcement custody.

- **Exploring ways to give clinicians rapid access to an ethics committee representative who can provide support for challenging situations.**

“It is useful for this person to have legal knowledge as well, or to provide access to someone with that knowledge base,” says Bates.

- **Discussing challenging cases after the fact.**

“Make sure that all sides learn from these cases,

and adjust education or available resources as appropriate in response,” says Bates.

## Take proactive approach

Discussing scenarios that lead to ethical conflicts in the ED makes it easier to address these in a crisis, says Bates. “This can’t just be at the beginning of the ED visit — it starts in outpatient visits,” he says, adding that while end-of-life issues are a challenging situation for emergency care providers, they are not the most common type of ethical dilemma faced.

Assessing decision-making capacity in patients who refuse treatment is a major part of emergency medicine practice that brings up numerous ethical issues, for instance, and patients in law enforcement custody also present unique ethical challenges in the ED. “Sometimes the only true advocate for their well-being is the health care provider,” says Bates. “The patient and law enforcement can have alternative agendas that cloud their judgment, leaving the health care provider with added responsibility.”

EDs are expected to bring up advance directives at every encounter, but this is very inconsistent with what primary care providers do, adds Bates. “An elderly patient with dementia who consistently sees their primary care provider should have at least some documented discussion about end-of-life wishes on the chart, and the family should have some understanding of that,” he says. “It is very hard to start that discussion fresh, in the heat of the moment.”

Ethicists often find that retrospective ED case discussions are a good way to address bioethical issues, says Iserson. “In the less adrenaline-filled setting of the conference room, clinicians often can more easily identify ethical dilemmas and discuss alternative, ethically acceptable action plans,” he explains.

Ethicists can also routinely attend ED case conferences, or attend conferences on ethically troublesome cases that clinicians have identified, Iserson suggests. “Unless the ethics consultant is also an emergency clinician, a good way to get them involved — and to have them learn more about the nature of emergency medicine practice — is to have one or more of them sit on the institution’s ethics committee,” he advises.

Iserson says the most productive way for bioethicists to positively affect ED practice is to help the clinicians identify recurrent ethical problems that they encounter, such as prehospital resuscitations that neither the patient nor the family desires. “Then work with them to develop institutional or regional policy or state statutes to provide long-term solutions,” he recommends. ■

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## Novel model provides “stat” ED ethics consults

*“Otherwise, it wouldn’t happen at all”*

A “rapid response” model for ethics consultations in the emergency department (ED) was developed at The Ottawa Hospital in Ontario, Canada, using terminology that ED clinicians familiar with “rapid response teams” can relate to. “We recognized that historically, emergency medicine does not rely on clinical ethics consultation support. We are trying to speak the language of the ED,” says **Thomas Foreman**, DHCE, MA, MPIA, director of the hospital’s Department of Clinical and Organizational Ethics.

When Foreman and his team looked into what bioethicists could do to support the ED, they quickly learned that clinicians saw ethics consults as a time-consuming process that wasn’t available on short notice. “We set out to see what we could do to change that,” he says. “We had to reconsider the model that was being used.”

In the traditional consultation model, ethicists receive a request, evaluate it, approach the care team, talk with the patient and family, and arrange meetings as needed over a period of days or weeks — none of which is possible in a busy ED. Ethicists agreed to make themselves immediately available to the ED.

“We abbreviated the process to meet the unique needs of emergency medicine practitioners,” says Foreman. “You don’t necessarily need a family meeting in the ED.” Instead, providers were looking for guidance and direction around some of the complex ethical issues that come through the ED. Patients are often transferred to the ED from long-

term care facilities, for instance.

“The traditional notion is that you show up in the ED because you want to be treated — otherwise, you wouldn’t be there. The fact is, though, many of these patients *don’t* want to be treated,” says Foreman. “Does the patient really want us to do chest compressions, or are they here for another reason? The mindset of the emergency physician (EP) needs to change a bit in this situation. The patient is not here to be ‘fixed,’ but we need to do something.”

### Three-minute process

Providers sometimes grappled with what to do when patients refused treatment, especially for time-dependent treatments such as thrombolytics for stroke. Bioethicists now help them to determine how to assess the person’s capacity to make the decision, and whether to allow patients to make a decision the provider believes will harm them.

“When the EP calls us, we ask them, ‘What are you unsure about? What can we do to support you and the patient?’ Really, the bottom line is that we allow the ED staff to tell us what their needs are,” says Foreman. “What we have found, most often, is that it’s really about walking the practitioner through the process of ethical decision making.”

Most of the time, providers are already on the right track, but want some reassurance that they’re doing the correct thing from an ethics perspective, he explains. Previously, ED providers had the attitude “We don’t have time to reflect. We’ve got to act or people die,” says Foreman, but now they feel more comfortable having this kind of conversation. Ethicists also had to change their mindset.

“Some ethicists take the approach, ‘I don’t do ethics consults by emergency. If it’s a crisis, don’t expect us to help,’” says Foreman. “I agree that early involvement and being proactive is the best way to avoid ethically contentious situations. But emergency medicine does not lend itself to that.”

Foreman’s office is located near the ED, which allows him to respond on a moment’s notice. Bioethicists developed pocket-sized “trigger” cards to help physicians determine if they need a consult.

Foreman says that bioethicists’ training and experience allows them to offer a rapid, quick session when necessary. “I have a library of scenarios in my mind, so instead of it being a three-hour process, it can be a three-minute process,” he says. “I wouldn’t say it’s the perfect way to do ethics consults all the time, but otherwise it wouldn’t happen at all.”

### Ethicists give support

Bioethicists don’t make concrete recommendations, but, rather, help practitioners to decide what they believe is the right direction to go in. Recently, an emergency physician called for an ethics consult on an elderly man who stated that he did not want his percutaneous endoscopic gastroscopy tube put back in and wanted to be left alone to die. “The family told him, ‘Don’t listen to him, he is just depressed. Put the tube back in,’” says Foreman, who began by asking the physician whether, based on his assessment, he thought the patient was clinically or situationally depressed. The emergency physician responded that it was situational, which meant he had the obligation to respect the patient’s decision for or against intervention.

“The physician said, ‘Based on that, I’m going to listen to my patient.’ I then told him, ‘If you want me to participate in a conversation with the patient and the family about how you’ve gotten to this place, I’m happy to do that,’” says Foreman. “At times, the bioethicist’s physical presence adds a level of support to the physician and the family, to facilitate a very difficult conversation as a neutral third party.”

In another case, a physician asked for help interpreting the advance directive of a woman transported from a long-term care facility with a gastrointestinal (GI) bleed. “The physician said that on the surface, the advance directive sounded like he should leave her alone and not treat the GI bleed, but it was an easy fix and she’d go back to the same level of quality of life. If it wasn’t addressed, she would bleed to death,” says Foreman. “We walked very quickly through what the physician anticipated was the mindset of the patient. He concluded that he would treat the GI bleed because it was life-threatening but not related to a underlying comorbidity.”

Most bioethicists were taught a “one-size-fits-all” approach to consultations, says Foreman, “but ethics must be dynamic. We must meet the needs as they present themselves, not as we want them to be. There is a perception that if you don’t go through a lengthy process, that you somehow lose quality. I’m not so sure I believe that. The quality of the consult isn’t based on the length of the consult.”

Without access to ethics consults, emergency physicians will face increased moral distress leading to burnout over time, adds Foreman, and if bioethicists do not meet the needs of different care providers, they “will soon become irrelevant.” ■

# Providers' obligation: Protect both patients and society

*Excessive use of involuntary commitment is concern*

Unfounded and ineffective excesses in the use of involuntary commitment proceedings could result from the public's horror over recent mass shootings, according to **John Z. Sadler, MD**, Daniel W. Foster, MD, professor of medical ethics and professor of psychiatry and clinical sciences at University of Texas (UT) Southwestern in Dallas, TX, pointing to the sociological concept of the "outrage dynamic," which emerges in the face of rare but horrific tragedies.

"The media coverage is excessive, the public becomes outraged, and political opportunism and legislative haste can generate quick and bad policy," he says. "Providers should understand the context and limitations of using involuntary treatment as a social control mechanism for the very infrequent events of mass shootings."

Sadler says what is needed is widely accessible and good quality mental health care, including prevention. Encounters with mental health professionals are avoided by potential offenders, he says, and mental health and nonspecialist health care providers are very poor at predicting violence and tend to over-predict rather than under-predict. The best mental health experts can do is identify long-term risk factors, which are relatively useless for predicting behavior over the next few hours or days, says Sadler.

"This means that the prevention rate of an actual violent event is going to be very low, even with an aggressive, low-threshold commitment policy," he says. "To increase the capture rate, we would have to involuntarily seclude many more people than could be ethically tolerable in terms of tradeoffs between safety and the preservation of civil liberties."

## Difficult risk/benefit decisions

The decision to commit someone should be based upon a thorough examination, and alternatives to hospitalization should be vigorously sought, says Sadler. "A consideration of the long-term consequences of involuntary treatment should be made for the patient," he says. "These often provoke difficult risk-benefit decisions." For instance, providers might have to decide whether to commit a

depressed patient who is likely to lose her job as a result of the hospitalization.

"Finally, the clinician needs to ask him- or herself whose interest the commitment is serving. In my professional travels and consulting, I've seen too many doctors tempted to treat their own anxiety by committing patients who could be better served by less restrictive alternatives," says Sadler.

Recent mass shootings may have providers assessing a patient's risk to him- or herself, providers, or third parties more in-depth, and possibly considering these risks with patients that they may not have done so in the past, says **Marianne L. Burda, MD, PhD**, a Pittsburgh, PA-based ethics consultant and educator. "Each patient's medical care and treatment should be based on that particular patient's history, physical exam, and evaluation," she emphasizes. "Hopefully, recent events will result in an increase in resources and access to mental health services for those in need of these services."

Providers should weigh preventing harm to the patient, health care providers, and/or third parties, with respect for a patient's autonomy, especially if the patient is refusing recommended medical care and treatment, when deciding whether to involuntarily commit a patient, says Burda. She says providers should do the following:

- **Ensure patients have access to needed medical care and services, including mental health services.**
- **Respect the patient's autonomy by providing a full informed consent and shared decision-making with the patient, along with assessing the patient's decision-making capacity in that particular situation.**
- **Maintain patients' trust in their providers and the health care system.**

Burda says, "Confidentiality is one important aspect of this trust and the provider-patient relationship."

- **Determine if there is a clear and identifiable threat from the patient to him- or herself, providers, and/or third parties.**

If there is a threat, preventing harm by breaching confidentiality or involuntary commitment is the right thing to do ethically. "If no threat exists, providers must balance breaching the patient's confidentiality or involuntarily committing the patient with the possible result of loss of the patient's trust and damaging the provider-patient relationship, which may result in the patient avoiding obtaining needed medical care and treatment," says Burda.

## Unintended consequences

A policy of overuse of involuntary commitment

proceedings will have unfortunate unintended consequences, such as potential patients becoming even more wary of seeking psychiatric help for fear of being “locked up,” says Sadler. “A policy intended to protect the public at the expense of patients’ civil liberties will drive away patients whom we would most want to obtain treatment,” he says. “The answer is to provide full and easy access to mental health care in the United States. We are distinctive among our industrialized neighbors and European countries in both having a mass shooting problem and the poorest access to mental health care.”

As access to good quality mental health care increases, the need for involuntary treatment decreases, adds Sadler. “This suggests that our poor record in providing adequate mental health services for Americans substitutes the value of autonomy for the coercion of sick, neglected people through involuntary treatment,” he says. “This is an ethical failure of our society.” (See related story, p. 32, on how providers should make determinations regarding involuntary commitment.) ■

## Providers face these ethical challenges with commitment

*They must make clinical, legal determinations*

The need to protect others from a potentially harmful patient is a pressing ethical issue not just for health care providers, but for *society* to contemplate at this juncture, according to Gary E. Jones, PhD, JD, professor in the Philosophy Department at University of San Diego (CA).

“If there is an ethical dilemma surrounding involuntary commitment, it is society’s heretofore unwillingness to address mental illness as a whole,” says Jones. “Involuntary commitment is only one aspect of mental illness, albeit a significant aspect when lives are lost as a result of a mentally ill person who is dangerous.”

The legal and clinical worlds have mechanisms in place to involuntarily commit a person when they are a danger to themselves, to others, or when they are gravely disabled, says Jones, but “the whole process of involuntary commitment is only as effective as the laws which regulate it.”

Thus, if society as a whole believes the laws governing involuntary commitment are ineffective, the onus is on society to change the laws, he argues. “There is virtually no opportunity during the process of involuntary

commitment to make an arbitrary decision as to committing a person if the clinician, law enforcement personnel, and legal representative are following the law and their particular training,” says Jones. “Simply put, if the person in question meets certain clinical and legal criteria, he or she may be involuntarily committed.”

### Awareness of laws

There are *two* determinations to make — a clinical and legal determination — before a person is involuntarily committed, says Jones. Clinically, a psychosocial history is taken, the person is questioned as to the imminence of the danger to self, to others, or grave disability, and a provisional diagnosis of a mental illness is made or a person’s previous psychiatric diagnosis is reviewed.

“Much information must be gathered and put into context in order to determine whether a person is a danger to themselves, to others, or is gravely disabled,” says Jones. Legally, the threshold, or burden of proof, to determine or persuade authorities that there is an imminent danger to self, to others, or grave disability is very low — that of probable cause, which is a relatively low standard of evidence, he notes.

When a person is put on a 72-hour involuntary hold, he or she is continually observed and assessed with the goal of stabilizing that person, says Jones, and the psychiatric facility must make the determination to petition the court to extend the involuntary hold or release the person. “Many factors are taken into consideration as to whether the facility will release the person or extend the hold,” says Jones. For example, if the person has little or no psychiatric history and has been stabilized, he or she is usually released and given referrals for outpatient treatment, but if the person has not been stabilized, and there is a previous psychiatric history, the hold is usually extended.

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## EXECUTIVE SUMMARY

Unfounded and ineffective excesses in the use of involuntary commitment proceedings could occur in light of recent mass shootings, but ethicists argue what is actually needed is better access to mental health services.

Some ethical concerns:

- Potential offenders might avoid encounters with mental health professionals.
- Both mental health and nonspecialist health care providers are very poor at predicting violence.
- The decision to commit someone should be based upon a thorough examination, and alternatives to hospitalization should be vigorously sought.

“The Sandy Hook school shooting will not change the way a clinician or a legal representative determines whether a person should be involuntarily committed,” says Jones. “This horrific massacre *should* change society’s awareness of the laws governing involuntary commitment, and more broadly, treatment for the mentally ill. Through this awareness, the laws must change.” ■

## SOURCES

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# Online behaviors need ethical clarification

*Consequences vary for violations*

There is low consensus among state medical boards as to whether derogatory speech toward patients, showing alcohol use without intoxication, and providing clinical narratives without violation of confidentiality constitute a violation of online professionalism, according to a recent study.<sup>1</sup> Researchers found moderate consensus on whether depicting alcohol intoxication, violating patient confidentiality, and using discriminatory speech are violations, and high consensus that citing misleading information about clinical outcomes, using patient images without consent, misrepresenting credentials, and inappropriately contacting patients are violations.

Areas of high consensus suggest that these are online behaviors that physicians should never engage in, and increased awareness of these specific behaviors might reduce investigations and improve online professionalism for physicians, the researchers concluded. “In the pre-survey interviews with key informants in the licensure community, we encountered a lot of concern about these online behaviors. We were expecting boards to demonstrate high consensus around the most egregious behaviors,” says **S. Ryan Greysen**, MD, MHS, MA, assistant professor in the Division of Hospital Medicine at University of California, San Francisco.

“What was most interesting was learning more about the thought process of boards and the importance of contextual elements for the vignettes in ‘gray areas,’ such as alcohol use,” says Greysen. The boards

are clearly not interested in “policing” doctors who post pictures of themselves drinking online, he explains, but if the online pictures suggest problematic use of alcohol, or if the doctor in question has a history of problematic use, then this can become an important piece of the overall picture.

“The overwhelming message here is to apply the same principles of professionalism to online and offline actions,” says Greysen. “Sometimes, doctors feel that what they do online has no bearing on their professional obligations. On the contrary, boards clearly view public actions — online or not — as part of the physician’s duty to maintain professionalism.”

## Clarity is needed

While some online behaviors are clearly unethical — for example, posting information identifying a patient without consent — “others are becoming clear, such as the idea that providers should not post anonymously,” says **Matthew DeCamp**, MD, PhD, a post-doctoral fellow in bioethics and health policy at the Johns Hopkins Berman Institute of Bioethics and Division of General Internal Medicine in Baltimore, MD. “For those areas where clarity is lacking, providers should proceed cautiously, keeping in mind that information spreads rapidly, can be beyond one’s control, and is essentially permanent.”

Almost half (49%) of 180 first-year medical students reviewed or changed their online presence immediately after attending a two-hour session on online professionalism.<sup>2</sup> “This reflects the urgency experienced by our students to build their professional online presence early in their training,” says **Desiree Lie**, MD, MSED, clinical professor of family medicine and course director for the Professionalism and the Practice of Medicine

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## EXECUTIVE SUMMARY

There is high consensus among state medical boards that citing misleading information about clinical outcomes, using patient images without consent, misrepresenting credentials, and inappropriately contacting patients constitute violations of online professionalism, which clearly suggests that physicians should never engage in these behaviors, but other online behaviors are less clear.

- There is low consensus as to whether derogatory speech toward patients, showing alcohol use without intoxication, and providing clinical narratives without violation of confidentiality are violations.
- Boards clearly view public actions — online or not — as part of the physician’s duty to maintain professionalism.
- Bioethicists help physicians to think critically about their online activities.

course at the Keck School of Medicine of the University of Southern California in Los Angeles.

“Their responses reinforce to educators that we should introduce this curriculum early in medical school training,” argues Lie. “We were impressed by the thoughtfulness of students’ reflections about their developing professional identities and about the responsibilities inherent in the transition from student to physician.”

Current providers who have been educated in a less digitally connected age are likely to be surprised by the attention paid to professional and personal online presence by their younger new practice partners, adds Lie. “They may see a rise in the use of social media for the marketing of professional services — a practice that will certainly be subjected to greater public scrutiny in future,” she says.

## Major role for bioethicists

Bioethicists can engage with physicians in helping them to think critically about their online activities, says **Amy DeBaets**, PhD, an assistant professor in the Department of Bioethics at Kansas City (MO) University of Medicine and Biosciences — for instance, they can point out that physicians should assume that anything they write in an online format, including “private” networks like Facebook and Twitter, can be made public.

“All it takes is one friend to make it known to the world. So don’t talk about your patients online, even when you think it’s private,” she says. “Likewise, don’t use the Internet as a sounding board for complaints you may have about colleagues or those who work for you.”

Bioethicists have already been helping to sort out some of these issues, such as helping institutions understand and navigate the ethical challenges of recruiting and conducting clinical research via social media and social networks, says DeCamp, but also have a major role to play in clarifying some of the gray areas. For example, bioethicists can help determine whether providers should separate personal and professional identities online, or if this is even possible.

Bioethicists can help by working with hospitals and health care systems to develop and implement guidelines for online activity and public statements made by physicians, adds DeBaets. “We can work with existing professional codes, expand them to include the utilization of new technologies, and give guidance on specific questions as they arise,” she says.

Bioethicists are already helping hospitals and health systems to think through some challenging issues, says DeCamp. For example, a health system might have its providers post expert content about diseases or treat-

ments on its social media sites. “How can that health system ensure meaningful disclosure and management of providers’ potential conflicts of interest, such as commercial funding and industry relationships, given the brevity and format of most social media content?” asks DeCamp. “Bioethicists are actively engaged in brainstorming ways to accomplish this, to ensure the veracity of online information.” ■

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1. Greysen SR, Johnson D, Kind T, et al. Online professionalism investigations by state medical boards: First, do no harm. *Ann Intern Med* 2013;158(2):124-130.
2. Lie D, Trial J, Schaff P, et al. Being the best we can be: Medical students’ reflections on physician responsibility in the social media era. *Acad Med*. 2013;88(2):240-245.

## SOURCES

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## Ethical responses to surreptitious recording

Is a patient recording a physician without the doctor’s knowledge? If so, the reason could be that the patient simply wants to remember complicated discharge instructions, or that he or she intends to use the information as evidence against the physician in a legal proceeding.

“Based on my experience in the acute care context, surreptitious recording of health care providers is an increasing trend,” says **Sally Bean**, JD, an ethicist and policy advisor at the Joint Centre for Bioethics at University of Toronto’s Sunnybrook Health Sciences Centre. “Covert recording is symptomatic of an impaired therapeutic trust relationship which normally forms the foundation of a healthy patient-physician relationship.”

Bean says she is aware of covert recordings that were done to address general concerns, such as a patient or family member creating a record for peace of mind in case something bad should happen, as well as record-

ings done in response to specific concerns, such as when a pediatric patient cannot be accompanied at all times by a parent.

Alternatively, patients or family members have resorted to covert recording in response to a particular situation, in order to substantiate a claim that inappropriate care was provided. “Once the recording has been made, it can easily be uploaded to a variety of file-sharing services for broad public dissemination,” says Bean.

Covert recordings might lack important context that would provide a fuller understanding of the interaction, and unfairly depict one side or perspective of the issue, and the autonomy and privacy of the health care provider might be undermined, says Bean. “Vulnerable patients, such as children and persons with cognitive impairments, cannot provide consent to have their own privacy potentially infringed by covert recording,” she adds. Providers should consider these practices:

- **Communicate with patients to understand what need they seek to fulfill with the recording.**

“Not all purposes may be as sinister as they initially seem,” Bean says. For instance, a patient with limited English proficiency might be recording the conversation to have for later reference, but feels too embarrassed to ask for permission to record the interaction.

While some patients record physicians with the intent of using what they have said as proof in a later medical malpractice action, others just want to remember what was said when considering a major medical decision, says **I. Glenn Cohen**, assistant professor at Harvard Law School and co-director of the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics.

“Physicians have a fiduciary duty to their patients, the cornerstone of which is trust. Being surreptitiously recorded is a strong violation of that trust,” says Cohen. “If they came to believe that the practice was widespread, some physicians might alter the depth or even the content of information they provide patients, for fear of future liability.”

Patients should clear the request to record with the physician in the first place, says Cohen. “Under the Affordable Care Act’s reforms and incentivizing to move to electronic health records, many physicians are already giving new ‘Clinical Summary’ documents to patients through many electronic health record applications,” he notes. “These include a list of medications and physicians’ recommendations that may fill the void in the benign usage cases.”

- **If a patient asks to record an interaction and the health care provider feels that it is inappropriate under the circumstances, the provider should explain his or her rationale.**

“Emphasize that you cannot record patients without their consent and to please extend you the same

courtesy,” Bean says. “Perhaps a compromise can be reached where a patient takes notes for later reference, or a professional medical interpreter is used to facilitate communication.”

Cohen says that an ethical response, mirroring what many faculty do when lecturing, is to explicitly inform patients that no recording devices may be switched on without explicit permission during the session. “If a patient disobeys, it is not clear the physician would have legal recourse,” he says. “But in many cases it will discourage patients who would have been tempted to record, by invoking moral suasion.”

- **Be aware of applicable state laws regarding use of covert audio and video recording without consent.**

“If it is deemed that a punitive response to an ongoing pattern of covert recording is warranted, for example, the response should be thoughtful and proportional to the infraction rather than an emotional knee-jerk response,” says Bean.

There are also ways in which patients may jeopardize their own confidentiality in these recordings, notes Cohen. “Recordings made for private purposes on an iPhone, for example, may fall into someone else’s hands and could even be posted online,” he says. ■

## SOURCES

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## CME OBJECTIVES

Upon completion of this educational activity, participants should be able to:

- Discuss new developments in regulation and health care system approaches to bioethical issues applicable to specific health care systems.
- Explain the implications for new developments in bioethics as it relates to all aspects of patient care and health care delivery in institutional settings.
- Discuss the effect of bioethics on patients, their families, physicians, and society.

## COMING IN FUTURE MONTHS

- Making bioethics more relevant
- New high-tech, high-cost interventions
- Ethical responses to online reviews
- Health care reform and informed consent

## CME QUESTIONS

- Which is true regarding predictive testing in minors, according to **Amy L. McGuire**, JD, PhD?
  - There is clear evidence that predictive testing for adolescents who actively seek testing and do so with associated counseling is significantly harmful from a psychosocial perspective.
  - It has long been common practice that physicians did not test children for adult-onset disorders, under the rationale that since there was nothing that could be done during childhood, the child should have an opportunity to make an autonomous decision about whether he or she wants to receive that information when they reach adulthood.
  - Parents are less often requesting genetic information about their children, even if it is related to childhood diseases, due to ethical concerns.
  - It is unethical for physicians to provide appropriate education, support, and follow-up testing for children who receive results outside of the medical system.
- Which is true regarding the role of bioethics in the emergency department, according to **Thomas Foreman**, DHCE, MA, MPA?
  - It is never advisable for ethicists to routinely attend emergency department case conferences or attend specific conferences on ethically troublesome cases that clinicians have identified.
  - Ethicists should agree to make themselves immediately available and abbreviate the consult process to meet the unique needs of emergency medicine practitioners.
  - It is unethical to offer abbreviated consults to emergency department providers because evidence clearly shows this practice can harm patients.
  - When providing consults to emergency clinicians, bioethicists should always make concrete recommendations about clinical decisions, as opposed to helping the practitioners to decide for themselves what they believe is the right direction to go in.
- Which is true regarding ethical considerations for providers making a decision as to whether a patient should be involuntarily committed, according to **John Z. Sadler**, MD?
  - Providers should remember that there is no evidence that encounters with mental health professionals are avoided by potential offenders.
  - Even nonspecialist health care providers are very good at predicting violence, and tend to under-predict rather than over-predict violence.
  - The decision to commit someone does not need to be based upon a thorough examination, and alternatives to hospitalization don't need to be vigorously sought.
  - Mental health and nonspecialist health care providers are very poor at predicting violence, and the best they can do is identify long-term risk factors that are relatively useless for predicting behavior over the next few hours or days.

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