

Study lays foundation for more patient access to medical records

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A new study by researchers at Wake Forest University School of Medicine suggests that many patients are dissatisfied with the way they receive results of radiology tests and want more access to information in their medical records, specifically, detailed, lay-language results from those tests.

The study, published today in the November issue of the *Journal of the American College of Radiology*, reports that in general, patients are not happy with the way they receive information about radiology imaging tests, such as MRIs (<u>Magnetic Resonance Imaging</u>), CT (Computed <u>Tomography</u>, or "CAT") scans and ultrasounds, and how long it takes to get results

"Most of the patients in our study were decidedly dissatisfied with how they find out about their radiology test results," said Annette J. Johnson, M.D., M.S., an associate professor of radiology and lead investigator on the study. "Specifically, they were unhappy with the delay before getting results and the lack of detail when they do find out what the tests showed. The classic, most common story we heard was that the patient went to her doctor for a symptom such as pain, was sent for an MRI and then heard nothing until their next regular doctor's appointment. Then, when the patient asked what the MRI showed, her doctor gave a generic answer - 'Everything was fine.' The patients in our study said that they don't want to hear 'fine' weeks after the test. They want to know details and they want to know them as soon as the results are in."



For the study, researchers created two focus groups - one comprised of patients who had recently had an MRI with normal results and the other of patients who had recently had an abnormal MRI. A facilitator was brought in to ask the two groups open-ended questions separately about their experiences with the tests, their perceptions about which aspects of radiology information and access to results are important to patients, and what methods of results information access would be preferred by patients. The discussions were audiotaped and transcribed to analyze results.

"Typically, if you need a scan, your doctor sends you to a radiologist to get the test, but you never actually see or speak to the radiologist," Johnson said. "Some time later, commonly a few weeks later, you go back to your regular doctor, who gives you a brief summary of the results. Patients in our study aren't happy with that system. They want their results quickly, in writing, and they want detailed information about the test results in language they can understand."

The majority of participants said they would be interested in a system where they were able to get their radiology results securely online as soon as they were available. They predicted that such a system would give them time before their next doctor's appointment to prepare questions for their doctor, learn about their own condition or disease, and get a jump start on setting up referrals if needed. They believed having access to their own medical records would put them on a more even level with their doctor so that, as patients, they don't have to depend on their doctor to cure their ailments, but rather they can work as a team with their doctors and play an active role in helping themselves.

While some of the study participants expressed concern about getting bad news while alone and not wanting to substitute online access for a follow-up visit with the doctor, they generally were dissatisfied with the current way radiology test results are relayed back to patients and



thought the option of accessing results online would be much preferred.

"It's pretty well known that our system of reporting radiology tests could be improved," Johnson said. "Patients aren't happy and evidence is mounting that physicians are also dissatisfied and think that the system for conveying results needs improvement. It's clear from this study that, if you were to try to create a system where patients could look up on their own test results, that system would have to be set up so that the patient has the ability to choose whether or not they want to access detailed results or not. We wouldn't want someone to log into the system to schedule an appointment, for instance, and inadvertently find out, perhaps all alone at home, that the MRI they went for a week ago came back showing a tumor. In addition, if the patient chooses to have online access, the system would have to allow the patient access to full details (if they choose to access them) in layman's terms, not just 'medical-ease' or a short summary of the test results."

The focus groups also revealed that some patients believe that radiologists are the experts in reading scans and patients want to hear from radiologists more directly, Johnson said.

"In the past, radiologists have been like the undercover agents of medicine," Johnson said. "We supervise the tests and evaluate them but most patients have no idea who we are or that we are the ones reading their scans. We report the findings to the patient's regular doctor, and he or she verbally summarizes the information we conveyed, often providing the patient with very little detail. If we believe the patients in our study are typical, then this is a system that's just not meeting patients' needs anymore."

Co-authors on the study were Doug Easterling, Ph.D., of the School of Medicine, Linda S. Williams, M.D., and Richard M. Frankel, Ph.D., of Indiana University School of Medicine, and Sharon Glover, of Sharon



Glover and Associates, Inc.

As a follow up to this patient study, the investigators conducted similar research in a physician population. In that study, radiologists and physicians who use radiological testing often were interviewed in focus groups about the current way radiological tests are reported, what they think could make the system better and how they think patients feel about the existing system. Somewhat surprisingly, Johnson said, physicians are aware that patients aren't satisfied with the way they currently get their results and agree that patients should have more access to their own personal health information. However, physicians were very concerned about the potential negative effects of making radiology results available to patients online. That study is also scheduled to appear in a future issue of the *Journal of the American College of Radiology*.

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