

‘Are you married?’ Why doctors ask invasive questions during treatment

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The demographic data collected at doctor's visits is useful to medical researchers.

MoMo Productions/DigitalVision via Getty Images

It’s a rare occasion when my worlds of biomedical informatics and serialized lesbian melodrama fandom collide.

But that’s exactly what happened earlier this summer when two of my favorite actresses appeared on a popular podcast. I was excited to hear them talk about their new book and their history of working together, so I was confused but delighted when their conversation took a turn toward my area of expertise – electronic health records.

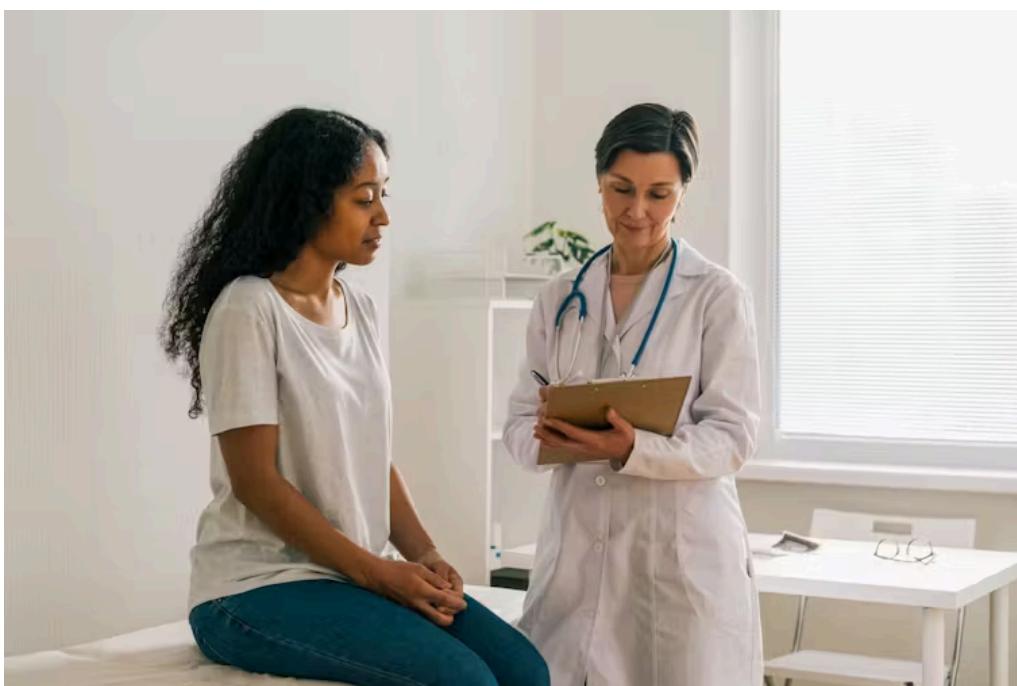
One actress noted that on a recent trip to the optometrist, she was asked about her ethnicity. “And I was like, what difference does it make?” she said.

The host chimed in with her experience of being asked similarly personal questions before a mammogram. “Like, it doesn’t matter if I’m married or not. It doesn’t matter if I’m white or Asian, you know?” she remarked.

Listening to the host and actresses question a process that, to me, seems straightforward and purposeful served as a stark reminder of the chasm that often exists between how researchers like me use patient data and a patient's actual experience of clinical data collection.

For those of us who use demographic data collected during health care encounters to conduct research and design interventions, it does matter whether patients answer their doctor's demographic questions. But as a patient myself, I can see how these questions might seem unnecessary and even invasive.

So it may help to understand why your doctors collect this data, how researchers use it and what medical discoveries might be possible when we know more about who patients are.



Your doctor's questions might sometimes seem arbitrary and invasive.

Natalia Gdovskaia/Moment via Getty Images

Why your data matters

When you answer the demographic questions your doctor logs in your electronic health record, you're doing more than disclosing personal information. You're adding one small piece to a giant puzzle of data that allows researchers like me to see a bigger picture.

Your health information can help us understand who gets sick and why. It might even be used to design real health interventions.

As a researcher focused on improving health and health care for moms and their babies, I consider myself lucky to live in Indiana, a state with one of the nation's most comprehensive health information exchanges. These exchanges are interconnected networks of hospital system electronic health record databases from all over the state that allow researchers like me to learn about how individuals and groups experience health and medical care.

For example, my colleagues and I in the Indiana University Better AI for a Strong Rural Maternal and Child Health Environment Lab use this data to train machine learning models that predict preeclampsia, a life-threatening condition of high blood pressure during pregnancy, before a mom gets really sick.

We could use only clinical data: diagnoses, labs and vital readings like blood pressure that contribute to the outcome of preeclampsia. But for conditions like preeclampsia, Black moms are diagnosed at higher rates than their white counterparts. Research shows that race and racism can be major contributing factors to this disparity.

In order to predict preeclampsia accurately and use these predictions to help doctors monitor, diagnose and treat the condition, my team needs to factor in other information that can illuminate these different outcomes, called social determinants of health.

Social determinants of health are the parts of ourselves and our environments that drive our health status. Race itself isn't a social determinant of health, but racism is. This includes structural racism, like a ZIP code's history of school segregation or redlining. If available, we also include information you might have given at your doctor's visit, like if you haven't had enough food to eat in the past month, or if you have a history of intimate partner violence or homelessness.

Because there is more variation within races than between them, race alone actually tells us very little. Including social determinants of health in our datasets provides added context as to how you move about the world, what resources you have access to and how your environment might shape your health.

Putting the pieces together

This is why your cardiologist asks about your marital status. Your response might help researchers understand why single moms are more likely to have cardiovascular disease than their married counterparts. And telling your optometrist your race is one of the only ways to learn what role race might play in patients using weight loss drugs experiencing vision loss.

Other researchers have used data from electronic records to determine how many people in a geographic area or of a certain demographic group have diabetes, to predict dementia and even to track gum disease.

During the COVID-19 pandemic, researchers used data from electronic health records to determine what types of people were getting sick. They investigated COVID-19 patients' race, geography and insurance status. Researchers continue to use this data to track long COVID, a condition that health professionals still don't completely understand.

Honoring patient privacy

Of course, these health information exchanges are careful about how and with whom they share patient data. The data is tailored to the needs of the study and shared in compliance with the Health Insurance Portability and Accountability Act, or HIPAA.

For instance, for my most recent preeclampsia study, the health care system sent a dataset that contained limited pieces of personal information, like the baby's birth date, the mom's birth date – since we often need to know how old she was when she gave birth – and their ZIP code so we can see trends in preeclampsia across geographic areas.

The data wasn't allowed out of the health system's virtual private network, so the data remains within our firewall. This ensures that the data remains safe. And all of this must be approved by our university's institutional review board, a rigorous process that ensures our research can't harm participants.

Improving health care for everyone – including you

All of this research drives innovation and serves as a basis for the programs, protocols and policies that improve health – from you as an individual all the way to the national and even global level.

Your doctor can use the information you provide to recommend services or therapies for you. For instance, if your doctor finds out through check-in questioning that you haven't had enough food in the past month, they can refer you to a nutrition program, sometimes run by the hospital system itself. If you were married at your last appointment but now list your marital status as "separated," your doctor can check in with you to see if you need any additional mental health or social services.

While it's normal for these personal questions to feel a little uncomfortable, it helps to remember that there is a good reason your doctor is asking them. Your data can help move medical research forward.

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