Collecting Data on Patient Race, Ethnicity and Primary Language is Helping Hospitals Improve the Quality of Care

Robert Wood Johnson Foundation program helps hospitals decrease disparities, increase patient-centeredness in heart care

Leaders of U.S. hospitals say they provide the same level of care regardless of a patient's race, ethnicity or language, but few, if any, really know for certain. That's because most of America's hospitals do not have a uniform system for tracking the race, ethnicity and language preferences of their patients. Those that do collect data often 'eyeball' patients to make those determinations, rather than asking patients directly, and hardly any hospitals use these data to gauge how their care of minority patients stacks up against known quality standards.

To address concerns about the poor quality—and equality—of American health care, Expecting Success, the nation's first multi-hospital collaborative focused on reducing disparities, is helping 10 hospitals measure the quality of cardiac treatment they provide to patients based on their race, ethnicity and primary language. While simultaneously working to improve the quality of care for all heart patients, the hospitals are, for the first time, tracking data to identify if there are racial and ethnic disparities in the care they provide. The Robert Wood Johnson Foundation sponsors the ground-breaking program.

"By uniformly tracking information on patients' race, ethnicity and language preferences, these hospitals are discovering powerful tools for ensuring that consistent care is provided to every patient," said Bruce Siegel, M.D., M.P.H., who heads the Expecting Success program. "Seeing the data has opened their eyes. When we started this project, hospital leaders told me that they provide the same care to everyone, even though they didn't track the data. That's assumed equity. If they don't gather and analyze the data, they don't really know."

Dr. Siegel's program is helping 10 hospitals produce consistent data on more than 20 cardiac care quality indicators, all analyzed by patient race, ethnicity and language. Despite concerns about how to begin uniformly collecting the data, CEOs at all 10 sites say the data-collection process has been easier than they anticipated.

"We had a lot of worries when we began this process, from convincing hospitals that collecting these data were legal, to having to redesign computer registration systems. We worried about training staff on how to ask these questions, and patients potentially being offended," Dr. Siegel said. "Only a

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Toolkit Helps Hospitals Tackle Data Collection

The Health Research & Educational Trust, a division of the American Hospital Association, has developed a helpful toolkit to guide hospitals through the process of collecting data on patients' race, ethnicity and primary language.

The kit includes information on the nuts and bolts of collecting the data, including resources for training staff, such as sample scripts.

Access the toolkit at www.hretdisparities.org.



How to Begin Collecting Patient Race, Ethnicity and Language Data

All 10 Expecting Success hospitals now track the race, ethnicity and language of every patient. While the process has been relatively smooth, hospitals were concerned about potential problems with staff, patients and technology.

The Expecting Success program brought in Romana Hasnain-Wynia, Ph.D., who spearheads programs to increase data collection for the American Hospital Association's Health Research & Educational Trust. She provided hands-on advice and a framework that helped the sites get started. The Expecting Success team then helped the hospitals hard-wire the data collection into their procedures by providing the sites with ongoing assistance for collecting and interpreting the data.

"Hospitals were extremely anxious about the change," said Marcia Wilson, M.B.A., deputy project director. "The registration staff was concerned that they would have to start asking patients sensitive questions about their race, rather than guessing. Their concern alarmed the registration managers, which in turn raised concerns with the quality improvement staff and many others—all of which was then elevated to the senior leadership. At the end of the day, the anticipated pushback from the patients simply did not materialize. It was a much smoother process than expected."

Dr. Hasnain-Wynia believes following a process tailored for each institution is critical to the success of the data collection process.

"We helped each site design its own comprehensive strategy for collecting this information," she said. "Even though they already collected race data, none were collecting ethnicity or language information, and the methods they followed were inconsistent. Some sites compiled information at three or four

different points in the process, so the same patient had inconsistent data entered multiple times. Others used different terms every time."

The Expecting Success staff and Dr. Hasnain-Wynia agree on several key steps to help begin the process:

Gather opinions from top to bottom.

It's important to discuss the purpose and process for data collection with everyone from the CEO to frontline staff.

Affirm the legality of the process.

Some hospitals think it's illegal to collect these data but published research from a variety of sources affirms its legality for improving quality.

Identify the time and place for data collection.

All sites determined a time, place and person responsible for gathering the data, usually at registration.

Think through the technology issues.

IT staff must ensure the data transfers to all relevant patient databases—including programs that track the specific care received.

Use consistent categories.

The current race and ethnicity categories used by the Office of Management and Budget are the recommended standard.

Have patients provide the information.

All sites rely on patients or their caregiver to provide the information, rather than registration staff 'eyeballing' patients.

Provide detailed staff training.

Sites provided sample scripts, role-playing and trouble-shooting scenarios to make registration staff comfortable.

few hospitals in the country had gone down this path. To collect data consistently across 10 diverse hospitals and report it back had never been done before but developing and implementing the data collection has been largely free of problems and very effective."

The result is that some sites are discovering that they have disparities in the care they provide, some of which are significant. Some have noticed more patients than anticipated speak a language other than English. All agree that collecting the data has been eye-opening and will improve both the quality and patient-centeredness of their care.

Why Data Collection is Important

Dr. Siegel and his team say many of the hospitals find that they don't really know their patient population until they see data that have been collected over a period of time. Without a uniform way to collect data, information about patient demographics may remain unknown (see graph, page 3).

"All of the *Expecting Success* hospitals were collecting information on race at patient registration, but we found that the registrar often guessed the race based on appearance or left the field blank," said Marcia Wilson, M.B.A., deputy director of the *Expecting Success* program. "When every site started asking the same questions of every patient, it made a huge difference in what their numbers showed."

Now the data provide accurate answers about who their patients are, which drives decisions about languages for discharge materials, whether more interpreters should be hired and where cultural competencies of the staff can be improved.

"Hospitals need this information in order to be vibrant contributors to their communities," said Dr. Siegel. "It affects so much about the patient experience—what food they might like, how they should receive information about follow-up care, what signage might be needed in the hospital and what cultural barriers they face in getting better."

Even more important, collecting these data allows hospitals to analyze how well they meet specific quality performance measures by patient race, ethnicity or language.

"Once patient sample sizes are large enough, you can actually see if there are disparities in the quality of care that is being provided," Dr. Siegel said. "That's the only way you will know if there is a problem—and knowing about the problem is the precursor to fixing it."

Putting the Data into Practice

Expecting Success staff work with hospitals to analyze the data to learn more about their patients and determine whether disparities exist.

For the first year of the program—while a significant amount of data on race, ethnicity and language preferences of their patients was being generated—the hospitals focused on developing interventions to ensure that all of their heart patients consistently received all of the recommended care for their condition.

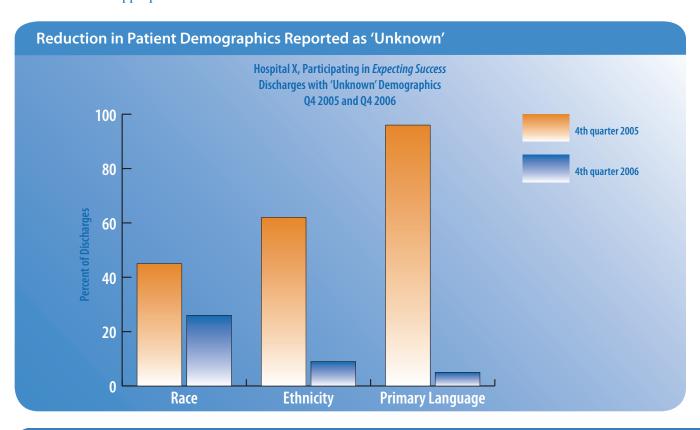
"The ideal situation is for 100 percent of the patients to receive all of the appropriate care all of the time. Then

there are no disparities for anyone," said Dr. Siegel. "And while the *Expecting Success* hospitals are making tremendous progress toward that goal in a short period of time, we now have enough data to show what is happening specifically with minority patients."

Dr. Siegel believes the data show that care is usually consistent among most patients, but there are some statistically significant racial and ethnic disparities in the heart care being provided to minority patients.

"The data are starting to show trends, and trends lead to questions," said Dr. Siegel. "How come some black patients aren't getting aspirin when they enter the hospital with a heart attack? Why are some Hispanic patients consistently not receiving discharge instructions? Why do some minority patients not follow the recommended medication regimen? Why are the readmission rates so much higher for minority patients? Looking at the data creates a moment of examination for these hospitals."

Overall, Dr. Siegel thinks the data show that racial and ethnic disparities are not just a hospital issue or a problem with specific physicians or frontline staff, but emblematic of a larger problem facing communities.



From One Hospital to Another: Two Hospitals Offer Tips

Montefiore Medical Center in The Bronx, N.Y., is located in one of the world's most diverse cultural melting pots, while the University of Mississippi Medical Center in Jackson, Miss., has little diversity in its staff or patients. Although these two academic medical centers, both Expecting Success participants, launched their data collection efforts in different ways, they have similar insights to share with other hospitals.

Reject preconceived ideas about who your patients are.

Both Montefiore and UMC thought they knew who their patients were, but through this process, both produced hard data that challenged or confirmed their assumptions. In Mississippi, officials learned that more patients want to communicate in Spanish than the hospital realized. "Because of the data, we are rethinking what kind of language services we need to provide and whether our materials are culturally appropriate," said Michael Winniford, M.D., director of the cardiovascular division at the University of Mississippi Medical Center.

Get the CEO and senior leadership on board.

The hospitals agree that having the CEO support the new procedures helps cut through hospital politics. "Fields on a computer screen are valuable real estate in a hospital," said *Expecting Success* deputy project director Marcia Wilson, M.B.A. "Several technology departments balked at adding fields for ethnicity and language. In those instances, it was very handy when the CEO could instantly send a note saying 'make this happen!"

Build support top-down and bottom-up.

"We spent a lot of time building consensus throughout the organization," said Rohit Bhalla, M.D., M.P.H., chief quality officer at Montefiore. "This isn't the type of assignment that can be dictated. We asked everyone for input, from senior leadership to IT to registration to others. Getting everyone on board makes the process go smoothly."

Registration managers hold keys to success.

Both Montefiore and UMC believe that registration staff managers were paramount to making sure the new procedures worked. Both sites extensively trained the managers on the program so that they could in turn train their staff. At Montefiore, where more than 600 registrars are spread out over 90 locations, this training required a logistical tour de force, but is largely credited as a main reason the adoption ran smoothly.

Engage the frontline care staff.

Both hospitals explained the need for the data to caregivers. "Frontline workers generally come from the community," said Bruce Siegel, M.D., M.P.H., Expecting Success project director. "Telling employees that you are going to track your care to eliminate disparities sends a powerful message to diverse employees. These patients are their brothers and sisters, spouses and children. That makes the staff vested in the process and incredibly powerful advocates for change."

Be flexible with registrars.

Both Montefiore and UMC found that registration staff wanted direction but not too much. "They wanted a script, but they also wanted latitude," said Dr. Bhalla. "We didn't say that there is one right way to ask patients about their race, ethnicity and language. There are many ways, and as professionals, they know what is best for each situation."

Check progress.

After data collection began, both sites monitored progress. "We analyzed data by registration staff to see which staff had a high number of empty fields or 'unspecified' answers," said Dr. Winniford. "That helped us counsel them accordingly. When staff know why this is important and are educated on the procedures, they become very comfortable asking the questions and find that patients respond positively."

"I am more convinced than ever that racial disparities are closely tied to the transitions when people move from ambulatory care to hospital care and back again," Dr. Siegel said. "This transitional care is bad for everyone, but it's a crisis for minorities."

Expecting Success staff and participants from the 10 hospitals say that much more coordination between hospitals, primary care providers and community service agencies is needed to improve the quality of hospital—and ambulatory—care provided to heart patients. Nevertheless, they say collecting this data on patients in the hospital has been a giant step.

"If collecting race, ethnicity and language data was the first step on the ladder, then learning from the data and applying it to the community is the next rung," Dr. Siegel said. "Because they were brave enough to gather the data, these 10 hospitals can now analyze their performance in ways nearly no other hospitals can. If they have disparities, they are starting to pinpoint what the problem might be and explore how they can tailor their quality improvement initiatives or work with others outside the hospital to address the issue. The important thing is that they have begun the process. With America's changing demographics, my guess is that they will be far better positioned against their competitors because of it."

For more information on Expecting Success and a list of participating hospitals, see www.expectingsuccess.org.

An article published in the *Journal for Healthcare Quality* explains early observations from *Expecting Success* on how hospitals view disparities in care and data collection. See www.nahq.org/journal/ce/article.html?article_id=288

A brief report on how Expecting Success is improving heart care for minority patients is available at www.expectingsuccess.org/uploads/
FirstYearAchievementsEBriefMarch07.pdf.