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Collecting EHR Data on Gender Identity Vital for Clinical Research

Expanding data to include gender identity helps researchers study, address population-specific health issues

Miami Beach, Fla. – Sept. 25, 2018 – Collecting data on gender identity facilitates research into health issues that affect specific gender populations, according to information presented today at the [American Health Information Management Association's \(AHIMA\) 90th Annual Convention & Exhibit](#). Details of an initiative to include data on gender identity in patients' medical records at the National Institutes of Health (NIH) Clinical Center in Bethesda, MD, were presented by Tricia Coffey, RHIA, CPHIMS, CPHI, director of health information management (HIM) at the Center. The Clinical Center is the largest research hospital in America.

To implement the program, HIM professionals consulted with the NIH's Sexual and Gender Minority Research Office as well as the Fenway Institute, a non-governmental organization working to enhance the well-being of the LGBT community.

Under the new system, patients and healthy volunteers who register at the Clinical Center can select from five gender identity options: female (F), male (M), neither exclusively male nor female (N), transgender female (male to female), transgender male (female to male) or other (O). "It's important that patients self-report, and staff are trained to never make assumptions," Coffey said.

The program was designed by a working group comprising staff from medical, nursing, behavioral health, administration, admissions, other clinical care departments and HIM, with input from the hospital's Patient Advisory Group.

"We were not just looking for a technical solution; our approach was more about education that would create and maintain an inclusive and respectful environment for our patients," Coffey said.

Components of the program include:

- Education at all levels of the organization. Clinicians were trained on transgender health and the range of experiences related to sex and gender identity; front desk and patient registration staff received training on sex and gender identity, best practices in health-related communication and achieving quality care with diverse patient populations; and patients were educated about why it is important to communicate this information and be assured that it will be used appropriately.

Staff training included initial train-the-trainer sessions; a three-hour training session that included video scenarios and audience participation role playing; and online training modules on 1) the basics of the project, 2) implementation of gender identity data collection at the Center, and 3) communication strategies through gender identity case scenarios.

- Development of educational materials, including carefully worded scripts for use at registration, FAQs, a quick-reference guide, brochures and documents posted on the hospital's website.
- Review of registration and patient history forms to remove gender-specific terms such as "husband/wife" or "mother/father," and replace them with terms such as "relationships," "partners" and "parent(s)".

"Accurate data is a powerful tool that not only enhances research but also improves the quality of patient care," said AHIMA CEO Wylecia Wiggs Harris, PhD, CAE. "The National Institutes of Health's initiative to include data on gender identity in a patient's medical record is a good example of how adding information such as gender identity provides a more complete picture for both research and patient-centered care."

Since the updated process began in late 2017, more than 11,000 patients have been asked about gender identity. Providing a gender identity is optional; patients can decline to answer. A total of 105 reported a gender identity that differs from their sex. Of these, 70 selected "other," eight said they were neither exclusively male nor female, three were transgender male, four were transgender female, six reported their sex as male and their gender identity as female, and 14 reported their sex as female and gender identity as male.

The presentation, "Gender Identity at NIH: An Organizational and IT Effort," is one of several addressing hot topics in HIM. For details on additional presentations on this topic and others, visit the [educational tracks page](#) of the AHIMA Convention & Exhibit website.

About AHIMA

The American Health Information Management Association (AHIMA) represents more than 103,000 health information professionals in the United States and around the world. AHIMA is committed to promoting and advocating for best practices and effective standards in health information and to actively contributing to the development and advancement of health information professionals worldwide. AHIMA is advancing informatics, data analytics, and

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