



Society Welcomes First Director of Patient Engagement

Sue Sheridan, a nationally renowned leader in patient safety, has joined the Society to Improve Diagnosis in Medicine (SIDM) as the organization's first-ever director of patient engagement. Sheridan is spearheading efforts to ensure that the patient and family perspective informs all facets of SIDM's work.

"The patient perspective is often missing from strategies to improve healthcare delivery and reduce medical errors, including diagnostic errors," said Paul Epner, SIDM's chief executive officer. "Any solution to reduce the harm and cost of diagnostic errors must integrate the patient and family perspective."

In 2015 the National Academy of Medicine (formerly the Institute of Medicine) issued its seminal report on diagnostic errors, *Improving Diagnosis in Healthcare*. A key recommendation from the report was for healthcare professionals to partner with patients and their families to improve the diagnostic process.

Based on extensive work with and on behalf of patients and families, Sheridan observes:

Patients are now "co-developers" working with prominent research organizations, health systems, and government agencies, such as the Patient Centered Outcomes Research Institute [PCORI], the Agency for Healthcare Research

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Transgender Patients and Diagnostic Safety: Back to Basics

By Susan Carr

Seeking treatment for a broken arm, J has to explain their transgender status before the physician would tend to the immediate problem, the injured arm. In "The Dangers of Trans Broken Arm Syndrome," J reports:

In the five minutes it takes to grill me on gender stuff and write it all down, the orthopod has squandered a quarter of the time they've got to fix my broken arm, in order to waste another doctor's time by telling her [J's primary care physician] something she already knows.¹



Jay Kallio encountered barriers to getting the care he needed for breast cancer. Having had a biopsy, with no word for weeks about the results, he thought everything was alright. Suspecting Jay had not heard that the biopsy confirmed the breast cancer diagnosis, the radiologist called to tell him. The original surgeon admitted that he was so uncomfortable with Jay's transgender status, he could not convey the diagnosis or communicate with him at all. Kallio arranged to have a mastectomy performed by a different surgeon. Then he needed chemotherapy and again had trouble finding a doctor for whom his being transgender was not a problem.^{2,3}



Responding to a survey in 2016, a Canadian physician describes feeling anxious and uncertain about treating transgender patients:

There's this fear that run of the mill problems aren't run of the mill. What if there's something related to something I'm not aware of, ... I have a lot of anxiety seeing these people, not because of who they are, but because I feel I'm not well educated, I'm not well prepared about what the potential concerns are.^{4(np)}



These examples illustrate some of the challenges transgender patients encounter in healthcare, many of which affect diagnosis. The problems often derive more from clinicians letting the patient's gender identity get in the way of delivering good care than from medical issues related to the patient's transgender status. The presence of bias, uncertainty, and anxiety in clinical encounters leads to poor communication, all known to erode patient safety and contribute to diagnostic error. The first step toward ensuring the safety of transgender patients should be to provide sincere patient-centered care that accepts and respects the patient and is tailored to their individual needs and preferences.^{4,7}

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Transgender Patients and Diagnostic Safety: Back to Basics

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Looking at the transgender population as a whole, there are some circumstances those providing care should be aware of. Because transgender patients often face social, structural, and economic barriers when they seek care, they tend to have unmet medical needs.^{8,9} On average, they are more likely than cisgender patients to be uninsured and socioeconomically disadvantaged, and many lack access to routine, preventive care.^{8,9}

Little is known about the demographics and health trends of the transgender population. Most federal health surveys omit gender identity and transgender status;^{7,8} the United States census also does not record data related to gender identity.¹⁰⁻¹² Susan Boisvert, a nurse, senior risk specialist, and mother of a transgender son, points out that being invisible is a unique feature of the transgender population and the single most important risk transgender patients face.¹¹

Although largely absent from federal data, there are estimated to be 1.4 million transgender adults in the United States,¹⁰ all of whom will need at least primary care at some point. They often have trouble finding available providers.⁸

Medical schools are beginning to include transgender medicine in their curricula, but there is currently a shortage of providers with the training and experience that transgender patients need.

There is very little clinical evidence related to transgender medicine, and that which does exist comes from studies done in Europe with populations that are not representative of the United States.¹³ Transgender care is more often informed by guidelines than evidence-based medicine. Some guidelines, such as those published by the University of California, San Francisco, (<http://transhealth.ucsf.edu>) are based on reliable, expert experience and consensus.¹³ There are areas of transgender medicine, however, such as hormone therapy and gender-related surgeries, for which long-term outcomes are not yet known.

In addition to being absent from national data, information about gender status, which can be crucial to good patient care, is usually not recorded in electronic health records. If transgender patients do not share their medical history with their physicians—either because they don't feel comfortable or don't know the information is important—physicians may not realize, for example, that a transgender male patient has a uterus and ovaries. Transgender men may need to be screened for breast cancer, and transwomen screened for prostate cancer. Knowing a patient's gender history also could be important to laboratory testing; hormone therapy may produce results that don't match expectations—estrogen in a patient with male reproductive organs, for example.¹⁴

Despite cultural challenges and lack of evidence-based guidance, caring for transgender patients is not inherently difficult or different from caring for cisgender patients.⁴ Medical conditions specific to transgender patients are generally not complex or challenging. Providing good care and avoiding diagnostic errors come down to practicing good communication, offering acceptance, and managing bias—universally applicable, patient-centered practices.

Actions for Improving Diagnosis in Transgender Care

The following strategies can be used to improve the diagnostic safety and quality of healthcare in general for transgender patients:

Little is known about the demographics and health trends of the transgender population.

Glossary

Transgender: A person whose gender identity differs from their sex at birth.

Cisgender: A person whose gender identity matches their sex at birth.

Transgender male or man; trans-man: Assigned female gender at birth based on biology and now identifies as male.

Transgender female or woman; trans-woman: Assigned male gender at birth based on biology and now identifies as female.

Gender dysphoria: Distress experienced by some individuals who feel their gender does not match their biology, or for whom the gender assigned them at birth is not the gender with which they identify.

Gender identity: The personal experience of gender; the gender with which an individual identifies, which may not match their gender at birth. Gender identity may also include not identifying with strict binary distinctions of male and female.

Gender expression: How a person exhibits or expresses their gender identity, through choices of behavior, mannerisms, clothing, hairstyle, etc.

Gender nonconformity or gender variance: Feeling and behaving in ways that do not fall within societal expectations or accepted, binary norms for male and female.

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- Develop a list of specialists—endocrinologists, gynecologists, urologists, psychiatrists, dermatologists, and others—who understand and treat transgender patients. Transgender individuals are at high risk of depression, suicide, substance use, and HIV,^{7,8} and should be referred for screening and counseling to providers who are experienced and comfortable with transgender patients.
- In consultation with each transgender patient, do an “organ inventory” to inform diagnosis and treatment and to assess the need for preventive screening.
- Ensure that the environment, including the behavior of all staff members, is welcoming and respectful of transgender patients.⁶ At registration, provide options for recording gender identity that allow flexibility—eg, check boxes for male, female, and space provided for other responses. Also, ask transgender patients which pronouns they prefer be used when referring to them.

Assessing transgender status in young children is a specialized science. Norman Spack, MD, co-director of the Gender Management Service at Boston Children’s Hospital, estimates that up to 80 percent of children who engage in cross-gender behavior are not transgender, but it is not currently possible to know which children are truly transgender until they reach puberty.¹⁹ Spack observes:

... when children don’t accept their birthright to the puberty that’s consistent with their sex,

then those children are almost certain to be transgender.^{19(ip)}

In early teenage years, to allow more time for the child’s gender identity to become known, puberty is often purposefully delayed with medication.

Back to Basics

To improve diagnosis for transgender patients, primary care physicians (PCPs) need first to ensure they are practicing sincere patient-centered care. If they feel unprepared to manage particular needs of these patients, they should ask for help; specialists and resources are available (see resource list on p4). The transgender community can also be asked directly for guidance. Boisvert says:

Transgender individuals know that some cisgender people feel uncomfortable around them. They also know many are coming from the right place and want to do the right thing. PCPs need to accept that they may make mistakes. If they say something awkward to a transgender patient, they just need to apologize and move on. Some providers may want to say right up front that they don’t have a lot of experience with transgender patients. They may need simply to clear the air: “I’m happy to be working with you. I hope you’ll feel comfortable pointing out any mistakes I make. Feel free to let me know if I’ve misspoken” (Susan Boisvert, personal communication, December 2017).

Commenting on an article about the health needs of transgender people, David Matheson, MD, similarly recommends putting assumptions aside:

... if one uses Ludwig Wittgenstein’s dictum: DON’T THINK, BUT LOOK, one sees what is there without imputing values or inappropriate judgments.^{5(ip)}

Clinicians may feel anxious facing a transgender patient and sense they are practicing in uncharted waters, which in many ways, they are. For successful clinical encounters, clinicians and patients alike need to be accepting and patient, practice good communication, and treat each other with respect.

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Is “Transgender” a Diagnosis?

Similar to homosexuality, being transgender has been considered a pathological disorder in the past, but that is now changing.^{15,16}

In 1980, being transgender was included for the first time in the *Diagnostic and Statistical Manual (DSM)-III*¹⁷ as “transsexualism” and listed under “gender identity disorders.” In *DSM-5*,¹⁸ published in 2013, transsexualism was re-labeled “gender dysphoria,” with separate diagnoses for children, adolescents, and adults. Gender dysphoria refers to acute distress an individual may feel related to an incongruity between their gender identity and their gender assigned at birth.¹⁶

The [International Classification of Diseases](#) still uses the term “transsexualism.” It is, however, expected to shift the diagnosis in the next edition from the mental disorders section to one that covers sexual health.¹⁶

Although seen to be helpful in accessing and paying for care, considering “transgender” to be a diagnosable medical condition is thought by many in the community to reinforce discrimination.

Resources for Transgender Care

Center of Excellence for Transgender Health. University of California, San Francisco. <http://transhealth.ucsf.edu>

Disorders of Sex Development and Gender Management Service. Boston Children's Hospital. <http://www.childrenshospital.org/centers-and-services/disorders-of-sexual-development-dsd-and-gender-management-service-program>

Lesbian, Gay, Bisexual, and Transgender Health. Centers for Disease Control and Prevention. <https://www.cdc.gov/lgbthealth/health-services.htm>

Transgender medicine and surgery. Boston Medical Center. <https://www.bmc.org/center-transgender-medicine-and-surgery>

Vanderbilt Program for JGBTI Health. Vanderbilt Health. <https://vanderbilthealth.com/lgbtihealthprogram/>

World Professional Association for Transgender Health. Standards of Care. http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351

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Society Welcomes Director of Patient Engagement

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Sue Sheridan, MBA, MIM
Director of Patient
Engagement

and Quality, and the Centers for Medicare and Medicaid Services. But more must be done to make sure patients' and families' voices are heard.

Before joining SIDM, Sheridan served as the patient and family engagement adviser in the Center for Clinical Standards and Quality at the Centers for Medicare & Medicaid Services (CMS), where she developed strategies and processes to integrate CMS's newly launched Person and Family Engagement Strategy throughout the CMS community.

From 2012 to 2016, Sheridan served as the director of patient engagement at PCORI, where she was responsible for creating networks and engaging patients nationwide to provide broad-based input on the development and execution of PCORI's research.

Inspired by her family's adverse experiences in the healthcare system, Sheridan has been a tireless patient advocate. She is co-founder and past president of Parents of Infants and Children with Kernicterus, which works in partnership with private and public health agencies to eradicate kernicterus. In 2003, she co-founded Consumers Advancing Patient Safety, which she served as president from 2003 to 2010.

Sheridan received her BA from Albion College, her MIM and MBA from Thunderbird School of Global Management, and her Honorary Doctorate of Humane Letters from Adrian College.

To learn more about SIDM's efforts to engage patients or join our network of patients who have experienced harm due to diagnostic error, please email Sheridan at:

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FROM THE FIELD

New Framework Proposed for Improving Diagnosis

Olson APJ, Graber ML, Singh H. Tracking progress in improving diagnosis: a framework for defining undesirable diagnostic events. *J Gen Inter Med*; 2018; doi:10.1007/s11606-018-4304-2

Measurement is a perennial thorn in efforts to improve healthcare delivery, including diagnosis. Being a relatively new science, diagnostic safety lacks established ways to measure the quality of diagnostic performance, the incidence of errors, and the results of actions intended to prevent them. Developing useful, rational, and reliable systems for measurement is therefore a priority.

In the *Journal of General Internal Medicine*, Andrew Olson, Mark Graber, and Hardeep Singh, propose a framework for identifying "undesirable diagnostic events" (UDEs) that can be used to measure diagnostic safety. UDEs are situations that include a condition, such as bacterial meningitis or sepsis, that meets certain criteria that determine the UDE's suitability as a target for diagnostic improvement. The criteria include a clinical setting, such as the emergency department or inpatient unit; a clear reference standard for verification of diagnosis; sufficiently frequent occurrence to provide a reasonable denominator; and

having a "balance measure." The balance measure provides a way to monitor the UDE for unintended and undesirable effects of improvement efforts. For example, the number of MRI exams performed in the ED for back pain can be used to watch for over-testing that may result from desire to improve diagnosis of spinal epidural abscess.

In addition to the condition itself, there are eight criteria for identifying UDEs that will yield meaningful results.

The framework is rooted in a desire to better understand the incidence of error, to ground improvement efforts in the real world, and to improve patient outcomes:

The framework identifies clinical situations that denote potentially preventable breakdowns in the diagnostic process for which improved diagnostic processes would lead to improved health for patients.(pe1)

The authors suggest convening a group of stakeholders in diagnostic safety to pilot the framework and move toward identifying high-priority UDEs. ■

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<http://tinyurl.com/supportSIDM>

Assessment of Reasoning Tool Tracks Learners' Progress and Guides Improvement

By Andrew P.J. Olson, MD,
FACP, FAAP

The ART is a one-page tool that highlights key domains of the clinical reasoning process.

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Developing excellence in clinical reasoning is one of the most important goals in medical education, yet many teachers have difficulty giving accurate, actionable feedback about learner performance. This difficulty arises for many reasons and can result in learners not being able to identify specific ways to improve their clinical reasoning. Many learners receive non-specific, non-actionable feedback about their clinical reasoning from experienced educators, resulting in many lost opportunities for improvement.

The lack of high-quality, standardized, easy-to-use tools to assess a learner's clinical reasoning in the clinical setting poses another challenge. Many educational programs use simulation for assessment but need methods for assessing clinical reasoning in clinical environments. High quality, evidence-based tools will not only allow educators to track a learner's progress over time (assessment of learning) but also identify specific areas for learners to improve (assessment for learning).

In order to fill these gaps in clinical reasoning education—the lack of tools to aid teachers in giving high-quality feedback and of tools for real-world clinical reasoning assessment—the SIDM Education Committee, supported by the ABIM Foundation, developed the Assessment of Reasoning Tool (ART).

This project, led by Satid Thammasitboon, MD, MHPE, associate professor of pediatrics at Baylor College of Medicine in Houston, developed an easy-to-use tool that teachers can implement immediately and use to assess a learner's clinical reasoning during an oral presentation

of a patient encounter—formal discussions between clinical teachers and learners after they have interviewed and examined a patient. These encounters happen during rounds or after a clinic visit and serve as a key opportunity for clinical teachers and learners to discuss clinical reasoning and diagnostic decision-making.

The ART is a one-page tool that highlights key domains of the clinical reasoning process: data gathering, problem representation, prioritization of differential diagnosis and diagnostic evaluation, and reflection on the diagnostic process. As learners present a patient's history and physical examination, as well as their thoughts about the patient's diagnosis, teachers can use the ART to identify strengths and weaknesses in those key domains and give learners a more accurate and precise assessment of their clinical reasoning. Further, the tool allows teachers to give specific feedback for improvement, such as improving prioritization of differential diagnosis or focusing diagnostic testing on likely conditions.

In addition to the assessment tool itself, the SIDM Education Committee developed five short, engaging videos for faculty development. Each video highlights one key domain of the clinical reasoning process and gives examples of high- and low-performing learners. These videos are important, as many faculty members do not feel equipped or prepared to provide specific feedback about clinical reasoning.

The ART and the faculty development videos are available on the SIDM website:

www.improvediagnosis.org/art

Faculty and learners are encouraged to download and use the tools. Validation studies of the tool are currently being conducted.

Andrew Olson is co-chair of the SIDM Education Committee. He is assistant professor at the University of Minnesota Medical School and the director of the Subinternship in Critical Care Clerkship as well as the Becoming a Doctor Course. Olson may be contacted at olso5714@umn.edu.