# The Dish: Sharing Your Electronic Health Record (EHR)

[www.youtube.com/watch?v=z9g6HbCRHF4](http://www.youtube.com/watch?v=z9g6HbCRHF4)

## Title Slide

The Dish

Sharing Your Electronic Health Record (EHR)

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## Scene Change

Eric Dishman standing in front of a white board.

## Mr. Dishman:

I want to talk a little bit about electronic health records today. It’s important to understand, for all participants or future participants out there, that getting your holistic longitudinal health record is just a fundamental pillar of the program. It’s really key. And most of you are doing that already. There’s more than 4,000 people who have been through the entire protocol already and done all the pieces. There’s more than 6,000 people who are somewhere in the process—have started at the beginning and are moving somewhere through that process. Only about 2% of you have declined to participate further because of needing to share your electronic health record program—or your electronic health record.

At the same time, what we don’t know is how many people may have heard about the program and decided, “Hmm, I don’t want anything to do with that, because I’m actually nervous about sharing my electronic health record.” If you’re nervous about it, it’s good, because you should pay attention to something that has such precious and personal data and know what’s going to happen with it. In fact, we’ve gone to extra lengths. Some of you have given great feedback about “our consent process is so long!” But we’re really going to make sure that you understand what might be in your electronic health record. Certainly, most people know it might have your medication history. It has, you know, the kinds of diagnoses that you’ve been through or the procedures or surgeries that you’ve been through. All of that is really important to understand for the research that we’re trying to do to come up with precision health and cures in the future. At the same time, it might have some really sensitive information—your mental health history. Sometimes it has drug abuse and those kinds of substance abuse challenges in there, and those may be something that you want to really think twice about.

Now, in all these cases, we de-identify your health record so it’s not associated with your name and address. In all these cases, we’re using encryption and other cybersecurity technologies that are the latest and greatest. But we want you to understand fully what you’re signing up for, and we also want you to understand that signing up to share your electronic health record data is going to be a fundamental piece of it. If you’re only comfortable sharing surveys, there’s a certain amount of research that researchers can do with that, but you won’t be invited at that point to go participate in, like, physical measurements or get your blood or urine drawn. You’re coming on a long journey with us. You may not even have your electronic health record yet, but if you consent, we’re going to be making some investments to help you, as an individual, get access to an increasingly richer and deeper record about yourself and then de-identify that and share with the researchers. In some cases, it may take a year or more for us to figure out the strategy to do that, but it’s a fundamental commitment to the program, a value proposition of the program, and a necessity for really changing the game with precision medicine research.

So thanks so much for those of you participating so far. And we’ll talk more about security and some of these other topics in a blog in the future.

## Closing Slide

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